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Families Affected by Addiction

A Handbook

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Introduction

This handbook is about how family members, affected by a close relative's use of alcohol or drugs or gambling, have been impacted by this use, and how, all-too-frequently, they have not received either help or acknowledgement about the issues that this raises for them.

More than 10 years ago, Jim Orford and colleagues published a seminal paper entitled 'Addiction in the Family Is a Major But Neglected Contributor to the Global Burden of Adult Ill-Health' [1]. Based on the available evidence at that time, the authors concluded that more than 100 million people globally are impacted by addiction problems of their relatives, and that these affected family members experience multiple stresses, coping dilemmas, and lack of information and support. At a similar time (2010), the idea of 'Harm to others' related to problematic alcohol use was embraced by the World Health Organization (WHO) as a priority component of the Global Strategy to Reduce the Harmful Use of Alcohol [2], using an approach that did not only focus on addiction but included all kinds of harmful effects of alcohol drinking and intoxication, indicating an increase in public awareness of the negative effects that intoxicating substances can have on third parties.

One year after the Orford et al. paper was published, the authors, who had been working in the area of 'addiction and the family' since at least the early 1980's, founded the Addiction and the Family International Network (www.afinetwork.info) to bring together researchers, practitioners, and politicians from all over the world.

The aims of this network are to:

- Promote research about the experiences of family members affected by their relatives' addictions around the world
- Promote good, evidence-based prevention and treatment practice relevant to the needs of affected family members
- Disseminate internationally a non-pathological, family member-centred model of the circumstances and needs of family members affected by their relatives' addictions
- Advocate with policymakers, including international organisations and national governments, for greater awareness of the circumstances and needs of family members affected by their relatives' addictions and for better services for them
- Raise awareness at a global level of the needs of families affected by addiction

AFINet started to hold international conferences and webinars on a regular basis, and during the first decade, more than 900 members from 58 different countries joined the network. The network offers resources such as training materials, newsletters, and updates on research in the field, available on its website. As a small NGO, AFINet has undertaken various other small-scale projects in its first decade, including a survey of members to ascertain what methods had been used across various countries to reach out to affected family members to either collect information or be able to offer help; work to understand the extent to which the needs of affected family members were included in government policies across various countries; and a survey assessment of how formal help ('treatment' or 'care') was offered across various countries: this covered (for each country that responded) an examination of the treatment concepts that were used, the range of types of help that someone might be able to access, how such help was financed, and the extent to which online was available. Furthermore, an international survey of experts was conducted to assess the effects of the COVID pandemic on burden and care offers for family members [3].

Although there has been an increase in research on family members affected by addiction, there has not been a key publication that brings together the main issues in an accessible form. Therefore, a key project for AFINet was the systematic synthesis of the scientific literature on the impact of addiction-type problems on families, with the intention of developing a comprehensive 'handbook', the result of which is the present book. To ensure good scientific practice, all chapters underwent independent peer review.

The aim has been to produce a resource for policymakers, practitioners, and researchers alike, where key information is summarised and synthesised, in an accessible form; where contributors take a critical-reflective stance and base their contributions on research and evidence (including both qualitative and quantitative data); and where the implications for policy, practice, research, and theory are made explicit. We have aimed to take a truly global approach, with a strong emphasis on the experience of AFMs in low- and middle-income countries, and the policy, practice, and research implications of those experiences, as well as covering the more commonly reported work in high-income countries.

The editors, all AFINet members with international experience in the area, and coming from both the Global South (Mexico and India) and the Global North (Europe), developed the content areas of the book and then approached renowned authors with a body of work on each of these content areas. We have been especially pleased that we were able to recruit such highly respected colleagues with diverse backgrounds and work in different parts of the world. We are most grateful for their collaboration.

The title of this handbook (and of the network itself) contains two constructs that need to be described to establish the scope of this book. First, with *family members* we do not only include individuals who have a blood relationship or who are living in a partnership or a family with someone with addiction-type problems. We are using this term to include all individuals affected by those who themselves are experiencing alcohol, drug, or some other form of addiction (who we will be referring to as 'relatives'). As such,

we are using the term 'family members' to include various types of relations (spouses, parents, children, and other close relationships, such as close friends). Thus, although most research has focused on partners, children, and parents, this book is not restricted to relationships within the nuclear family. There are various terms which have been used over the past decades to describe those affected by their relatives' addiction-type problems, including affected family members (AFMs), family members affected by addiction (FMAs), close and supportive others (CSOs), children of 'alcoholics' (COAs), children affected by parental alcohol problems (ChAPAPs), and other terms. In this handbook, most chapters use AFMs; some chapters use other terms; but the group of people being referred to remain the same—a largely underserved group who suffer major negative effects resulting from their relative's addiction-type problem.

Second, the term 'addiction' can be controversial and emotive, to both practitioners and AFMs, as it can imply mostly extreme problems, and this might exclude AFMs who are suffering from a relative's addiction-type problem which has not been recognised as such or is not sufficiently severe to formally meet the diagnostic criteria used within medical classification systems, such as ICD (the World Health Organization's International Classification of Diseases) or DSM (the Diagnostic and Statistical Manual of Mental Disorders). In this handbook, our interest is in including any AFM who feels they have been affected by somebody else's use of alcohol and/or other drugs and/or gambling and/or other similar behaviours. So, we are using the term 'addiction' as a shorthand, to include the spectrum of use of alcohol/drugs and gambling by an individual that can adversely affect their family member(s). Hence, the overall focus within this handbook is on the AFMs experience and not the nature and severity of the '*relative's* addiction-type problems'.

The book has four different parts: In the first part, we address fundamentals, starting with the AFM experience as outlined from qualitative research, with subsequent chapters dealing with the dimensions of the problem and the concepts that have been (and still are) used to describe the experience and situation of AFMs.

The second part, entitled 'the AFM experience', looks at both the similarities and differences among the wide range of AFM experiences around the world and gives an overview of how various factors, such as culture, interpersonal and personal characteristics, contribute to commonalities or variations in the experiences encountered by AFMs.

The third part, 'barriers to services working with AFMs', analyses potential reasons for the gaps between the number of AFMs identified in the general population and the low proportion of those who seek help and support to deal with their situation, including political neglect, under-representation in both policy and service delivery models, lack of involvement and encouragement from health and social care professionals, and stigmatisation and bias as barriers to care.

The fourth part gives an overview of interventions for AFMs that have been developed, both in terms of concepts and in terms of efficacy, ranging from interventions that include AFMs in the treatment of their relatives, to interventions offering support for AFMs in their own right.

Lastly, a concluding chapter, written by the editors, provides a summary and outlines unmet needs as well as perspectives for future research, policy, and practice.

Finally, we would like to pay special tribute to Guillermina Natera Rey (the lead author of Chap. 9), who died while this handbook was in the later stages of being assembled. She personally, and the Ramón de la Fuente Muñiz National Institute of Psychiatry in Mexico, to which she dedicated the whole of her professional life, played a key role, from the 1980s onwards, in the international development of research and practice relating to family members affected by addiction. She was well-known and much loved by several of us and is much missed by many.

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Part I

Fundamentals

1 First Person "Lived Experience" Accounts of Being an Affected Family Member (AFM)

Richard Velleman, Abhijit Nadkarni, Gallus Bischof, Marcela Tiburcio, and Jim Orford

1.1 Introduction

In the introduction to this book, we described what this book is about: how family members,[1] affected by a close relative's use of alcohol or drugs or gambling, have been impacted by this use, and how, all-too-frequently, they have not received either help or acknowledgment about the issues that this raises for them.

In this first chapter, we want to allow some of these affected family members (AFMs)— family members affected by a close one's use of alcohol or drugs or gambling—to tell their stories: their "lived experience." We want to do this for at least two reasons:

- First, because the rest of the chapters in the book synthesize information about AFMs experiences and attempt to summarize and present an overview of what is known about the subject. However, each of these summaries relate to the agglomeration of thousands of sets of individual experiences and by aggregating the experiences of many individuals, we run the risk of forgetting or losing sight of

[1]There are various terms which have been used over the past decades to describe this group of family members (wives, mothers, husbands, fathers, children, and other close family members) impacted upon by those who themselves are experiencing alcohol, drug, or some other form of addiction: affected family members (AFMs), family members affected by addiction (FMAs), close and supportive others (CSOs), and other terms. In this chapter we will use AFMs, other chapters use other terms, but the group of people being referred to remain the same—a majorly underserved group who suffer major negative effects.

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the individual. We hope that the brief summaries of individual stories in this chapter will act to offset that.
- Second, as stated above, each chapter in this book focusses on one aspect of AFMs experiences, and in so doing, there is a danger that the complexity of AFM's problems, and of the complex interplay between psychological, social, and environmental factors can be overlooked. So, by starting with the personal and the complex, we hope to provide a context to situate the models or the quantitative approaches in later chapters.

The range of possible personal stories we could have curated is very large: different types of family relationships (children, spouses, parents, and many others), different types of addiction (alcohol, gambling, many different types of illicit drug), different genders and sexual orientations, of both the AFM and the person with the addiction-type problem, and so on. In this chapter we have presented select examples of the more common experiences of AFMs:

- a child affected by her mother's drug and alcohol use;
- a young man, who grew up with a father who drank problematically;
- a middle-aged couple, living with a parent/in-law who drinks problematically;
- wives from different cultural contexts, affected by their husbands' drinking;
- two parents (and grandparents), affected by their daughter's drug use, who are now also taking responsibility for their grandchild; and,
- two different spouses, affected by their partners' gambling.

Although we have given examples of spouses, parents, grandparents, and children, we could also have given examples of other affected family members—siblings, uncles and aunts, cousins, and so on.

What we want is that the stories gathered here give you, the reader, some indication of the range of ways that people are affected.

All these personal stories come from qualitative studies (usually narrative interviews) or from accounts published on-line; most have been previously published although some come from material collected during those qualitative studies that has not previously been published. Some of these stories are told in the first person, taken from interview transcripts, some are in the third person, extracted from research interviews. While all of these are real stories, identifiable information, such as names, has been changed to ensure anonymity.

It will be clear both from reading these narratives and from inspecting these key themes that there are major similarities across these stories (summarized at the end in Box 1.1), even though they are told by AFMs of different ages, who are inhabiting different roles in the family, and which are related to different addictions. That should not obscure the fact that there are also differences across each of these domains, and these are examined in Chaps. 4, 6, 7, and 8.

1.2 Julie, a Child, Affected by Her Mother's Alcohol and Drug Use

Julie is 14 years old. She says that her mother's drinking and drug taking has ruined her Christmases and birthday parties for as long as she could remember. Julie talks about "*never knowing how my mum is going to be*." She says that sometime her mum is nice and quite kind, and at other times (when she has been drinking, especially when drinking a lot, or taking drugs, or the next day when she feels awful because of the drinking or drug-taking), she is "*quite horrible*"—moody and snappy and not interested.

> "If mum is going through a bad patch with her drinking and her drugs, I just get so angry! I think I have a very short temper—but so does she, when she's using or when she's hungover." "Sometimes I get so frustrated, and then I seem to get into trouble at school—teachers tell me I am 'talking back' at them. Or they blame me for getting into an argument with my mates."

"Mum's been on her own for ages—I can't remember my dad at all—but it gets worse when she gets together with someone else. She's with John at the moment, and he drinks a lot too, and takes loads of different drugs, and when they both drink and take drugs, it's even more horrible at home—if they get pissed together or take some of their drugs, they argue and start to shout and scream—I just need to get out of there, it does my head in so much! And with some drugs they take, they just slump down and are so 'out of it' I might as well not be there."
She says that sometimes, John and her mother hit each other—the shouting gets worse, and then usually Julie's mum hits John, and then he hits her back, but much harder. "I want to stop them, but I'm just too scared—I think that John will hit me, so I just go away and try to block it out—turn my music up loud!"
Its just horrible really; I hate my life! School sucks, home sucks, I know everyone talks about me behind my back! But it is really scary, and I feel really stressed out. Basically, I don't want to be here, and I don't think that mum wants me to be here either—and I know that John thinks I am a spare part and get in the way.
I just don't know what to do. I'm too scared to try to stop them fighting, and I don't think they'd listen to me anyway. Before John moved in I tried to get mum to stop drinking AND to stop using, but we both 'lost it' and we ended up shouting and screaming at each other, which was even more horrible. We live in a small place, but I do have my own room, and I do go to my bedroom and listen to music as loud as I can, to drown out the rows. Sometimes I'll go out and sit by the canal, but that's usually cold or wet, and I don't really feel safe there either. I just think that the drugs, and the drinking, and the fighting, will carry on—there's nothing that I can do about it—it is just 'here we go again'! I'm going to get out and leave, as soon as I can!
I've never talked to anyone about this. I mean, noone has ever asked me about how I feel about any of this. And anyway—who would I talk to about any of this?! My teachers aren't interested—I know they think I'm just a pain and a troublemaker. I don't want a 'social worker'! My dad's disappeared, and I don't get to see anyone from his side at all. And mum doesn't have much to do with her family—and anyway, I'd just be a nuisance to them! But also, I don't know what would happen if I did talk to anyone—maybe they'd take me away and put me in a children's home, and that would be even worse! At least I can go to my room and listen to music! So, I just get on with things, and wait until I can get away.

Key Themes Highlighted by Julie's Narrative

- Very long-standing problem;
- Inconsistent parenting from mother, absent or negative father-figure;
- Violence and aggression at home, scared about violence, feeling unsafe;
- Uncertainty about how to cope;
- Acting out at school, isolated, no social support;
- Not revealing the situation to others, noone to talk to, and fear of consequences if revealed.

1.3 David, a Young Adult, Affected by His Problem-Drinking Father Throughout His Childhood

David was in his late 20s when he talked about how his father's drinking affected him. David described his father as having drinking and emotional problems throughout his childhood, problems that David attributed to his paternal grandfather's excessive drinking and violence.

David said that the worst times—both for him and for everyone in the family—were when his father had been both drinking and was in a bad mood: he would get very irrational, and become verbally, emotionally, and physically violent: according to David he would "*rant and rave for hours*": David described his father as "*paranoid, stubborn and arrogant, and inadequate*." David said his father nearly always drank a bottle of whisky or more each day: "*the drinking was constant, the central core of his social activities*." David's father had no treatment for his drinking throughout his childhood.

David's father was regularly violent toward him, hitting him with sticks and canes, kicking him—a "*regime of terror*" as David described it. Both David and his mother had been hospitalized following such violence. When David was 16, he

"*lost his head*" and attacked his father, which finally put a stop to his father's violence toward him. David described himself as stubborn like his father and he resented his father "*getting away with unreasonable moods and ranting on*," so eventually he felt he had to try and stop him. Throughout his childhood, when his father was drinking heavily and in a bad mood, David would be very tense and anxious.

David recalled his parents' relationship as "*really very bad, extremely traumatic*": there would be terrible rows every few weeks, followed by several days of tension and not speaking—conflicts were never resolved. A sense of insecurity pervaded the family atmosphere most of the time, and David felt a great difference between his own and his friends' families, and also between the family life that they had to appear to lead, and the reality that needed to be kept hidden. Holidays were very uncomfortable, invariably involving awful scenes.

David describes strong loving feelings toward his mother and lots of shared activities and closeness with her as a child; he said that she was basically the symbol of security within the house: a main support that the family relied upon. However, he also described her as very protective and suffocating, and said that he felt he had been indoctrinated in childhood with her view of his father as mentally ill. He felt she had played on their loyalty, made his father very jealous, and reinforced the children's feelings of guilt.

David recalled no difficulty in making friends as a child, but did describe a definite separation between home life and friends. He brought friends home with great trepidation and mainly went round to others' homes. Out of loyalty, when outside the home he would not admit to anything being wrong in his family. However, throughout his childhood, David said he had "*nervous tics*," was "*neurotic and emotionally disturbed*," and "*very obsessive and anxious*," but had no treatment. He said that he failed his "A" levels (the main school-leaving examinations at age 17/18) because of a big row between his parents at the time.

Throughout much of his 20s David had been a smoker, a comparatively heavy drinker reaching a maximum intake of 40 units or so a week in his early 20s, a regular weekly user of marijuana, a regular monthly user of "speed" (Amphetamine), and a regular weekly consumer of "magic mushrooms" when they were in season. He had taken cocaine more than weekly for a period of 6 months in his early 20s. But by the time he was interviewed he had given up smoking, cut his drinking down to around 20 units a week, and had stopped taking all other drugs. He had worried when he left university that for a couple of years he was drinking a lot as an integral part of his social life. Now he felt in no danger from drinking and enjoyed it, although he did not like spirits and thought he never would. Because of his father, he felt drink was more "*an issue*" with him than with other people, and also being a "*nervy*" type of person who tended to "*go the whole hog*" with anything, he used to drink quite a lot and as stated, he had taken a lot of drugs in the past, although he took no drugs now because he felt that it was "*totally incompatible with my work and my lifestyle*."

David did think that there were a number of elements in his life that were related to his upbringing. He was concerned that a theme in his relationships with women was his tendency to play the "*role of rescuer*," and he worried that he undermined his partner's independence by being too protective. He did have friends and was particularly positive about a relationship with one male friend whom he described as having a "*more female outlook*" on life—David had always felt closer to women or to men with a feminine outlook, he said. He said that his upbringing had made him more self-critical, sensitive, quiet, and shy, although he recognized that he had gone through a phase of being "*rather brattish and arrogant*."

Key Themes Highlighted by David's Narrative

- Very long-standing problem;
- Inconsistent parenting, especially from his problem-drinking father;
- Problematic parental relationship;
- Violence and aggression at home, scared about violence, feeling unsafe;
- Tension, anxiety, insecurity, negative effects on schooling;
- Uncertainty about how to cope;
- Not revealing the situation to others;
- Careful about his now-adult alcohol use.

1.4 Sunil, an Adult from an Indian-Origin Family, Affected by His Father's Alcohol Use

Sunil is 53 and lives with his wife, Rekha. Their children Usha (21) and Ashok (19) have left home for work and university, respectively. Sunil's father, Ramesh, is 82 and has recently had a fall that resulted in a hospital admission. On his discharge from hospital, he moved into Sunil and Rekha's home as he was not able to look after himself. Ramesh is an independent person and is quite resentful of having to be "looked after" by someone else. Since living with them, Sunil is now more aware that his father has been drinking quite a lot. The hospital implied that the fall was caused because Ramesh was drunk, and they advised Sunil and his wife to get Ramesh some help for his drinking.

Sunil mentioned this when he took his father to his general practitioner (GP) for a check-up and to get some more painkillers. The GP was unsure how to respond in terms of getting Ramesh some help as Ramesh himself was adamant that he did not have a "drink problem" and does not want to talk about it with either Sunil or the GP. As Ramesh cannot get out of the house very well, Sunil and Rekha buy alcohol for him. Sunil has tried to "cut down" the amount that his father drinks by buying less but Ramesh was quite abusive when Sunil tried to do this. This upset Sunil as he felt he was trying to "control" his father who was already feeling really stressed because he did not like being looked after and was drinking to deal with this. However, Ramesh's drinking and behavior is also causing rows between Sunil and Rekha.

Rekha is feeling the strain of looking after her father-in-law who is very demanding. She has very little space to herself as he is constantly calling for her before she goes to work and as soon as she gets home. She is feeling tired and rundown and has begun to suffer regular headaches. Ramesh has also become increasingly aggressive toward her. Recently, on helping him prepare for bed, she tried to tell him that she was getting looks when they went to buy his alcohol in the local shops. She told him she had heard people whispering that it was Sunil that was drinking too much. On hearing this Ramesh became verbally abusive and slapped Rekha causing her to fall over and hit her head on the bedside table. On finding out, Sunil had words with his father and told Rekha that he was sure his father did not mean it and she should not have raised his drinking.

Rekha's injuries resulted in a black eye, and she had to take a few days off work because of her injuries. The neighbors have commented on it and on the rows that have happened in the house. Rekha is angry with Sunil for his lack of support and their relationship has started to deteriorate. When they talk about the problem, they end up rowing. Rekha is starting to stay later at work and is trying to be out of the house as much as possible after dinner. She has been able to talk to Usha on the phone, but she feels disloyal doing so.

Sunil is torn between helping his father and asking him to leave because of the impact it is having on his relationship and home life. He believes his father is not trying to be awkward, but he does not realize the impact his behavior is having on everyone. Sunil does not feel able to talk about what is happening to anyone. Sunil and Rekha have tried to talk to Ramesh to get him to see how the whole community is talking about

them but he says that if he was not living with them and having to cope with the humiliation of being looked after he would not need to drink.

Sunil makes excuses for his father, but he has also pleaded with him to drink less. Rekha has decided to have as little to do with her father-in-law as possible but she believes that he will never leave and the problem will never get any better.

Key Themes Highlighted by Sunil's Narrative

- Hidden alcohol problem, unacknowledged by the father;
- Family arguments related to drinking: its effects, attempts to restrict, etc.;
- Some violence and aggression at home, feeling unsafe;
- Different coping strategies, none very effective;
- Symptoms of strain: tension, headaches, tiredness;
- Impact on relationships, between couple, with father-in-law, within the community.

1.5 Huia, from a Māori Family, Affected by Her Husband's Alcohol Use

Huia is in her early 40s and married to Paul who is in his late 40s. They have two teenage children, Sam (16) and Mark (14), and also have Ariana (12), Huia's niece, staying with them temporarily. Paul's drinking has been heavy for about 10 years. Recently, it has been causing friction at home and his job is at risk. Paul's boss has warned Paul that he may lose his job and Huia is unsure how they will make ends meet. He has been in a detoxification unit once about a year ago but was not able to stop drinking.

Huia feels desperate and, after speaking with her whānau (extended family group), was encouraged to see her GP for depression; she has been signed off from work for a while now. She also went to see her kaumatua (elder) for Karakia (prayer and spiritual support), which is common practice in her whānau when the Wairua (spirit) has been negatively affected. She worries about Paul, his health, and the future of the family, including Ariana, as she is the eldest sister in her whānau and it is important that she is a good role model for her younger siblings. Huia is really worried about how the children are affected. They hardly talk to each other or do things as a family or whānau. Mark is always arguing with his father. Huia finds him more difficult to control and worries because he spends more time away from home. Mark feels that Paul is not a good father, and he keeps telling her that he is "bad news" and to "get rid of him." Sam is responsible and older than her years. She appears calm and collected but deep down feels a sense of fear about what might happen to her father and the family.

Initially, Huia thought that she could do more to deal with the problem. She used to talk to Paul about the situation but found it difficult not to cry or become angry. All that resulted in was Paul drinking more and she would just end up having to clear up after him. Now, she avoids him a lot and leaves him alone, especially if he has been drinking. She finds it difficult to come to terms with how she responds to the problem. She feels very angry with Paul but also cares for him and is worried about the future.

Huia's mum lives close by. They get on well, but she is now in poor physical health and Huia does not want to trouble her with her problems even though her mum knows that something is wrong. Paul is close to his mum; they see her a lot but Huia and her do not get on. She is always criticizing Huia and telling her how to run the family. Paul's father lives further away; he tries to be supportive, but Huia feels too ashamed to talk to him.

Huia has tried going to Al-Anon but found the meetings really upsetting and felt like she was being disloyal to Paul. Huia has thought about taking her whānau friend but is worried about sharing her problems with the other members of the group, many of whom are Pākehā (White) and have no links to her whānau. Huia is becoming more and more desperate and lonely. She feels hopeless and takes medication for her depression. She cannot afford to be off sick from

work for too much longer. She used to feel that she wanted to fight for her marriage but now has little hope that anything will change.

Key Themes Highlighted by Huia's Narrative

- Friction and arguments at home, job at risk, potential financial problems;
- Husband has had treatment, but still drinking;
- Symptoms or strain: worry over husband and children (boy, out of control); desperate, lonely, hopeless, depressed, signed off work;
- Different coping strategies, none very effective;
- Some support from extended family, but variable;
- Tried Alanon but "disloyal."

1.6 Sandra, from an American Family, Affected by Her Husband's Alcohol Use

Living with my alcoholic husband is one of the most challenging experiences I have ever faced! The unpredictability of his behaviour, his mood swings, his irrational thinking—all of this makes it difficult to maintain a stable home environment. I always find myself 'walking on eggshells', never knowing (but always worried about) how he will react to a situation or to anything I say!

It is emotionally draining to watch this man, who I love (or who I used to love …) struggle with addiction. And the shame, and guilt, and embarrassment that I feel when his behaviour causes him to harm either himself, or others, are overwhelming.

I feel isolated and lonely. I feel very hesitant to share my struggles with either my friends or members of my family members—I suppose I fear that they will judge me and find me wanting—and I know how much stigma there is about alcoholism.

The intimacy and trust in our relationship has been severely affected by his alcoholism: he has neglected his responsibilities, he has prioritized drinking over spending time with me, or any of his so-called 'loved ones'! In fact, he has become emotionally quite distant. So now I generally feel resentful, and angry, and mistrustful—and all of that just erodes our relationship even more!

The toll on my physical health is also pretty big! His alcoholism has caused us a lot of financial problems, and that has leads to me feeling very stressed and anxious, and to my sleep being really disrupted. I feel really tired—well, chronically fatigued really—and that has affected my ability to get even simple day-to-day tasks done!

I've read about this, and I think that dealing with him has meant that I have become 'codependent'! I feel responsible for his behaviour and I take on his burdens; and that just seems to make my feelings of guilt, and anxiety, and depression worse—so we've got this vicious cycle, where things just seem to get worse.

I try to keep this from as many people as I can, as I am so ashamed of it all. A friend said I should get help, but I don't know who can sort his drinking out! I've heard of Al-Anon, but I hate the thought of sitting in a circle, running my husband down! I just don't know what to do!

Key Themes Highlighted by Sandra's Narrative

- Unpredictability of his behavior, his mood swings, his irrational thinking;
- Intimacy and trust reduced;
- "Walking on eggshells," emotionally draining;
- Symptoms of strain: resentful, angry, mistrustful, shame, guilt, embarrassment, financial problems, very stressed, anxiety, depression, sleep disrupted, chronically fatigued, isolated, and lonely;
- "Codependent"—feel responsible for his behavior;
- Very hesitant to share this, try to keep this from as many people as I can;
- I just do not know what to do.

1.7 Malcolm and Lynn, Two Parents (and Grandparents), Affected by Their Daughter's Drug Use

Malcolm is 52 and married to Lynn. Their 18-year-old daughter Sylvia is currently living at home, with her 1-year-old son, Jamie. Malcolm feels rather desperate and has recently experienced difficulty sleeping during the night. During the last 3 years, Malcolm has witnessed the unfolding story of his daughter's drug use. It started as a series of events that made him think that something was not right. At that time, Sylvia was living with them, and her moods were becoming increasingly difficult, but Malcolm thought that it was all part of growing up and that it would sort itself out.

Time has proven him wrong. The first shock came when Malcolm saw track marks on Sylvia's arms and hands and with it came the realization that she was injecting drugs—although he remains uncertain what drugs she is using: "*I don't really know what Sylvia is using—although I know she has used heroin at times as once she got help to come off it—it didn't last!*". In the last 6 months, Sylvia has been arrested on a number of occasions for shoplifting. Malcolm thinks that this is related to her need for money for drugs.

After Malcolm found used needles in the house, he confronted Sylvia. He remembers that he was very upset at the time, but her reaction was rather surprising to him. She was very matter of fact and replied that he should have broken the ends before throwing them away.

Sylvia is very difficult to live with, her moods are very changeable, and she is often rude and irritable. At times she seems like a loving mother to Jamie, her 1-year-old son (and their grandson), but at other times she seems rather dismissive of Jamie and leaves a lot of the looking after of him to Malcolm, and especially to Lynn. And at other times, she gets very low: deep down Malcolm wonders what he has done wrong as a father for Sylvia to be in this situation. He feels at a loss and unsure as to how to respond. When he tries to sit down and talk to Sylvia, their conversation normally "*degenerates*" into an argument. On one occasion, he become so frustrated that he said to her "*I haven't got a daughter now*." He felt very upset after this event and wished he had not said that. If he stays away from her, he worries to the point of not being able to think about anything else. Strangely, Malcolm can relax more when he knows that Sylvia is upstairs even though she is usually in a bad state. At least he knows that she is not "*out there*."

Malcolm is finding it increasingly difficult to concentrate at work, but although he knows it is affecting his job, he has not discussed the situation with anyone at work—he feels it might create problems, and anyway, it is a very private matter. This makes him feel isolated. Lynn is also very worried but she deals with the situation in a different way. She tries to support Sylvia and does not talk about the use of drugs. At times, Malcolm and Lynn have had disagreements as to how to deal with Sylvia and this has created further tension in the home. Both are, however, very careful to avoid talking to anyone about the situation as they feel a great deal of shame. Both are also really worried about any potential Social Work involvement, in case Jamie is taken away and put "into Care."

It is not all bad—on one occasion Sylvia came off the drugs and Malcolm felt as if they had recovered their daughter, although the process of coming off was difficult. She came off heroin with the help of the doctor who prescribed some medication and something to stop her feeling sick. It was a bad time for everyone at home, but when she came through the withdrawal, she was completely changed. However, then, it took just one party for the situation to revert, and the shutters came down again. Today Malcolm feels desperate. Recently, he has broken down a couple of times at work. He does not know where to turn.

1.8 Helen, Partnered to Alex, a Man With a Serious Gambling Problem

Helen and Alex, both in their late 40s, have been together for 5 years. Helen has two children from a previous marriage; Jess who is 16 years old and Joe who is 14 years. Helen did not know that Alex gambled, until the day she received a call from the local A & E department. Alex had taken an overdose of paracetamol while Helen had gone out with Jess and Joe to the cinema. Alex had called the ambulance and been rushed into hospital straight away for emergency care and had to stay overnight.

Alex had been depressed for over 2 years and was getting better ("*or so I thought*" as Helen says) since starting the antidepressant medication prescribed by his GP. "*What I hadn't known was that he had started gambling at about the same time that he got depressed*," initially as a self-medication, to "beat depression," as he put it. Initially he would only bet on a few football matches over the weekend but gradually he started gambling more and more. He would play online poker, often at night, after Helen had gone to bed. Later, he also started to gamble while at work, on the office computer, and had been warned twice by his office supervisor. As a result of his gambling, he had amassed over £30,000 in debts, and all this while Helen was unaware of Alex's problems.

Alex had felt he would win the money back soon, and hence continued to keep his gambling problem to himself. He felt Helen would be disappointed in him if he told her. Eventually, the pressure got so strong for Alex that he decided he would be better off dead, so he took an overdose. On hearing this, Helen felt a massive rush of conflicting emotions—she felt upset, guilty, angry, and helpless. Helen was concerned about the impact on her two children's relationship with Alex if they came to know about his suicide attempt and his gambling. She was also worried about the debt they found themselves in. Helen had planned on supporting Jess financially in continuing her education at university: "*I don't know how were going to be able to do that now!*". Both children had a difficult year ahead with exams and Helen also had noticed that although Jess had spoken to Alex since his return from hospital, Joe seemed quite withdrawn and was spending more time in his room on his computer. All in all, "*I feel that I'm caring for three children not two!*" and was unsure how she would manage to support them in the coming months.

Key Themes Highlighted by Malcolm's Narrative

- Daughter: very difficult to live with, very changeable moods, rude, and irritable;
- Daughter: inconsistent parenting to her 1-year-old son;
- Malcolm: symptoms of strain: feels desperate, shock, upset, worry, difficulty sleeping, concentration difficulties at work, feels isolated;
- Questions his own parenting;
- Arguments when raises the issue;
- Disagreements with partner over how to deal with it; tension between them;
- At a loss and unsure as to how to respond; not discussed with anyone; shame; worry over grandson being taken into care.

Key Themes Highlighted by Helen's Narrative

- Shock to discover husband gambled; he was also depressed; attempted suicide;
- Shock to discover significant gambling debts;
- Conflicting emotions: upset, guilty, angry, and helpless;
- Concerned about impact on her children; about the debt; about impact on future plans;
- Unsure how she will manage in the coming months.

1.9 Wendy, Married to Trevor, Who Has a Gambling Problem

Wendy is 34 years old, has been married to Trevor for 6 years, and they have a son James who is two and half years old. Wendy first found out about Trevor's gambling on the eve of their wedding day when she found out from her parents that he had stolen from them, using the catering money for the wedding, for gambling.

Since that time Wendy describes how she has "*been on a 'roller-coaster'*" in her marriage, initially believing Trevor that he had stopped gambling but then finding out on several occasions that he had continued or restarted. They are approximately £20,000 in-debt (or maybe more) due to Trevor's gambling—a situation Wendy has not been in before.

Trevor is a train driver and works shifts. He bets at the bookies during the day when there is free time before he collects James from nursery. Wendy says, "*I check his pockets for betting slips when I get back from work, especially if I haven't been able to speak to Trevor during the day*." Wendy feels that Trevor just cannot be honest about his gambling. They also have a computer at home, and Trevor now also logs into the world of online gambling. When Wendy realized that this was happening, she confronted Trevor—he said that it was even more difficult than betting at the bookies, because "*You don't even see the money when you gamble online. You use your card, and before you know what's happening you're placing higher and higher stakes and losing so much money*." Trevor describes how his online gambling online escalated: "*the video poker games were the worst for me – I just spent more and more money and time on them, and lost loads of money, which made me feel really physically ill—physically sick—and the more I lost, the more I wanted to win back the next day what I'd lost. I did have some wins of course, but they never matched what I'd lost.*"

Trevor agreed that he needed help with his gambling and has attended Gambling Anonymous. Now, Wendy supports Trevor by having complete control of their finances, but that is difficult for both: she feels resentful at having to manage all the money and Trevor feels frustrated with having to ask for money and explain why he wants it. This has meant there have been several arguments and Wendy has noticed their son getting upset in response to seeing and hearing these.

Wendy has a very close family but feels that she cannot talk to them about Trevor's gambling: "*I don't want them to think badly of Trev, and I don't want to rake up the past—they think his gambling before their wedding was a one-off, as he was stressed about getting married*."

Wendy currently feels very low, pressured to work extra hours to earn more money, and isolated from her family who do not know the extent of her husband's gambling. She is doubting herself both as a mum and as a wife, and feels helpless about her situation. She loves Trevor very much and feels if they could just sort out the gambling then everything would be okay.

Key Themes Highlighted by Wendy's Narrative

- Major debt; loss of trust; now she controls the finances;
- Husband has tried Gambling Anonymous;
- Arguments at home, impact on son;
- She feels resentful, very low, pressured to work longer hours to earn money;
- Doubting herself as wife and mother;
- Feels cannot talk to family, so feels isolated;
- Feels helpless.

1.10 Conclusion

What we have tried to show through these various "snapshots" or "personal accounts" is how unique each family is, as well as how there are recurring themes (shown in Box 1.1) that run throughout these narratives. Many readers will understand how family members can feel upset and bewildered by the behavior of a loved one, how they can feel very uncertain over who to tell

or discuss the issues with, and over how best to react to the person who is drinking or taking drugs or gambling in ways that cause the family these uncertainties. On the other hand, some of the reactions to and behaviors of the affected family members recounted in these narratives might be harder to understand. Primarily, we hope that these personal accounts might provide a bridge to put the chapters to come into context.

Box 1.1 Recurring Themes Throughout These Narratives

- Sometimes very long-standing problems;
- Problem often hidden, certainly from outsiders;
- Inconsistency, unpredictability, trust reduced;
- Frequently: arguments; often aggression; sometimes violence;
- Impact on relationships, leading to problematic relationships;
- Financial problems;
- Symptoms of strain: very stressed, worry, tension, anxiety, depression, headaches, sleep disrupted, tiredness, insecurity, resentful, angry, shame, guilt, embarrassment, shock;
- Self-doubt, doubts about role competence;
- Isolated, limited family or social support, not revealing the situation to others;
- Uncertainty about how to cope, helplessness, "I just don't know what to do."

Cases Drawn From:[2]

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2. Templeton L, Velleman R, Velleman G. Responding to alcohol, other drug and gambling problems in the family: a handbook for practitioners trained to deliver the 5-step method. 4th ed. (and previous editions, plus New Zealand self-help edition: *Alcohol, drugs, the family, whānau and you*, co-revised by Makua Raki, Velleman, R. and Velleman, G.). UK; AFINet; 2021.
3. Velleman R, Copello A, Maslin J. Living with drink: women who live with problem drinkers, Reissued Edition. London: Pearson Education (original edition, London; Longmans); 2007.
4. Velleman R, Orford J. Risk & resilience: adults who were the children of problem drinkers. London: Harwood; 1999.

Further Reading

Orford J. Addiction dilemmas: family experiences from literature and research and their lessons for practice. Chichester: Wiley-Blackwell; 2011.
Velleman R, Copello A Maslin J. Living with drink: women who live with problem drinkers, reissued edition. London: Pearson education (original edition, London; Longmans); 2007.
Velleman R, Orford J. Risk & resilience: adults who were the children of problem drinkers. London: Harwood; 1999.

[2]Plus the personal accounts posted on the websites of various online organizations (all changed sufficiently to ensure anonymity).

2 Addiction-Affected Family Members (AFMs): A Group of Colossal Size World-Wide

Gallus Bischof and Anja Bischof

2.1 Introduction

Most knowledge about the negative effects of addiction-type problems on family members stem from generally small-scale qualitative studies of populations recruited via media or treatment settings (including individuals known by health care providers to be affected by someone else's addiction-type problem), as outlined in most chapters of this book. While these studies give valuable insights into the stress and strain that addiction-affected family members (AFMs) suffer from, it is unclear how generalizable these findings are to all AFMs in the general population, and how addiction-type problems in the family contribute to the Global Burden of Disease. In order to estimate the public health impact to family members of these problems, it is crucial to quantify the extent of the problem using a population-based approach.

Past research focused primarily on children affected by parental addiction-type disorders [1] (see Chap. 5). Interest in quantifying the public health relevance in adults based on prevalence estimates, with a main focus on alcohol-related problems, increased when the World Health Organization (WHO) in 2010 introduced 'Harm to Others' (HTO) as a priority component of the Global Strategy to Reduce the Harmful Use of Alcohol [2]. However, in the literature on AFMs, prevalence estimates show considerable variability. A major source of variation is how AFMs are defined. First, there is considerable variability in definitions over what constitutes a family member (e.g. only family members living together vs. all nuclear family members vs. all blood relatives and partners vs. individuals with close bonds to the individual with addiction-type problems). Second, different definitions are used as to what constitutes addiction (e.g. any kind of substance use or gambling/gaming problems vs. only individuals meeting criteria for addiction-type disorders according to ICD-11 or DSM-5 vs. individuals showing disordered behaviour; and individuals meeting ICD-11/DSM-5 criteria vs. those defined by an FMA as having 'a problem'). Third, definitions vary widely regarding what constitutes 'being affected', ranging from unpleasant experiences to severe, sometimes life-threatening situations and living conditions.

Given that the negative effect of parental addiction-type problems on children has been a prior concern in the addiction field for decades (see Chap. 5), several studies have been conducted to estimate the number of children affected in the general population. A common strategy to estimate this number is to analyse sociodemographic variables of individuals identified to have an addiction-type problem in the general popula-

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tion, and then use a 'multiplier' to calculate the number of affected children. Estimating the rate of adults who are exposed to addiction-type problems is less straightforward, especially since qualitative studies show that many adults affected by someone else's addiction-type problem do not necessarily live together with the individual whose behaviour is seen as problematic. Here, we can distinguish between studies that have focused on 'harm to others' (often unpleasant experiences that result from being exposed to intoxicated individuals, where these individuals may have addiction-type problems, but equally may simply be intoxicated) and studies that have estimated the prevalence of family members affected by addiction-type problems either on the basis of prevalence rates for addictive disorders or by asking adults from the general population if they have someone close to them with these kind of problems.

2.2 Research on Children Affected by Addiction-Type Problems

Effects of substance use on others initially focussed on children affected by parental substance use problems. These children are known to be vulnerable to various problems during their childhood and later, including developing substance use problems of their own as they reach adolescence (see Chap. 5). Usually, the number of children affected by parental addiction is estimated using epidemiological data on adult respondents showing signs of substance use disorders and the number of biological, step, adoptive, or foster children aged 17 or younger living in the respondent's household; and whether another parent is also living in the respondent's household at the time of the interview [3].

Based on data assessed between 2002 and 2007 on an annual basis from the USA National Survey on Drug Use and Health (NSDUH), it is estimated that in the United States alone, 11.9% of all children aged 18 or less lived with at least one parent who was dependent on or 'abused' alcohol or illicit drugs according to DSM-IV [4], equalling more than 8.3 million children. The majority of these children were affected by alcohol only (6.2 million), 1 million were affected by illicit drugs only (no data on specific substances provided) and 1.1 million were affected by both alcohol and illicit drugs. The estimated prevalence of substance abuse disorders in the general population aged 12 or older according to NSDUH was 22.3 million individuals, suggesting that in the field of alcohol or drug-related addiction-type problems, the number of children affected is about 35–40% of the number of adult individuals suffering from addiction-type problems. Data from the NSDUH surveys conducted between 2015 and 2019 [5] that used a different methodology for defining addiction-type problems and therefore cannot be directly compared to the 2002–2007 data indicate that the number of children affected in this time span was 6.5 million for any substance use disorder, with the largest number of children affected by a parental alcohol use disorder (5 million), followed by marijuana use disorders (0.87 million) and opioid use disorders (0.72 million). The differences between the number of affected children according to different substances reflect methodological changes in the NSDUH-assessment introduced in 2015, but also the impact of the opioid crisis in the United States that escalated from 2015 onwards.

A German representative study estimated the proportion of children living in a household with at least one adult with a substance use disorder (alcohol or illicit drugs) according to DSM-5 to be between 5.3% and 9.8% of all children, which equals approximately 1 million children [6]. It has to be noted that other addiction type problems (prescription drugs, gambling) were not included in this estimation. The corresponding number of alcohol and illicit drug use disorders in the adult sample was 10.1%, equalling 3.5 million individuals.

In line with data on treated populations in high-income countries, the share of children exposed to parental addiction-type problems is lower compared to the share of children in a reference group of individuals without these problems, indicating a lower reproduction rate in individuals with addiction-type problems. Still,

both studies suggest that it can be roughly estimated based on the ratio of estimated number of children and estimated number of adults with substance use disorders (SUDs) that every second to third individual with addiction-type problems is at least temporarily living with a child.

2.3 Research on Adults Affected by Addiction-Type Problems: Harm to Others (HTO)

One approach used in epidemiological surveys to quantify the problem is to ask representative samples if they have experienced any negative effects due to others' alcohol or drug use or gambling and specify the type of harm.

In the same way that the idea of 'second-hand smoke' has been shown to be a powerful tool for establishing tobacco control policies, this related idea of 'alcohol-related harm to others (AHTO)' has been investigated with large and often representative samples. Most studies mainly assessed a wide range of possible immediate consequences arising from the drinking of others, such as substance-associated traffic accidents, substance-induced violence, or subjective negative experiences such as feeling threatened or unsecure as a consequence of someone else's alcohol use [7].

Many studies have differentiated between AHTO experienced from strangers and AHTO from known people. The beginning of the AHTO paradigm was a large-scale study conducted in Australia in 2008, indicating that up to 70% of all Australians have been negatively affected in one way or another by someone else's drinking during the previous 12 months [8]. When asked if someone has been negatively affected by 'a household member and/or other relatives and friends', they considered to be 'a fairly heavy drinker, or someone who drinks a lot sometimes', more than one quarter of all respondents still reported negative effects, with the highest number in younger age groups. Respondents also rated how much the behaviour of the drinker affected them, on a scale from 'a little' to 'a lot'. Among adult Australians, altogether 9% reported that they were negatively affected 'a lot' by the drinking of a household member, relative or friend. Compared to men, women were more likely to have been affected 'a lot', but the differential between men and women in each age group was marginal for those reporting being affected 'a little'. In the time since this seminal study was undertaken, several other large-scale studies on AHTO have been conducted in various countries, usually showing a similar distribution in the general population [9].

Following the AHTO paradigm, harm to others was also researched in the field of illicit drug use and gambling, albeit less extensively. For use of illicit drugs, a study conducted in four Nordic capitals (Oslo, Copenhagen, Helsinki and Stockholm) among participants aged 18 and above showed that more than half of the respondents on a lifetime basis had known and worried about the drug use of someone they knew [10]. Differences between countries reflected the different prevalence rates of illicit drug use. When asked about the severity of harm, a significant minority of respondents (10%) reported a score of 5 or higher on a scale from 0 to 10, indicating that about 5% of the adult population of these countries had been significantly affected by someone else's drug use. Self-reported harm was elevated in females and in individuals where the drug using individual was a family member. Furthermore, self-reported harm was positively associated with the number of known drug users.

For gambling problems, again prevalence rates of 'concerned significant others' exceeded the number of individuals with gambling problems. Data from Australia including an assessment of emotional and relationship harms showed that up to 6% of the general population report to have been negatively affected by someone else's gambling, and negative consequences were most strongly pronounced in intimate partners, followed by other family members, while non-family members reported a lower quantity of harm [11].

These studies are very useful in identifying the range of negative experiences due to the intoxicating use of substances and/or gambling and also often show a high incidence of such experiences, e.g. for alcohol alone, between 25%

and 53% [12], with most studies consistently showing that people reporting these negative experiences are more likely to be younger, more often single and are more likely to report risky consumption patterns of alcohol or other intoxicants themselves. Within subjects experiencing HTO, effects on self-rated health increased with the number and severity of problems and proximity of the known substance user [13–15]. However, measures used in the majority of studies on HTO do not specify if these harms are caused by a family member, nor are they restricted to symptomatic use of substances or gambling, i.e. to 'addiction-type problems'.

2.4 Effects of Others' Substance Use on Mental and Physical Well-being

Most studies assessed only a self-rated degree of impact on personal well-being and compared subgroups of individuals reporting HTO; but a few studies compared health-related variables in individuals experiencing HTO to individuals reporting no HTO: all these studies were restricted to alcohol-related harm. In general, being exposed to heavy drinkers was related to lower self-rated health and lower quality of life and/or well-being, increasing with the number of known heavy drinkers and the number of types of harm. Not unexpectedly, these problems are more pronounced in more closely associated relationships or in individuals living in the same household as the heavy drinking person. According to a newer study conducted in Australia, 5.8% of all respondents reported being 'affected a lot' by a drinker they knew; however, again no clinical outcome measures were assessed [9]. Furthermore, neither the type of relationship/acquaintance with the drinker nor any meaningful clinical measures of strain/impairment were assessed. However, qualitative interviews conducted with a subgroup of survey participants who endorsed items stating that they had been affected 'a lot' due to someone else's drinking, reported distinct and more severe types of harm, suggesting that the assessment of degree of harm in surveys in general is valid, although respondents named quite heterogeneous experiences [16].

Studies that did control for the participant's own alcohol intake suggested that individuals with their own problematic alcohol use tended to be more severely affected, although findings were inconclusive [17].

These findings above suggest two things. The first is that studies of HTO often capture rather immediate experiences, often from individuals who are themselves risky users of substances. The second is that items used for assessing HTO in surveys typically measure type of harm and not severity. A recently published analysis based on a survey of leaders of such national alcohol surveys suggested that further studies should focus in more detail on the harms with a perceived high severity [18].

Some epidemiological studies are available that used a more problem-oriented definition of interpersonal harm caused by problematic substance use, i.e. examining consequences resulting from someone's pattern of using substances as opposed to consequences following single episodes of use. According to data from the 1992 National Longitudinal Alcohol Epidemiologic Survey (NLAES), 25–38% of the general population in the United States reported having a blood relative with an alcohol problem [19], and approximately 30% of adults indicated that alcohol use had caused difficulties within their families. In addition, just under 20% reported similar difficulties regarding other drug use. Although no in-depth information on the type of difficulties was assessed, these numbers give a first estimation of the degree of the problem, with results being in line with estimations from HTO studies.

One approach that focused more strongly on both the pattern of substance use and the type of relationship was conducted in Switzerland. In a nationwide representative population survey (n = 2,469), individuals aged 15 years or older were asked if they were aware of alcohol- or drug-related problems (defined as regular use of illicit drugs or daily or symptomatic consumption of alcohol) in their social network [20]. Alcohol-

or drug problems in the social network (including friends and coworkers) were endorsed by 36.8% of all respondents, with 14.4% of the entire sample reporting that a family member had an alcohol or drug problem. Most respondents with family members with alcohol or drug use problems (6.1% of the entire sample) mentioned that the individual with the drug/alcohol problems was a distant relative (aunt, uncle, cousin, etc.), with siblings also being mentioned quite often (3.9%). Fathers were mentioned more often (2.5%) than mothers (0.8%), and children were mentioned less often (1.1%). Having a partner with an alcohol or drug problem was mentioned by 1.5% of the sample. Regarding strain caused by the alcohol or drug problems of others, 21.2% of respondents facing alcohol problems stated they were strongly or very strongly burdened. The corresponding number for drug-type problems was 24.7%. These numbers suggest that about 7–8% of the population report to have been strongly or very strongly burdened by drug or alcohol problems in their social network. Only a minority reported that they sought help themselves for dealing with the drug or alcohol problem of their relative (8.7% and 3.9%, respectively). Individuals reporting to have sought help most often consulted a psychologist, followed by addiction counselling centres and informal sources. Like in the studies on HTO, a rather broad definition of alcohol and drug problems was provided in this study, and no clinical outcomes regarding impairment were assessed. At the same time, this study gives valuable insights into effects of persistent substance use and abuse on third parties.

2.5 Prevalence of AFMs of Individuals with Specified Addiction-Type Problems

While there has been a plethora of studies on HTO in the general population, only a few published papers have tried to estimate the prevalence regarding the more severe spectrum of substance use and gambling. The method that Orford and colleagues used was to apply a multiplier to the estimated prevalence of addiction problems, in order to estimate the numbers of AFMs in the general population [21]. According to their widely cited paper, if it is assumed, cautiously, that on average one adult is adversely affected by each case of addiction, then the number of AFMs worldwide may well be more than 100 million. Based on the data from Global Burden of Disease, the average global prevalence of substance use disorders (alcohol and/or drugs) is estimated to be 2.2% of the adult population [22], which would—as a rough estimate—equal 112 million individuals worldwide suffering from substance-related addiction.

Another methodological approach was chosen by Copello and colleagues [23] for the number of AFMs in the United Kingdom who do not have a dependence issue themselves, but who are living together with someone with an illicit drugs problem. Since AFMs usually are a hidden population, they extrapolated the number of AFMs in the general population, using prevalence estimates based on the relationship status of individuals treated for drug problems, which in most countries is below 10% of all individuals with drug use disorders. They estimated, in the United Kingdom, that the number of AFMs (mainly partners or parents) in the general population was nearly 1.5 million, about 140,000 of whom had a relative in drug treatment. The authors acknowledge that this number is a substantial underestimation of the size of the problem given that these figures excluded AFMs who were not living with the user, who of course can also be severely affected. Additionally, AFMs using drugs themselves were excluded from the estimation, although for some this might be a way to cope with the situation. Furthermore, the model was restricted to AFMs affected by illicit substances, while the prevalence rates of alcohol use disorders is far higher in the United Kingdom.

The estimates are useful in different ways. For example, the estimate of the number of family members of those in treatment is useful for the planning and provision of services, whilst the wider population estimate is useful for broader strategic planning of services for family members.

An epidemiologic approach was chosen by Bischof and colleagues [17, 24]. A first study proactively recruited 2273 patients aged 18–64 in general practices (response rate 81.4%) and general hospitals (response rate 88.9%) in three different regions of Germany and asked them if they had a relative with a current or remitted addiction-type problem (excluding tobacco), the type of addiction, as well as their relationship to the relative. From the sample, 15.6% named someone with an ongoing addiction-type problem and an additional 7.2% reported to have a relative with an addiction-type problem that was not active anymore in the last 12 months. People who self-identified as AFMs showed significantly elevated depression scores. The study gives a first insight into the prevalence of AFMs in primary health care. In a next step, the same questions were used in a nationwide representative population survey in Germany among adult individuals ($n = 24{,}824$). Of all respondents, 9.5% reported having been affected by a relative's addiction-type problem in the past 12 months, and an additional 4.5% reported having experienced these problems prior to the last 12 months. The vast majority reported to have been affected by someone's alcohol use disorder, followed by cannabis and then other illicit drugs, reflecting the prevalence rates of these disorders in Germany. The majority of AFMs (79.3%) reported having one relative with one or more addictive disorder, 14.1% named two relatives, another 4.6% identified three relatives. Less than 2% of the sample reported to have four or more relatives with addictive disorders. Compared to individuals not reporting to have been affected by a relative's addiction-type problem, AFMs showed significantly elevated depression rates, with 21% of AFMs reporting having a relative with current addiction-type problems showing rates of clinical depression and an additional 16.3% of AFMs with relatives who had past addiction-type problems showing clinical depression, compared to 8.6% of respondents reporting not to have a relative with such problems. This would equal approximately 3% of the adult population, which would correspond to the number of individuals aged 18–64 with a diagnosis of alcohol dependence in the general population in Germany [25]. The higher number of AFMs identified in health care settings is likely to be a result of elevated rates of morbidity and help seeking resulting from their FMA status [26, 27]. However, in both studies, no specific negative experiences of AFMs were assessed, and due to the cross-sectional assessment, no causal inferences can be drawn between depression and FMA status. Furthermore, qualitative studies show that AFMs experience a multitude of strain, indicating that focusing solely on depression certainly leads to an underestimation of the proportion of individuals impaired in other ways, due to addiction-type problems. Further, although the type of relationship was specified, no data was assessed regarding the amount of contact. Also, the definition of 'addictive disorders' in assessing FMA status relied on subjective estimations of the participants and was not clinically validated. Accordingly, they reflect the perception and knowledge of the participants, which is likely to be based on what they were able to observe about the behaviour of their relative(s) and the attributions they were then able to make about the relationship between these observed behaviours and the relative's use of substances or gambling.

2.6 Discussion

Studies focusing on harm to others as well as studies focusing directly on substance use and related disorders in the general population indicate that the burden of suffering from these problems on third parties is substantial. Data from high-income countries on the number of children (approx. One child for every two to three individuals) and partners (approx. One child out of every two individuals) of individuals with addiction-type problems already suggest that the number of AFMs more or less equals the prevalence rates of addiction-type problems in the general population. If AFMs are defined as individuals with recurrent negative experiences due to addiction-type problems and elevated levels of stress and strain, the data suggest that among family members (including partners), the prevalence tends to be slightly higher than the

prevalence of addiction disorders in the population. If close relationships outside of blood relations and partnership that also can have meaningful effects are also considered, it appears more likely that the number of individuals affected is at least twice the size of the prevalence of addiction-type problems. This estimate is also plausible given that about 10% of the general population in HTO studies reported to have been affected 'a lot' due to a relative's drinking and a similar number reported to know someone with an addiction-type problem that was active in the previous 12 months.

At the same time, data indicate that only a very small minority of AFMs seek help to improve their situation. All studies that have focused on harm to individuals who are closely connected to individuals with addiction-type problems indicate the need to improve services, and that this should become a public health priority. However, the proportion of individuals in the general population who need (and thus might improve through) such help, or who might take up such help if it was on offer, can only be estimated.

If problems related to single episodes of use by strangers are included, as in studies on HTO, prevalence rates of well above 50% in the general population suggest that harm, at least statistically, is rather 'normal', but usually levels of impairment resulting from this seems minimal as well. Furthermore, among people reporting single incidents of negative experiences, a substantial number reported elevated alcohol/drug use themselves, indicating that a part of these associations can be explained by interactions among subgroups of adults with heavy use.

The other extreme end of the spectrum includes family members that have been exposed to severe forms of violence or that have been bereaved through drug or alcohol use by a close relative (see Chap. 10), and prevalence rates here are substantially smaller, given that severe violence as well as unexpected premature death affects only a portion of individuals with severe addiction-type problems. These data indicate that the method used to ascribe who is regarded as a family member affected by addiction-type problems leads to tremendous differences in prevalence estimates. Data suggest that the more severe the addiction-type problem and the closer the relationship between the individual with addiction-type problem and the FMA, the more burden or problems are reported by the FMA. Figure 2.1 depicts the relationship between prevalence and strain as a function of severity of addiction problems and emotional closeness of the family member to the individual with addiction-type problems.

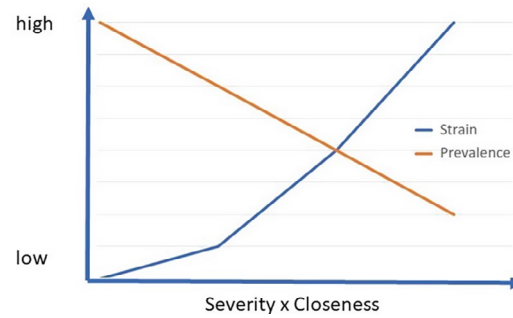

Fig. 2.1 Prevalence and strain as a function of problem severity and closeness

In general, the severity of burden on third parties appears to be strongly influenced by variables such as the severity and chronicity of the problem (single episode vs. chronic exposure), patterns of use and associated problems including pharmacological effects (see Chap. 7), cultural influences (see Chap. 9), the proximity and level of bonding to the person using (see Chap. 6) including AFMs' gender (see Chap. 8). Furthermore, qualitative research suggests that the coping mechanisms used by the AFMs and interpersonal factors, such as worries regarding the well-being and health of the using person, also impose stress and strain on AFMs that can result in clinically relevant impairment. In order to identify other moderators and mediators, more comparative studies using representative samples are warranted, and standardized questionnaires are available that assess central features of the Stress-Strain-Information-Coping-Support model that was developed based on qualitative research [28].

All studies conducted so far show some methodological problems and are restricted regarding their explanatory power. For example, since all studies have been cross-sectional, no causal conclusions can be drawn. However, a longitudinal study on the health care costs of several thousand spouses and children of patients receiving treatment for an alcohol or other drug problem with a matched control group showed significantly elevated medical conditions and associated health care costs at baseline and a reduction of family members' average healthcare costs to control group levels in years when their relatives had been abstinent [29]. Although restricted to a subgroup of AFMs (given that the majority of individuals with addiction-type problems never enter treatment), these findings indicate that AFMs' medical conditions are rather strongly correlated to the presence of addiction-type problems. Furthermore, given that a predictor of treatment entry is severity of dependence [30], it can be assumed that data based on treated individuals with addiction-type problems tend to overestimate the severity of burden placed on the average family member affected by less serious addiction-type problems. Other major methodological problems include the fact that there are no agreed definitions of problematic consumption or behaviour—for example, some surveys equating a single glass of beer or wine per day with 'symptomatic consumption' [20] or define problematic use/misuse of illicit drugs (such as cannabis) as 'any use' in the past 12 months [5].

Overall, more research is needed in order to study both the prevalence of family members in need of support, and the overall costs of addiction-type problems in the general population.

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3 Conceptual Models of Families Affected by Addiction and the AFINet Approach

Richard Velleman, Torkel Richert, Gallus Bischof, and Alicia S. Ventura

3.1 Introduction

As Chap. 1 (which provided some brief personal accounts) and many of the succeeding chapters in this book will show, living in a family where one member has an 'addiction-type' problem (related to use of alcohol or drugs or gambling) creates difficult situations for family members: they are often badly affected by this, hence the term 'affected family members' (AFMs).

There have been many suggestions put forward as to how and why AFMs are affected in the ways that they are: some of these models also relate to assumptions around the part that families (and individual family members) might play in the generation of the addictive-type problem, in its maintenance and its resolution. This chapter will outline some of the main perspectives. However, first, it is important to outline why this is an important question to examine.

The answer is that *how* we think about why a phenomenon occurs, influences everything we then go on to do. The preconceptions that we have influence what research is undertaken: what research questions are asked, what methods are used to answer these questions and how the results are interpreted. They influence what interventions we develop, what the popular discourse is about the phenomenon and whether the phenomenon is seen positively or negatively, sympathetically or prejudicially.

Hence, if (as *the coping perspective* does) we consider that AFMs are caught up in a chaotic situation, not of their making, and are simply attempting to cope with the changes that are taking place in their families as a result of someone else's addiction-type behaviour, then we are likely to be sympathetic to these people. However, if (as for example *the co-dependency* or *the*

This chapter draws on the structure and some of the content of Velleman et al. (1998/2007) Living with Drink [1], especially the chapters by Cottman [2], Fryer [3], Orford [4], Ussher [5], and Vetere [6].

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genetic perspectives do) we feel that the AFM has somehow 'brought it on themselves', where their own psychological (or even genetic) makeup and needs mean they are drawn inextricably into relationships where they become AFMs, or even cause the relative to develop or maintain their problems with alcohol or drugs or gambling in the first place, then it is likely that we may be less sympathetic.

If media representations are of AFMs in need of help and comfort, they will be less likely to be greeted in stigmatizing ways; but if they are represented as the cause of their problems, they are much more likely to be blamed and stigmatized.

This chapter will outline some of the main perspectives that have been used to describe the part that families (and individual family members) play in relation to the addiction-type problems of a relative. However, it is useful briefly to consider the history.

Much of the early work to understand AFMs role and experiences focused on blaming family members, specifically wives and mothers, for a male family member's alcohol use. This early work suggested that some women chose heavy drinkers as partners to meet their own unconscious needs [7]. This was termed the '*disturbed personality hypothesis*' and it suggested that being in a relationship with a heavy drinker removed attention from the woman's own inadequacies. As such, it was further suggested that such women would actively seek to stop the resolution of an addictive-type problem, and that if the drinker's problematic behaviour did stop, wives would then develop their own severe psychological problems, such as depression or anxiety. This was termed the '*decompensation hypothesis*' [8].

A great deal of work has gone on which refutes the ideas of both a '*disturbed personality*' and '*decompensation*', with later work demonstrating the same diversity of personality styles in women who live with addiction-type problems, as there are in all women (and generally, in all genders). More modern research has included family members of all genders and relationships to the person with addiction (e.g. parent, child, spouse, partner, sibling) and has sought to describe AFMs impacted by drug use and gambling in addition to alcohol. Such research has allowed new perspectives to arise for understanding the experience of AFMs and their relationship to a relative with addiction-type behaviour. However, many stigmatizing views of AFMs remain, and some of these ideas remain in *the co-dependency perspective* and more broadly, within the *psychodynamic perspective*, which are outlined later in this chapter.

A different perspective suggests that AFM symptomatology is most logically explained by considering the stress they endure. As addiction is often characterized by bouts of relative stability interspersed with sometimes frequent relapses, an enormous amount of uncertainty will remain even after family members appear to have stopped drinking, taking drugs or gambling. Concerns, for example, about whether this will be the last time, or whether it is safe to stop using the strategies that have helped the family survive for so long, will be present. Some AFMs talk of finding it difficult to go back to feeling the way that they had about their relative, particularly because of some of the things that their relative had said: '*although I know it's the drinking … you can't erase them when they're said*' (Ruth, [1], p. 29). In addition, the relative with the problem often receives all the praise when they manage to stop, with little or no attention given to the family members for enduring such hardship and keeping the family together. This acknowledgement of stresses resulting from living with a problem drinker was first proposed in 1954 [9]: we will discuss *the stress-coping perspective* later in this chapter.

Another way that people have conceptualized these issues is by looking at the relative's addiction-type behaviour within the family context. Steinglass et al. [10], writing from such a perspective, suggest that the excessive use of alcohol '*is a condition that has the capacity to become a central organising principle around which family life is structured*'. In this view, drinking is integral to the family system, maintaining rigidly established behaviour patterns. Again, we will discuss a *family systems perspective* later in this chapter. Other perspectives that

we will look at include a *feminist perspective*, and at the broadest level, we will discuss the issues from a *community/socio-cultural/political perspective*.

3.2 The Range of Perspectives

3.2.1 Genetic and Biological Perspectives

These perspectives will not be discussed in detail because this book is concerned with psychological and social perspectives. However, there are two varieties of idea here. The first is the generalized one: all activity is underpinned by brain activity, and much of that activity is also majorly influenced by our genetics. Hence, AFMs' responses when a relative develops addiction-type behaviour are also underpinned by brain and genetic mechanisms [11]. This would suggest that how an AFM reacts or copes with a relative who develops an addiction-type problem is influenced, or even determined, by their biological and genetic makeup, and these would be likely also to impact on AFMs' ability to cope with stress, as well as the risk of developing depression or other mental health problems related to being in a relationship with someone with addiction. The bio-genetic perspective might also suggest that there are individual vulnerabilities on the part of AFMs as to how resilient they are; these vulnerabilities might be affected by or even caused by biological factors. This idea might relate to the 'co-dependency' ideas described later, suggesting that certain people may have a genetic predisposition to develop relationships with other people who may have certain characteristics that make them more likely to go on to develop addiction-type problems.

The second set of ideas are more specific: that there are genetic causes underlying the development of addiction-type behaviours. As such, the children (and other family members who share genetic makeup) of people with these problems are at strong risk for developing the same or a similar addiction-type behaviour; or make it more likely that they will develop relationships with people with addictive-type problems [12].

3.2.2 Psychological Perspectives

3.2.2.1 Psychodynamic

Psychodynamic perspectives examine an AFMs understanding of their experiences in terms of patterns of behaviour (or thoughts or feelings), which are likely to relate to similar patterns laid down in the past [2]. Counsellors using this perspective would then encourage AFMs to reflect on these similarities, and have 'agency' to react in different ways.

Psychodynamic perspectives are concerned with four tenants.

1. Early experiences in relationships shape later experiences of ourselves and others and the ways of thinking and behaving that derive from that experience.
2. A key psychodynamic assumption is that many causes of a person's behaviour are unconscious, and that these unconscious causes can be identified by analysing the feelings or behaviour evoked in someone by their interaction with someone else who they are close to: in this instance, 'what are you feeling, thinking, behaving in relation to the relative with the addiction-type behaviour, and how does that relate to ways that you felt, thought and behaved in relation to key others in your past—parents, siblings, other key individuals?'.
3. Those behavioural and emotional interactions can thus be identified and observed, and hence thought about, reflected upon and brought into the area of awareness and choice, e.g. 'that's interesting—I am getting angry again: is it warranted by what is happening now? Even if it is, do I want to let it get to me so much?' etc.
4. This process of exploring one's experience with one's relative, and reflecting on it, is itself the effective agent in promoting or facilitating psychological change. This is in contrast to the 'successful' achievement of

particular preset goals or objectives: in effecting change, the acquisition of 'insight' is less important than the process of reaching or constructing that insight.

The psychoanalytic perspective would also argue that these processes outlined above, of drawing unconscious material into consciousness and then guiding reflection about them, requires the participation of another person, specifically a psychoanalyst, and that without their assistance, this realization cannot occur.

This perspective acknowledges that this process of noticing one's reactions and thinking again about one's experiences can often be difficult, but that the process involves realizing that we all have the power, however, limiting our circumstances, to look at ourselves and our lives differently, at the same time as accepting that we all have our 'reasons' for having done things the way we have, up until now. This self-dialogue and drawing of unconscious processes into awareness (with the help of a counsellor, often a psychoanalyst) can allow us to revise and amend our responses to what life brings us, and reconstrue ourselves and our capacities in the process. With a different sense of ourselves, we can then widen our options and find ways out of unproductive patterns of relating that are no longer necessary or appropriate [2].

3.2.2.2 'Co-dependency'

Although definitions of 'co-dependency' vary, it usually refers to a range of psychological characteristics among persons who are affected by a relative's problematic substance use, including an extreme focus 'outside of self' and on others' needs, being self-sacrificing and adopting dysfunctional coping aimed at preventing conflict or securing approval [13]. 'Co-dependency' is a term that has been used in addiction treatment and self-help groups since the 1940s, but the concept was popularized during the 1980s and 1990s [13]. It is usually claimed that a 'co-dependent' person becomes reliant on others' emotional fulfilment and adapts their social life, behaviours and thoughts to the person to such a large extent that they neglect themselves and their own needs [14].

Whether 'co-dependency' should become an official medical diagnosis has been debated. As early as 1986, psychiatrist Timmen Cermak [15] defined 'co-dependency' as a diagnosable disorder with a set of distinct symptoms and argued for the inclusion of co-dependency as a separate personality disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM). However, 'co-dependency' has not been accepted as a diagnosis within the mental health community and has not been included as a medical condition in any edition of the DSM or International Classification of Diseases (ICD).

Advocates believe that a diagnosis can mean that AFMs' problems are taken more seriously, that their rights to assistance are strengthened, and any resulting support can be better adapted to their needs. Identifying oneself as 'co-dependent' can also be a way of seeking an explanation, and a remedy, for one's problems, as the label can provide access to an identity with ready-made symptoms, causes and possible solutions, something that can also involve reduced feelings of guilt and shame [16]. Critics of 'co-dependency' [17] cite the lack of a clear definition of the term, that no specific personality type can be distinguished among relatives of people with addiction, and that the concept pathologizes support and care for a loved one. Critics [18] also argue that behaviours of AFMs are best understood as a reaction or adaptation to an extreme and stressful situation, and that the experience of being 'co-dependent' is relational, rather than emanating from individual psychological characteristics.

In connection with 'co-dependency', AFMs are sometimes accused of '*enabling*'. The concept primarily emerged within the 12-step movement and organizations for AFMs. The term '*enabling*' implies that providing support and tangible resources (e.g. money or doing things that reduce negative consequences of the addiction such as clearing up vomit or contacting work to say that the person is 'sick') to someone with an addiction problem facilitates or exacerbates destructive addiction-related behaviour [14]. Common advice to relatives, not least in self-help

literature, is to set clear boundaries towards the relative with the addiction. Such advice emphasizes that AFMs must care for themselves *instead of* their loved one with addiction, as opposed to caring for themselves *and* their loved one.

There are a number of ways in which this model has been seen as positive. The concepts of '*co-dependency*' and '*enabling*' can provide certain insights into possible problematic or destructive behaviours, which can be important to identify, reflect on and sometimes find ways to change. Further, this model was the first to popularize the suffering of AFMs and encouraging them to seek help. Also, as well as being a key part of the 12-step programmes, the co-dependency movement has influenced and been influenced by the work of writers such as Melody Beattie, a USA author of self-help books on co--dependent relationships, and Pia Mellody, and her Model of Developmental Immaturity, both of which have been taken up by many mutual support groups and organizations such as the 'Meadows Model' (https://meadowsoutpatient.com/about/the-meadows-model/).

However, there is very limited published research on either co-dependency or the Model of Developmental Immaturity, and many other commentators (including the Editors of this book) suggest that such ideas warrant great caution, as they pathologize normal stress reactions, are stigmatizing and can lead to unhelpful or harmful interventions.

3.2.2.3 Stress-Coping

Unlike some of the other perspectives outlined in this chapter, the stress-coping perspective makes no assumptions about the origins of the addiction-like behaviour that the AFM is coping with, nor does it make any assumptions about any part AFMs might play in the development or maintenance or even resolution of an addiction-type problem. Instead, the stress-coping perspective [4] sees AFMs as people who find themselves in a highly stressful situation, who are then trying to cope as best as they can.

A few assumptions underpin the stress-coping perspective. First, when one person has a serious problem with their drinking, drug-use or gambling, this can be highly stressful for close family members (for the reason that other chapters in this book have laid out in detail). Second, all AFMs, whether parents, partners, children, siblings, and so on, come to this experience essentially unprepared for coping with living with such a problem and all the stresses that may involve.

The third assumption is that AFMs face a large and difficult 'life task', involving a great deal of mental struggle and many dilemmas, of understanding what is going wrong in the family and what to do about it. This task includes the core dilemma of how to both understand and respond to the relative with the addiction problem. The ways of understanding reached by the AFM at a particular point in time, and ways of responding, are collectively referred to as 'coping'. The word is certainly not limited to well-thought-out and articulated strategies, nor to ways of understanding or responding that the AFM believes to be effective, although these are included. It includes feelings (e.g. anger, hope, etc.), tactics tried once or twice and quickly abandoned (e.g. trying to shame the PDP by getting drunk oneself), philosophical positions reached (e.g. 'I've got to stand by him because nobody else will') and 'stands' taken (e.g. 'I'm not coming back until ….'). Part of the assumptions about these ways of coping is that AFMs find some ways to be more effective than others, either in impacting upon the relative's addiction behaviour or in terms of the AFM's own health and wellbeing or both.

A fourth assumption is that AFMs can be helped or hindered by other people and other activities they may undertake. So how other family members, friends, neighbours, professionals, members of self-help groups and so on act towards the AFM, and what the AFM does in terms of 'personal support' (such as listening to music, reading, doing exercise, etc.), can make a great deal of difference to the AFM. From the coping perspective, the important ingredients within how these other people act are such things as whether the supporting person understands the stressors and dilemmas faced by the AFM, appreciates the ambivalence that the AFM feels towards their relative, does not inappropriately 'take sides', understands the difficulty of finding a way

of coping that feels 'right' and reinforces the AFM in her or his chosen ways.

The stress-coping perspective has evolved over the years as research findings have been incorporated. The most recent variant of the stress-coping perspective is the 'Stress-Strain-Information-Coping-Support' model [19], as outlined in Fig. 3.1. This model suggests that living with someone with an addictive-type problem is stressful, and this stress results in strain for the AFM, often shown via them developing physical or psychological symptoms, and that the amount of strain any given level of stress causes is influenced by three factors—how informed the AFM, how they cope and how much support they are able to get. This model has also given rise to an intervention method—the 5-Step Method (see Chap. 18).

The stress-coping perspective contrasts with some of the alternative perspectives outlined in this chapter [4]. For example, it rejects the idea (in family therapy) that the relative's problematic behaviour is likely to be a 'symptom' of a more fundamental problem elsewhere in the family system, and that the excessive behaviour may be serving a function for the family in maintaining the status quo (albeit with discomfort) or by diverting attention from the more basic problem. From the stress-coping point of view, these serious problems in the family serve no functions: they are a serious hazard to the health and happiness of all members of the family and ways need to be found to deal with it and its consequences. As another example, it rejects the 'co-dependency' idea that suggests that the AFM both '*enables*' their relative's behaviour (because that fulfils their own needs) and gains psychologically from their relative's problem (as it allows them to be 'self-sacrificing').

3.2.2.4 Family Systems

From a family systems viewpoint [6], both the relative's addiction problem and the reactions of the AFM are themselves symptoms of underlying issues within the family. Interactions within the family play a role in both the development and the maintenance of individual's difficulties: the addiction problem and the relative with that problem are the overtly 'identified problem', but the reasons for that problem lie within either or both the existing family or one or more of the members' family-of-origin. However, one problem with this perspective is that it runs the risk of being seen to be blaming AFMs, by suggesting that they are part of the problem.

A systemic view of families posits that a family system functions through the interdependence of its members. Family systems therapists explore patterns in relationships, beliefs and behaviours, such as describing family rules that underpin observed sequences of interactions, and identifying hierarchies of feedback and control, where

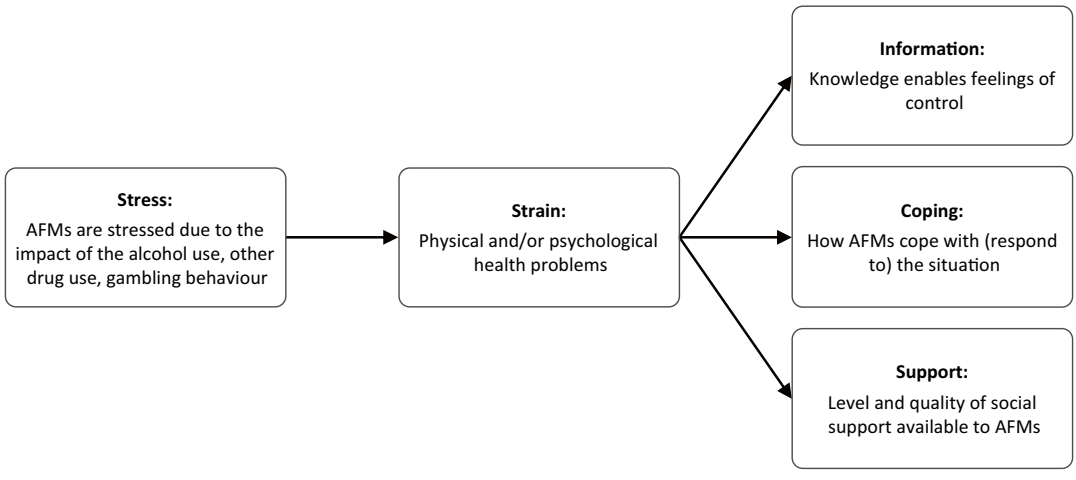

Fig. 3.1 The 'Stress-Strain-Information-Coping-Support' model

each family member's behaviour is recognized as the stimulus for some later behaviour within the family. Thus, explanations for behaviour embrace circular notions of causality, where family members respond to one another's behaviour in cycles or patterns.

As applied to AFMs, family systems theory focuses on the sequences of connectedness between people, events, beliefs and behaviours. The focus would *not* be on the AFM, or the relative with the problematic behaviour; instead, it would be on the family as a system.

Thus, *both* the behaviour of the relative with the problem (their drinking or drug-taking or gambling) *and* the reactions of the AFM are seen as elements used to maintain stability within the family and help to ward off fears of change.

Some family systems theorists think of symptoms as *functional*, helping the family to stabilize, such as when an adolescent or older child develops an addiction-type problem, which unites the parents in mutual concern for their child, thus distracting them from dissatisfactions within their own relationship, which if addressed, might lead to separation and disruption within the family.

Other theorists think of symptoms as *proposed solutions* to dilemmas and difficulties faced by family members, which in turn become *problematic in their own right*, and demand further reorganization within the family to accommodate and adapt.

The systemic approach also explores the rules, both overt and covert, that can be said to govern interactional patterns and the different beliefs that might underpin them. An example might be where an AFM would be stressed and tearful when the relative returns home in the evening; the AFM might put the children to bed and then go to bed herself; the relative might stay up, drink even more and maybe fall asleep downstairs, and then go off in the morning, to come home at night where the AFM would again be tearful, and so on. Clearly, such patterns arise within a larger context of stress, resources, disappointment and unmet needs that need to be included in understanding a particular behavioural pattern. However, these patterns that repeat, day in and day out, take on their own meaning and significance, and exploring such patterning in relationships can help understand the role that addiction behaviour can play within a family.

Other important ideas within a family therapy or family systems perspective [6] include the following:

Emotional closeness and distance: Families display a range of emotional styles, from 'enmeshment' with intense closeness to 'disengagement' marked by emotional distance. While providing support, enmeshment can hinder independent development, leading to reliance on one relationship. Disengagement involves emotional unavailability, inhibiting emotional fulfilment.

Family roles and boundaries: Families operate with rules governing behaviour and participation. Boundaries define roles, tasks and interactions within the family. Boundaries can be rigid or diffuse, influencing autonomy and decision-making. Enmeshed boundaries may lead to isolation or inhibit sharing with outsiders, while closed boundaries sustain secrets.

Family behavioural patterns: Patterns such as coalitions and triangulation shape family dynamics. Coalitions form alliances against a third party, leading to disengagement. Triangulation involves diverting conflict through a third person. In AFMs, children often navigate between parents' conflicts or take sides, impacting their role and well-being.

Family belief systems: Family belief systems shape behaviours and interpretations. These beliefs filter cultural norms, reflecting gender and cultural influences. Customs, rituals and experiences pass down beliefs. Beliefs about loyalty, secrecy, violence and substance use influence AFMs' access to support and their reactions.

Family life cycle and transitions: Processes evolve over time and through life-transitions such as births, deaths and marriage. These transitions require adaptation at different stages. Symptoms and distress can emerge

during transitions as a means of maintaining family stability. Inadequate negotiation skills can hinder transitions.

In all of this the role of the 'family therapist' is to promote change in the family systems and patterns to help the family as a whole move away from the need for the 'identified patient' to own the problem as a personal or individual problem. If the family can develop healthier ways of dealing with their transitions, roles, boundaries and emotional relationships, they will no longer 'need' the person with the addiction-type problem to have that problem or to be the 'identified patient'.

3.2.3 Sociological/Political Models

3.2.3.1 Feminism

The feminist perspective contributes to understanding AFMs, particularly focusing on the impact of gender-based power dynamics and patriarchal control. Ussher [5] argues that despite varying feminist viewpoints on the origins of gender inequalities, the acknowledgment of gender-based power and control remains fundamental when analysing the relationship between AFMs and addicted family members.

This recognition changes the understanding of working with AFMs into a 'political' endeavour, where power distribution among family members and professionals becomes a central concern. The feminist lens offers a unique vantage point through three interrelated levels: 'discourse', 'materiality' and 'intra-psychic' factors [5].

1. Discourse:

   The feminist perspective examines the societal portrayal of women within a patriarchal context. According to feminism, gender is not innate but learned through societal influence. Women navigate contradictory representations of femininity, molded by family, education, media and cultural norms, attempting to reconcile conflicting roles. These representations often place women in secondary positions to men. A prevalent narrative emphasizes that women's lives revolve around men and that securing a man is the pinnacle of a woman's existence. This perpetuates unequal power dynamics within relationships where a woman is an AFM, because women are expected to transform their relatives with addiction problems, and simultaneously find fulfilment through them. Such discourse perpetuates the cycle of women staying in damaging relationships and associates their self-worth with their ability to support and help their relative with addiction.
2. Materiality:

   Feminism recognizes material factors existing at societal and institutional levels that perpetuate inequalities in heterosexual relationships. Economic dependence, lack of support systems, legal barriers and the presence of children are key material factors influencing AFM's experiences, and can hinder women's ability to act as autonomous individuals, able to leave harmful relationships and access services without fear of repercussions. Feminist analysis highlights that material factors often mitigate against women: women are often economically, physically and socially disadvantaged compared to men.
3. Intra-psychic factors:

   Individual psychological factors play a crucial role in understanding the choices of AFMs. Low self-esteem, past trauma, guilt, shame and idealizing traditional gender roles can make women blame themselves for the addiction problems of a relative. These factors intersect with the societal discourse and material circumstances to perpetuate the cycle of shame and stigma experienced by women impacted by addiction. Additionally, societal blame from others further exacerbates their feelings of guilt and responsibility. Mothers of a child with an addiction and female partners of someone with an addiction both experience shame due to the assumption that they are the primary cause of their child's or partner's suffering.

In examining the experience of female AFMs, these three levels provide insights into their struggles. Economic dependency, emotional reli-

ance and adherence to societal norms often bind women to their relative with an addiction. Psychological defences and the internalization of gender expectations act to maintain an AFM's position within what is often an unequal relationship. It is also a discursive issue in that the AFM's position will often conform to that deemed 'normal' within the dominant constructions of families that exist in society, constructions that enforce silence and shame. Masculine aggression and substance use are glorified in certain contexts, reinforcing toxic ideals of masculinity. A feminist lens reframes what are often viewed as inherent masculine traits as sources of abuse and hardship for women. Furthermore, the traditional script of femininity that places women as catalysts for men's transformation fosters self-blame. This narrative perpetuates a cycle where women feel responsible for their partner's destructive behaviours and hold themselves accountable for their inability to 'fix' them.

In summary, the feminist perspective provides a much more political and less individual-focused view of the experience of being an AFM, with far greater attention paid to wider social or discursive factors, and with acknowledgement of the repetition of cycles of behaviour, or of commonalities with other women. This perspective underscores the need for systemic change and support to empower AFMs and challenge the cycles of gender-based power and control that contribute to their experiences [5].

3.2.3.2 Community Psychology and Broader Sociological Perspectives

The community psychology and sociological perspectives see the problems relating to both a relative's addiction problem and AFMs responses, as being strongly influenced by social factors, not individual ones. Hence, the view is that social and political issues such as unemployment, job insecurity, occupational strain, exploitation and social stratification by income, class, sex, gender, race and a host of other societal level factors are intimately responsible for the *social causation* of many mental and physical ill-health problems, including addiction, and that these factors will also influence AMF's *vulnerabilities and possibilities for help* [20, 21].

Nevertheless, such a perspective does not negate personal agency: community psychology specifically highlights the importance of reconciling the *external* determination of mental and physical states by powerful social with forces, *internal* self-determination, as subjective social and moral agents. People experience themselves as making constrained but real choices. To that end, '*it is vital that personal agency is not neglected. To de-emphasise the person and overemphasise the network of structural factors is to render the individual a mere cipher of social forces and to end up with a simplistic and naive parody of sociology. However it is also vital that structural factors are not neglected, or one renders societal factors mere accumulations of individual behaviours and ends up with a simplistic and naive individualistic parody of psychology, exemplified by Margaret Thatcher's notorious claim (Women's Own, 31 October 1987) that there is "no such thing as society".*' ([3], p. 165).

As with a feminist perspective, community psychology and sociology understand that power and mental health are undeniably linked, and in Western industrialized societies power is structured through relative wealth, socio-occupational stratification, gender, dominant (especially ethnic) group membership and age. The corollary of this—reduced power or disempowerment—is fundamentally related to relative poverty, low socio-economic status and disempowered gender, ethnic and other disempowered group membership.

From this perspective, AFMs are disempowered individuals (by society and also by themselves, as people who embody societal views). Part of that disempowerment is shown by society's view that family members are at least partially responsible for their relatives' addiction problem (hence the ideas of family members '*enabling*' the addiction, or not being sufficiently supportive of the relative with the addiction problem, or creating home circumstances such as controlling the finances, which could all be viewed as hindering the relative's ability to change their behaviour). Frequently, the relative with the

addiction problem would be given the status of being 'sick' or 'ill' with a diagnosable and diagnosed medical/psychiatric condition, whereas the AFM (if anyone noticed how stressful the situation was to them and how strained they were by this situation) would be seen as simply 'reacting' to their relative's 'condition'.

Community psychology understands this disempowerment, the result of these many structural causes, as often pushing AFMs to a position of chronic helplessness (or learned helplessness, [22]), with extremely limited support available from wider family networks or friends (from whom the worst is hidden) or from professional support networks, who focus on the relative with the problem and do not notice or attend to the resulting problems for AFMs; or even worse, see them as being partly responsible and 'to blame' for the situation.

From the perspective of community psychology, given the numbers of AFMs in all societies, interventions to help AFMs need primarily to target structural issues rather than individual 'one-on-one' approaches in order to generate societal impact and become sustainable [20]. However, many community psychologists would argue that there does not have to be a conflict between trying to help individuals (AFMs) to manage their distress, and also working to try to better deal with the underlying structural factors that perpetuate the problems.

3.3 Implications of Conceptual Models for Theory, Policy and Practice

As outlined at the start of this chapter, the way that we think of family members of those with addiction problems determines what we then do in terms of our interventions, policies, research and theories.

All of the conceptual frameworks outlined above view the centre of 'the problem' in different ways, and by doing so, all are somewhat reductive. As authors of this chapter, we all hold a view of both addiction and about AFMs that the problems need to be understood 'in the round', using a bio-psycho-social-cultural framework, within which there is a place for all of these ideas.

This book has a clear 'psycho-social' focus, which means that often the 'bio' and the 'cultural' are only examined tangentially. Nevertheless, both of these components are of great importance.

Hence, although a strong 'bio' view can be overreductionist, a medical perspective can in some cases be an important complement—certainly medicine is often a complementary part of treatment for the person with addiction, and this is the case too with many AFMs who live with extensive physical and psychological issues (such as sleep problems, anxiety, depression, etc.) where medical and pharmacological help can be extremely useful. We can also factor-in the idea that there are individual vulnerabilities on the part of AFMs as to how resilient they are, which might in part be affected by biological factors. So, the 'bio' component can usefully be incorporated within such a bio-psycho-social-cultural framework.

Similarly, only seeing the problems through a 'cultural' or sociological lens can be reductionist, ignoring the individual suffering and distress of AFMs. Many people who adopt a political or sociological framework suggest promoting interventions that focus on altering the political landscape, so that the setting conditions for both addiction and for the responses of family members are changed. Many of these interventions would be political, aimed at changing society to reduce the incidence of these setting conditions—poverty, unemployment, patriarchal or gendered institutions and frameworks, non-inclusive (race, gender, LGBT) societal approaches and so on, and research would also be focused on these levels. The design of this book incorporates these sociological and cultural perspectives, and that is why the chapters on Culture (Chap. 9), Indigenous Populations (Chap. 11), Intersectionalities (Chap. 12), the Political/Policy Landscape (Chap. 13) and Stigma (Chap. 15) are so important.

Similarly, frameworks developed following psychological or social-psychological perspectives can also be reductionist, developing inter-

ventions and research that focus on particular aspects of AFMs experiences and ignoring the wider issues. Hence, following a psychodynamic perspective would involve working with an AFM to help them recognize repeating patterns of thoughts, emotions or behaviour where their interactions with their addicted relative would mirror in important ways their interactions with previously important figures, and where realization of this mirroring would trigger a reassessment of current ways of responding. Following a co-dependency perspective would involve assisting the AFM to be less self-sacrificing, to set up clearer boundaries towards the person with an addiction problem and to help them understand why so many of their needs are met by having a close relative with an addiction problem who they can help. Following a stress-coping perspective would involve trying to empower the AFM to reflect on their coping strategies and consider alternative strategies, and to clarify where they get support from and to increase such support. Following a family therapy perspective would involve working with as many of the whole family as possible to help them recognize that there are underlying problems (relating to communication, or roles, or other major areas within the family) and that these are the problems that need to be dealt with, as opposed to the 'identified' problem of the addiction.

The policies that would be adopted if one followed these psycho-social perspectives would be ones advocating for greater attention and resources to be placed on AFMs, and on funding services that would offer help to AFMs, as well as on research to develop effective AFM- or family-focused interventions.

An important conclusion arising from this analysis is that each of the different perspectives focus on different but important aspects of the problem, and that different perspectives and solutions may need to be combined in order to most effectively help AFMs.

3.4 Conclusion: The AFINet Approach

Although the 'AFINet approach' is most closely aligned with the 'stress-coping' perspective outlined above, AFINet as a network organization welcomes members who hold a wide range of perspectives, representing the bio-psycho-social-cultural framework outlined above, within which there is a place for all of these ideas. AFINet has drawn inspiration from many of the perspectives outlined in this chapter and, as a network, holds the view that AFMs are at the brunt of a tremendous burden of suffering, which has been largely neglected by policy, practice and research. We feel that family members and others who are affected by addiction have received far less attention than they deserve, that their experiences need to be better publicized and their voices better heard, that they have a right to receive appropriate services in their own right, and a right to be much more involved with policy and political issues as they pertain to their 'Expert by Experience' status as AFMs. In addition to this, AFINet also holds that AFMs need to be much more closely involved with interventions aimed at helping their own relatives who have addiction problems to resolve their difficulties.

Elements of all of the perspectives, which together form the bio-psycho-social-cultural framework, are apparent within the AFINet approach, but at its centre is a strong belief in a non-pathological, family member-centred model, of the circumstances and needs of family members affected by their relatives' addictions.

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Part II

The AFM Experience

4 Commonalities and Variations

Sari Kaarina Lindeman and Lillian Bruland Selseng

4.1 Introduction

An individual's addiction has significant and harmful effects on close others, such as family members [1, 2]. Living with a relative's addiction is often described as highly stressful, with severe and far-reaching consequences, including uncertainty, worries, and complicated family life [3, 4]. Although there are commonalities, the experience of addiction from a family perspective is complex, diverse, and multifaceted [4, 5]. People with addiction are different, and their addictions are diverse and influenced, among other things, by how often, how much, and what kind of addiction they have. Families are also different, closeness and love between family members vary, and the societies where families live are diverse. This chapter aims to provide insight into some commonalities and variations of the experiences of addiction-affected family members (AFMs). Variations in family position, variations in the problem situation, variations in time lived with addiction, and variations between cultures and societies are included. Also, when describing commonalities, it is essential to keep in mind that there are always individual variations.

In this chapter, the focus is mostly on drug and alcohol addiction. When discussing gambling-related experiences specifically, we use the term problem gambling. The terms problem gambling and problematic substance use encompass a range of variations of addiction, also problems that do not meet all the criteria for substance-related and addictive disorders but nevertheless may impact AFMs significantly [1, 6, 7].

This chapter builds in particular on two articles from Orford and colleagues [1, 5], which summarize and comment on decades of research on the consequences of substance-related addiction for family members, and on three systematic literature reviews: two dealing with problematic substance use [4, 6] and one dealing with problem gambling [2]. First, insight is given into some dimensions of commonalities; stressful life-situation, addiction overshadowing family life, endless adaptation, and an invisible family. After that, variations are described.

4.2 Stressful Life-Situation

The overwhelming nature of addiction impacts several areas of AFMs' lives with serious short- and long-term implications for individual family

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members and the whole family [1, 4–6]. It impacts AFMs' physical and psychological well-being [3, 8], with serious health consequences such as depression and anxiety [9]. In research concerning AFMs' experiences, living with a relative's addiction is commonly described as highly stressful [2, 10].

A characteristic that makes addiction so stressful for family members is *uncertainty*. Addictions, such as problematic substance use, are often a long-term process with uncertainty unfolding over time. Addiction is often unpredictably linked to conditions such as access to alcohol, drugs, and money and ambitions and attempts to reduce the use of substances. The risk of new use episodes remains high for a long time, and also when a person with addiction is recovering. AFMs may be especially vulnerable to periods of relapses and breaks in treatment and therefore experience increasing harm [11]. Addiction is also a process with an unknown course because it can be a life-threatening and long-lasting illness. The burdens of living with such uncertainty about the outcome are documented to be part of the lives of AFMs dealing with addiction [4, 6].

4.2.1 Involvement and Possibility of Influence

The AFMs are involved and often wish to stay involved in the lives of family members with addiction. Family members are often crucial to their relatives for successful treatment or recovery. However, simultaneously, it is the individual's possibility and responsibility to choose to work with the problem and accept treatment or other assistance. AFMs cannot make these decisions, but still, the recovery process has little chance of success without the support of a network. Research literature describes how demanding it can be for AFMs to balance involvement in their relatives [4]. Family members often must cope with little knowledge of what has happened and worry about their relatives, their own lives, and the whole family's lives. All this uncertainty impacts that AFMs often experience being in a disempowered position and losing control over their own lives and the lives of their families [1].

4.2.2 Fear and Aggression

Addiction in a family often means fear, worries, and upsetting situations [6, 12]. It causes an unpredictable existence, which family members often describe as constant fear and preparedness for something frightening and dangerous to happen. Some family members constantly fear something can happen to their substance-using family members. As one mother expressed it:

> My daughter feels controlled, and I feel left out. I know that things happen that give me a good reason to be worried. She does not contact me because she does not want me to see her like that. She waits and sleeps in, so I do not see how bad it is. I know that she has been assaulted and raped, and I know that she has overdosed, but she does not say much. I think that with her, it is how it is with me. There are two levels. I do not need to know everything, but I need to know that she is alive and that she has plans and that she is safe, which she is not as long as she is taking drugs ([13], p. 64).

AFMs for family members with problem gambling may fear their relatives' gambling will result in the loss of job, home, family, and freedom [2]. Some AFMs experience physical violence, and even more AFMs some form of aggressiveness, such as irritability and criticism [1]. The family member with addiction is often described as unstable; sometimes, they would be the person the families knew, and other times as a stranger in the family, strongly influenced by substances, hence acting accordingly [6]. Violence and aggression in families can also be directed against the person with addiction [14].

Studies exploring the situation of AFMs describe terrifying situations and numerous episodes of violence [1, 4, 6, 12]. For example, some of the parents were afraid of being attacked by their children using drugs and worried about the safety of their other children [15]. One mother described it: "I am always scared when he needs these drugs because he becomes so violent and disruptive; you can see that he can kill anyone" ([15], p. 99).

The research literature describes how the AFMs managed emerging conflicts and frightening situations by controlling their actions, such as avoiding discussing problems and choosing their words with care [16]. AFMs often experience an atmosphere of mistrust and tension, as fear of relapses or conflicts makes it necessary to be in constant preparedness.

4.3 Addiction Overshadowing Family Life

Persons with addiction and their family members are often pulled into demanding life situations, with challenges that infiltrate several aspects of their lives over a long period [4, 6]. Addiction may influence essential elements of everyday family life (e.g., emotional support, trust, feeling safe). It meant that family members lost much of what they experienced as valuable to their families. Their earlier dreams and wishes for life were no longer achievable [17].

The AFMs describe how ordinary family situations are changed and ruined. In many families, everything in the lives of the families, at emotional, practical, and economic levels, revolves around the family member with addiction [4]. One individual's problems became the main focus for the whole family, and family functions were organized around and ruled by that focus.

The demanding life situation create conflicts between family members. AFMs can try to handle their fear and stress by searching for more information and control. An often-used strategy is trying to control the addiction, such as limiting access to drugs, alcohol, or money. The AFMs could switch between being helpful and supportive to being punishing, angry, and controlling. As one spouse expressed it: "I tried nicely. I also beat him, just to make him stop drinking, but nothing helped" ([18], p. 429).

4.3.1 Structure and Roles

Family members' addiction often affects family structure [2, 19]. Roles in the family could be changed and reversed because of addiction, such as a child becoming the parent's caregiver [8] or siblings expecting little from their parents because a brother or sister with addiction needs the parents' focus [19]. The familial nurturing roles were extended—parents prolonged their involvement in their adult child's life, and adult children took much responsibility for caring for their drug-using or alcohol-using parent [4].

4.3.2 Economic Worries

Family members with addiction may struggle with their responsibilities in the family [2, 4]. AFMs often describe how this affected the economic situation for the whole family and resulted in conflicts over money. For example, Orford and coauthors [1] told how this could include buying things for a relative, which the relative then sold, and borrowing and taking things from home. Families with problem gambling experience a financial burden due to problem gambling, such as being unable to meet daily living expenses and even experiencing the loss of a home [20]. The economic impact also includes lacking contribution to the family's finances, which in countries where the welfare system has fewer resources could have severe consequences for the family's financial situation [21].

4.4 Endless Adaptation

Research concerning AFMs describes life with addiction as endless adaptation [4, 6]. The change often emerges in layers, and addiction seems to have been a long-standing problem before family members understand it [16]. For example, can parents of young persons perceive the first changes as part of normal teenage behavior and seek explanations other than addiction, such as mental health problems, school problems, or past events in family life [16]. However, the escalation of the crisis often forces AFMs to relate to it, and the time following is often described as a long-lasting "rollercoaster" between hope and mistrust [4]. Many AFMs try to help their relatives and use lots of time and resources to get help for the family member [19].

Orford and coauthors ([1], p. 55) describe three positions that AFMs worrying about family members with excessive behavior can adopt: "She (or he) can put up with it, or try to stand up to it, or she can withdraw and try to maintain her independence." "Putting up with it" describes a large category of actions as resignation, inaction, or accepting things as they are. "Withdrawing and gaining independence" is strategies such as moving away from the relative or putting distance, physical, emotional, or both, between the relative and the family member. Finally, "standing up to it" describes strategies by which AFMs attempted to maintain control over their living situation and change the rules of engagement that regulated their lives with their relatives ([1], p. 55). The authors remind us that each way of coping shades into others, and no distinct boundaries exist between them.

The AFMs' reactions to addiction often seem more reactive than planned. They apply what appeared to them to be the best strategy available at any particular moment [1, 4]. Every new strategy can initially bring hope to the families, but often, hope soon turns to despair when it becomes clear that the adaptation strategy is insufficient. AFMs may also experience a lot of ambivalence, doubt, conflictual positioning, and paradoxes. This ambivalence is between protecting the family from addiction and being the family member they wished to be, and in idealized descriptions of family life ought to be [13]. Conflictual positioning between trying to stop addiction and loving and caring relationships in the family creates doubts, helplessness, and pain.

The AFMs' understanding of the problem often changes, involving reevaluating their resources for helping their family members. Eventually, many AFMs experienced painful resignation upon realizing that their attempts to help had no effect. One study described it: "It is really, really difficult, because you don't… Because it's not your problem" ([22], p. 214). Families experiencing recovery from addiction may still find that it takes time to repair trust and painful experiences together [7, 13].

4.5 An Invisible Family

Many AFMs experience loneliness and isolation. Systematic reviews present several factors that seem to impact this isolation [2, 4, 6]. The isolation can be both self-selected and externally applied. It can be linked to that AFMs experience stigma in their societies, associative stigma [23], and the AFMs may also self-stigmatize. The stigma has an impact on whether and how AFMs get help and support and whether they can accept help and support. AFMs may isolate themselves from close friends, extended family, and the community. They experience an inability to seek help or talk to other people about their problems because they feel that others cannot understand their complex situation [24]. AFMs also describe isolation inside the family because it is difficult to speak about their problems. They may blame each other or themselves, and their different ideas about how the addiction should be dealt with lead to disagreements [10].

Across countries and cultures, addiction is, to a certain extent, perceived as a family matter. Systematic reviews have shown how cultural, discursive, and strong family values (such as independence and success) can make addiction a family secret [4, 6]. As a result, AFMs can be concerned about what people outside the family think. Many AFMs may feel shame and blame for being closely related to a person with addiction and distance themselves from social relationships outside the family. The research literature also describes how some AFMs experienced that support from outside "comes at a price" and felt humiliated [24]. As one mother explained:

> What can I say to my sister? He stole? I can't say that, I am ashamed. What can I say about my children? Because another person will take it differently, he will look at them differently afterwards […] I mean my sister knows my children, she raised them with me and she knows them, but still I can't say anything bad about them. The serious stuff I have told nobody ([24], p. 330).

AFMs isolation is compounded by services, communities, and societies often failing to help families with addiction. In countries where the welfare system has fewer resources and citizens

may experience insecurity, families are left alone because help and support are rarely available, with severe consequences in the form of violence and crime [15, 21]. However, in countries where services exist, AFMs face problems getting help and support [1]. Systematic reviews have also shown that AFMs sought help late in the process, not until they were utterly exhausted and not managing to cope with the consequences of escalating problems [4, 6]. Moreover, AFMs often sought help primarily for those with addiction and not for themselves. AFMs found the help was insufficient or lacking [22]. The mainstream substance-use services did not have the capacity or resources to offer help to family members. There are indications that alcohol and other drug services struggle to incorporate family involvement into routine treatment practices. Focusing on individual health tends to dominate practices in the field [25]. In addition, professionals were not attentive enough to address the problems [4, 6].

4.6 Variations: Family Position

Research with family perspectives on addiction is often presented to include all AFMs, but it often turns out that specific family roles and positions are more represented than others [5, 6] (this volume: Chap. 6). The main emphasis is often on the parents' experiences, including the experience of mothers more than that of fathers, while, for example, siblings are less represented [19]. The studies presenting the male perspective indicate that fathers may experience stresses similar to mothers [1]. However, in many existing studies, the mother is the sole provider and has to cope with several practical and economic burdens without a public or private safety net [1, 6].

Orford and coauthors point out that the hardship AFMs experience will be more significant when the family relationship (partner, parent, sibling, etc.) between the AFM and the relative is closer. AFMs in different relationships seem to be affected to different degrees, depending on the closeness of the relationship and how dependent the AFM is on the person with addiction [5]. The family members' role and positions in the family affect their experiences [2, 9]. It is also confirmed in other types of research about families and illness. Although most people find it stressful to be relatives of seriously ill people, the experience will vary with their life situation and family positions (children, parents, spouse, and other relatives) [26]. Different family positions imply different degrees of responsibility and various tasks. In most countries, it is mainly the parents that have responsibility for the children, which makes their position different from siblings, children, and spouses. Parents of adult children with addiction often extend parenthood. The parents may also feel shame and guilt and find that the environment holds them responsible. Parents may accuse themselves and doubt whether they have made the right choices while their children have used substances.

The addiction also interrupts the balance of romantic relationships [2]. The entire life situation of a partner to a person with addiction can be affected. Selbekk and coauthors' systematic review [8] reports that partners, primarily females, describe a family climate of conflicts and stress. There is also a correlation between domestic violence and addiction. Orford ([5], p. 14) also points out that the hardship for AFMs seems more significant in close family relations, particularly those in which the family is characterized by structural subordination with dependence and several burdens. The most vulnerable AFMs are often children, who are the least protected from the consequences of unstable living situations and could not escape them alone. The impact on children and different relations is described more comprehensively in Chaps. 5 and 6.

4.7 Families with Multiple Problems

The problems of the individual family member can also be one of the many challenges in the family or even a response to these challenges. A lack of parental involvement and social support may be part of the picture. For many families,

addiction, such as problematic substance use, is a multigeneration theme, and some family members have a family history of a difficult childhood or childhood maltreatment [27]. Familial, social, and individual risk factors increase the possibility of an individual developing addiction [28]. In addition, social problems such as poverty, socioeconomic deprivation, unemployment, and familial problems may often be present simultaneously.

For many families, addiction has been present among several family members [6, 16]. Parents of children with addiction may have an upbringing with parents with addiction, and some parents may have problems themselves [6, 16]. The multigenerational theme shows a family vulnerability, where troubles may have been part of family life in different ways for generations. Orford ([5], p. 14) suggests an essential hypothesis about the impact of variation in the accumulated burden AFMs experience. The more that an AFM lacks financial or socioeconomical resources and the more that an AFM faces other hardships, the greater the burden of addiction. The more significant the accumulated burden AFM bears, the more challenging it is to cope with a relative's addiction. As Orford explains the consequences to AFMs:

> The greater the degree to which an AFM (affected family member) is exposed to family disharmony associated with a relative's addiction problem, the greater the level of AFM coping difficulty and strain. Family disharmony, or lack of family cohesion, maybe a complex concept with multiple indications. Still, a critical index of disharmony is the presence and extent of domestic violence, including physical violence, emotional abuse and coercive control ([5], p. 14).

Families in which upbringing has been characterized by turbulence and neglect, maybe for generations, and families in which those challenges have not been present, have different struggles and service needs. In contrast, families with little other difficulties, good communication, strong finances, and more social support, as well as the resources to seek help, have more resilience to deal with the difficulties it creates for the family. These variations call for attention from researchers and practitioners, and more research is required within different societies and societal conditions.

4.8 Variations in Time

The AFMs' life with addiction is characterized by changing understanding and endless adaptation. Addictions as problematic substance use often start as a youth or young adult. They can develop into lifelong chronic health challenges and risk for substance use related death, but they can also lead to recovery. For many people, it leads to recovery, and addictions are the psychiatric disorder with the highest odds of recovery [29]. The AFMs cope differently with other family members' substance use at different periods of time [30]. From a family perspective, the experience of addiction and recovery from addiction is complex, diverse, and multifaceted. For example, AFMs experiencing young family members developing addiction, AFMs facing long-lasting problems, and AFMs experiencing long-term recovery are in very different life situations and have a different focus.

Based on systematic reviews, a picture is drawn of how the first years of addiction are characterized by the intense seeking of help and a need to understand the problem [4, 6]. Eventually, AFMs lose more and more hope that help is helpful. Some resign and distance themselves, while others find ways to live with the challenges. For some, it is a lifelong struggle. One bereaved brother described his mother's situation as follows:

> She should not have been put in the position to offer help. It is possible that, in the long run, your love for your child makes it virtually impossible to make tough decisions. This had been going on for 15 years—the same situation over and over and over again. So, where would it end? It was very sad when he died, but it was also a relief. I am fully convinced that, unless a miracle happened, he would've continued using for another 20 years. And that would've worn my mother out completely. For me, his death was a relief without a doubt (Lindeman et al., in press).

The dominant polarized understanding of the addiction and recovery process is often presented

as either a demanding process of addiction in which the AFMs must protect themselves or as a resolved process in which addiction and its associated challenges are over, inviting to dualized and short-term thinking. The aim of earlier studies has primarily been to describe the experiences of AFMs living with ongoing addiction. In contrast, the long-term family recovery perspective has been given a limited research focus [7]. There is little research on long-term processes in families experiencing addiction. The findings of two recent studies point out that families' challenges do not end when addiction ends; for example, doubts and relational troubles can be present for life. Nevertheless, families in long-term recovery are often left alone to try to make meaning of choices made in families, the doubts they have, the healing they need, and the possibilities for growth and joined meaning-making may be lost [7, 13].

4.9 Variation Between Cultures and Societies

The authors of this chapter are from Norway. The Norwegian and Nordic contexts are characterized by developed welfare schemes, relatively small class differences, and more democratic relations between women and men and parents and children compared to other countries. People with addictions and AFMs in Nordic countries can expect help and support from formal sources, although there are shortcomings in the help that is offered. This exemplifies how mutual influence between the individual and society affects the experiences. Both existing social support and help and the expectations that it should be available may affect AFMs' experiences.

Recently published systematic literature reviews [4, 6] and three decades of research activity from Orford and colleagues [3, 5] suggest how important it is to keep in mind the societal conditions of families. The included studies in the systematic literature reviews represent countries with different political, economic, and cultural situations. The authors point out that when there is a low level of safety and security in society and the society lacks an inclusive welfare system, this exacerbates the lack of protection for the substance-using family member and AFMs. As a result, families faced crime, threats, and violence alone, without any assistance available to them. For some families without a safety network, threats such as homicide related to addiction were present daily.

Social support from other family members, extended family and other social networks, is essential for AFMs [5]. However, there may be several reasons such support is not provided, affecting the AFMs' life situation. Cultural notions of the family and addiction differ between countries, and systematic reviews indicate that there are different levels of stigma and associate stigma in different societies [4, 6]. For example, attachment to the nuclear and extended family is significant in Mediterranean or Latin families [17, 24]. Ideas of what should be handled inside the family and what matters for society differ and impact how accessible social network support can be.

Orford [5] describes how in Mexico shared cultural beliefs and values, such as that family problems should remain inside the family and that a wife should expect her husband to drink and get drunk, influenced the possibilities of social support. Also, studies from South Africa describe complex relations between AFMs and their neighborhoods. For example, AFMs avoided social engagement and community events because of the criminality of their substance-using family member [15, 21].

Orford [5] contrasted how interviews with Indigenous Australian AFMs show different attitudes. For example, excessive drinking was seen as a public and community affair, threatening the group, its children, and its survival, and not simply as a private, family matter. Interviews from Nigeria showed how extended family members, friends, and community leaders tried to talk to the relative with addiction to stop or reduce the use of substances and offered moral and material support to AFMs.

4.10 Conclusion

This chapter reflects on the overwhelming consequences family members' addiction has on AFMs' lives and the commonalities and variations in the struggles AFMs experience in managing a demanding life situation. The focus of the chapter has been mostly on substance use addiction, but there seem to be many similar commonalities and variations concerning gambling problem. However, more research is needed concerning problem gambling and families. As the systematic review [2] concluded, it is important to better understand how different family members are affected by problem gambling and how the variations could be understood.

One of the commonalities is that both AFMs experiencing problem gambling and problematic substance use in their families lack support and help. AFMs' experiences may suggest that they were not understood in their complex landscape of needs either from social networks or from services. It may also indicate that implications should be aimed not only at practice but also at policy. Many countries still struggle to incorporate family involvement into routine treatment practices and need better structures to include AFMs. Family-oriented help must be readily available when required for all phases of addiction.

Another similarity between AFMs experiences is how the experience of a family member's addiction difficulties is linked to the family's overall challenges and resources. If the addiction is intertwined with other difficulties in the family, such as living conditions, challenges, exclusion, relational difficulties, and other psychosocial traumas and difficulties, the needs of the family are more complex and demanding. Seeing and meeting AFMs experiences and needs in context is, therefore, a key need, regardless of country and the addiction challenges the individual family member struggles with. For AFMs experiencing the accumulated burden, with several problems simultaneously, and often also multigenerational troubles, increased awareness is needed. An important conclusion is that complex social problems such as addiction require global political attention. The most vulnerable family members in countries with welfare systems with scarce resources are often left on their own without support.

It is also important for practice, policy, and the public to note how much isolation, stigma, and self-stigmatization AFMs experience. Stigma impacts whether and how AFMs get help and support and whether they can accept help and support. Therefore, providing policymakers, health-care professionals, and the general public concerned that stigma exists with information and increased knowledge is essential in the work to change attitudes and remove the stigma.

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Children Affected by Parental Substance Misuse

5

Hannah Todman and Sarah Galvani

5.1 Introduction

To understand the impact of parental substance misuse (PSM) on the lives of children, both the associated risk factors and the protective factors needed by children will be explored. The term 'substance' encompasses all drugs, both illicit (e.g. cocaine and heroin) and licit (e.g. alcohol and medication). Although there may be differences between substances relating to their effects and the social and environmental factors surrounding their use, the similarities of the impact of parental drug or alcohol misuse outweigh the differences [1]. The overall 'core' experience of children remains the focus of this chapter. The adopted term 'parental substance misuse' (PSM) is purposeful, and it is important to outline the rationale for the use of the term throughout this chapter. The 'misuse' of substances refers to the harmful effects of substance use [2, 3]. It is, therefore, the misuse and not the use of substances that contributes to harmful behaviour [4]. The term 'misuse' accurately reflects the focus of this chapter in seeking to understand the needs of children where PSM is causing harm in relation to a child's emotional, social or physical well-being. This is not to say that all parents who misuse substances pose a direct risk to their children, or that no parent misusing substances will be able to parent successfully. However, to allow for an accurate understanding of the needs of these children, the negative aspects of PSM should be identified [5].

5.2 Understanding the Complexity of Risk Factors from Parental Substance Misuse

Understanding the lived experience of children affected by PSM requires attention to the physical care needs of children and to their emotional well-being; for example, consideration of how it would feel for a child living with a parent who is unable to provide consistent comfort and emotional warmth [6]. For children living with PSM there is often a continuous cycle of unpredictability due to the visible changes in parents' behaviour. The negative impact of PSM is prevalent not only when a parent is under the influence of a substance but also when they are experiencing the after-effects of their use, referred to as the 'before and after' parent ([5], p. 114). Research findings have evidenced that 'child maltreatment'

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can be associated with a broad range of substance misuse behaviours among adults, including the neuropsychological effects of certain substances, and the impact of acute intoxication and/or withdrawal that affects a parent's ability to respond to their child's needs [7].

An impaired parent–child relationship, categorized by low emotional warmth and parental involvement with their child, can impact on a child's emotional, physical, social and academic progress [8]. The relationships between PSM and a child's experience of negative parenting behaviours is explored in a study with participants aged 15–24 [9]. The findings conclude that PSM led to a decrease in positive and an increase in negative parenting behaviours. The negative impact of substance misuse on parenting behaviours included coercive control, harsh discipline and lower levels of parental involvement [9].

Prolonged and 'heavy' use of substances by parents is associated with a 'chronic failure' to respond and meet their children's basic physical and emotional needs ([7], p. 52). Research has also highlighted the impact of specific substances on parenting and the connection between PSM and a decrease in positive parenting behaviours. Central nervous system (CNS) depressants, such as heroin and alcohol, can result in states of extreme drowsiness and impaired concentration, whereas CNS stimulants such as amphetamines and cocaine can be associated with states of agitation and restlessness [10]. Prolonged substance misuse has also been noted in the literature as resulting in heightened levels of mental health symptoms such as suspiciousness, hostility and delusional beliefs [10].

The negative impact on children living with PSM is brought to the fore by the emotive accounts shared by children of their experience of PSM [11]. Children shared feeling unsafe at home, not just because of PSM but also because of the adults whom their parents associated with, who in some cases 'treated them badly or exposed them to drugs and drug paraphernalia' ([11], p. 3). The compounding issues of family conflict, poverty, neglect, isolation, family separations, secrecy and fear, alongside PSM, evidence the multiple risk factors experienced by children [11]. The impact on children's lives and their need to be 'strong' to endure such hardship is emphasized by Moore et al. ([11], p. 7):

> The young people were strong and resilient but also vulnerable. They had survived and were still trying to survive through tough times.

In a study by Barnard and Barlow ([12], p. 51), children identified a range of behaviours that had 'puzzled' them, including experiencing parents' bad temper and parents being too busy to spend time with them. Children reported knowing when their parents were in another room taking drugs, and many had witnessed parents injecting drugs [12]. The extent of children's knowledge of PSM and the difficulties within their family can be seen in a study by Galvani [13]. Children aged 10–15 who participated in the study were acutely aware of their parents' substance use. The emotive accounts by children illustrated their knowledge, insight and understanding of substances and of predictors of harm and violence [13].

For many children, their experience of PSM is of parents being physically absent, not just in another room but being away from the family home for prolonged periods of time, leaving children with feelings of uncertainty, fear and not knowing when their parent will return, as portrayed by a child aged 12:

> Then the other time was when I was poorly […] I was left by myself for like 4–5 hours […] it was making me really sad because I was just looking out the window and she wasn't there and so it made me a bit upset ([6], p. 4).

A key message from the research is that when parents struggle to manage their substance use, they often struggle to implement effective positive parenting behaviours. The impact on children is a lack of consistent parenting, exposure to irrational behaviours and living in a chaotic environment [14, 15]. Managing a child's behaviour and responding to their emotional needs requires parents to have intrinsic motivation and emotional regulation, which is arguably incompatible with PSM and varying states of withdrawal [16]. The negative impact of a home where parents'

behaviour is unpredictable, marred with heightened threats of violence towards them and of witnessing domestic abuse, is profoundly shared by a child aged 7:

> It's not very nice or right for a kid to see it ([6], p. 1).

5.3 The Burden of Secrecy

The association between PSM and children's experience of keeping family secrets and of parental denial has been referred to in literature as the 'elephant in the room'. The substance is the elephant in the room that nobody within the family talks about, despite its large presence and which can become the focus of investigation by professionals, while the needs of the children remain hidden [17].

A report by the Children's Commissioner for England [18] explored the lives of children aged 6–19 years, living in households where PSM, domestic abuse and mental ill-health coexisted. Children reported feeling unable to speak out, to seek support and, when professional support was offered, they often felt the focus was on the needs of their parents [18]. Similarly, a study asked 15 young people aged 11–17 to share their perspectives on how substance misuse affected their families [11]. The findings from the study revealed that the lives of young people living with PSM were marred with a deep sense of stigma and social isolation because of the need to conceal PSM [11]. The findings echoed other studies where children had recalled their experience of living with PSM and the acute burden they felt about concealing PSM. Children spoke of the importance of keeping secrets within their family but especially with 'outsiders' ([12], p. 51).

The challenge for professionals attempting to support children affected by PSM is that families who may be in most need of support, may also be the families most reluctant to be contacted. This can further exacerbate the feeling of isolation children experience, leaving them to carry the burden of secrecy for longer [19].

5.4 Parental Substance Misuse and Domestic Abuse

Research has identified that where PSM and domestic abuse coexist, there is a debilitating impact on the capacity of parents to meet their children's needs [14]. The study by Holland et al. [14] illustrates the challenges faced by parents attempting to manage their substance misuse and meet the needs of their children. Common factors included domestic abuse, frequent home moves to escape violent partners, experiences of poverty and 'the stories told by mothers wove strands of abuse and neglect in childhood' ([14], p. 1503).

The negative impact and strain on children living under considerable stress due to PSM and domestic abuse, often for prolonged periods of time, is evident in a cross-European qualitative study [20]. Witnessing distressing incidents had left children at best feeling sad and angry, but for many (36% of 57 children aged 12–18 years) the impact of their exposure to PSM and domestic abuse was a causal factor in children reaching clinical levels of mental health concern [20].

The connection between PSM and domestic abuse, and the impact on children, was further evidenced in a study that found all 13 children (aged 12–18 years) who participated had experienced hearing fights or having witnessed a parent being hit, or had been hit themselves when trying to protect another family member. The children's experiences of living in a household where PSM and violence coexisted was depicted as a life of fear, isolation, stress and feelings of being unloved [21].

It is important to consider that children's experience of PSM and violence within the family home is not always linked to domestic abuse, as threats of violence and exposure to violent behaviour can be related to drug debts, further compounding children's experience of unpredictable and frightening adult behaviour [6]. The negative impact on children's emotional health due to their unpredictable home environment is documented within domestic abuse literature. The term 'hypervigilance' is adopted to describe the symptoms experienced by children who have been exposed to domestic abuse: they include an

'exaggerated startle' response, 'nightmares and flashbacks' ([22], p. 153).

Children who have been exposed to repeated incidents of domestic abuse, where their home is no longer a 'safe haven', and 'marred by danger' also have difficulty regulating their emotions, due to constantly being on alert to possible dangers ([22], p. 152). The negative impact on children's emotional health due to unpredictable and frightening adult behaviour can be found in domestic abuse literature but is largely absent in PSM literature. There is a need to understand the negative effect PSM can have on children's emotional health, in relation to hypervigilance and children's experience of the perpetuating cycle of uncertainty [6].

5.5 Understanding PSM and the Risk of Contextual Safeguarding

Understanding the risk of contextual safeguarding is an important consideration when seeking to understand the needs of children living with PSM. Contextual safeguarding is defined in UK safeguarding legislation as 'extra-familial threats' outside of a child's home. The threats outlined include children being vulnerable to exploitation by criminal gangs and children being victims of sexual exploitation ([23], p. 22).

When children are faced with a perpetuating cycle of uncertainty, unpredictability, danger and inconsistent parental warmth and care at home, there is a risk that they will endeavour to meet their emotional needs elsewhere. This increases the risk to and vulnerability of children being victims of child sexual exploitation (CSE) and/or child criminal exploitation (CCE) [24]. An important consideration of the impact of PSM on children is the timing in terms of their age, development and the accumulative impact over years of exposure, all of which can lead to further vulnerability. This is of significance when considering children who are older and at risk of CSE/CCE, especially if they are viewed as being independent, 'self-governing', and perceived to have agency and choice in risk-taking behaviour [24]. The key message is that the risk factors associated with PSM do not reduce as children grow older, they simply change [6].

5.6 Understanding the Impact of Prolonged Exposure to PSM

Pivotal to understanding the long-term impact on children exposed to PSM, associated risk factors and emotional and physical health problems in adult life is the study of adverse childhood experiences (ACEs). One study categorized ACEs into seven forms of abuse: 'psychological, physical, sexual, household dysfunction, substance abuse, mental illness, mother treated violently and criminal behaviour in the household' ([25], p. 248).

Children's exposure to 'substance abuse in the household' was the most prevalent of all seven categories of abuse, with 25.6% of the respondents experiencing this ACE [25]. The study concluded that children who experience four or more ACEs are more likely to suffer long-term adversity in relation to physical and mental health, as well as the risk of developing substance misuse problems in adulthood [25]. The findings from this seminal ACEs research are mirrored in subsequent research, drawing parallel conclusions regarding the correlation between adversity in childhood and negative outcomes, including poor mental health and substance misuse in adulthood [26].

A longitudinal study conducted in Finland of 63,639 children born in 1991 who were followed until their 18th birthday found that both maternal and paternal substance misuse were significant predictors of mental disorders and harmful substance use in children aged 13–17 years [27]. Findings from an Italian study of 15 young adults (aged 18–24) experiencing substance misuse problems also concluded that young people experience more severe neuropsychological impairments such as clinically diagnosed anxiety, depression and poorer cognitive function, where PSM was present during their childhood [28].

Though the studies of ACEs have provided clear evidence of the correlation between adversity in childhood and poorer mental and physical health in adulthood, they do not provide insight into and understanding of the child's wider environment and the compounding impact of social inequalities upon them. As Asmussen et al. ([29], p. 4) propose, ACEs 'do not occur in isolation' because the prevalence of ACEs increases for children who experience poverty and deprivation: the narratives around ACEs need to reflect that.

5.7 Understanding Protective Factors and Strengthening Resilience

Whilst it is important not to shy away from the negative realities of the lives of children living with PSM, it is also important to recognize that there may be significant protective factors in children's lives, which can act as a buffer against the risk factors they experience from PSM or other 'addictive' behaviours. Protective factors are recognized in research as being of vital importance when considering the needs of children affected by PSM [30].

The concept of resilience is often inextricably linked to research relating to protective factors in childhood. Newman and Blackburn ([31], p. 1) simplify the clinical definitions of resilience and suggest resilience is: a child's ability to 'bounce back from adversities'. Sattler and Font ([32], p. 3) suggest protective factors can be identified at multiple levels: these include familial factors such as 'nurturing and cognitively stimulating parenting'; but they also include community factors including living in a positive neighbourhood and experiencing 'social cohesion'.

Although protective factors are important, their existence in a child's life does not necessarily equate to reduced risk, or risk factors being cancelled out [33]. It is therefore the role of professionals to support families to reduce risk factors and help to nurture and develop protective factors, which can strengthen a child's resilience.

5.8 The Importance of Parental Warmth

A significant protective factor in the lives of children is the presence of consistent parental warmth in childhood. Parental warmth supports children to develop their resilience and their ability to regulate emotions, thus reducing the risk of children developing behavioural problems in adolescence [34]. Rothenberg et al. ([35], p. 837) explain the concept in relation to the 'acceptance–rejection theory' and state that 'humans have developed the need for warmth from their caregivers' and experiencing parental warmth may serve as a 'universal protective factor' for children. Their international study, across 12 countries including the USA, Kenya, China and European countries, included 1,298 children aged 8–14, who completed a youth self-report behaviour checklist. The study concluded that parental warmth protects against the 'emergence' of children's internalizing and externalizing behaviours ([35], p. 848).

5.9 The Role of Safe and Trusted Adults

Some protective factors stand alone in their significance, such as having a parent at home who does not misuse substances or having a positive bond with at least one adult in a caring role, for example grandparents or older siblings [30, 36]. For children who live with PSM, trusted adults such as a grandparent who lives outside of the family home can provide a much-needed break. This safe place provides respite for children and is a significant protective factor [30, 37].

Having support inside and outside of the family home is key to helping children feel they are being 'looked-out for' and to feel less isolated [37]. It is evident that family relationships play a pivotal role in helping to secure and shape a child's safe base, affording children the best opportunity to develop positive emotional health and well-being [5]. However, what is assessed as a protective factor for one child may not be a protective factor for another. Not all families

play a significant role in safeguarding children, as the identified trusted adult may become embroiled in the difficulties associated with the parent's substance misuse and thus the focus may return to that of the adult and not the child [38].

Children who experience PSM need multiple protective factors in order to become resilient both within and outside of their family [6]. Positive and nurturing adult relationships in a child's life when they are growing up and living with PSM play a vital role in preventing the harmful effects of PSM. Sources of protection need to be understood from the child's perspective; listening to children to understand who they feel they can trust and confide in is crucial [6]. Alongside positive familial relationships, children also benefit from support from professionals such as teachers and social workers. This support must not be time-limited, to afford a child the opportunity to recover from the web of risk factors they have experienced, many of which will have been severe and enduring, as depicted by a child aged 7 ([6], p. 13):

> I know I've said this loads of times, but just talking to people [can help]. Probably if I couldn't talk, I'd just be upset all the time.

The presence of safe, stable, nurturing and trusted relationships is vital in mitigating the harmful effects of childhood adversity and in the recovery from such adversity [26]. The importance of children's connectedness to trusted adults is also recognized as a significant protective factor in reducing the risk for children who are vulnerable to child sexual and criminal exploitation [39].

5.10 Conclusion

This chapter has presented findings from the international literature in seeking to understand the experiences of children living with parents who misuse substances. The findings illustrate the web of risk factors, which can be multiple, severe and enduring for children of all ages. The need for children's voices to be heard, to reduce the risk of isolation and to alleviate children from the burden of secrecy are reaffirmed. The connection between the impact of PSM on older children (teenagers) and the risk of contextual safeguarding concerns evidence that the complexity and severity of experienced risk factors do not reduce as children grow older, they simply change.

The multiple, unpredictable and enduring risk factors suffered by children, both within their immediate and wider environment, require the presence of multiple protective factors. While protective factors cannot erase risk, the absence of multiple layers of protection for children will undoubtedly exacerbate the negative impact of PSM on the lives of children. This chapter has presented the need for children to have trusted adults, adults who can provide safety, warmth and nurture in the most difficult of times. It is the presence of these vital trusted relationships that can act as a buffer against risk factors to afford children the opportunity to recover from adversity and become resilient. Significantly, a multilayered protective system for children living with PSM is more than simply providing children with the ability to merely survive; they need the opportunity to thrive.

Commissioners, policymakers, educators and service providers need to listen and respond to the needs of children living with PSM. Recommendations for policy and practice are presented in Chap. 23.

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Impact on AFMs: Relationship

6

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Historically, family members of patients with addiction have not been seen as an affected party, but rather as pathological in their own regard (e.g., codependent), and occasionally colluding with the patient's maladaptive behaviors. However, since the emergence of a stress–strain perspective in the early 1980s, clinical researchers also started looking at family members' distress as a consequence of the so-called spillover effects of addiction on surrounding people. In fact, relatives of individuals with addiction are generally forced to deal with personal, relational, social, and/or economic costs deriving from the relative's addiction. Indeed, research in this field has produced mounting evidence that family members of patients with addiction do experience hardship and increased risk for mental and physical ill-health [1]. Factors buffering or amplifying the impact suffered by family members exist: family members' individual attributes (e.g., personality, resilience, age), type and severity of addiction, or the global functioning of those with addiction can and do shape the occurrence of specific stressors in the family, along with family members' capacities to appraise and cope with such stressors.

Along this line, this chapter will provide an overview on the effects that addiction may have on family members (for a review, see also [1]). Rather than focusing on family members as a homogenous group, this summary reports quantitative research findings related to individuals holding specific relationships with the subjects with addiction: offspring, partners, and parents.

6.1 Offspring

Several studies documented effects on offspring. Among them, many recent findings focus on morbidity, indicating exposure to parental alcohol or substance use as a risk factor for developing psychiatric and medical conditions. For example, children aged 0–7 with substance-abusing mothers were found to be more often hospitalized because of injuries and infectious diseases than other children [2]. Longitudinal analyses indicate that exposure (vs. non-exposure) to parental alcohol or substance use is related to increased psychiatric morbidity in offspring [3–5]. Excess psychiatric morbidity between 15 and 25 years old was found to be particularly high for children exposed to paren-

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tal alcohol or substance use at earlier developmental stages (i.e., before 9 years old) or in case of repeated exposure [5]. Longitudinal studies also show that offspring of people with substance use are at particularly high risk for developing alcohol or substance use disorders themselves [3] and for earlier onset of such disorders [4]. This risk increases even further across the lifespan when more than one parent has an alcohol use disorder [6]. Alcohol and substance using parents also have children with higher risk of conduct and attention deficit/hyperactivity disorders, mood, anxiety, and psychotic disorders [3, 4], and with earlier onset of depressive and anxiety disorders [4]. In other words, risk is not limited to substance use but broadly encompasses internalizing and externalizing psychopathology and even global medical conditions.

Beyond official diagnoses, studies have also shown that children of substance or alcohol using parents manifest broader impairments in cognition and emotion, and subthreshold psychological disorders [7]. For instance, Rochat and colleagues [8] found 7- to 11-year-old children of caregivers with problematic alcohol use to have lower cognitive performance compared to children of nondrinking parents, along with higher mean scores for psychological problems. Offspring of individuals with a lifetime history of alcohol use also manifested higher negative emotionality [9]. Moreover, the severity of parental substance use was associated with both offspring's negative moods and physical and psychological symptoms [10].

While studies are mostly concordant on the negative emotional impact of parents' substance use, some studies found more mixed or even seemingly positive correlates in offspring. For example, parents' lifetime history of drug use has also been independently associated with higher social potency in adolescence, an aspect of positive emotionality [9], while adolescent social adjustment was found to be unaffected by the severity of parental alcohol use [10]. Also, although parental drinking was related to offspring retrospectively reporting higher family disharmony and childhood problems than controls, studies also found adult children of substance users to be equal to controls in current levels of adult adjustment (e.g., purpose in life, relationships quality), self-esteem, and locus of control [11, 12].

These findings suggest that the strength and duration of the effects of substance use on children may depend on the complex interplay of several risk and protective factors. Indeed, a recent systematic review, although limited to children of "alcoholic" parents, summarized four classes of intervening factors: individual, parental, familial, and social [7]. To name a few, the review suggests that children of alcohol using parents are more severely affected when they are temperamentally more difficult and exposed to parental alcohol use earlier in life (individual factors), when global parental abilities are more compromised (parental factors), when the severity of alcohol consumption and the number of alcohol using parents are higher (familial factors), and when external support is lacking (social factors).

6.2 Partners

There are several studies that focus on the difficulties experienced by partners of individuals with either subthreshold or diagnosed alcohol/substance use. Most of the times, evidence comes from women's reports, partnered with substance using men [1]. This certainly mirrors the higher prevalence rates of addiction in men compared to women; however, it is of note that the gender gap in substance use seems to be narrowing recently [13], suggesting that research data cannot yet offer a comprehensive view of this topic.

In a series of studies conducted in India [14, 15], where wives tend to be the primary care providers to their substance using husbands, most wives of patients with a diagnosed substance use disorder have been found to suffer from moderate to severe levels of burden of care. The concept of burden indicates how family members who take care of any vulnerable relative (e.g., substance users, elderly, people

with disabilities) experience a deterioration in health and quality of life. The studies mentioned above measured burden as a blend of several aspects, including but not limiting to excess economic costs, disruption of family interactions and leisure time, and physical and mental problems (objective burden), as well as the distress associated with these difficulties (subjective burden). In these studies, the highest levels of burden were found in case of patients' heroin use (compared to alcohol), patients' lower level of education, and wives' younger age [14], as well as patients' broader medical and social impairment [15].

Unsurprisingly, heightened levels of burden have also been associated with reduced mental health and quality of social life in individuals who perceived their partners to have a problem with alcohol or substance use. For example, a UK study found that higher perceived difficulties in relating to a partner with a drinking problem were associated with greater psychological distress in women [16]. Moreover, US women reporting concern over a partner's substance use also described overall poorer social adjustment compared to controls [17], including arguments at work, quality of leisure time, or arguments and relationships within the family.

A further consequence associated with living with a substance using relative is the risk of being subject to violence: in fact, the link between substance use and violent behavior is generally quite established, although variably explained. On the one hand, acute and chronic intoxicating effects on neuropsychological functioning and inhibitory control can result in heightened aggression; on the other hand, substance use could share common causes with aggressive behavior (e.g., antisocial tendencies) or exacerbate preexisting aggressive predispositions [18]. As an example, a US case–control retrospective study [19] showed that partner's problematic drinking not only determined and eightfold increase in the likelihood of intimate partner violence toward women but also resulted in a twofold increased risk of femicide or attempted femicide compared to the one associated with nondrinking partners.

6.3 Parents

Despite the relatively limited research findings, an alcohol/substance using child can be distressing and disrupting for parents' life. In a recent study by Richert and colleagues [20] conducted with a sample of more than 600 parents of substance using children—the majority of which were mothers—around 85% of parents described their child's substance use as having negative consequences to a great or very great extent on their lives. This included impact on their social and relational life and on their mental health and emotions: more than 90% of parents believed to have been greatly affected emotionally, experiencing powerlessness and grief, and—to a lower but still high extent—guilt and shame in relation to their child's substance use.

Interestingly, Oreo and Ozgul [21] demonstrated that average levels of trauma-related distress and grief in parents (again, mostly mothers) of substance using children were similar to those reported in previous scientific literature by family members of patients with a serious mental illness. More than half of the parents enrolled in their study showed clinically relevant psychiatric symptoms (e.g., somatic, anxiety, depressive symptoms). Moreover, grief was related to greater distress and life disruption, lower mental-health, and reduced family cohesiveness, suggesting a central role of this emotion in parents' reactions.

Alike partners, parents of substance users can also be subject to violence. In fact, the contribution of substance use to child-to-parent abuse is still open to investigation: on the one hand, a relationship between children's substance use and violence perpetrated against parents is frequently reported in the literature; on the other hand, the strength of this relationship is unclear and may depend on intervening factors, such as gender and different types (e.g., substance used) and patterns (i.e., severity and proximity in time) of substance use [22]. Among others, cross-sectional investigations conducted on a large Swedish sample [23, 24] demonstrated that, in parents of adult children with alcohol or substance using problems, there was a 40% prevalence of lifetime

exposure to property damage [24] and up to 50% prevalence of lifetime exposure to property crime (i.e., being stolen things from children). Parental victimization to physical violence at some point in life was less but still common (around 20%) [24]. These studies also indicate a number of intervening characteristics: a current active substance use in the child was related to higher likelihood of past-year property damage and property crime [23, 24], while longer duration of substance use was related to higher likelihood of *lifetime* property crime [23].

6.4 Comparisons by Relationship Status

While the studies reviewed above focused on specific family relationships, most existing studies investigated the impact of substance use on samples of mixed family members, with different relationships to the user(s). These studies were very rarely designed to offer comparisons in stress and strain between relationships statuses [1]. In spite of this, a few of them still offer some information and report direct between-group comparisons, especially when it comes to the partners vs. parents distinction.

As to the stressors, there is some evidence that partners are subject to more violence than parents [25]. On the other hand, mothers and fathers were found to have greater *lifetime* financial and legal problems compared to partners [26]. Yet, depending on the study, *current* financial problems were either greater in parents [27], or in partners [26], or equal across the two groups [25]. Moreover, Kirby and colleagues [26] also noted that the differences between partners and parents in *lifetime* legal and financial consequences were only significant for relatives who did not live with the substance user: living in the same household may therefore somewhat flatten differences in financial and legal burden. Finally, it is also important to note that there is no evidence of significant differences between partners and parents in other dimensions of perceived stress, including emotional problems, family problems, health-related problems (mental and physical), or social and occupational ones [25, 27]. In addition, Rafiq and Sadiq [28] found no significant difference in caregiver stress across wives, adult daughters, and sisters of substance users, and Mattoo and colleagues [29] report no difference between wives and other relatives of substance users in their levels of objective burden (e.g., financial burden, disruption of family routine).

As to the measures of strain, there again seems to be little evidence of an impact of relationship status on these outcomes, although few direct comparisons are available in mixed-family-member studies. For example, some studies found partners and parents to be equal on measures of health-related quality of life, happiness, or frequency of physical and psychological symptoms [27]. Beyond the parent–partner comparison, no difference emerged between wives, adult daughters, and sisters of substance users in either perceived substance-related stigma or mental health [28]. Additional studies with adult family members failed to identify significant differences by relationship status in symptom-related distress, hopelessness, concern [30], or global subjective burden [29].

Overall, it seems that differences in family members' experiences may be better explained by more prominent factors that overlap with relationship status. These include, for example, the living arrangement of the person with substance use [26]. In fact, multiple studies agree that family members living with the substance users (vs. independently) report greater life problems [20, 25], more frequent exposure to antisocial behavior in the past year [23, 24], and greater psychological distress [31], namely higher levels of both stress and strain. After all, living with the substance user more likely leads to taking on an active caregiving role, including setting up laypersons' strategies for controlling the relative's substance use, participating in formal treatment, and investing emotionally in the perspective of remission, therefore being highly affected by events of relapse.

6.5 Critical Remarks and Future Directions

As shown, there is limited evidence of significant differences on the effects of addiction on family members depending on their relationship with substance users. However, a few more speculative thoughts can be advanced on this matter. Even in the absence of direct children–adult comparisons, it is interesting to note that several studies on offspring target and highlight increased psychiatric morbidity in children [3–6], with a heightened risk persisting in the long-run and especially in case of earlier exposure [5, 7]. On the other hand, research on adult family members mostly focuses on broader emotional and objective distress related to caregiving, although evidence of excess morbidity in adult populations is also available [32]. In this sense, it is reasonable to expect underage children—due to their greater sensitivity, vulnerability, and dependence upon the parent(s)—to be subject to more disruptive consequences of addiction compared to adult relatives. In particular, offspring may face higher risks for persistent psychopathological outcomes, beyond the sole caregiving burden. On the contrary, adult family members could most likely incur in stress- or trauma-related conditions that are more related to their direct involvement in the management of the substance using relative. In this regard, it is also of note that living with the person with addiction—which is in fact associated with increased distress—is most likely inevitable for the underage child, while an adult family member may rely on higher degrees of and opportunities for independence and freedom.

These differences between adults and underage children, however, will need confirmation by novel research. In fact, methodological issues make such comparisons potentially hazardous. First of all, as a general remark, research targeting family members can be highly heterogeneous in terms of severity and types of addiction, sample size of affected family members, and also recruitment strategies: for example, family members have been recruited both from the general population and from clinical groups, enrolled in formal family support and treatment programs, who can be expected to be more severely affected and distressed. This large degree of heterogeneity and lack of systematic mapping of intervening factors can limit the clarity of research findings, let alone the conclusions pertaining fine comparisons between relationship statuses.

In addition to this, it is important to note that most studies on adult family members rely on cross-sectional designs, only providing a static frame of the phenomenon [1], while more longitudinal data seem to be available only on children of alcohol and substance users. However, additional longitudinal studies would be needed for at least two reasons. First, more general for this field of research, is that only longitudinal evidence can guarantee an assessment of family members' preexisting levels of functioning, therefore precisely indicating whether distress and psychopathology are exacerbated, or rather generated, by a relative's addiction (see also below for a discussion of individual differences). The second reason, more specific to the investigation of differences by relationship status, is that longitudinal studies are essential to compare the long-term consequences of addiction across groups of family members (e.g., adults vs. offspring).

When looking at these comparisons, one should also consider the possibility that studies with different populations select different outcomes in the first place. For instance—inspired by varying degrees of developmental considerations—researchers may tend to focus a priori on psychiatric morbidity (i.e., diagnoses) when studying underage offspring and on subthreshold distress or caregiving burden when targeting adult relatives. This upstream selection of outcomes results in uneven research findings and does not allow for definitive group comparisons.

Whether cross-sectional or longitudinal, it is important to note that current research still needs to dispel doubts on the specificity and mechanisms of the spillover effects of addiction. Furthermore, these mechanisms may differ across different relationship statuses. In children, it seems that both internalizing and externalizing disorders can derive from exposure to a parent's

addiction, indicating somewhat unspecific heightened risk for mental distress. At the same time, the pluri-confirmed accentuated risk of developing alcohol or substance use suggests specificity in the impact of parental addiction on children's functioning. As to the mechanisms by which difficulties are transmitted from parent to child, they may as well be highly kaleidoscopic. In fact, high risk in a child of a substance user can be due to reduced parental sensitivity to infant signals [33], indicating that the detrimental effects of parental addiction on children may be indirect (mediated by reduced parenting capacities). At the same time, the socialization with alcohol or other substances could also directly explain offspring's increased risk for substance use disorder. Finally, third variables may account for both parents' and offspring's psychiatric risk (e.g., common genetic vulnerabilities) [34]. Direct, indirect, and confounding effects are also not necessarily conflicting, as these mechanisms can have summative and multiplicative effects on the final outcomes.

As for the specificities and mechanisms generating strain in adult family members, particularly partners, the gene vs. environment debate is possibly less relevant, although the issue of individual differences remains of crucial centrality, in line with the implications of a broad stress–strain-coping perspective. Ways of coping with a relatives' addiction, for example, can depend on family members' social and psychological resources, including defensive strategies, attachment styles, personality traits, and so on. While the stress–strain-coping perspective fostered a lot of research in this sense, the high prevalence of cross-sectional designs is again limiting our understanding of the dynamic mechanisms linking addiction with a relative's strain. In other words, studies to date only scratched the surface of all the possible intervening factors that shape the effects of substance use on all types of family members. This is probably also the reason why negative effects on family members, though very likely, are not deterministic, with a few studies also reporting good adjustment in family members (e.g., in children of substance users).

One last aspect to consider stands in comorbidity. It is of note that disorders of addiction are frequently comorbid with other psychiatric conditions. Among them, personality disorders (PDs) are quite common in substance using patients, especially Cluster B PDs: a recent review [35] suggests that the prevalence of PDs ranges from 34.8% to 73.0% in patients with substance use. Several studies demonstrate that PDs drastically reduce patients' global functioning and put relatives at high risk for negative psychological consequences, such as harsh punishments and intrusive behaviors toward offspring [36] or increased psychological distress in both parents and partners [37]. Research should therefore also aim at disambiguating the spillover effects of addiction from those deriving from comorbid conditions that also have known negative consequences on different family members.

6.6 Conclusion

While understanding the effects of addiction on family members is a matter of high complexity, spillover effects of substance use can hardly be overlooked or reduced to chance. Offspring are subject to increased psychiatric morbidity, including increased risk for addiction but extending to several internalizing and externalizing problems. Partners report high levels of subjective burden, experience reductions in global adjustment, and are more likely to be victims of violence and lethal aggression. Mothers and fathers experience negative emotional reactions (e.g., grief), heightened psychological distress and, again, can be exposed to aggressive behaviors, both against themselves and their goods.

While there is limited evidence that relationship status explains major differences in stress and strain, findings suggest that the level of intimacy with and proximity to the person with addiction are instead relevant factors. Overall, limiting spillover damage is an important challenge with public health implications. Targeting affected family members reduces the societal cost required to take care of the excess physical and mental difficulties of this population.

Prevention with at-risk offspring is particularly relevant to reduce the long-term consequences and costs of parental addiction, including costs for future treatment. Ad hoc support, information, and treatment for partners and parents can help them develop effective coping strategies to reduce the risks of strain and victimization. Meanwhile, research will have to advance to detail the specific short- and long-term risks associated with relationship status to the user, their determinants, and the risks and protective factors implied.

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Impact on AFMs: Type of Addiction

7

Gallus Bischof, Anja Bischof, and Richard Velleman

7.1 Introduction

Many chapters in this book examine the impact on families and individual family members caused by them living with or being part of a family where someone exhibits problematic or addictive-type behaviour in relation to their use of alcohol or illicit drugs or gambling. In many of these chapters, whilst variations in the effects that these addictive-type behaviours are mentioned, there is an assumption that the similarities in negative effects are far more striking than are the differences.

In many ways, this is a strange conclusion. The range of different substances or behaviours that can lead to addiction-type disorders is very wide, and there is very significant variability along many domains, as outlined below. That being the case, it certainly should not be assumed that, if the behaviour of a problematic user is highly variable depending on the substance or behaviour that is used, the negative effects on the family would be consistent.

That variability between substances and behaviours is quite marked. So, whilst it is correct that there are some similar symptoms (such as craving, continued use despite problems, and narrowing of one's life towards the specific behaviour), it is also the case that there are very different psychosocial and health-related consequences for the user, depending on the substance or behaviour. These include great variation according to availability (e.g. legal vs. illegal substances or behaviours), pharmacological properties (e.g. stimulating vs. sedating effects), associated behavioural problems (e.g. increased aggressiveness vs. indifference), stigmatization (especially high in illicit drug users), preferred route of administration (injection, smoking, inhaling, oral ingestion, different types of gambling—slot-machine, casino, etc.) and health risks (e.g. pharmaceutical window, risk of overdose, long-term toxicity) to name just a few. In addition, even for the same substance or behaviour, addiction-type problems vary according to severity (e.g. in the DSM-5, substance use and related disorders are classified as mild, moderate and severe). An overview of the complex interrelationship between type of substance, route of administration and somatic and psychosocial associations that may impact family members can be found in Fig. 7.1. Please note that arrows do not indicate

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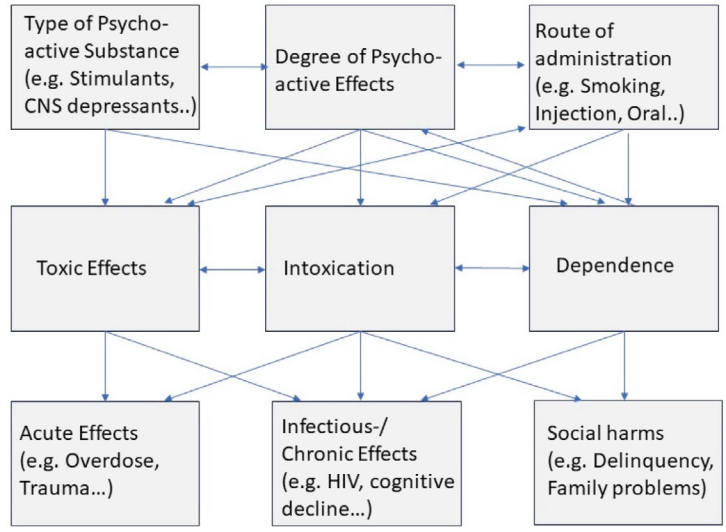

Fig. 7.1 Mechanisms of action and consequences of drug use. (Modified according to [1])

causal relationships and that all components interact with each other.

There are even more areas of variability. Different forms of addiction-type problems are reported to start at different ages, with internet-use disorders often starting at a very young age, whereas prescription drug problems often developing in older age groups. There are large societal and cultural variations regarding the prevalence rates of these disorders. And psychosocial vulnerabilities towards developing addiction-type problems (such as impulsiveness and family cohesion) differ between different types of addiction [2].

This chapter, then, will examine the relatively small number of research reports where differences in effects on the family or on individual family members are reported, depending on the substance or the behaviour, which is related to the relative's addiction-type problem.

As can be seen in the chapters of this handbook, addiction-type problems affecting significant others usually are defined by severe psychosocial consequences due to substance use or behaviours. Although tobacco dependence is an acknowledged diagnosis in the international classification of diseases, studies focusing on the strain experienced by significant others usually do not include tobacco dependence due to the lack of erratic behaviour caused by tobacco use. However, effects of 'second-hand' tobacco smoking on others (i.e. AFMs) was amongst the first large-wave of research within the 'harm-to-others' approach outlined below; and health-related effects of 'second-hand smoke' have been extensively studied as one mean to foster tobacco control policies. However, while effects on morbidity due to respiratory problems, cancers and other diseases have been well documented [3], psychosocial effects caused directly by smoking appear to be far less marked compared to such effects when individuals use mind-altering substances such as alcohol or opioids, which usually involve immediate effects and sometimes potentially mortal risks to self and/or others.

Furthermore, the use of illicit substances is among the highest stigmatized behaviours, users often need more money in order to obtain the substances (linked with a greater probability of committing illegal activities), and mode of use also differs between substances, with injection of especially opioids putting the user at high risk of fatal overdoses (see, e.g. chapter on Bereavement in this book). It is very likely that these variables will affect the level of stress on affected family members.

7.2 Attempts to Quantify Harm to Others Associated With Varying Types of Addiction

As noted in Chap. 2 on Prevalence, the relatively new paradigm of studying 'Harm to Others' has generated new ways of examining effects on family members. As discussed above, this methodology was first used in the tobacco world, and the revelation of the health-related effects of 'second-hand' tobacco smoking on others showed how such research could be used to foster tobacco control policies. This 'harm-to-others' approach has now started to be used in relation to other substances (alcohol, illicit drugs) and behaviours (gambling, gaming).

In general, survey data reveals large numbers of individuals reporting having been impacted by someone else's substance use, gambling or gaming in the previous 12 months (see Chap. 2), with very high rates (up to 70%) of respondents reporting having been harmed by someone else's alcohol use. Harms were more severe and more persistent if the harm was caused by someone close to them (in contrast to stranger's drinking). In most studies, 'being affected' has been assessed using a simple rating scale (mostly ranging from 'not at all' to 'very severe'), and the clinical meaningfulness has not been evaluated. In addition, most studies have been restricted to harm caused by one substance only and thus do not allow comparisons between different substances. However, a few direct comparisons based on the 'harm-to-others' approach have been published. One US study compared harm experienced through third parties due to their alcohol- vs. cannabis-use, in five cross-sectional waves of a survey, using representative samples of more than 4000 individuals aged 18+ from Washington State [4]. The largest number of respondents reported having been harmed in the past 12 months by someone else's alcohol use (21.3%), followed by marijuana (8.4%) or by both (4.3%). Perceived harm from marijuana use was substantially lower compared to harm from alcohol, even when prevalence differences were taken into account, especially regarding physical harm and family problems. A comparative analysis conducted in Norway on worries about someone else's use (i.e. not necessarily indicating problematic use) of cigarettes, alcohol or illegal drugs found that while the prevalence of worries in the general population reflected the prevalence rates of use, worries regarding cigarette use was more related to chronic harm, while worries regarding alcohol or illegal drugs were more related to acute harm [5]. Of those participants who did report having experienced harm, people reported substantially higher levels of harm regarding illegal drugs compared to alcohol or cigarette use [5].

Another approach to examining variations in degree of 'harm to others' associated with the use of different substances can be derived from expert opinion groups, attempting to quantify drug-specific harms according to different substances. In a seminal multicriteria decision analysis involving 30 experts, Nutt et al. [6] had 20 substances (including alcohol, heroin and crack cocaine, but also methamphetamine, cocaine, ecstasy, tobacco) ordered by their overall harm scores, differentiated into harm to self (9 harm criteria) vs. harm to others (7 harm criteria). Harm to others included the extent to which the use of the drug causes family adversities (with family breakdown, economic well-being, emotional well-being, future prospects of children, child neglect given as examples). All harm criteria were rated by experts on a scale from 0 to 100. Alcohol, heroin and crack cocaine were listed as the most harmful drugs to others, with alcohol (46/100) being rated as considerably more harmful than heroin (21/100), and with crack cocaine (17/100) being rated as almost as harmful as heroin. The ratings of 'harm to self' showed crack cocaine, heroin and methamphetamine as being the most harmful, and with them all being rated as similarly harmful (37, 34, 32/100), but all of them scoring lower than the harm caused to others from alcohol.

7.3 Harms to Offspring

Children of parents with substance use problems are a substantial group of AFMs, and some research has been undertaken on the differences in stress caused to, and strain shown by, children, depending on the type of substance or behaviour used by a parent. Slesnick et al. [7] combined observational and self-reported data to examine the effect of different addiction-type problems and different choices of drugs on the parenting behaviour of treatment-seeking mothers with respect to their 8–16 years old children. They found that mothers with opioid problems (compared to mothers with alcohol problems) less often undermined the autonomy of their children and showed higher maternal acceptance. As these mothers had not yet started the treatment programme for substance use disorders, the authors hypothesized that the observed differences might be associated with the clinical effects of opioid use, which include anxiety reduction, euphoria and a profound sense of well-being. Nevertheless, although mothers with opioid problems showed this more positive behaviour, the self-reported parenting scores for all of opioid, alcohol and cocaine/alcohol abusing mothers fell into the range that was observed in clinical samples, indicating that mothers with disordered substance use all struggle with parenting and parent–child interactions.

7.4 Harm to Adult Family Members

An overview of studies conducted by various members of the Addiction and the Family International Network (AFINet) of harm to adult family members included 12 studies (some of them unpublished) conducted in various countries and cultural settings and mostly with AFMs collectively facing different types of addiction (only three studies were restricted to one type of addiction) [8]. Among these, eight studies targeted AFMs affected by alcohol and drug use problems and one study included alcohol, drugs and gambling. The main sources of variation in the strain that AFMs were exposed to included economic hardship and closeness of the relationship, with partners, parents and those living under one roof with the individual with addiction-type problems, all reporting the highest level of strain. However, the illicit nature of some forms of drug use added to the hardship experienced by AFMs, especially when compared to alcohol [8]. Nevertheless, the author concluded that in comparing the impact of relationship and cultural as well as social factors, the similarities across the AFM's experiences outweigh the differences. On the other hand, the major forms of variation identified included the *accumulated burden*, consisting of three areas: family disharmony, material resources, and additional hardship, and all these factors can be influenced by the type of addiction (e.g. due to criminalization, acute effects, etc.).

A scoping review on mental and physical health in AFMs [9] that included 56 quantitative and qualitative articles, mainly confirms the findings from Orford et al. [8]. Variability in stress depended mainly on AFMs gender, with females reporting higher burden, but separately, lower socioeconomic status and cohabitating with more severe substance users were also major predictors of greater levels of stress, irrespective of gender. Although the majority of the included studies consisted of AFMs facing various addiction-type problems, only a minority of studies analysed the impact of type of addiction on AFMs experience. A consistent finding in those studies was that AFMs of polysubstance users and of injecting drug/opioid users experienced higher burden than single-substance users [9]. Single studies showed higher burden in female partners of heroin users compared to alcohol [10] and AFMs of illicit (versus prescribed) substance users reporting significantly more stressors (e.g. violent behaviour; [11]). Findings regarding the duration of substance use history on the well-being of AFMs were inconsistent [9].

Another recently published systematic review of qualitative studies that included 25 studies [12] did not even report the types of addiction that were covered by the studies that were included. Although several of the studies covered

different types of addiction, the review focused exclusively on shared experiences of AFMs.

Taken together, systematic and scoping reviews reveal little variation between the effects on AFMs of different addiction-type problems in terms of substance/behaviour of choice. However, the majority of studies that have focused on the experiences of AFMs have been conducted as qualitative studies, often with rather small sample sizes. Most studies rely on highly affected populations, often reporting polysubstance use of their relatives, making comparisons between AFMs facing different types of addiction difficult. Nevertheless, there are some individual studies that have examined this issue.

A mixed methods study conducted in Italy with sufficient large subsamples of AFMs facing alcohol-related addiction-type problems, drug-related addiction-type problems and AFMs facing both type of problems found no significant differences between the relative's substance use problem (alcohol, drugs, or both) and overall symptom levels, but unfortunately did not include a more detailed analysis of substance-specific effects in either the quantitative [13] or the qualitative [14] analysis. However, some important substance-specific issues are mentioned in the qualitative analyses that demonstrate that substance-specific issues influenced the experience of AFMs. Family members found problems with alcohol more difficult to recognize, especially in the beginning, because alcohol is such a widely used drug in Italy, commonly consumed within the family, and social networks often tended to minimize the problem. There were also specific effects of a relative's alcohol as opposed to drug problem: many AFMs reported avoiding social situations, because alcohol was likely to be a temptation for their relative, and this resulted in these AFM's access to social support being greatly reduced [14] AFMs also made different attributions, depending on whether their relative had alcohol versus drug problems: in the case of drugs, the problem was seen as being caused by environmental and social influences (i.e. 'bad company') as opposed to the personal attributes of the user [14]. In a 12-month follow-up of an intervention study analysing the effects of the 5-Step Method in an English sample of 143 AFMs, no significant differences between AFMs struggling with the effects of alcohol compared to drugs were found in terms of impact and coping. However, AFMs showed more symptoms when having a relative with drug problems compared to those dealing with alcohol problems and those dealing with multiple substance problems [15]. All three groups, however, improved significantly over time, indicating that interventions targeting AFMs in their own right reduce stress, irrespective of the type of addiction AFMs are facing.

A cross-cultural analysis of the experience of AFMs [16] using data from AFMs from Indigenous Aboriginal groups, Mexican slum dwellers and middle-class English families noted that the majority of research has been undertaken with volunteer samples, suggesting that this might lead to the neglect of other sources of variation. They suggest that using theoretical sampling approaches in order to make samples more diverse might be important to capture specific sources of variation, including the impact of addiction-type problems. However, the authors also noted findings from studies that indicated that, compared to alcohol-related addiction-type problems, drug-related addiction-type problems were more 'shocking' to AFMs, especially when the mode of use included injecting or was associated with clear signs of physical damage [16]. Furthermore, in the English sample, drug use was associated with a greater role of criminal involvement and interaction with police in families, which caused more family stress; however, this association was less clear in the study sample recruited in Mexico, indicating also an interaction of type of addiction with culture.

Another area related to addiction-type that might influence the AFMs experience could be the pattern of use. The relationship between drinking patterns and interaction of couples was analysed by Jacob and Leonard [17] in 49 couples where one of them was an 'alcoholic' husband. They compared 'episodic' and 'steady' (i.e. daily) drinkers, and whether drinking occurred inside or outside of the home. Marital dissatisfaction of spouses was highest in episodic

outside-of-the-home drinkers and lowest in steady in-home drinkers, suggesting that interpersonal stress is partially associated with greater unpredictability of the user's behaviour and worries about that user's behaviour when drinking away from home.

A narrative description of commonalities and differences according to type of addictive disorder in family members seeking help for an addiction-type problem of a family member (including alcohol, illicit drugs, gambling or Internet use disorders) was published by a counsellor and researcher from an intervention site in Vienna, Austria [18]. Although not accompanied by quantitative data, the author described experiences encountered in a counselling agency specializing in the needs of AFMs since the early 1990s. The author describes specific features and needs of AFMs that often are also associated to varying types of relationship according to type of addiction. AFMs seeking support for an alcohol use disorder or pathological gambling mostly were (female) partners, parents, children and siblings, while AFMs seeking help for someone's drug use problems mostly were parents and grandparents and sometimes siblings. Regarding the types of strain reported, AFMs facing addictive disorders due to alcohol or prescription drugs more often stated worries regarding the health of their family member and social consequences for the family, compared to behavioural addictions. Especially partners often reported being emotionally neglected, while neglect was reported less frequently to be relevant in AFMs facing pathological gambling. However, pathological gambling was reported to lead to much higher levels of financial problems when compared to other types of addiction. AFMs facing addiction problems due to illicit substances reported that criminalization of the substances is a specific stressor, but also often mentioned worries regarding the user's health (especially regarding hepatitis C and HIV) and the social situation of their relative. The author points out that family members affected by alcohol dependence mostly represented several age classes and that these AFMs quite often reported different needs according to their age and relationship to the relative with the alcohol use disorder. While partners were described as often reporting that they had distanced themselves, adult children more often seemed to support the idea that more controlling measures towards the relative could be helpful. Parents, on the other side, tended to blame the partners of the individual with addiction problems as being responsible for the drinking. AFMs of individuals with drug issues and Internet use disorders mostly were parents, and in this group a topic often discussed within help-seeking was responsibility. AFMs of gamblers showed most needs to obtain support in dealing with familial finances, and in the case of Internet use disorders, support needs were targeted at improving educational competences [18]. The aforementioned data shows the interrelation between type of addiction and relationship (see also Chap. 6).

Finally, drug-specific interventions targeting family members such as provision of naloxone (to treat opioid overdose) have shown beneficial effects that are specific to the risks associated with addiction-type problems regarding heroin (or other opioids posing the risk of fatal overdose) [19]. Furthermore, there is reason to believe that strategies regarding financial management seem to play a more prominent role in interventions for AFMs concerned by pathological gambling [20], although no studies have been conducted comparing effects on AFMs faced with pathological gambling in contrast to AFMs facing other addiction-type problems. In a study on the help-seeking behaviour of individuals with pathological gambling in New Zealand, 32 of their family members were also interviewed. Of those, 75% reported financial problems to be the reason for their own help-seeking behaviour [21].

7.5 Conclusion

Although substantial differences have been identified in individuals with addiction-type problems according to different substances and behaviours, variations in effects on AFMs have rarely been studied. This might be due to methodological issues, mainly due to selection pro-

cesses in the way the samples of AFMs are recruited (mostly volunteers, mostly when in crisis), and to the generally small and heterogeneous sample sizes used in most studies. Nevertheless, variations due to relational, cultural and economic factors (see Chaps. 5, 6 and 9 in this volume) as well as gender differences (see Chap. 8) seem to strongly influence the level of strain experienced by AFMs. Furthermore, data suggest that, for example, relationship status and type of addiction in most samples are linked to each other, especially when help-seeking samples of AFMs are analysed. There appears to be a strong relationship between age-related prevalence rates and AFMs seeking help. Because drug-addiction-type problems are much more prevalent in younger people (and certainly were when many of these studies were conducted), AFMs in related studies more often tend to be parents. Because in high-income countries, alcohol use (and problems) is much more prevalent, the majority of AFMs seeking support are affected by alcohol.

In reviewing this literature, it has become clear that, whilst variations are mentioned in the effects that these addictive-type behaviours can have, there is an assumption that the similarities in negative effects are far more striking than are the differences. Indeed, some reviews are so certain of this 'similarity of effects' idea that they do not even examine differences related to addiction-type as one of their review variables [12].

One of the conclusions of this chapter is that this assumption needs to be tested out far more rigorously. It is clear that there are many striking similarities over what family members say, who are affected by a range of addiction problems within their relatives (see, e.g [22, 23].), but the fact of this similarity may have blinded many researchers to a more detailed examination of potential differences in experience, depending on the type of addiction. Table 7.1 summarizes the limited data related to variability attributable to type of addition. One of the things shown is that there are many differences in the types of *stress* that different types of addiction create, but that the *strains* on AFMs are actually rather similar.

As can be seen, there is some data to suggest that there are type-of-addiction differences in AFMs experiences. However, in order to undertake further analyses specifically on the effects of different types of addiction on AFMs, it would be helpful to follow up the reasonable suggestion made by Orford and colleagues [16], namely to use methods of theoretical sampling, i.e. selecting AFMs with a similar relationship status, economic background and the like, and varying the type of addiction they are facing. It would also be useful to undertake more research using large-scale samples for quantitative research. Nevertheless, the existing data also substantiates the view expressed by many researchers in this area, indicating that there is a common core of both stresses, and especially the resulting strains, which AFMs experience, many of which can be modified, irrespective of the type of addiction they are facing.

Table 7.1 Variability attributable to type of addition (utilizing the SSICS Model of understanding family responses to addiction [16, 24])

Addiction type	Type of AFM	Types of concerns about the relative or their stressful behaviours that are problematic for AFMs	Types of strains shown by AFMs (strain/AFM-burden is greater if relative is polysubstance/behaviour user; and if injecting drug user)
Alcohol	All—Children, siblings, partners, parents, grandparents, others	More common: Behavioural disturbances, aggression/violence, concerns over physical health, more stresses related to child maltreatment and abuse	More common: Generally less worried than if illicit drugs; if within a drinking-normative culture, more difficult to recognize as a problem; greater effects on social support, as more likely to share social networks with the problem-user
Illicit drugs: Sedatives (e.g. opiates)	Predominantly parents/ grandparents; some siblings	More common: Indifference, unresponsiveness, lack of engagement, concerns over physical health, concerns over overdosing, concerns over illegality, greater role of criminal involvement, concerns over adulteration of substances, concerns over peer-group, concerns over relationships with dealers and criminality, more worrying if injecting, especially concerns over HIV and HepC, more stresses related to child neglect (as opposed to maltreatment or abuse)	More common: Greater shock than if alcohol-problem due to stigma of illicit drugs; feel very stigmatized, especially when injecting drug use; generally most worried, especially if injecting drug use; problems due to becoming involved with drug debts; more interaction with police
Illicit drugs: Stimulants	Predominantly parents/ grandparents; some siblings	More common: Behavioural disturbances, aggression/violence, concerns over physical health, concerns over illegality, concerns over adulteration of substances, concerns over peer-group, concerns over relationships with dealers and criminality, more worrying if injecting, more stresses related to child maltreatment and abuse	More common: Greater shock than if alcohol-problem due to stigma of illicit drugs; feel very stigmatized; generally more worried than if alcohol, less worried than opioids and injecting drug use; problems due to becoming involved with drug debts
Prescribed drugs	Predominantly adult children; some spouses	Concerns over physical health, concerns over long-term toxicity	Generally the least worried
Gambling	All—Children, siblings, partners, parents, grandparents, others	More common: Financial, surprise/ shock of discovery, user suicide	Generally more worried than alcohol, less worried than illicit drugs; greater sudden shock than other types of addiction, because so well hidden; problems due to becoming involved with gambling debts; major financial and related housing difficulties

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Further Reading

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Orford J, Natera G, Copello A, Atkinson C, Mora J, Velleman R, et al. Coping with alcohol and drug problems: the experiences of family members in three contrasting cultures. Routledge; 2005.

Impact on AFMs: Gender

8

Anja Bischof and Gallus Bischof

8.1 The Impact of Gender on the Burden on Family Members of Individuals with Substance Use or Gambling Disorders

Gender is an important factor when it comes to health. Females react in a different way to health risks than males, not only in a biological way but also in terms of gender roles, behaviours and societal attributions [1]. There are significant gender differences especially in terms of mental disorders: while females worldwide more often have 'internalizing disorders' such as anxiety or mood disorders, males suffer more often from substance use disorders [2].

Therefore, it can be assumed that there are gender differences also in addiction-affected family members (AFMs) in terms of experiences and processes. Nevertheless, samples in studies on the impact of substance use disorders or disordered gambling on AFMs conducted in the last decades in most cases primarily consisted of females [3], although a recent nationwide representative German study showed that men account for 43.1% of AFMs in the population [4]. Comparative studies to analyse differences between female and male AFMs are scarce [3].

In a recent comprehensive survey in Australia consisting of a representative population sample ($n = 1000$) and a panel survey ($n = 1574$), females reported significantly more often than males to be harmed by other's drinking, especially by someone living in the same household [5]. This has probably several reasons: as reported above, males show a higher prevalence of substance use disorders or disordered gambling. Traditionally, men are both more likely to use substances and more susceptible to substance use disorders, albeit the differences between sexes have been levelling out in the past years [6]. At the same time, females are generally more willing to talk about mental health and family problems and to seek professional help [7]. Furthermore, traditional gender role stereotypes such as expectations towards women to take care of the house, being supportive, reticent, nurturing, accepting, still exist, independently of the developmental state of countries or regions. Based on these reasons, the rate of males participating in studies examining the impact of addiction on family members is in most cases too small and gender comparisons are often statistically underpowered. For example, in the large GENATHO (Gender and Alcohol's Harm to Others) Project, the proportion of male participants living in a partnership with an individual with heavy drinking was less than 2% [8]. Overall, men are under-

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represented in studies that could lead to a neglect on the part of researchers of perception of stress, burden and coping strategies in male AFMs.

As previous studies have shown, the burden to and harm for AFMs are higher in closer relationships [9] (see also Chap. 6). For example, a recent study on harms to concerned significant others by an individual with gambling problems showed that especially partners perceived harm from the gambling problem, followed by parents, siblings and children [10]. This is also depicted in participation rates of volunteering study participants in general: parents and partners were more often willing to share their experiences and reported more often than other family members that they suffered from the stressful situation, while siblings and children of individuals with an addiction were often more able to withdraw, tolerate or become resigned and pay attention to their own needs [11, 12]. Therefore, this chapter will mainly focus on gender differences and commonalities in partners and parents, since the database for other relationships is rather scarce.

It is necessary to distinguish between physical harm and psychological burden. Both are prevalent in males and females, although in often different forms: studies on 'harm to others' in the general population (that are not restricted to AFMs; see also Chap. 2 in this volume) show that while men are more often involved in physical confrontations with people who are under the influence of substances, females more often experience physical harm by individuals in their close surroundings with increasing amounts of violence and domestic assaults [13, 14]. Concerning psychological burden, females more often suffer from mental health problems and stress caused by a close relative's substance use, which can be accelerated by living together and worrying about the consumption/gambling, the housing situation and financial issues [3, 10, 14]. Additionally, female AFMs are more often disturbed by embarrassment in social situations, by unreliability of the relative with substance use disorders and by financial constraints caused by the addictive behaviour [14].

The psychological burden for male AFMs, on the other hand, is more likely to stem from 'active disturbance', e.g. getting into arguments with the relative with substance use disorders, being threatened, or experiencing disturbances of family life, as shown in an Italian study with 113 AFMs (25% male participants) by Arcidiacono and colleagues [15]. Nevertheless, in this study female AFMs showed significantly higher scores on overall strain, too.

Furthermore, females—especially, but not only, in low-income countries (see also Chap. 9)—are more affected by low socioeconomic status, low education level, and therefore existential worries [3, 9]. For example, in an Indian sample of wives of individuals with an alcohol or heroin dependence, 75% of the women were housewives/unemployed, and almost half of the wives were illiterate [16]. However, in the European context, more traditional role models are still present: in the Italian study by Arcidiano and colleagues [15], 70% of the female participants stated 'housewife' as their occupation. In these cases, a financial dependence on the husband is to be assumed, which probably has a significant influence on coping strategies and freedom of action. Furthermore, the probability of the addiction having a massive impact on the working capacity and the productivity of the financial provider leads to additional stress and worries among female AFMs in case of financial dependence on the individual with an addiction [16].

Additionally, female AFMs report physical health problems significantly more often than male AFMs, as shown in a sample of 110 AFMs (55% females) [17]. Interestingly, being a family member of a female relative with a substance use disorder produced higher excess health costs in an analysis of insurance data in the United States than being a family member of a male relative. Ray and colleagues [18] interpreted these data to mean that the consequences for a family in situations where wives or mothers failed to correspond to their role as a caregiver for the family, as a result of their substance use disorder, created a greater burden for their family members, which in turn led to a higher health impact.

Research over the last decades has shown that female AFMs tend to differ from male AFMs in terms of coping strategies. In their large qualita-

tive study conducted on three different continents that also included male AFMs, Orford and colleagues [11] showed that female partners were more often engaging in 'tolerant-inactive' and 'engaging' coping strategies, both of which led to a higher burden. In a recent analysis by Horváth and colleagues of five different samples from previous studies in England (N = 323) and Italy (N = 165), female family members showed significantly higher rates of 'tolerant-inactive coping', which includes actions such as covering-up the substance use, self-sacrifice and acceptance of the situation as unchangeable [19]. Male partners of wives with a substance use disorder, on the other hand, tended to react more aggressively and angrily towards their wife [20].

What should not be overlooked is that, depending on the cultural background, coping strategies may vary. While a more collectivistic background is associated with 'tolerant-inactive coping', individualistic cultures show a greater tendency to use withdrawal from the relative with substance use disorders as a coping strategy [15, 19]. Nevertheless, a recent study examining alcohol-related harm to others in 11 countries, including both low- and middle-income countries as well as high-income countries, involving more than 20,000 participants overall, found similarities between sexes in all 11 countries in terms of 'caring for the drinker or cleaning up after the drinker's drinking', although the prevalence was higher in females and the intensity of 'caring' differed between males and females [21].

While earlier concepts and models in research on AFMs partly saw women as enablers of their partners' substance use disorder, which often led to a double stigmatization (of the addiction disease and the role as family member) or pathologized AFMs for being together with an individual with a substance use disorder, research in recent years has led to a greater awareness of the burden on partners of individuals with an addiction and developed models that take into account the difficult conditions of AFMs [22]. Nevertheless, the main focus of research is on female partners and spouses of husbands with alcohol, drug or gambling problems. Gender role expectations build one major issue in the stories of female partners: the caring wife, taking care of house and children, providing food and the warmth of a happy life [11].

In the GENAHTO Project, analysing data from 6093 females living with a partner with an alcohol use disorder in nine countries, perceived harm from the partner was correlated also with low life satisfaction, self-reported depression and anxiety, and heavy episodic drinking by the AFM [8]. Harm was not specified in this study and can cover a variety of behaviour patterns from inappropriate to violent. Not uncommonly, domestic violence such as psychological, physical and sexual abuse is a recurring theme in partnerships where one partner has an addiction problem. Women are particularly affected by this [11, 23–25].

Wives of husbands with an addiction disorder, especially in tradition-oriented, collective cultures with very pronounced gender role expectancies, are even more likely to be victims of harm caused by addiction (highest rates in GENAHTO: Vietnam, India, Sri Lanka) [8]. As described above, it can be expected that—with the duty to fulfil these role expectancies as a wife, with a strong internalization of gender role expectancies, low support by others due to societal expectations, financial dependence on the partner and lower levels of education resulting in worse access to the labour market—women in these cultural settings have less alternatives for coping with the addiction problem and therefore increased strain. This is represented also in the various studies conducted by members of the Addiction and the Family International Network (AFINet) in a variety of low-, middle- and high-income countries, where females have internalized the role of the (often multiple) caring wife and mother that is culturally prescribed for them and therefore have a higher burden [9, 26].

Little is known about male AFMs as partners of individuals with a substance use disorder. Even if the proportion of male participants in studies is sufficient, a gender comparison of burden, perception of stigma, gender-specific needs for support or other stressful factors are often lacking (as for example in a study by Brown and colleagues with a sample with 40% male caregiv-

ers) [27]. An Australian study examining predominantly male partners of females with a gambling disorder (with only one female partner) found significantly elevated rates of relationship dysfunctioning, but no higher rates of depressive symptoms or lower self-esteem when comparing the sample data of male partners with data from normative standardization samples. The authors suggest this unexpected finding to be a result of sample selection bias and/or the relatively brief course of disordered gambling in female participants [28].

In contrast to female partners of individuals with substance use disorders, husbands or male partners of females with an addiction are often met with less empathy for their situation, both by researchers and by representatives of the help system [11]. This happens, although their situation is comparable with female partners: the feeling of not being able to change the situation, taking responsibility for tasks the partner with the addiction problem cannot fulfil anymore, anger, feeling isolated and helpless, being worried about the psychological and physical well-being of children as well as the partner with addiction [11, 20]. Though financial dependence is probably far less prevalent in male partners, the emotional burden of living with a loved one with an addiction problem might be similar between genders. Depending on cultural conditions, the ability to cope with the addiction in their own right might nevertheless make a major difference.

As with partners, most studies on parents focus on stress and strain of the female parent, often neglecting the burden for fathers. It may be assumed that stress and strain vary between mothers and fathers depending on cultural setting, family bonding, housing situation, interaction and dynamics. Gender role expectations play a major role also in the family life. For a long time, the role of mothers was clearly defined: while fathers were seen as providers for the family, working all day to secure the financial income, mothers were assigned the role as stay-at-home, full-time caregivers for the children [29]. Accordingly, a closer bond between mothers and their children and a correspondingly higher burden in the case of addiction has automatically been assumed.

The role of females as primary caregiver for children has for a long time led to a societal definition of a ‘good mother’, which is reflected in the child’s behaviour and well-being, which in turn often attributes the blame for the development of an addictive disorder to the mother’s performance [29]. Having a child with an addiction puts parents—and especially mothers—in the position of being responsible. Smith and Estefan [29] report in their narrative literature review of parenting courses in family centres in the 70s for parents of young people with substance use problems that ‘dysfunctional family dynamics’ were blamed for having generated the problems. This attitude, i.e. that parents—and especially mothers—are held responsible for what happens to their child, even in adulthood, has been internalized by parents for decades. Accordingly, parents are known to blame themselves and feel responsible for their offspring’s development of an addiction problem [30, 31].

Furthermore, and depending on the cultural background, addiction of a child (even if they are now adult) is seen as a ‘family illness’, as described by the authors of a study on parents of individuals with an addiction in India [32]. Therefore, it is not surprising that in this study, the proportion of mothers reporting severe objective and subjective burden was twice as high than that of wives, and females reported a three to four times higher burden than males [32].

In general, coping with the addiction varies depending on the sex of the parent. Mothers as AFMs are—also corresponding to gender role expectations—prone to be more permissive, soft and caring towards their children, but also more confronting, while fathers tend to be more strict, disciplinary, but also conflict-avoiding [11, 29, 33].

A recent Swedish study with 684 parents recruited via an organization for parents of drug using children analysed gender differences and found that mothers more often reported guilt, shame and a higher impact of the addiction on emotions and family life, compared to the fathers [34]. The authors concluded, also considering the

low participation rate of fathers in their study (14%), that fathers 'take less responsibility than mothers for children as well as for problems within the family' (p. 2330). This conclusion disregards the fact that low study participation rates correspond to the generally low help-seeking behaviour of men (all study participants were recruited in help services for parents of individuals with drug use). Additionally, and according to the aforementioned gender role stereotypes, men may be more reserved concerning the expression of their own emotional states.

This does not mean that fathers are less burdened: in a recent study examining 167 parents (35% males) of adult children seeking treatment for substance use disorders, Russell and colleagues [35] found elevated rates of depression, anxiety, stress and decreased values in relationship quality in both parents, but mothers and fathers did not differ in these variables, which means that the burden for both sexes was the same when dealing with a child with substance use disorders.

In a German qualitative study on AFMs, 22 mothers and nine fathers were included [12]. Both sexes reported high levels of strain, impairment in family life and communication problems, but differences could be detected: while mothers expressed more psychological burden (e.g. depressive symptoms), fathers were more burdened by somatic consequences and suffered from violent behaviour by the child. Additionally, they expressed a strong feeling of helplessness. While mothers self-sacrificed themselves more, fathers could distance themselves better, set fewer rules for the individuals with addiction but stuck to these rules with greater consistency. Interestingly, when asked about resources, the fathers reported that their partners were the most important resource while the mothers complained about not handling the addiction problem together as a couple with their partners, which is in line with previous studies where mothers did not feel supported by their partners [9, 36]. Overall, these results might be associated with the aforementioned role expectancies and stereotypes, too.

Other groups of AFMs than partners and parents are rarely analysed in research, especially in terms of gender differences (for underage children of parents with substance use disorders, see Chap. 5). Haverfield and Theiss [37] found in an online survey with 622 adult children (537 females, 85 males) of a parent with an alcohol use disorder that females had a higher perception of stigmatization when the severity of the parent's substance use disorder was perceived as higher and when the topic was avoided, while stigmatization was only present in males when avoiding the topic. In both sexes, stigmatization was significantly associated with more symptoms of depression and lower self-esteem and resilience.

Examinations of siblings of individuals with substance use disorders are scarce. Although a small-scale qualitative study by Barnard [38], which interviewed 24 individuals with problematic drug use, their parents and their siblings (n = 20, age 16–26), did not compare gender-related burden, this study did show that sisters and brothers of individuals with drug use did not differ in the amount of worries, stress, relationship problems and difficulties in loyalty as consequences of the addiction. The only gender-related difference was that some of the brothers of male individuals with drug problems were more often victims of bullying and violence by other drug users who had business with their sibling.

8.2 Conclusions

In sum, the experiences of male and female AFMs do not differ strongly in terms of them feeling stressed and not knowing how to cope with the situation, i.e. the 'core' or 'essence' of how AFMs experience the addiction of their loved ones, as Orford and colleagues [11, 20] have elaborated. Nevertheless, due to expectations towards their gender role, the extent of burden, the ability to cope and the ability to withdraw and look after themselves vary, depending on gender and cultural context. Female AFMs especially have to deal with multiple problems, though our knowledge about male coping mechanisms and psychological strain is scarce. This is highly corresponding to societal and internalized

gender role expectancies and gender stereotypes—men do not talk about their worries—which are reflected in often low study participation rates and in low treatment utilization by men. Future studies should focus on reaching out for male AFMs to get a better understanding of their burden and concerns. Studies that did include higher rates of male participants used a variety of methods, including getting female patients in treatment to nominate partners as study participants [27] or recruiting AFMs via advertisements [17] or recruiting via online support forums [35]. Future studies could use these promising approaches to address male AFMs directly.

Furthermore, we need more comparative studies to be able to better classify the differences, especially against the background of cultural particularities. Additionally, it is highly necessary to build gender-sensitive counselling and treatment opportunities that take into account the different burdens, coping strategies and cultural realities to gently try to overcome internalized rigid stereotypes, so that female and male AFMs get the help they need—in their own right.

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9 Impact of Culture and Geographical Location on Affected Family Members

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9.1 Introduction

All human action is expressed within a cultural dimension, with culture being understood as the context where people live. It includes complex, supportive systems in which collective and individual awareness are combined and expressed through a common language and behavior of their members [1].

The purpose of this chapter is to assess the impact of the 5-Step Method (5SM) on an Indigenous community and to analyze the results from an anthropological perspective, observing the way individuals cope with their culture and deal with their emotions when they wish to modify a lifestyle marked by violence due to excessive alcohol consumption. In this chapter, we seek to show the influence of the cultural context, by describing the behavior of women who, using the 5SM, processed their emotions, modified their behavior, and adopted more beneficial responses that did not limit their everyday life.

Research in Indigenous populations poses a major methodological challenge, particularly because researchers and the community have a range of ways of interpreting the world. Additionally, language shapes social content that often differs between cultures. Finally, every culture has a mandate with symbolic, traditional content for a type of society.

> The community, insofar as it shares a common culture, is collectively interested in exerting pressure on its members to conform to its norms [2].

Approaches and reflections from research on health in rural or Indigenous communities in Mexico contain countless heartbreaking stories of family members, particularly wives, mothers, and children [3, 4]. On the one hand, women cannot complain about such situations caused by excessive alcohol use, usually by men, because they involve acts within the home. On the other hand, since the resulting emotional discomfort is not physically located in an organ of the body, women are unable to express it and get it treated with medicines. They therefore think that there is no cure for it and that no one understands them. Emotions are located in the realm of *beliefs* and hence women use care options typical of their culture rather than modern evidence-based psychosocial interventions, which are not usually readily available in Indigenous or rural areas.

The case study presented here represents our research conducted in an Indigenous area encompassing small communities with 600–1500 inhabitants, located 200 km from Mexico City. During an initial ethnographic exploration, we identified alcohol abuse as a major problem in these communities. Drinking alcohol is a deeply rooted custom in the community, affording group identity and solidarity, especially among men. Its

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consumption is often intended to strengthen friendship and it is common for employers to offer workers *pulque* at the end of the day, especially in the agriculture and construction industry. *Pulque*, a traditional fermented drink (4.5% alcohol) is mead obtained from the maguey stalk. It is produced for personal use and sale, is cheaper than beer, and consumed excessively daily. There has recently been a gradual shift from the inexpensive *pulque* obtained from people's maize fields toward commercially available beer, affecting the family economy.

Our ethnographic exploration also identified poverty as a barrier to accessing healthcare, partly due to the difficult geographical conditions and the limited transport services available. In some communities, even the nearest health center is over an hour's walk away, and people prefer to spend their time and scant financial resources on basic needs over healthcare.

Members of these communities lack clear information on alcohol use disorders. Only people who drink every day until they get drunk are regarded as having alcohol use disorders. When these individuals seek help at the health centers, health professionals scold them for misbehaving, especially if they find out they have behaved violently toward women, but no further intervention is provided. Health systems, especially those for treating alcohol use disorders, are limited or nonexistent in Indigenous areas. Where they do exist, they tend to focus on dealing with the individual who drinks alcohol and fail to address the problems of their significant others.

Although some men attempted to give up drinking, they soon dropped out of treatment. Alcoholics Anonymous (AA) groups have proved unsuccessful, mainly because of their proximity to the communities, and men are afraid that others in their community will find out about their drinking problems if they attend the local AA group.

After our psychologist had spent adequate time in the community addressing various issues, women trusted her enough to admit they were experiencing a series of family problems related to their partners' alcohol use and that they required support. They reported feelings of tension, sadness, and depression. They did not believe that these experiences warranted seeing the doctor because they expected the feelings to go away even though they were endlessly repeated and became part of their everyday life. This was a problem the women had initially tried to conceal.

9.2 The 5-Step Method (5SM) and Its Implementation

It was decided to address the emotional conflicts of a group of these women using the 5SM to determine whether a psychoeducational intervention would work within this social context with its entrenched patriarchal traditions.

This involved a rearrangement, an intersubjective reconstruction, and different behavior that entailed consequences within the community due to the women's "disloyalty" to men in a society where the patriarchal culture and habits posed a challenge for women. Addressing the manner in which they coped with their situation was expected to encourage women to attempt to modify the practices that led to their suffering and to function within their cultural context with a new perspective on their problems.

The 5SM was explained to the women, and were told that the following ethical aspects would be followed throughout the process: (a) the cultural practices of the population would be respected, such as their right not to report matters they did not wish to discuss with strangers; (b) the counselors would clearly, simply, and empathetically explain each of the components of the intervention, ensuring that they had been understood by women; (c) sessions would be brief, lasting no more than an hour; (d) the women would have access to the counselors who would be available to listen to them and be flexible as regards the women's schedules and the use of their time; (e) the counselors would promote the active participation of the women, in other words, they would tell them that they themselves would decide what to do throughout the entire process in keeping with their needs and by analyzing the advantages and disadvantages for them; (f)

confidentiality and anonymity would be guaranteed; and (g) the women would be asked to give their consent and told that they could drop out of the intervention whenever they wished.

When we suggested an intervention to help relieve part of this distress, we recalled what Mier (2002) said about the importance of an intervention and its ethical scope as a process of creating meaning [5]. An intervention is an extrinsic act unrelated to the autonomous development of the community, which disrupts a stable regime and can create an area of confrontation in response an unsolicited intervention. This begs the question of whether it is possible to promote a process of emotional transformation despite the cultural influences that normalize it. Is designing an intervention a feasible solution? We had already adapted the 5SM manual for this population, especially in regard to the language and meanings of terms such as coping [6].

Another important aspect to analyze was the role of the counselors, one of whom was an outsider and the other a local. The former had to earn the trust of the women and did so more easily, paradoxically, because of her outsider status, which made the women feel she would not betray a confidence. The latter was a local woman, who was forced to conduct the intervention in communities far from her own to encourage the women to trust her. However, she established an empathic relationship with the women more quickly, since status as a local facilitated her understanding of the cultural and linguistic codes [7].

9.2.1 Implementation

Women were invited to participate through the Health Jurisdiction serving several towns. The local doctor was asked to refer patients with health problems related to the alcohol use of a family member to the counselors. Over a period of 9 months, 73 women and one man attended, with only 43 accepting the intervention (comprising four to six sessions). The remainder agreed to participate as a control group and were evaluated at 3, 6, and 12 months, through the Coping Questionnaire [8] and Center for Epidemiological Studies-Depression (CES-D) questionnaire [9]. The intervention was regarded as appropriate because it enabled the women to know that they made decisions in keeping with their possibilities. Within their culture, they would have to choose the possibilities they were willing to accept.

In this chapter we share the process of understanding and explaining whereby the women progressed from one stage to another, through the metaphor of *social drama and experience*. Proposed by Turner (1974), this method analyzes a psychological process to understand conflict within a culture that can be construed as a *social drama* in the form of a ritual [10]. There are conflictive processes in which subjects experience dramatic moments. In these cases, the concept of social drama can be useful for describing situations within the four stages of the social drama: the first stage, rupture or the gap, deepens the second stage, the crisis. The third stage involves readjustment or transformation, while the fourth involves reintegration or reintegration and understanding how the actors construct the process of their suffering, and whether they can adopt new perspectives. In other words, what the 5SM seeks is to enable people to shift from one way of coping to another that is more beneficial and in line with their own culture.

The 5SM was implemented through its five steps, analyzing the advantages and disadvantages of the women's previous way of coping and identifying the ones they now wished to use. However, for analyzing the results, we altered the model. Although changes in the coping model continued to be identified through coping mechanisms, we highlighted an anthropological model in which women's responses are part of a specific cultural context such as that of small communities with a strong cultural mandate. This had previously prevented the women from requesting support, but in this case, they dared to participate in this intervention, which we believe could encourage its implementation in similar communities.

The analysis began by considering the *lived experience* as a reality organized through

language, in this case as a historical and cultural process, "*facts of awareness given by the interior experience*" [11, 12]. According to Turner, experience is a *volatile* but *productive* word that can be controlled. It is also "*crystallized secretions of a human experience.*" In other words, even though the experience is volatile, something takes root in the person, which is where we think that an intervention can mobilize what has been crystallized.

As mentioned earlier, we used Turner's ritual model, in which the first phase is *rupture accompanied by the initial crisis*. In this case, it was triggered by the decision to rebel against men and the patriarchy. By independently making the decision to receive help, the women broke the rule of not talking to outsiders about their domestic problems. During the sessions, they discussed information that would be regarded as opposing men, disobeying their orders since they had not told them or requested their permission.

Some testimonials from the first session, when the crisis erupted, included stories of violence and infidelity, and feeling powerless to change the situation. Women suffered because they feared they would be rejected, violated, and judged by the community. They admitted that they had been *cursed* for not obeying a man, and often feared that the curse could come true.

At this point, the cultural norm, which in this case is eminently patriarchal, had been broken.

The second phase saw a deepening of the crisis, which Turner calls the gap. From their testimonials, we realized that the line between the first and second phase (usually the second and third sessions) was quite subtle. They continued to dare to break the rules because they were in a difficult situation, and this was the first time they had talked about it. This second stage took place during the path to achieving self-awareness, although it did not happen in the same way with all the women, varying in intensity, space, and time. The intervention continued to focus on cognitive and affective aspects, with women beginning to see things differently. They began to clarify their responsibilities and feel less guilty. They realized that alcohol consumption was the man's problem. One of the women who used to give her husband money (tolerance mechanism) now said, "*Now I am going to tell you the truth. I refused to give him* (money) *because he spends it on drink*." She began a process of understanding and acknowledging herself and realized that refusing to give her husband money was not the wrong response. When she and the counselor analyzed what the advantages and disadvantages of giving him money would have been, she realized that that had been the best decision. She clarified this with the counselor, who did not judge her, and instead understood her and approved her decision. This produced catharsis, relief, and the realization that she had not make a mistake and that she had been entitled to do so. She accepted that she had made the right decision, and realized it was not an act of disloyalty. Part of this process involved recognizing her distress and its link with the way the other person, her husband, drank, and with having lived in suffering and isolation because of attempting to conceal her problems.

During this second stage, corresponding to the second or third session, some women began to see the situation more clearly. The only thing the counselor had done was listen to them, reflect with them on the advantages and disadvantages of implementing these new actions and discuss which of the two they would prefer to deal with. In this case, the crisis took place at two moments. One involved the sense of shock when an intolerable situation occurred that made the women violate the norm, which empowered them. The second occurred when the women had doubts about moving forward, when they realized they had violated a norm. Nevertheless, most of them continued, even though they assumed the community would have found out that they were seeking help. Most of them had not told their husbands they were going to the sessions but had said that they were going to the health center for the treatment of a physical ailment.

Readjustment or transformation, the third stage, happened between the third and fourth session, when delimiting actions and readjustment procedures took place. At this stage, there was no going back as the women has already achieved self-awareness. It is at this point that an

intervention can arbitrarily change culture. The women restructured their thoughts by analyzing and reflecting on the advantages and disadvantages of choosing a new course of action.

> …after the conversations with the young lady [the counselor], I calmed down and… it was then that I did a lot of thinking. We looked at several options and I decided to work to get ahead, while I am still young… before I was destroyed and wanted to die… I finally plucked up my courage and said to him [the husband], "If you want to go, go, and I didn't pay him any attention. I don't want to go down, only up. He [the husband] also changed. My attitude and that of my children chastened him. If he is rude again, he will have to leave, or I will go… Why should I die if he is the one with the problem?" (Jimena)

Enthusiasm emerged as another form of experience, with women learning how to handle the situation. One woman already had the support of her children, who were all males, which gave her strength.

> Now, I want to go to work. I want to get a job but first I want, how can I say this, to finish this and take some medication that can, let's say, control me so that I can work because otherwise I'm going to be a nervous wreck, which means I won't make it (Araceli).

The fourth stage was reinsertion, or reintegration. By this stage, five to six sessions had already been conducted. By this stage, the woman had been reintegrated or detached herself from the process, emotions had been restored, and they had changed from feeling fear, hopelessness, and emptiness to beginning to feel they could take public action. These could be formal, such as separation, or informal, such as deciding to do things they had been forbidden to do, such as getting a job (independent, assertive mechanisms). The final phase of reintegration not only involved them but also the community, which had realized that the women were changing. They felt moved by the recognition and acceptance they had received, which the community had witnessed. They set formal boundaries to respond to the husband's violence (*I will go to the Town Hall, I will talk to the mayor and report him*) as well as informal ones (*You can't come back to my house: either I leave, or you do*).

> No, not anymore, well, that's not right anymore (laughs). For me to be like this, for him to mistreat me. That's really bad. If you want to drink, I tell him, you can sleep up there. Just go to sleep (Bertha).
>
> I feel better. On the one hand, I no longer have problems at home, and I feel that I am going to be calm there. If I cry, I cry tears of joy and happiness., I feel that God hugged me and said, through you, that I should not feel guilty. I want to work because I need the money because I plan to shut off a room and open a window (to sell things) (Catalina).
>
> …Now after the therapy (intervention) I regret what I was going to do (kill myself). My children tell me I have set an example for them. Thank you. I really appreciate what you have done. I really appreciate it. If I hadn't come to this training, I would not have reflected on things but… hopefully and he will also come, but hey, it's his decision (Jimena).
>
> …Yes, but I thank God that I got this help and I'm getting ahead. Well, he doesn't affect me at all right now because I've already…I just look out for myself, so I don't look out for him anymore, just for myself (Juana).

As a result of these actions, some members of the community gained legitimacy and others lost it. However, social dramas, as Turner points out, represent the constant challenge of each culture to perfect its political and social organization. In them, personal and collective identities are reconsidered and modified, traditions reinvented and re-signified. This last stage of reconstruction is delimited by an action involving reconciliation with themselves and social reintegration. The testimonials show that the women recovered their worlds, becoming the subjects of their own lives. For example, Juana began to realize her children needed her, that her husband was no longer as important and that she had the right to be happy and do things for herself.

Or Carmen who, during the process, decided to start going to church to support her life, and said 6 months later:

> Now I know what he wanted was for me not to go out, since I never went out even on errands, … now they tell me that I am in charge, I am already in charge of myself … I tell him I don't like him to offend me. If you go on like that, I am going to go on fighting and you will realize I don't want to go on fighting, … I don't want to give up what I have found, I am happy to become a woman, I don't have to be a nun (Carmen).

All these changes had an impact at the community level, even if it was just within their circle of close friends, as when friends and neighbors said to one of them, "*Go and get that help. It has done her a lot of good*." In this way, women in the community also realized they could be helped in similar circumstances.

9.3 Discussion

This chapter seeks to describe the experience of implementing the 5SM in an Indigenous cultural context. We describe the experience of receiving the 5SM in a group of Indigenous women who were experiencing violence, neglect, severe stress, depression, anxiety, and even death wishes, primarily due to the excessive alcohol consumption of their partners.

The women were mainly driven by desperation and the inability to envisage alternatives for their lives. They were aware that seeking help without the consent of their partners was a bold move in a highly patriarchal society, which prohibited women from talking about family problems outside the home, where excessive alcohol consumption is a behavior men are "entitled to" and women are expected to tolerate.

In the beginning, the women expressed a great deal of pain, despair, humiliation, fear, anger, and resignation, as has been reported in other studies [13]. This can be understood as a *social drama*, which can only be resolved after the emergence of a crisis. As the intervention progressed, subjects concluded that they were not responsible for their partner's alcohol use and that they did not have to tolerate it. They gradually realized that they were doing nothing wrong by attending the sessions and that they had made the best decision. During this stage, an ambiguous feeling of anger also emerged. This involved the desire to use violence against their partners, and fear because they believed they were disobeying the patriarchal mandate to conceal family problems. At this point, they felt they would have to make decisions and plan how they would uphold them vis-à-vis the community, the partner's family and of course themselves. This was a difficult moment because they could have dropped out of the program because they felt confused, angry, pained, displeased, and sad, but despite their doubts and as a result of a cognitive, emotional process, and the support of the counselor, they used these emotions for their benefit, and completed all the sessions.

At the same time, during this stage, subjects perceived signs of support among community members and their neighbors, which encouraged them to continue. They were reaffirmed as women and learned to weigh up the advantages and disadvantages of the strategies they used. They acquired peace of mind, enthusiasm, and confidence, noting that their proposals were achievable and that their fear of men had decreased. They developed ways to earn money by working, which is what they needed most urgently to cover their basic needs and took up activities they always wanted to try but had never done.

Once the five stages had been completed, the *reintegration* of the person took place. As Turner (1985) would say, a temporary organization of meanings, values, and intentions occurred across three dimensions: cognitive, affective, and volitional [14]. The empathy of the counselors, who did not judge or criticize the women, had undoubtedly helped them [14]. They also obtained a positive response from members of their community and even their children.

The decisions they took may have been countercultural within their community, such as considering divorce or separation, reporting violence, or physically confronting their abusers, but they now felt empowered to do so. They knew that if legal action were taken against them, they would have the support of the Steward, the main leader of the community, since they had already spoken to him, especially in regard to marital violence. What was important in the community is that the women realized they could modify certain behaviors they had previously thought were regarded as impossible to change. In these small communities, where everyone knew each other, the community itself witnessed the changes that had taken place among some of its members and supported them.

This could serve as an example to other women and could even spark social change.

This experience enabled us to learn about the challenges an intervention of this nature entails in a nonurban context. On the one hand, the original language was Ñhañhú (Otomí in Spanish) and although all the women spoke Spanish, they had idioms and linguistic particularities different from the language spoken in urban settings. This challenge was overcome since the 5SM manual for the urban population was adapted to the type of Spanish used in the community [6, 15]. The second challenge involved the customs and traditions imposed by an essentially patriarchal culture, which prevented alcohol consumption from being framed as a problem, or women from complaining about it. Therefore, agreeing to participate in the intervention was a countercultural decision contradicting the customs and traditions of the community. However, the women coped with this seemingly insurmountable challenge and emerged stronger.

Communities like this one are beginning to transmit messages to women that there is no reason to endure violence. Other messages attempt to convince local authorities to legally intervene in the case of complaints about domestic violence, which was not possible before since they were regarded as belonging to the private sphere. Despite these changes, consolidating a public policy of this nature remains a remote possibility.

In short, as Marsella and Dash-Scheuer (1987) note, the function of coping behaviors is not merely to adapt, but also forms part of human beings' quest for growth, competition, and differentiation [16]. This is what happened with this group of women. We had the opportunity to support their mental health without imposing our views. They were the ones who identified their strengths and limitations to implement different ways of coping that would be beneficial for them.

Finally, the 5SM overcame the methodological challenge identified by Douglas (1979) regarding the difficulty of communication between researchers and the community due to differences in the way of interpreting the world. Based on the experience presented here, the 5SM can be regarded as an opportunity to support mental health in a broader sphere, namely the family [2]. One of the lessons drawn is the urgent need for community prevention, to contribute to developing an awareness of gender equality, positive ways of managing emotions, identifying the harm associated with alcohol consumption, changing relationships of power, justice, and designing harm reduction policies. It is essential to explore alternatives to offer less harmful forms of consumption and promote community actions in which alcohol plays a less important role as a facilitator of socialization, relaxation, and pleasure, particularly for the new generations.

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10 Bereavement Through Addiction: The Impact of Drug-Related Death on Families and Friends

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10.1 Introduction

Persons who succumb to any sort of addictive behavioral pattern, including the use of narcotics and alcohol, run an elevated risk of dying [1]. Causes range from those directly due to the intake of substances (e.g., an overdose of a specific drug) or indirect causes resulting from the addiction (e.g., suicide associated with the burden of gambling debts). Such deaths are generally understood to profoundly impact bereaved family members and close friends [2, 3]. Yet, relatively little research has been conducted to explore the experience of addiction-related bereavement. To our knowledge, there are no published studies concerning the bereaved following losses such as gambling-related suicides.

Bereavement following a drug-related death (DRD[1]) will be the main focus of this chapter. DRD has become a global public health issue. The drug overdose epidemic continues to worsen in the United States [4], and in European countries like Norway, the numbers of overdoses are stably high [5]. Deaths involving synthetic opioids such as fentanyl have increased in recent years in countries like the United States, overdose deaths accelerated during the COVID-19 pandemic [4], and for some countries, there is an increase in adolescent overdose deaths [6].

In this chapter, to illustrate the impact of loss through addiction, two large-scale research projects are described. We briefly highlight the main findings from the first project from the United Kingdom about bereavement following substance-related death, before we move on to summarize recent research about the experience of grief and grieving among those close to someone who died from a DRD from a project in Norway.

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[1] DRD describe a death that is related to drug use (e.g., overdose, health disorders which may be linked to drug use in various ways).

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10.2 Bereavement Following Addiction Deaths

Bereavement—understood as the situation of someone who has experienced the death of a significant person—is associated with heightened risk of mental and physical ill-health and adjustment difficulties [7]. In cases of "unnatural deaths," among which many addiction-related causes can be classified, the risk is intensified compared with that following more natural types of death. There are a number of reasons for this. Not only the circumstances of death (sometimes sudden, violent, volitional) but also other factors are likely to co-determine the relatively-even-greater excesses. Notably, in the current context and as elaborated below, interpersonal variables, including long-standing relationship difficulties with the close, deceased person who had used substances, and trouble coping with the loss due to stigmatization by others, have been well-documented (among other features) in research on DRD bereavement [8]. Identification of such factors brings us directly into the family domain: Typically, bereaved people do not grieve in isolation; most do so with family members who have experienced the same loss and together with other members of their social networks. Family dynamics affect personal grief and ways of grieving, and vice versa. What is more, family concerns (e.g., dealing with the legal consequences of the unnatural death or the financial burdens from debts relating to the addiction; changed family relationships since the troubled family member has died) have to be coped with. Understanding bereavement following addiction would, then, be incomplete without incorporating a family and friendship circle perspective and this leads to examination of the available research on DRD bereavement in family context and its implications for understanding other types of addictions.

10.3 Bereavement Following Substance-Related Deaths

Valentine and colleagues conducted the first large-scale research project concerning the experiences of bereaved family members and friends following a drug- or alcohol-related death in the United Kingdom [9]. The research was carried out in England and Scotland over 3 years from 2012 to 2015. One hundred and six bereaved adults were interviewed [2]. To highlight significant results for the present context: "Living with the possibility of death" was described as challenging by many of the participants in the project. The bereaved recounted a variety of manners in which substance use yielded detrimental consequences [2]. These encompassed both the physical and psychological dimensions of health, strained interpersonal connections and familial bonds, disrupted family life, and the subsequent consequences extending throughout the broader family structure and social circles. Stigmatization emerged as one of the most prominent and recurrent themes, surfacing in discussions within nearly three quarters of the interviews conducted [2]. Interviewees illustrated instances of both self-stigma and external stigma from various sources such as individuals in positions of authority, media outlets, family members, colleagues, and friends.

The data from the project showed that the process of discovering the body of the deceased individual emerged as an aspect fraught with heightened trauma often followed by an adverse experiences and interactions with law enforcement [2]. In close to 50% of the cases examined, there existed a degree of police involvement. Despite occasional positive encounters, interviewees consistently conveyed a sense of distress associated with police interactions. Specific instances included inadequately clarified procedures and families being left uninformed. In certain situations, families were burdened with

feelings of culpability or a perception that both they and the deceased individual were in some manner associated with criminality.

The bereaved family members and friends described diverse emotional responses in the aftermath of the loss [2]. Dominant reactions were those of grappling with the sense of a life's potential "gone to waste," navigating emotions toward individuals perceived as responsible for the death, and even experiencing a sense of relief due to both the deceased and themselves finding peace.

10.4 Bereaved People Following DRDs

The Norwegian research project "Drug Death-Related Bereavement and Recovery Project" (Norwegian acronym: END) studies experiences and the consequences following a DRD from family and close friends' perspectives (n = 255), their coping with bereavement, as well as the perspectives of public and nongovernmental service providers (n = 105) (see END project web page [10]). The studies in the UK project did not differentiate bereavement following drug- and alcohol-related deaths, except in one study where Templeton and colleagues exclusively studied the 32 bereaved individuals following a drug overdose [11]. Those who died of a drug overdose were reported to differ from those who died from alcohol use: the former were more likely to be male, young and had lost their lives at an early stage of dependency, sometimes on the first time the drug was taken [11]. In addition, alcohol-related deaths were often a result of chronic disease [12]. Potential differences between drug- and alcohol-related deaths were why the END project sample only included DRD.

Adding to the knowledge base acquired from the UK project, some main findings from the END project support the finding that time before death influences the bereavement process, DRD grief is described as disenfranchised (i.e., not acknowledged), and stigma affects the bereaved people. For many, grief is multifaceted, with complex emotions and reactions, and for a considerable proportion, prolonged grief levels are high [3]. Still, many adjust to life through awareness of potential stressors and acting in advance to prevent the stressors' impact, and some bereaved find new meaning through supporting and being supported by their close ones who are still alive [13].

We next explore main findings from the END project in more detail, addressing the topics "Time before death affects bereaved people's grief," "The psychological, physical, and social health consequences of DRD bereavement," and "Adjusting to the changed life using a variety of coping strategies."

10.5 Time Before Death Affects Bereaved People's Grief

There are good reasons to assume that having lived with someone using drugs affects the course of bereavement. This became evident in retrospective accounts by DRD bereaved of the time before death. It is well-established that being in a close relationship with someone who uses drugs is often challenging. Systematic reviews show that the negative impact an adult family member's high-risk drug use has on family members' relations to the member who uses drugs and family life [14] is similar to that on family members related to a young family member [15]. Many family members feel powerless and helpless, not knowing how to stay involved or how to help.

> It is extremely difficult to live so close, [the deceased] becomes a very demanding person. These extreme situations, where we had to call the police, are very demanding, it is shocking. And, especially, it is very demanding to constantly have a person who is sick, right? It rarely goes well. Then things went well for a period of time, I was optimistic, and then it went downhill, right, it was like a roller coaster (Father [16]).

Results from the END project demonstrate that the time preceding death also has significant implications for the time following death. Like the father in the quote, many bereaved experienced traumatic events, with a roller coaster of complex emotions such as fear and hope. As a

result, many bereaved people reported being exhausted when the death occurs. For parents, these experiences are described as being in a state of constant preparedness and extended parenthood. While dealing with their emotional roller coaster, the parents took responsibilities that their child generally should have handled (e.g., extended financial and practical support) [16].

Bereaved siblings in the END project often described how life with their brother's or sister's addiction changed relationships within the family [17, 18]. Siblings explained how they worried and felt responsible for their brother or sister. Many also felt grief for the sibling relationship that was so altered through the addiction, and anger because the brother or sister created turmoil in the family. In addition, they tried to help their parents with specific tasks and advice, and their relationship with their parents often changed too. The siblings tried to be strong and to take up as little space as possible in the family [17]. Adult siblings described a long process of finding the right balance between helping others in the family and caring for themselves [19]. For some siblings, the brother's or sister's high-risk drug use had been one of the many challenges in the family. These siblings have experienced inadequate care from their parents and explained their sibling's challenges due to a lack of parental support. Because of this demanding upbringing, many struggled to trust others and had difficulty accepting help from the social network later in life as adults.

Close friendships can also change due to a friend's growing drug use challenges. Friends described how they distanced themselves because they did not want to get involved in their friend's drug use and felt less fellowship with them [20]. Many bereaved close friends described how they had made less contact or how friendship had become less reciprocal, in the sense that they felt more like a helper than a friend. Such changes and some withdrawals of friendship were complex for them to think of later as bereaved friends, and many regretted that they had not kept closer contact. At the same time, new friendships also emerged for the person who used drugs, in the fellowship around drug use, reinforced by shared marginalized societal positions. In lives dominated by drugs, friends risk losing close friends in DRD.

Familial bonds, although strong, can falter under the weight of this relentless struggle and conflicts occur between family members about how to deal with the high-risk drug use [19]. When family members experience a death such as DRD, the bereaved may ruminate about the time before death, what happened, and why these fatal outcomes occur [16]. Intense rumination can complicate bereaved people's grief work. If, for example, such features as rumination becomes a dominant way of dealing with the loss for a family member, and/or levels of conflict between members run high, complications in grief may occur and become barriers to healing together as a family.

10.6 The Psychological, Physical, and Social Health Consequences of DRD Bereavement

Losing a close one following a DRD has consequences for many bereaved people's psychological, physical, and social health. Psychologically, DRD grief can lead to a myriad of emotional struggles. Grieving individuals may grapple with intense feelings of guilt, shame, and self-blame, as societal judgment and stigmatization insinuate a failure on their part to prevent the tragedy. This internalized blame can fuel a deep sense of personal responsibility, contributing to self-destructive behaviors and compromised self-esteem. Additionally, the lack of acknowledgment and validation for their grief can result in a profound sense of isolation, leading to symptoms of depression, anxiety, and prolonged grief [3].

The article "Does 'Time Heal all Wounds?'" [3] has reported data from the END survey, which included 234 family members. Parents, siblings, and children of the deceased all reported high levels of symptoms of prolonged grief (i.e., one type of complicated grief). One of the strongest associations to grief complications were

suicidal thoughts, withdrawal and blaming themselves. Hence, significant implications were observed for the bereaved individuals. In addition, healing took longer than most people assume, as those who had been bereaved 1–2 years previously had the highest level of prolonged grief symptoms [3].

On a physical level, the toll of DRD grief manifests in various ways. The chronic stress and emotional chaos associated with this form of bereavement can negatively affect the body [7]. Physical health may deteriorate as individuals struggle to cope with the immense burden of their grief. Parents interviewed in the END described sleep disturbances and physical reactions (e.g., nauseous, dizzy, feeling exhausted) [16] and a register study from Norway showed an increased susceptibility to illnesses as well as early death for parents [21]. Moreover, using substances as a coping mechanism or a means to numb the pain may further exacerbate the physical toll, leading to a vicious cycle of self-destructive behaviors [22].

The consequences for bereaved people's social health were illustrated in a cross-sectional survey, analyzing data from the 255 participants who replied to a survey in the END project. The analyses showed that participants, on average, rated their social health as poor, though with significant variations within the group [23]. Family members and friends reported lower scores than other bereaved populations on instruments measuring the quality of life, work and social adjustment, and social support. The participants who reported high satisfaction with professional help reported higher scores on the same social health-related variables [23].

Hence, DRD grief may exacts a heavy toll on bereaved people's social health. The bereaved may find it challenging to share their experiences and seek support, fearing judgment or encountering ignorance. This isolation can perpetuate feelings of loneliness, further eroding social connections and support networks. The stigma associated with DRD can also impact the bereaved person's relationships, as they may face blame or condemnation from friends, family, or community members [24]. Consequently, social networks may fracture, leaving individuals with limited avenues for support and healing. The lack of societal validation and understanding of this loss can result in profound self and social isolation [3].

10.6.1 Self-Isolation

Not being needed by others anymore and "losing" their identity as a helper was also a trait for parents who struggled the most to adjust to life after the loss [13]. For the parents, withdrawal (self-isolation) was reported to be characteristic of the bereaved who struggled the most [3, 13]. If the loss incorporated traumatic circumstances, bereaved may isolate because they struggle with severe emotional reactions and lack the energy to socialize and participate in their "normal" daily life [22]. Being troubled by self-scrutiny questions and rumination about why the death could not be prevented are among the questions that many bereaved after unnatural deaths pose to themselves.

Bereaved siblings experienced their grief as overshadowed by the grief of their parents because people outside the family may perceive the parents' burden as heavier. In addition, the siblings themselves were more concerned with helping and supporting their parents. While parents often felt guilt for not living up to their role as parents and blaming themselves for the death [16], siblings sometimes felt guilty for keeping siblings' secrets from their parents [18]. Siblings who grow up in demanding care situations, in particular, may find it challenging to be open about their feelings and grief reactions, both inside and outside the family [19].

Some bereaved following a DRD use illegal drugs themselves. For those left behind who use drugs themselves, disclosing their DRD loss to others poses a risk of having to share information about their own drug use, potentially exposing them to stigmatization and condemnation related to drug use [25]. Earlier experiences of stigma associated with their own drug use may lead to silence and social withdrawal in the event of DRDs [25, 26].

If social networks and professional helpers were involved, they usually focused on the immediate family. Hence, friends' grief can become forgotten and unacknowledged [27]. If the bereaved and deceased are "just" friends, it is not a matter of course that participation in rituals or social support will be opened to the bereaved friend. Bereaved friends in the END project described much loneliness because many had no contact with the deceased's family, nor did they have a shared network that could have "united them" in their grief. The friends hesitated to contact the family because they did not want to disturb them and did not define their grief as important [20].

10.6.2 Isolation from the Outside

Parents have described how their grief was difficult to share within the family and disturb the family dynamic [28] Though many parents interviewed in the END project had contact with close network members, and had coworkers who stepped up and helped them with practical tasks, the longing to share their grief with others was immense [13]. The bereaved siblings often hoped for support, though many described that support was not offered [19]. In contrast, many siblings who had a difficult upbringing did not want support and wished to be left alone with their grief.

After losing several close ones over time, many bereaved who use drugs learned that support from social networks and professional help were lacking. Several of them said that they struggled with thoughts and feelings of guilt after the DRD. It could have to do with their role in obtaining the drugs or that they felt that they did not do enough to prevent the death. The guilt could be intensified by accusations and exclusion from others in the person's social network. Feeling guilty and counterfactual thinking is well documented to be associated with grief [29]. However, the experience of a lack of cultural acceptance of the bereaved person's drug use seems to prevent them from sharing their experiences of guilt and responsibility and thus hinder them from getting support to cope with their feelings [25]. Bereaved persons who use drugs also experienced that their drug use led to mutual withdrawal between them, and others close to them. The drug use made them inaccessible for social contact, and likewise they experienced that the people around them who did not take drugs kept a distance when they were on drugs. If the health or social services responded, it primarily targeted reducing their drug use [26]. Some bereaved friends also felt highly alone in their grief, either because they did not know the deceased's family members or because their network had difficulty understanding that the friend had maintained that friendship, and expected the grief to pass quickly [20].

From the parent's perspective, the family's needs become the bereaved parent's responsibility when help from services is not provided [28]. Sometimes even becoming their parentally bereaved grandchildren's foster parent, parents experienced overwhelming responsibilities, like this family who cared for three parentally bereaved grandchildren:

> (…) and then I was a mom for three more with completely different needs. And (…) they had a complicated relationship with their mom, and the boy to the father. He has not seen his father in many years, and it is a process that is always difficult. And then (sigh), I felt I had octopus arms with hands in all directions. And then I was supposed to satisfy all kinds of things, and I was quite overstretched. Both physically and mentally (Emma, lost daughter [28]).

Thus, professional family-oriented help efforts for the DRD bereaved families were called for by parents in the END project. The help that was perceived as needed was related to the family's need and the ability to adapt to new roles and the new reality, but it was also to create a space and environment for emotional sharing and joint meaning-making processes in the family [28].

10.7 Adjusting to the Changed Life Using a Variety of Coping Strategies

Each person's grief journey is unique and finding appropriate coping strategies often involves a process of trial and error. It is important to note that coping strategies can vary greatly, and what works for one individual may not work for another. Following DRDs, bereaved individuals who participated in the END project described that they faced immense challenges adjusting to life without their loved ones [13, 25]. They used various coping strategies to cope with the profound loss and navigate the complex emotions accompanying it.

Parents interviewed reported using cognitive and communication strategies to heal. In addition, craving knowledge about what happened and focusing on back to day-to-day activities were essential for them too. Many had received services from different health professionals to learn cognitive strategies that helped them deal with complex emotions and reactions such as guilt and anger. Hence, as time passed, many managed to control the direction of their thoughts better, oscillating between deciding when to grieve and putting aside grief. Being open to others about the circumstances of death and the child's drug use were experienced as therapeutic for many. However, they were particular about whom they communicated with about the loss. Also, that the bereaved parents were open about the circumstances of death, served to help people in the bereaved people's network who struggle with what to say and when.

Many bereaved parents had caring tasks for the deceased child(ren) and their other still-alive children [13]. They reported that taking care of others helped them cope. Some bereaved siblings also said that their family was the most crucial support when family members managed to cope with grief together [18]. Notably, the deceased's friends were highlighted by both parents and siblings to be important in meaning-making processes.

> When I saw all the people and, of course many people using drugs… eh, like him, who came to that funeral, I thought that his drug life had been something more, than just what I had seen. And that was good (Sister [19]).

Siblings, like this sister, often valued contact with close friends of the bereaved and appreciated their perspectives on the deceased friend [19]. Bereaved friends, too, have regarded contact with the deceased's family as significant in their grief [20]. A bereaved friend explained how contact with his friend's family felt like confirmation that he had been significant to the deceased and that his friendship and love had mattered.

Several bereaved friends explained how losing a friend engendered a critical awareness of one's values in life and a renewed appreciation of friendship. Some also wanted to honor the deceased friend by working for less stigmatizing societal attitudes. Bereaved using drugs presented drug use as a substantial strategy to deal with the loss. Whether or not they were using drugs at the time of the death, several spoke of more intense drug use following the loss [25]. Even though the drug use could be accompanied by suicidal intentions and ideations, some reported that it helped them confront the loss, while for others, it helped them imagine that the death was not real. Hence, drug use was experienced as providing them with temporary pain relief but also, like Eva's story, it brought out positive memories of the deceased:

> When I cook up heroin and smell it, it reminds me of the early days of love. It reminds me of everything, inserting the syringe and feeling the hit of the heroin and the heat in my body reminds me of him and the security he gave me. And that's often the main reason I take heroin, it justifies it somehow. It's okay to do heroin because then I feel closer to him [25].

Some bereaved using drugs reported responding to the DRD experiences by reducing their drug use [25]. The decrease was related to the death being a wake-up call, giving them new reflections about the risk of drug use and the intense pain of being bereaved, or giving them the strength to honor the deceased by reducing or stopping the drug use.

10.8 Comparison Across Contexts: The Two Projects Compared

Retrospectively, the results from the UK project (i.e., substance-related death) studying bereavement following substance-related death and the results from the END project (i.e., DRD) exploring grief following DRD showed more similarities for the bereaved people's reactions and situations than differences. Researchers in the UK study also found severe stress of living with a person's high-risk drug use before and after death, stigma, disenfranchised grief, lack of professional help and support from network members. Still, grief is contextual and influenced by various situational factors. Hence, how someone mourns in the United Kingdom may differ from how someone mourns in Norway due to contextual and interpersonal factors. To place such features in broader context: One example is a result of the UK project concerning official processes such as police investigations and postmortem, which differ from how the police investigate a DRD in Norway. The participants in the UK project described very mixed experiences, both with regard to these processes and the officials involved (e.g., delay in releasing the body between several months to over 1 year—often without explanation, lack of compassion, and consideration of the bereaved people's situation). Hence, holding the funeral could be delayed for a year, complicating the bereaved people's grieving process [11]. Another interpersonal factor that differed was the expectations to get help in Norway versus the United Kingdom. Norwegian national guidelines recommends that municipalities activate psychosocial crisis teams for the bereaved following a sudden and potentially traumatic death. The END project showed that DRD-bereaved people seldom received public services in line with the guidelines. Hence, END project participants described feeling their grief was not acknowledged by public services [16].

10.9 Closing Reflections

Bereavement following addiction can significantly disrupt family dynamics and relationships. Research highlights the strain high-risk drug use and subsequent deaths can place on family structures, communication, and trust. Understanding these dynamics helps identify areas where support and intervention are needed. Research emphasizes the importance of education to dispel myths, reduce stigma, and promote awareness of high-quality support services and coping strategies. Many bereaved people eventually adjust well to the loss when using various coping strategies. Engaging in self-care activities, seeking professional help, joining support groups, and finding meaningful ways to remember and honor the deceased can facilitate healing and resilience. Understanding these coping mechanisms can guide the development of bereavement support programs.

We have covered many factors that impact on families and friends coming to terms with a DRD. There are additional aspects to research, for example, the availability of social support, mental health before the death, and challenges in the relationship and/or the family's coping style can also have an impact on the level of grief, post-traumatic stress, and level of functioning. Prolonged and intense grief experienced by the bereaved can also challenge the social network support to a significant extent.

Overall, there is also a call for more research on bereavement through addiction. Notably, a literature search and contacting an expert on gambling research identified no scientific papers that study bereavement following suicide associated with the burden of gambling debts. The lessons learnt so far from the research reported above suggests that additional research following death from this type of addiction can potentially help the bereaved by validating their experiences, providing guidance on coping strategies, connecting them with appropriate support networks, and

empowering them to advocate for change. Recognizing the unique needs of those bereaved by addiction and tailoring support services accordingly is essential.

The silence after a substance-related death like DRD is deafening for many bereaved family members and friends [16, 25]. Unlike more socially recognized forms of loss, such as the death of a family member from natural causes or accidents, grief following addiction-related deaths often remains marginalized, stigmatized, and invalidated by society, exacerbating its detrimental impact [2, 24]. Family members and friends report that lack of help from professionals and people in their network who are struggling to talk to them about the decedent person are examples of why bereavement is experienced by many as disenfranchised.

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11 The AFM Experience Among First Nations, Indigenous Populations, and Ethnic Minorities

Marcela Tiburcio Sainz and Pilar Bernal-Pérez

11.1 Introduction

Living with a person who uses substances is, in itself, a significant problem for family group members. This impact is even more significant in families belonging to an ethnic minority since they have characteristics determining relationship dynamics, values, and social norms that color their experience and can help or hinder access to care services [1]. The central objective of this chapter is to analyze how living with a relative who consumes alcohol or other substances impacts the health of families that belong to an ethnic minority or are part of an indigenous population in different world regions. It concludes with the findings of a study conducted with an Indigenous community in central Mexico.

11.2 What Is an Ethnic Minority?

As part of its efforts to combat racism and defend human rights, the United Nations [2] recognizes various vulnerable groups experiencing discrimination, injustice, and health and social disadvantages around the world, such as (1) Afro-descendants, (2) Roma, (3) Indigenous people, (4) migrants, (5) refugees, (6) people living in extreme poverty, (7) women, (8) LGBTQI+ people, and (9) minorities.

September 2022 marked the 30th anniversary of adopting the Declaration of the Rights of Persons Belonging to National or Ethnic, Religious, and Linguistic Minorities. Despite the significance of this event and what it represents in the fight to improve the living conditions of people belonging to minority groups, there is currently no single, agreed-upon definition of what a minority is. Nonetheless, the existence of a minority combines objective and subjective elements. Objective elements include the presence of an ethnicity, language, or religion shared by a group. In contrast, subjective elements involve self-identifying as a member of a national, ethnic, religious, or linguistic minority [2].

The sociological and anthropological literature also notes that "minority" is a dynamic concept involving the inclusion of elements self-selected by the group in question. In other words, the group defines itself based on specific elements or characteristics [3]. An ethnic group or minority is, therefore, a group identifying with the same linguistic and cultural community.

Smith [4] defines ethnic groups as human populations that share myths about their ancestry, stories, and culture associated with a specific ter-

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ritory, which, at the same time, share a feeling of solidarity. These groups also share identity elements such as (a) symbolic systems such as religion, mythology, and ritual, (b) food culture, (c) clothing, (d) art, and (e) physical appearance. Ethnic groups can share a narrow or broad spectrum of genetic ancestry depending on group identification, with many groups having mixed genetic ancestry.

Despite the difficulty of defining the concept of an ethnic minority, some studies suggest that these minorities share certain common factors such as (a) marginalization, (b) stigmatization, (c) inequality, (d) lack or scarcity of resources and infrastructure, and (e) challenges for survival [5, 6]. These characteristics create precarious living conditions for members of a minority in general and for members of the minority group with alcohol and other substance use problems, in particular, since it poses a high risk to their mental health and that of the most immediate context, the family.

11.3 Factors Contributing to the Marginalization and Disadvantage of Ethnic Minorities

Belonging to ethnic minorities often becomes a barrier to accessing essential services for any human group. Factors such as poverty, underdevelopment, marginalization, social exclusion, and economic disparities are closely linked to inequality of power and opportunities, and more specifically, affect their quality of life and health, as when they suffer from the impact of alcohol or substance use, at either a personal or family level.

This marginality reflects a need for more effective economic and societal participation. Rural communities do not control the production system nor participate in its benefits. Exclusion from full participation in the national economy leads to poverty [7], one of the most powerful social determinants of psychopathology [8], including psychoactive substance use.

11.4 Substance Use: Cause or Consequence of Marginalization?

Excessive alcohol consumption has long been the focus of interest of researchers from various disciplines who have helped identify factors related to the onset and maintenance of substance use, as well as its adverse effects at the individual and social levels.

Epidemiological studies have also proved helpful in understanding the extent of the problem at a local and international level. According to recent WHO data, 5.1% of the global burden of disease and physical injury is attributable to alcohol consumption, reflected in disability-adjusted life years. Among people ages 20–39, approximately 13.5% of total deaths are attributable to alcohol [9].

Socioeconomic development is one of the factors associated with the increase in substance use in certain countries. For example, Vietnam saw a 50% increase in alcohol production within a decade, with the proportion of adults who drink increasing from 46% to 77% among men and from 2% to 11% among women between 2002 and 2016. There was an association between the risk of heavy drinking and the rate of harm and negative impact on people's lives [10].

11.5 Substance Use in Ethnic Minorities Around the World

This section provides information that sheds light on the use of psychoactive substances, particularly alcohol, in minority groups in different parts of the world, whose common denominator is the invisibility of the problem, marginalization, and poverty.

For example, among First Nations in Manitoba, Canada, alcohol use among women is regarded as a threat to the concept of femininity, meaning that women who drink conceal the fact and are reluctant to seek help. Once they enter treatment, they have different needs from men, such as (a) opposition and lack of

support from family and friends, (b) unemployment, (c) economic barriers, (d) family responsibilities, and (e) stigma and social disapproval. There is widespread distrust toward health professionals due to the power imbalance existing in the therapeutic relationship, exacerbated in the case of women as they are challenged by being labeled and judged and the advice offered when they seek help. Other vital topics for these women include (1) guilt and shame, (2) unresolved core issues, (3) resilience, (4) tenacity, (5) recovery process, (6) family and friends, and (7) tradition and spirituality [11].

The authors conclude that little is known about the recovery process of Aboriginal and First Nations women or the reasons why this critical topic has remained under-researched [11]. However, other authors have acknowledged the absence of members of indigenous and aboriginal peoples in the Canadian recovery scenario, raising questions about possible racism [12].

Also, in Canada, Morton et al. **[**13**]** explored the process members of the Anishinabek community in Ontario undergo when they decide to stop using and begin their recovery. After exploring the sources of strength and resilience of those in the community, the authors proposed five elements they consider crucial to the success of substance use treatment programs:

1. Formal support is obtained by users or their families when they face challenges due to substance use, violence, and mental health problems.
2. Informal support, such as family and friends, is a source of strength and resilience.
3. Individual practices and internal forces were crucial for the healing process.
4. Beneficial effects of support that ensured their privacy and confidentiality, providing a safe space where they were not judged for what they were experiencing.
5. Forward-looking vision of how services and support were a source of strength and resilience. Participants highlighted the need to improve these services for those who need them and for a greater awareness of the issue. They also pointed to the need for more support and necessary services.

In South India, as in many other cultures, the family is the primary resource in the care of people with mental illness and substance use. Family members provide care for users. This is related to the Indian tradition of interdependence, the concern of close family members in the face of adversity, and the shortage of mental health professionals. However, providing care for a family member takes a toll on the health of caregivers. This adverse impact has been described as a burden. The family environment determines it through the coping styles of family members and their tolerance of the user's aberrant behavior. This burden disrupts the life of family members in the financial and emotional sense, placing spouses, in particular, at a greater risk of stressful life events and medical and psychiatric disorders, as well as increasing their use of health care services [14].

Another study conducted in Chile sought to explore the meanings associated with problematic alcohol use and dependence in rural Mapuche communities. For this group, alcohol use was defined as problematic when its frequency and intensity had a direct and indirect impact on various areas of a person's life, negatively affecting both the person who used alcohol and third parties. The researchers attributed this type of consumption to the impact of colonization on culture, which entailed significant changes in how alcohol was consumed [15].

Finally, an ethnographic study with women farmers and users from the Adamawa community in the northeast of Nigeria found that in Africa, there is no adequate way to measure substance use. Nevertheless, alcohol and drug use is known to be high because of its consequences. Before colonization, people in this area drank local beverages and subsequently began consuming what their colonizers imported. An abrupt change was observed in both traditions and the role of women, who are regarded as responsible for obtaining food for their families. The most common activity is agriculture, primarily female, mainly due to poverty, cultural factors, and polygamy. Although

data on substance use among women is almost nonexistent in these communities, a significant proportion of them are known to consume and sell drugs. Some do so to make their work bearable since farmwork can be hard and tedious, while those who do not work on farms engage in sex work. The study revealed an increase in drug use among young women and girls to be able to do their jobs, which is a matter of concern [16].

This information shows that the use of substances, particularly alcohol, acts as a social disorganizer in various Australian, Latino, and Aboriginal cultures. It is, therefore, essential to implement substance use prevention and health promotion for minority groups. It is also crucial to design culturally relevant problems that will permit the timely identification and prevention of these problems.

11.6 Alcohol Consumption in Ethnic Minorities in Mexico

In Mexico, the Drug, Alcohol, and Tobacco Consumption Survey [17] reports a lifetime prevalence of alcohol consumption in the total population of 49.1%, with rates of use in the past month of 35.9%, excess use of 19.8%, and regular use of 8.5%. The survey also mentions a general upward trend over the years. A comparison of the sexes shows that men still consume more alcohol than women, although changes in women's drinking habits are reflected in an increase in their alcohol use.

Although there is a wealth of information on the epidemiological behavior of psychoactive substance use among the general population, the same cannot be said of its use among ethnic minorities and indigenous groups [18]. Besides being scarce and difficult to identify, these data provide highly local, specific information about certain areas or zones. They are often drawn from anthropological or sociological studies, meaning their interpretive conceptual framework may differ from those with a health and well-being approach.

According to the Pan American Health Organization [19], the mental health conditions of Indigenous groups are usually worse than those of non-Indigenous groups. For example, they have significantly higher suicide rates and more suicide risk factors: discrimination, conflict, trauma, stress caused by acculturation and cultural displacement, harmful alcohol use, and barriers to accessing care services.

Alcoholism is one of the most prevalent chronic diseases in Indigenous peoples of the Americas, who have higher alcohol use rates than the general population [20]. Mexican ethnic groups constitute a complex mosaic due to their plurality and the social, economic, and political difficulties they experience, exacerbated by excessive alcohol use and lack of social protection. Mexican ethnic groups produce at least 172 different fermented beverages, 87% of which are drinks with alcoholic content [21], some of which are being replaced by beer.

Camacho et al. [22] studied an indigenous population from the State of Tabasco and their relationship with alcohol use. They observed that ethnic identity should be analyzed to understand the influence of culture on an individual's alcohol use. This identity is regarded as a construction that develops within social frameworks, determining the position of people within society and guiding their representations or actions within the culture by which they are circumscribed [23, 24].

Concerning alcohol use in the total population, a lifetime prevalence rate of 81.4% was found, together with rates of 45.7% in the past year, 15.7% in the past 30 days, and 4.3% in the past 7 days. Regarding sex, a lifetime prevalence rate of 85.7% was found for men and 78.6% for women, with rates of 50% for men and 42.9% for women in the past year and 17.9% for men and 14.3% for women in the past month. The age of onset of alcohol use in this community is lower than the national average. The authors note that in the indigenous worldview, alcohol is present in religious ceremonial acts, which can contribute to the normalization of alcohol use and, therefore, to a lower age of onset.

A study undertaken of the Indigenous population residing in and originating from Mexico City found that 20.9% of Indigenous men and 24% of non-Indigenous men drink excessively. Among Indigenous women, the prevalence of alcohol use was 22.9% compared to 21% for non-Indigenous women. It was also observed that the Indigenous population had little or no access to health services. At the same time, alcohol use has a more severe effect on organisms weakened by malnutrition and extreme poverty [25].

Through semi-structured interviews, Hernández [26] explored alcohol consumption practices and their social, economic, and health consequences in Huehuetla, Puebla, where the most common beverages are beer and a type of liquor called "kuchu" in Totonaco. On average, they drink 3.5 days and spend 437.50 pesos a week. Eleven of the 13 men interviewed reported getting drunk every time they consumed alcohol. When asked about the reason for this, they replied, *"Because that's the point," "We have drinks with friends," "(We do it) when we feel excited or sad,"* and *"to loosen up the body."* They said all the men in their families drink: grandparents, fathers, uncles, cousins, and even children. They consider that they drink for pleasure because they live with people who drink and teach them to drink, and like their fathers before them, their grandfathers drank, so *"It gets handed down from generation to generation."* Others drink to forget their problems due to the stress of work and fatigue, *"I imagine it was a way to relax."*

There are marked differences between the characteristic consumption patterns of Mexico's urban and rural and Indigenous populations. The available information suggests that these differences are due to the diversity of uses and customs, values and beliefs, social norms, and contact with other cultures, as in the case of the migrant population. Other factors may contribute to the more severe consequences of consumption among the rural and Indigenous populations, such as poor education on issues related to consumption and the absence of treatment centers close to their locations.

Another area where differences occur is the way alcohol consumption affects those close to the user. This topic is the focus of this article, which seeks to provide information to understand better the possible similarities, differences, and challenges that families of ethnic minorities experience and face when one of their members uses psychoactive substances. The outlook in rural and indigenous communities is a matter of concern since they are the population sector with the most significant lag in terms of mental health care. Treatment centers are scarce, inaccessible, and often poorly accepted by the social groups they aim to serve [27]. To attempt to answer this question, we will use a study of Otomi women in the central area of Mexico as an example.

11.7 Community Views On the Effects of Excessive Drinking on Family Well-being

The study described below is part of a larger project whose purpose was to culturally adapt the 5-Step Program for use with the Otomi population of the Mezquital Valley in the State of Hidalgo, Mexico. This required obtaining information on alcohol consumption practices and their consequences on the mental health of the inhabitants of an Otomi community. The information was obtained through (1) ethnographic observation and field diaries, (2) semi-structured individual interviews, and (3) semi-structured group interviews. This chapter only presents the information related to the last strategy.

The following inclusion criteria were established for the groups: being a community resident, wishing to share their opinions on the population's health, and agreeing to participate in the study. Based on these criteria, three groups of women were established, each with seven, six, and four members. The sample size was subject to the voluntary collaboration of the interviewees. Subjects were aged between 18 and 65 and were mainly homemakers or shopkeepers. Another interview was conducted with two men, aged 27 and 37, respectively.

The interview guide addressed five general topics: (a) How does drinking occur in the community? (b) Problems related to consumption, (c) How does it affect family members? (d) What should be done when someone drinks a lot? (e) What can be done to prevent the problem? Some questions corresponding to each topic were drawn from Jellinek's Informant Method questionnaire [28].

Subjects were contacted through the Community Assembly, where the project's objectives were announced, and authorization to implement it was requested. Subjects in the Health Center waiting room and at the end of the "Oportunidades" social program meetings were also invited to participate. When subjects expressed interest in participating in the study, they met in a multipurpose room. The objectives were explained again, authorization to record the sessions was requested, and the confidentiality of the information was guaranteed.

11.7.1 Consumption Practices and Associated Problems

Different responses were obtained from the groups in the initial approach to this topic. Whereas men said excessive alcohol consumption is obviously a problem in the community, women tended to say that there were more consumers in the past and that nowadays, people drank less. However, during the interviews, this point of view gradually changed.

The groups agreed on two issues: (a) the transformation of consumption patterns in the community due to migration, among other factors, and (b) the existence of gendered social norms concerning alcohol intake.

The first issue is informed by the notion that migration to the United States results in the "importation" of a way of drinking that differs from local traditions:

> They bring the problem of consumption from outside. When they leave the community, I say they bring another change. When they emigrate, they bring the drinking problem with them.

Specifically, they note that beer has replaced pulque as the beverage of choice. This phenomenon may also be linked to the loss or transformation of community identity, especially among the youngest, as can be seen in the following account:

> Today, we see many young people who are there but do not touch pulque; some people don't drink it either.
> Pulque consumption has decreased. Those who drank it more are already dead or sick. The new generations feel sorry for them; they are ashamed and already have a different mentality, so we have forgotten about our culture, our roots, what is ours. Because pulque is something, something that identifies us… But now we are ashamed about pulque! Just as wearing cotton clothes makes us ashamed, you know? Drinking pulque is something people are ashamed about.

The social norms governing consumption coincide with traditional gender roles, whereby men are allowed to drink, and stricter rules apply for women:

> Men are also bad; they take advantage. They are free to drink whenever they want, you know. But women who drink have to watch out. Because if they get drunk, they get into trouble.

Men begin drinking during adolescence with groups of friends. At first, they do so covertly because many drink without parental permission, but as they grow older, they start drinking in public. Adult males drink in various settings, including the home and liquor stores. In these places, it is customary for men to drink in groups and for each person to take turns buying a round of drinks for the entire group.

Men sometimes drink at work, especially as day laborers in the irrigated Mezquital Valley region. In this situation, it is common for workers to drink pulque during lunch. Sometimes, the employers provide them with the drink so that "they are happy." However, no one would allow someone in a state of intoxication to work.

Women, for their part, report that they generally start drinking after getting married, only drink at family gatherings, and require their husband's approval.

"Being able to hold your drink" is a desirable male characteristic. Men who drink excessively command the admiration and respect of other men and women, while those who do not drink are regarded as "weak." Women who drink are frowned upon. For them, abstinence is considered a virtue and, to a certain extent, an obligation.

The truth is that alcoholic consumption is part of the life of community members. Pulque, in particular, is reputed to have nutritional properties. In the past, children were "weaned" with mead due to the lack of water and milk. This practice continues in some families, although increasingly less frequently.

> When I weaned my children, I had that problem, you know? They were anemic, and one of my aunts always said, 'Give them a small glass, just a small glass at mealtimes,' and I used to give them a small glass at mealtimes, and thank God, my children are healthy, they don't have any problems.

In the discussion, it was clear that community members have some knowledge about the risks involved in alcohol consumption but that this knowledge clashes with tradition, resulting in a reluctance to speak openly about what is happening in the community regarding alcohol.

For example, they know that excessive drinking can cause dropsy or cirrhosis and that many people have died because of this. Others say that alcohol "burns the body," which is why no one should drink it. Among the problems that they realize are associated with the consumption of alcoholic beverages are (a) accidents, (b) the possibility of leading to rivalry between families over the ownership of land or animals, (c) family disintegration, (d) violence, since "it is easier to fight with someone when you have been drinking," and (e) setting a bad example for children.

The discrepancy between their practices and the "the way things should be done" imposed from outside the community began to emerge more clearly when the reasons why people drink or decide not to drink were discussed. The main reason they think people drink is habit, without thinking about their decision. In this regard, they pointed out that there are other practices among members of the community that are also the result of custom and can be as questionable as excessive drinking, such as having more than one wife.

Alcohol is also used as a social lubricant and to strengthen friendships. Precisely, in the case of men, it is thought to help them deal with personal problems and emotional states that are difficult to manage, such as sadness, anger, and worry. Other less important reasons for drinking alcohol include taste and the need to cool down.

Conversely, one of the most frequent reasons for not drinking was that spending on alcohol affects the family economy, the adverse effects on the health of drinkers, being educated, and, in general, having a different mindset from that of the rest of the community. Other positive aspects that can serve as protective factors are happiness, having a job, and family integration.

When this issue was being addressed in one of the groups, one of the participants expressed a different opinion from the rest of those present. She pointed out that nothing justifies excessive alcohol consumption and that when someone decides to drink, they always find the means to do so regardless of the barriers they face:

> If they don't have enough money, they get it from friends. Health?… I know many people who are on the verge of dying from drinking, yet they go on drinking. For me, there is no [reason], and they are not worried about what the neighbor or someone who doesn't drink is going to say. Here, everyone drinks.

This intervention was relevant not only because of its content but also because it at least allowed the participants of that group to express their opinions regarding alcohol more freely, assuming, from that moment onward, that the men in this community drink excessively.

11.7.2 How Does Consumption Affect Family Members?

The discussions also revealed what, in many cases, appeared to be first-hand knowledge of this topic. Since the confidentiality of the information was guaranteed at the beginning of the interviews, every effort was made to ensure that

the discussion did not focus on specific cases but on what was happening in the community in general.

One of the ways alcohol consumption affects the family is by altering the routine and quality time spent with other members. *"The family is destroyed"* means that male consumers spend little time with their children. They do not express interest in their activities or provide them with the means to *"get ahead."* In extreme cases, children grow up without parental supervision and "run wild."

The four groups mentioned that the presence of a consumer in the family affects the mental health of other members, especially women who experience various types of malaise. For example, they feel bad knowing their husband has "the vice." They get scared when they see him come home drunk. They feel afraid and worry about money and the drinker's health. They suffer a lot, do not eat properly, despair, and can get sick because of this.

> Well, yes, I do see that it is worrying because, for example, when they come home at night, they are already out there or, for example, they are drinking here in the center, and then you live over there, and you wonder where they are. In other words, it is something to worry about because when he drives a car and gets very drunk or drinks too much, he no longer realizes what he is doing, and he could kill himself. In other words, he does not worry about what he will do, where he will be, or whether he'll be right. I mean, it's worrying. Is he going to fall? Will he be able to drive? Will he be able to come back home…?

Women carry this "burden" alone, and in addition to dealing with their suffering, they are given the responsibility of protecting other family members, including the person who drinks:

> If the woman puts up with it, she suffers a lot; maybe she can't talk about things or the problems at home because it is a burden for the woman alone. A burden, because if the woman more or less knows how to get ahead, she helps the children, but if not, it will be the downfall of the family, totally… the children… because they stop going to school, they won't have a better life, food, hygiene, a mother cannot give everything, and it is a problem because the household won't progress.

> Well, her concern is that she worries about how to get ahead with her children, and the other thing, well… about her husband, that if he gets sick, who is going to look after him? Who is going to be responsible for him? And when the families do not hide it, it is also because the burden falls mainly on the woman. It is a burden for you as a woman.

As can be seen from these stories, there are various reasons why living daily with a heavy drinker is a highly stressful situation, which threatens the health of all family members, combined with another series of material difficulties that aggravate living conditions in this community.

11.7.3 What Should Be Done When Someone Drinks a Lot?

Given the problems caused by a family member who drinks, a range of options could improve the situation. However, the effectiveness of these solutions needs to be made clear. In some cases, opinions on the matter appear due more to what people have learned than to their own experience.

Most strategies that respondents considered could help solve the problems involve persuading users to stop drinking. The most frequently mentioned ways were "convince him to go to treatment," "seek help," "take him to a psychologist or a doctor," or "put him in an Alcoholics Anonymous group." These actions could certainly be a solution but are unrealistic measures due to the total lack of forms of treatment in the community. It was not until 2 years ago that the first group of Alcoholics Anonymous was created in the municipal head town approximately 30 km away.

Other actions that the participants mentioned included talking to the drinker, making them see how their drinking is affecting their health and their family, making them reflect, or asking a family member or friend to talk to them, for example:

> Talk to him, find a time when he is willing to talk, and really talk about the problem. Make him see what problems drinking causes and what the ben-

> efits of not drinking are so that he comes to his senses. Give examples, and as they say, well, there are children involved, so show him that his children need him.

These ways in which problems can be solved contrast sharply with the way drinkers are expected to react since they consider that once they have adopted this *"vice,"* it is almost impossible to go back. One participant said, "They dig in their heels and carry on." The optimism implicit in their proposals contrasts with a problem that, based on experience, has no solution until illness or death arrives.

> Talk to them, but they really don't understand, the only thing they say, 'No, well…,' my children are grown up, my children are already grown up, and they really don't understand no matter how much you talk to them, no matter how much you tell them. You try to talk to them, but no. They don't pay any attention.

They assume that if they try to convince them "nicely," drinkers will not understand or accept the problem or do their part. They might take that approach as *"a joke"* and become angry. That is why *"you have to get them when they are sober"* and *"take them by surprise"* to reduce the probability that they will refuse to listen. No specific cases were explored. However, it is striking that during the interviews, not a single case was mentioned in which these measures have been successful despite the fact that they are regarded as the most suitable ways to resolve family problems associated with alcohol consumption. On the contrary, users are assumed to be incapable of change.

As for what family members should do for themselves, contradictory suggestions were also found, one referring to duty and the other to everyday experience. Despite feeling sad, worried, or angry, relatives should "pick themselves up," "not give up" and support the rest of the family, including the drinker:

> Well, I say that you should do something because if I see that the family is getting worse day by day, then I am not only going to destroy my health but that of my family. I can't collapse, and instead have to think very carefully about what I'm going to do, and more than anything, stay strong…
>
> God is giving him the opportunity to recover, and he doesn't do anything, so even if it's just a little bit, she can work behind the scenes to help him recover, that's one [way], and another is to try… if he's a son, as a son. If he is a brother, as a brother, and a husband as a husband, try to give him the place he deserves, you know? Like, my love, I don't want to help you out of obligation, but I help you because I want to, because I want it that way because you are the father of my children because we started a family when we were young and it's worth living again, isn't it? Yes, now with no conditions, I'm not putting any conditions on helping you because that is what I want to do.

"Not giving in" and "picking yourself up" were frequent responses. However, only two specific strategies were mentioned to achieve this. The first involves spending your free time on activities that benefit other people, and the second has to do with courage and faith:

> I have always said that as a woman, you have to have a lot of courage. Perhaps there comes a time when you do feel discouraged by your problems, but by thinking about it, trusting God, and I have had a lot of faith that as a woman, you can get ahead no matter what the problems are. As a woman, you have to know how to cope with problems in life. There are good times and bad times, and you have to go through all of them. It is a matter of knowing how to cope with them and thinking a lot about how to solve them, how to know how to solve the problem, and then not getting through it with alcohol. Maybe I'll have a beer, but then I shouldn't drink it for two or three days and just grit my teeth and get on with it. You shouldn't look for a solution but think that the solution is knowing how to cope with life. One of the most important things is knowing how to cope with it, not being afraid, and having a lot of courage. It is difficult, but it can be done. You can pluck up courage.

In addition to the many concerns that arise from living with a drinker and a minimal repertoire of options available to achieve a minimum level of well-being, families, particularly women, must also deal with the pressure exerted by the community through expectations regarding their behavior. Below is an example of what would happen if a woman decided to end her relationship with a drinker:

> They say you didn't care about him, and he is not to blame; the woman is the one to blame, you were to blame, and that's it, even though the husband

left the woman, \the woman is at fault. Who is to blame? You were always to blame and that's it, the woman just left her husband, but the woman is to blame. It doesn't matter what the woman does, the errands, the children, the animals, hanging her clothes, everything, it's still her fault.

People talk for the sake of talking… they don't worry about why, why she left her children or why she had to leave her husband, and they say, 'Oh poor man! Because he's a drunk, there's nothing he can do.' They looked for another life, and they left, but for those of us who understand, we see that it wasn't like that, and you get fed up and desperate when you see that type of problem. But others only see outside and do not know what the problem really is. And that is what has sometimes kept us shut in because sometimes we have to put up with things because of what people are going to say, what they will say, the gossip, but sometimes we don't think about ourselves and how important it is for us to take care of ourselves with these types of problems.

In the process of exchanging views and revealing that fear of community opinion is a significant source of discomfort and, above all, a barrier to action, the possibility arose of reaching a tacit agreement regarding the need to share experiences and support each other as a way of finding relief and contacting other organizations that could be useful:

Well, you have to set an example to be able to advise others because if I am the first one who is down and I want to help my neighbor to be strong, to defend herself, then I should start with me and give myself the place I deserve. It is up to me as a woman in relation to my home and to society above all. So, when I feel strong enough to do those things, I can easily tell my friend, look, I did this, and you can too. Also, let's say the friend that I am going to advise because her case cannot be the same as mine; it is a very different case, you know? So each family has its own problem, you know, so there we have to see what can be done in that case, you know, but set an example more than anything, an example so that they can live it, because if you don't set an example, the person is going to say, 'She's telling me, but how come you don't do that in your home?' 'She lets them treat her like that, and she's giving me advice on how to defend myself, right?' That's why you have to start by setting an example.

Well, you can meet and talk to psychologists and, if not, trust people. Women should trust each other because sometimes there is no trust, and they will divulge what happened, but as long as you have experience, and you want to say do this or that, you can more or less guide them.

These opinions reveal the need to create spaces where women living with heavy drinkers can share their experiences, learn from strategies that have worked for other families, and benefit from the knowledge that external actors can provide them to find better ways of dealing with adversity.

11.7.4 What Can Be Done to Prevent the Problem?

The previous sections described how two levels of discourse around alcohol use were identified and what should be done when this problem occurs in the family. Opinions about what can be done in the community to prevent problems associated with excessive alcohol consumption also highlight the discrepancy between knowledge and practice.

On the one hand, people suggested drastic measures such as restricting the sale of alcoholic beverages. However, as soon as it was proposed, this type of action was expected to fail since consumers "always look for where it is." In addition, these types of measures would be ineffective in a place where pulque is produced in most households.

For most of those interviewed, education is another way alcohol abuse can be prevented. From their point of view, *"talks"* are the best strategy for modifying *"the mindset"* of young people to positively change the behavior of adolescent girls and prevent them from suffering what they did:

Right now, the girl is here; she is going to high school; after a while, they are different; she will no longer have [the same] ideas as us because what she is learning is different. She's going to say, 'Oh! Mom put up with my dad the way he was, but I'm certainly not going to!' So that is changing and education… I think education is what brings about change.

The idea that knowledge can influence behavior persists, but the possibilities for change are much more limited for adults than young people. Nothing can be done for those who have already started drinking, so preventive efforts must focus on the younger population.

Interestingly, the opinion of the youngest participant (a high school student) contradicted those of the rest of the group. In her words:

> The talks are not very important because we already have the information; one way or another, we have it. Young people are bombarded with information, they tell us at school, at home… I've had enough!

The alternative seems to be to keep busy, find activities that distract the mind, and avoid succumbing to "the temptation to drink." In line with this idea, the respondents believe that employment can contribute to reducing consumption since it not only makes it possible to satisfy the family's needs but also to achieve personal fulfillment, as described by one participant:

> I say that time changes this a little bit, but also this… it's education, occupation… people who don't have a job, people who don't have a job, they tend to do things they shouldn't, you know? But if a man has a job, he is given a job, he comes home tired and wants nothing more than to eat and have a job, and that's it, but people who don't have a job or even a woman who doesn't have a job, is going to do things they don't want to do, or start talking about things that aren't helpful, you know? And when there are things to worry about, there is no longer time, there is no time to make nasty remarks and talk about other people's downfall, and instead you do things that do obtain results, you know?

The following testimonial shows that the conception of using free time as a preventive measure also applies in the case of young people:

> What I would say is that there is a need for recreational workshops, where young people can occupy their time because since they have nothing to do, they start drinking; they should create basketball groups, have areas for recreation…

Although the options available in the community for work and recreational activities are extremely limited, it is worth asking whether these types of proposals are the result of knowledge learned in everyday life or whether they are part of a discourse that is not theirs but is more in line with what they think researchers want to hear.

It should be pointed out that the community has a basketball court that is usually empty. Furthermore, work with high school adolescents has shown that most collaborate with domestic work after leaving school. Many take the animals to graze, remove weeds, work the land, or cut firewood in the hills. However, these occupations have not been effective enough to prevent the onset of alcohol consumption.

11.8 Conclusions

The group interviews showed that, as has been reported in different regions of the country, alcohol consumption by men is widely accepted. In contrast, alcohol use by women is more heavily sanctioned [29]. They also mentioned various reasons why alcohol is consumed, as well as reasons why there are people who do not drink and the reasons why no one should drink. It was observed that, as also happens in the marginalized urban population, consumption sometimes serves as a means of coping with realities that are difficult to manage, such as lack of work, poverty, and even the absence of recreational activities [30]. It is clear that consumption is accepted as part of the life of the people who live in the area and that eventually, at least at the discourse level, they realize that consumption can become a severe problem that has equally significant consequences for the health of the person who drinks and the health of the family and the household economy, as well as having social repercussions.

The information that the participants provided was sufficiently rich to identify the stressors implicit in living with a drinker. Data on the effects of living with an alcohol consumer are very similar to what has been found in the urban Mexican population [31]. In both contexts, it is a situation that creates confusion, discomfort, fear, and concern and generally exceeds a person's capacity to respond. In both the city and this rural community, it is considered that it is the responsibility of women to deal with these problems even though they are the ones most severely affected, as the mothers, wives, daughters, and daughters-in-law of men who drink excessively. This research provided them with a space to share their experience.

It is important to note that some participants were initially reluctant to express themselves for fear that others would find out. Reluctance to speak and distrust have been documented as characteristic limitations of anthropological work in which issues traditionally considered part of the private sphere are explored [32]. Despite this, their contributions contributed to identifying some of the problems felt by women in the community. Similar information was collected through individual interviews. In both approaches, references to violence, the decline in the economy, and, above all, the impact on the mental health of all family members were observed.

Sometimes, the absence of migrants makes family problems involving alcohol use temporary. This circumstance contributes to minimizing the impact on family health since, in some instances, these people have stopped being part of the household's everyday life. However, the severity of these problems is not diminished because they are short-lived; on the contrary, this characteristic requires special attention as it is a distinctive feature of community dynamics.

Addressing the problems of family members in a social context where alcohol abuse is common practice is vital for the reasons stated above. It is essential to consider the sociocultural context since culture dictates how a symptom is defined, whether as a disease, a metaphysical event, or another event in daily life [33]. That is why this research explored the way families in an Otomi community define their experiences involving alcohol consumption and how they explain the existence of this health problem in the locality.

Implementing any intervention program in a group different from that for which it was created requires in-depth knowledge of the recipient group's sociocultural characteristics to make the necessary modifications to increase its acceptance and likelihood of success while respecting local values and norms. As Babor [34] states, culturally appropriate solutions are necessary for socially defined problems.

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12 Stigma and Discrimination in Families in Mexico with Substance Use: An Intersectionality-Based Approach

Jazmín Mora-Rios, Adán Aranda Reynoso, and Victor Daniel Vaugier Mora

12.1 Introduction

Addictions are a growing problem worldwide, contributing significantly to the burden of mental and addictive disorders [1]. Although approximately 100 million people in the world are estimated to experience substance use by a close relative [2], only a minority can access adequate services for their care, mainly due to stigma [3].

Stigma and addictions have attracted enormous interest among researchers in recent years [4]. Goffman [5] introduced the term "stigma" to describe the social rejection suffered by a person with a condition that socially discredits them. According to sociologists Link and Phelan [6], stigmatization involves an asymmetrical process of power from which an anomalous identity is constructed through the interaction between those who stigmatize and those who are stigmatized. For the purposes of this analysis, we consider the definition of stigma proposed by Medina-Perucha et al. [7] to be of interest:

> a social process involving the segregation of social groups and individuals based on socially valued attributes and leading to inequities based on social, political, or economic power (p. 316).

Stigma related to substance use interferes with the timely search for care. A study by Kohn et al. [8] revealed that the substance use disorder treatment gap is greater in Latin America (83.7%) than in North America (69.1%). Furthermore, in low- and middle-income countries, the scope of this problem may have been underestimated due to the limited research available on stigma [9].

Within this complex reality, the social stigma experienced by people with substance use disorders intersects with other axes of discrimination and inequality. When viewed through an intersectional lens [10], this stigma can reveal patterns of exclusion and discrimination essential to understanding and addressing the problem of addictions. Intersectionality is an analytical tool exploring the interconnectedness of sociopolitical categories that contribute to discrimination

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in various areas, including ethnicity, gender, immigration status, social class, and age. These categories overlap, creating a synergistic effect [11]. For Grzanka [12], intersectionality *"is the study and criticism of how multiple social systems intersect by producing and sustaining complex inequities"* (p. 453), with an emphasis on the role of justice. In this respect, this approach is useful for addressing addictions, since they are a public health problem closely linked to globalization, worldwide production and commercialization networks involving other social determinants based on social inequality, power structures, and gender, as well as the ideological, political, and cultural aspects concerning drugs.

In recent years, international research has visibilized the needs of families dealing with substance abuse and gambling [13, 14]. In a systematic review of research on family and addiction, Mardoni et al. [15]. identified five broad dimensions in the experience of families, including (1) initial shock, (2) being in a fog, (3) sequence of disorders, (4) internal chaos within the family, and (5) self-protection. Families undergo evolutionary processes with stages and transitions. Individual life processes intersect complexly within family interactions, emphasizing the importance of a holistic approach to analyze biological, psychosocial, historical, and cultural levels. Although intersectionality is becoming more relevant in addiction studies [16, 17], research from this perspective remains scarce [18]. Furthermore, studies using this perspective to specifically explore the experience of family members are even more limited.

Our aim in this chapter is to use an intersectional perspective to examine the stigmatization of families in which some of their members are under treatment for substance use and to determine its scope by meeting with a small sample of family members, interviewed as part of a larger study on stigma and mental illness. At the end, we analyze the importance of adopting an intersectional perspective to guide future interventions and contribute to public policy development.

12.2 Background Research in Mexico

The data used for this study were originally drawn from a mixed methods research project designed to explore mental illness stigma and discrimination among various groups (relatives of people with substance use disorders) in Mexico City [19]. Although the study's original focus was stigma, for this chapter we focused on the experience of relatives of users in outpatient treatment with a substance use disorder diagnosis. Data collection took place from January 2009 to July 2010. Details of the methodologies utilized for data collection have previously been published [20]. Participants provided informed consent, and the research protocol was approved by the Ethics Committee of the Ramón de La Fuente National Institute of Psychiatry (Approval No. EP09 4225.0).

In this study, we focus on the qualitative analysis of the experience of family members coping with substance use by one of their members to understand the impact of stigma and discrimination on their experiences, using an intersectional approach.

12.3 Participants

Twelve relatives of substance users in outpatient treatment were interviewed (Table 12.1). The majority (10 out of 12) were women, with a predominance of mothers, followed by wives, a grandmother, father, and son. The ages of the participants ranged from 33 to 67, with an average of 49 (SD = 11.8).

Only one of the users related to the interviewees was woman, one identified as gay. All of them were in ambulatory treatment in psychiatric specialized centers. Seven had dual diagnosis and the rest substance abuse; the age range was between 18 and 60 years of age.

Five of the interviewees had lived with the user for over 10 years. Five of the relatives were partnered and the remainder lived alone. Most were self-employed, and only one had social security. The majority (six) were Catholic,

Table 12.1 Characteristics of participants

Relative	Scholarity	Occupation	Age of the user	Diagnosis	Age of onset of consumption	Time in treatment	Time living with the user	Religion
Mother (48)	High school	Domestic worker	23	Dual diagnosis: Substance use disorder and schizophrenia	14 years	5 years	27 years	None
Mother (58)	Middle school	Retired	30	Dual diagnosis: (schizophrenia, substance use disorder: Cocaine and LSD)	14 years	10 years	30 years	Christian
Grandmother (70)	Technical career	Retired	23	Dual diagnosis: Substance use disorder and schizophrenia	16 years	4 years	4 years	Presbyterian
Son (35)	College	Freelancer/activist/ own business	60	Dual diagnosis: Obsessive compulsive disorder and substance use disorder: Alcohol and cocaine	20 years	–	4 years	–
Mother (40)	Bachelor	Merchant/activist	20	Depression, alcohol, and ecstasy	15 years	9 months	–	Catholic
Mother (51)	College	Trader	20	Substance use disorder	15 years	23 years	Less than a year	Catholic
Mother (62)	Middle school	Retired/housewife		Substance use disorder: Heroin	–	2 months	–	Catholic
Mother (50)	College	Medical representative	24	Substance use disorder: Marihuana and solvents	4 months	4 months	24 years	Catholic
Mother (48)	College	Freelancer	18	Substance use disorder: Alcohol and ADHD	15 years	13 years	18 years	None
Wife (33)	High school	Merchant	34	Dual diagnosis: Obsessive compulsive disorder and substance use	–	3 months	12 years	–
Mother (52)	College	Dentist	17	Substance use disorder: Alcohol, LSD, and marihuana	15 years 2 years of consumption	1 year	28 years	Catholic
Stepfather (67)	Elementary school	Merchant	29	Dual diagnosis: Schizophrenia and substance use	–	2 ½ years	25 years	Catholic

followed by Evangelical Protestant (two) and two atheists. Interviews were conducted in suitable areas within the institutions where the study was undertaken, enabling participants to express themselves freely.

12.4 Data Collection

Data for this study was collected in a semi-structured interview designed to explore the following topics: (1) family background, (2) history of substance use and its impact on the family, (3) experiences of stigma and discrimination associated with the relative's drug use, (4) coping responses of the family member, and (5) recommendations for dealing with stigma and discrimination. The interview strategy involved asking open, exploratory questions to encourage dialogue with relatives, such as: "What has your relative's substance use meant to you?" and "Have you experienced a situation in which you or your family, including the user, have been mistreated because of their substance use?"

12.5 Information Analysis

A thematic analysis (TA) of the interviews was conducted using an inductive method based on Braun and Clarke [21]. The process began with reading and individual review of each of the interviews by the authors of this study, who coded the categories obtained at the group level individually and then by consensus. The general context of the interview was used to determine which specific category the text belonged to in the cases when team members disagreed. The ATLAS ti program (version 6.2) was used to organize the information.

12.6 Results

As a result of the thematic analysis, we conducted it using the following categories, based on the participants' accounts: (1) family history, (2) effects of the illness on the family, (3) experiences of stigma and discrimination, (4) coping responses, and (5) social support resources (agency) (Fig. 12.1).

Family History

Ten of the 12 family members interviewed reported a history of substance use in their own family or in the user's family of origin, six of whom had a history of violence (whether physical, emotional, or sexual) in their childhood. One user's son mentioned that his father had a difficult childhood and that his grandfather was also an alcohol user. In addition to the physical violence he experienced, the relative father was also sexually abused, which led to him using alcohol and drugs in his adult life. The participant remarked that his father had also exercised physical and verbal violence. He recalled that, when he was about 11 or 12 years old, his mother summoned him and his siblings and told them their father used marijuana. She asked them whether he had ever offered them any and warned them that if he did so, they should turn it down, telling them that "people who use marijuana are bad" (Participant 2).

Another participant admitted that her grandson had been the product of teenage pregnancy and had experienced childhood neglect since his parents had not been emotionally prepared to raise him. The grandson had begun using drugs as a teenager and admitted to an "Anexo,"[1] a center for punishing drug users. He had been sexually abused there but never talked to anyone about that experience and could not stand being touched (Participant 3).

The stepfather of a drug user explained that due to the lack of opportunities, his son had been forced to emigrate to the United States, where he had begun working with drug traffickers. However, by the time he returned to Mexico, he was already abusing substances, which created various problems in the family and divided

[1] In Mexico "Anexo" means recovery residence. Usually, they are associated with a traditional AA group (24 h). Some of them have been critized for its punitive methods, whereas others have been of great help for the users, it depends on each center.

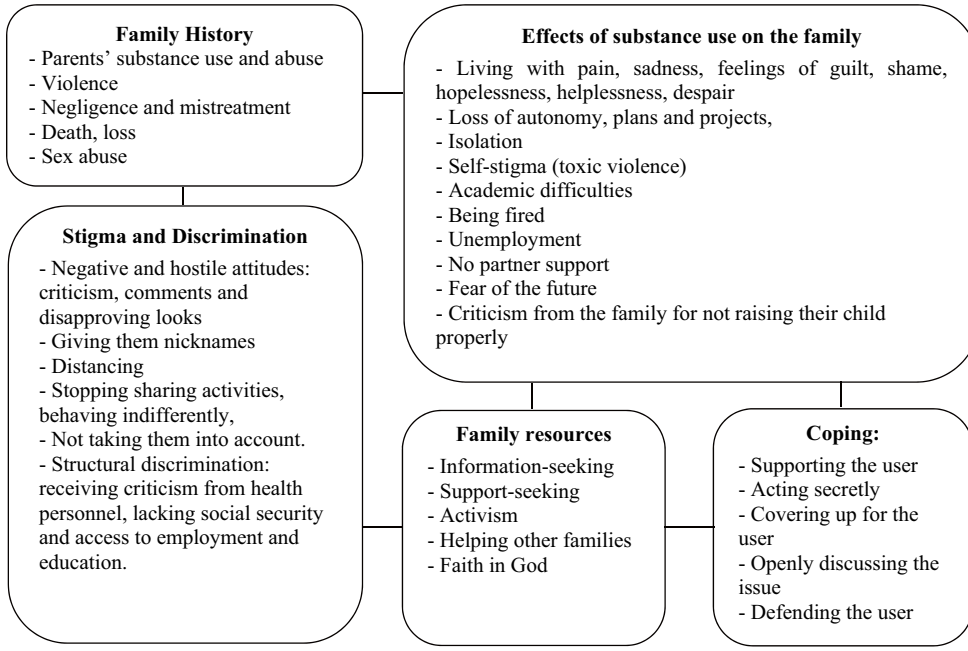

Fig. 12.1 Aspects surrounding subjects' experience

it. Although the man's stepson had received treatment, he had not adhered to it and, therefore, reacted aggressively. As a result, the mother left the house, taking the younger children with her and leaving the father alone with the older children, including the user, who had problems with the law at the time of the interview (Participant 12).

The Impact of Substance Use on Families

Substance use has implications for the family, mainly for the mothers of male users, who constitute the main support networks. They reported feeling alone when dealing with their children's use and not receiving support from their partners. However, it is interesting that a stepfather served as the young man's primary caregiver, although he no longer lived with his former partner, the user's mother (Participant 12). At an emotional level, the impact of substance use is primarily expressed through feelings of sadness, anger, guilt, shame, frustration, helplessness, and despair. Subjects reported a negative impact on their health and mood since their plans and projects tended to change at various levels (social, work, and family).

The son of one user remarked that his father's marijuana use had not been problematic. Concerning his alcohol use, he said that his father only drank at parties or gatherings, which did not make him act aggressively. The interviewee described his father as a *"cool drunk."* Problems had arisen when his father not only started using cocaine but when he began smoking it. The addiction led him to spend all their money:

> … there were constant car accidents and money problems. He used any excuse to get money. His use affected him in many ways, especially financially. My father spent his money on alcoholic beverages and things got worse when he began using cocaine and marijuana. My father sold houses, cars, televisions, and canned food and sentimentally blackmailed the family so that they would give him money wherever he was so he could support his habit (Participant 4).

There was only one case, the grandmother of a user, who said she had not been affected in any way by her grandson's use. On the contrary, she enjoyed being able to help him now that he lived with her and had a good relationship, even though her grandson has cognitive impairment due to his dual diagnosis (schizophrenia and drug use). The

grandmother reported that her grandson had no friends, kept to himself, and found it hard to relate to other people.

The impact on families due to a relative's use is exacerbated when other family members use drugs, as occurred with three interviewees, who also had to cope with their partners, siblings, and offspring' consumption (Participants 2, 4, and 5). The example described below concerns the mother of a user who has been severely affected by this as well as the alcohol use of her son's father:

> ...it has really affected me. My husband has stopped helping me, he turns a blind eye and does not deal with problems. He does not like to be bothered. I used to tolerate him because of his alcohol addiction, and now he drinks heavily from Friday to Sunday. I told him, "This is affecting you a lot, you raise your voice, you shout," and all this has also affected my relationship with him and my children... (Participant 2).

Experiences of Stigma and Discrimination

Stigma and discrimination based on substance use are common experiences among the family members interviewed. Nine relatives reported incidents in which their loved ones were discriminated against. These expressions of discrimination come from various sources, such as family, friends, neighbors, strangers in the street, and even the workplace.

Acknowledging a substance use problem at home is a significant challenge for families. In many cases, the issue remains a secret, and it may take many years before they finally acknowledge that a family member has a substance use problem. The stigma attached to mental health and drug use is deeply ingrained in society.

The wife of an alcohol user, who also had obsessive–compulsive disorder, reported that it had initially been difficult for her to persuade her husband to accept psychiatric care:

> I remember him telling me, "No! I'm not crazy, I don't need a shrink!" … but now that he's received help and feels better, he even asks me to support him so he can continue receiving care (Participant 10).

According to another participant, ignorance of mental health issues prevails in society. For the average person, the term "psychiatry" refers to meanings associated with being admitted to an asylum, straitjackets, confinement, high fences, and bars (Participant 4).

Family members also internalize stigma. One participant had a son in outpatient treatment for a dual diagnosis (substance use disorder and obsessive–compulsive disorder). However, during the interview, she admitted living in uncertainty. On the one hand, she was sure her son used drugs, while at the same time, she said he did not use them because he had tested negative in anti-doping tests. As a family member, she internalized the stigma associated with her son's drug use during this process.

> … my husband doesn't know my son uses drugs. I haven't told him because I don't have conclusive evidence that he does. That's why I don't share this family problem with people because they might single out my son and doors might be closed to him later on (Participant 6).
>
> … at first, I was ashamed. I often told my friends that my son had been hospitalized for severe depression. For me this is a family matter, so I prefer not to tell anyone; only one friend knows the truth (Participant 7).

"Toxic Shame"

Participant 4, whose father and brother use drugs, explained that the impact of stigma is expressed as a kind of "toxic shame," which creates a barrier to help-seeking for families. She had experienced this with her father and other families who had shared their experiences with her. In this regard, she noted the following:

> …there is a lot of prejudice that continues to exist in families. People are afraid to admit that there is a mental health or drug problem… families always minimize problems. They have a hard time accepting this situation and even naming the issue, which is why they say that their family member uses substances sometimes or rarely without giving any more details (Participant 4).
>
> …I felt embarrassed because relatives asked me. One day when I took my son to his medical appointment, a cousin of his turned up and asked me why he looked like that and it made me feel ashamed because of his addiction more than any-

> thing… For me, it's a tragedy that he has made a mess of his life and it has destroyed me emotionally (Participant 2).

The grandson of Participant 3 experienced discrimination in his nuclear family, not only because of his substance use but also because of his sexual orientation, which is an example of intersectionality. In this case, it is interesting to note how these social representations concerning drugs are linked to the idea of contagion and the user's mother's attempt to distance herself to protect her daughters, as can be seen in the following example provided by a grandmother, whose daughter discriminated against her grandson:

> …my daughter thinks that my grandson could infect her family. She had a fit once when she saw my grandson hugging an older man on the street. She said, 'He's a fag: what if he infects my daughters?' – and since then, she has no longer allowed him to stay at her house, which is why he now lives with me (Participant 3).

Another interviewee said she had faced the pain of witnessing other people's attitudes toward her son, enduring ridicule from the neighbors, other young people his age and family members. However, she had also tried to strengthen herself and her son. She said that when that happened, she always tried to defend him.

> They didn't treat him like a normal person. They would say, 'He's crazy,' or he would talk, and they wouldn't pay attention. Then my son used to say, "My cousin so-and-so was talking to me, and he acted as if I was crazy, he didn't listen to me" (Participant 2).

At the same time, this rejection is also expressed in the form of commiseration, in this case from a teacher of the subject's son:

> My son was rejected from the time he was in school. They singled him out as if he had a big problem. One day a teacher went up to him crying, saying that he had a big problem but that she would help him. At home, his sister has criticized him and said, 'That he is a moron, an alcoholic, his friends have given him nicknames, they say he has Down's syndrome, or they say he is a disaster' (Participant 9).

Another participant mentioned that the police had unjustly arrested her son, because when she had asked him to buy some things at the store, they had arrested him, thinking he was on drugs, whereas he was on medication. Although she had tried to explain this, the police refused to believe her, and she was forced to bribe them to release her son. Finally, a mother said that her son had been unable to secure a job because of his condition:

> …Since my son's last spell in hospital, he hasn't been able to hold down a job. He does not pay attention to things anymore. He wants to get ahead but when they see him, they don't want to give him the job (Participant 2).

Coping Responses and Cultural Aspects

Mexican families face a complex dilemma when one of their members uses substances. This experience not only involves care-seeking at the community level but also a long journey full of obstacles, stigma, and distrust of health services. In their despair to find solutions, some people resort to alternative/folk practices, such as seeking the help of witches or spiritual ritual practitioners, as can be seen from the following examples:

> Since all this started, I have seen six psychologists, a psychiatrist and I even went to see a man who does "limpias".[2] That day I told my son to come with me because my brain was hurting…he also gave my son a spiritual cleansing and then he said, 'Your son is very smart, but he uses drugs.' I have also taken him to therapists, I've been everywhere, and all that involves money (Participant 6).
>
> …sometimes I wonder why so many bad things happen to us in the family and I've thought that perhaps someone has cast a spell on us (Participant 12).

For the participants, most of whom are mothers, faith in God is the main source of support for dealing with this situation. In Mexican and Latin American culture, religion is a vital source of comfort and strength [22]. However, it is important to note that in some cases, religion is also

[2] "*Limpias*" are spiritual cleansing and a physical-symbolic procedure to restore balance used in Mesoamerican and Amerindian ethnomedicine. They date from ancient times and link the person with themselves and their environment (physical-natural, social-community, and cultural-religious-spiritual).

used to control and criticize the actions of other family members. Some examples are given below:

> I feel alone, in the ocean, lost, I feel very sad. I always ask God to give me strength and not to abandon me (Participant 6).
>
> Praise be, things happen because God wants and then he brings things down on us. Fortunately, I've finished raising my children and thank God, even though I'm retired now, I can take care of something that nobody wants; it's nice to feel useful (Participant 3).
>
> …I have taken refuge in God a lot because I have a lot of faith and I ask him to give me the strength and understanding to continue because I am powerless to sort out my son's life. I leave everything in His hands and in the hands of specialists and that gives me physical and moral strength (Participant 11).

At the same time, God is a resource for controlling the actions of other family members through criticism and negative comments, either to hold one of the members responsible or to attempt to involve them in the care of substance users, as can be seen in the following example:

> Your father is going to die because of you or what you do to your father. God is going to punish you; you have to take care of your father (Participant 4).

This same participant remarked that, on one occasion, he allowed a religious group to use a ballroom and in exchange he asked the group to say a prayer for his father. They gathered around his father, laid their hands on his head, and one of the members said a few words. They said, *"We are taking you out of this body. Jesus Christ, free this person from his addictions and physical abuse"* (Participant 4).

The mothers interviewed tended to behave secretively, making a desperate effort to keep substance use hidden to protect their children from criticism from family, neighbors, and others. Participant 1 said that, to protect here told her family and friends she was the one receiving psychiatric care rather than her son: "I tell them that I am the crazy one, not him". Another respondent confronted her son's friends in the neighborhood who criticized him by calling him "crazy stoner" and had also given him a nickname. She told them: *"Hey, don't call my son that. That's not his name"* (Participant 2).

However, *families* are not simply sources of criticism and discrimination. Sometimes, they also provide care and support, particularly when coping with similar experiences within their nuclear family, which can lead to greater solidarity and understanding.

> In my family, we all spend time together. We cook, all my brothers' and sisters' children are there, and my husband spends more time with my family. My sister says, "Let's do everything we can, we have to get this kid back on his feet, he's sick" (Participant 7).

During this journey, some family members are empowered and look for ways to help not only their loved ones but also other families in similar situations. This activism, whether through training or participation in organizations, is a show of resilience and solidarity in the context of substance use. In this case, two participants became activists. For example, Participant 4, whose father was using substances, contacted family organizations and began to receive training in these issues, even traveling to other countries for training. Participant 5 became involved with ALANON groups and has been active in helping other families.

In summary, despite the implications of the user's consumption, families develop resources to cope with a close relative's substance use, deal with the situation, and try to get ahead, even if the situation seems overwhelming. They also support other families and constantly look for places offering treatment and information.

12.7 Discussion

One of the main contributions of this study is that it enabled us to adopt an intersectional approach in the narrative of the family members interviewed. This approach provides a nuanced understanding of the multiple conditions leading to social exclusion of families dealing with a

substance use disorder. Based on the thematic analysis, we identify five dimensions that characterize the experience of families: (1) a history of substance use and other mental health problems in the family of origin, together with adverse experiences in the user's childhood; (2) consequences of substance use for family dynamics; (3) experiences related to the stigma associated with substance use; (4) coping strategies used by family members; and (5) resources available within the family to manage substance use. These dimensions reflect the universal aspects and particularities of living with a family member who abuses substances. Some of these findings are consistent with the systematic review of qualitative studies presented by Orford [23, 24], according to the stress–strain-coping and support model, confirming the universal impact of living with a user.

Religious beliefs were one of the main sources of support for the mothers of users. In this regard, Allport [25] defines two types of religiosity, the institutionalized one, which implies an active participation by its practitioners (e.g., going to church and following rituals) and the interiorized religiosity, which expresses itself in a more private or spiritual way. One example of this phenomenon is when the mothers of the interviewees felt very stressed and expressed phrases like the following: "If god wants" or "let's put everything in the hands of god." In Mexico, the most practiced religion is Catholicism (80% of the population). For this group, God represents a source of faith, strength, and hope.

Using an intersectionality-based approach enabled us to determine how different social determinants interact and affect the experience of these families. It is striking how certain conditions, such as a history of abuse in families of origin or the traumatic childhood experiences of users, aggravate the situation, as has been widely documented in the literature [13, 16]. In addition, the presence of a dual diagnosis in six of the relatives shows the additional complexity of having to deal with substance use, and another psychiatric disorder. Factors such as structural discrimination, migration, and lack of care for mental health problems also play a significant role in the prognosis and care of these families.

Regarding structural discrimination, the stepson of one participant was a migrant, which, coupled with substance use and delayed care-seeking, exacerbates the problem not only for the user but also for family members. Likewise, as part of the context of these families, other factors mentioned by the participants were identified, such as precarious living conditions, unemployment, and insufficient income to support the family, hamper the timely care of these problems.

Concerning gender, women and user's mothers are still the primary caregivers. In our study, seven of the 12 interviewees were the mothers of male users, corroborating previous studies showing the stigma and social isolation experienced by mothers and wives in Latin America [26, 27]. The religion in the narrative of the women interviewed, conferring meaning and represents an organizing framework for the life course that involves periods of intense suffering and abandonment. It is important to note that we also had the testimonial of a stepfather, whose role as primary caregiver reveals the variety and complexity of family dynamics.

As seen in the testimonials of the family members interviewed, stigma constitutes a significant source of stress and social disadvantage for those who use substances [24]. It significantly impacts their well-being, constituting an additional burden that intersects with other conditions that create double and triple disadvantages. According to the literature, certain vulnerable groups, including women, are most exposed to violence when they eschew their gender role as caregivers. However, further research is required on the resources available to this population to cope with adversity and adopt a more reflective and critical position in the face of stigma and discrimination in defense of their rights, beyond focusing on the problem by blaming those who use substances and their families, who directly suffer the consequences [22].

Limitations of the Study

A key limitation of our research is that an intersectional approach was not used from the start. This approach was adopted after the interviews had already been conducted. If we had adopted this perspective from the outset, we would probably have achieved greater depth in analyzing the social determinants, affecting the experience of families with substance use disorders. However, despite these limitations, the subsequent adaptation of the intersectional approach yielded promising results. It is particularly relevant in the context of low- and middle-income countries, highlighting the relevance and potential of intersectionality for future family research.

Implications of the Study

Culture and religion play a vital role in the experience of Mexican families forced to deal with substance use. Previous works have already highlighted the importance of these aspects, particularly for families in Latin America [21–23]. For our interviewees, being the mothers of substance users became a source of resilience and motivation [28]. However, some families have also used religion to delegate care responsibilities.

At the same time, regarding self-care resources, for example, in only one case did a user's mother seek a solution through a healer. This finding underscores the diversity of responses and resources used in different contexts, emphasizing the need for further research on cultural dimensions concerning to addictions, primarily in Low-and middle-Income countries (LMIC).

Given the relevance of the family as a support network in LMIC, it is essential to expand research on addictions using an intersectional approach as it can provide valuable tools to design inclusive and culturally relevant public policies, ensuring adequate care for the most vulnerable groups and promoting social inclusion.

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Part III

Barriers to Services Working with AFMs

13 The Political/Policy Landscape: Representation of AFMs in Policy and Service-Delivery Models

Candice Groenewald, Dane Isaacs, and Jim Orford

13.1 Introduction

Addictive disorders are complex and highly prevalent public health problems that threaten the health and well-being of those who experience addiction and their significant others. The 2022 World Drug Report produced by the United Nations Office on Drugs and Crimes (UNODC) indicates that drug use accounted for 9% of the global substance use-related disability-adjusted life years (DALY) in 2019 while drug and alcohol use collectively accounted for approximately 124 million deaths [1]. Problem gambling has also been identified as a significant concern, with a recent systematic review finding that 0.23% of the global population has sought help for problem gambling, with higher help-seeking prevalence reported for those with increased gambling severity [2]. In addition to the established harms caused to the person with addiction problems, addictive disorders have a profound impact on the quality of life of families and significant others. Yet, as is evident throughout this book, family members often suffer in silence and with little formal support, intervention, or policy priorities to help them cope effectively with the various challenges they face due to the relative's addiction and related behaviours.

The current chapter aims to understand the extent to which family members who are affected by a relative's addiction problem (AFMs) are prioritized in policy and service delivery models. To do this, we draw on two review studies that employed different review approaches. First, we draw on findings from a scoping literature review, which was conducted to synthesize the literature that identifies policy directives for AFMs. Second, we consider the outcomes of a purposive review, which was undertaken of relevant policy and related documents across eight countries represented in the membership of the Addiction and the Family International Network (AFINet: www.afinetwork.info). While both studies focused on AFMs, the scoping review only included studies pertaining to AFMs of relatives with substance use problems, while the purposive review had an expanded interest, also including a focus on AFMs of relatives who have gambling problems. The findings of these two approaches will now be presented followed by concluding

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comments with thoughts on the way forward to better support affected families.

13.2 Scoping Review

13.2.1 Overview

The aim of the scoping exercise was to map out key priorities identified by the literature pertaining to how current policy priorities can be strengthened to accommodate the support needs of AFMs of relatives with substance use problems.[1] To do this, three databases were consulted, namely, EBSCO-host web, Scopus and Taylor and Francis, using Boolean phrase options to search within databases. These databases were identified, given their collective comprehensive coverage of peer-reviewed articles pertaining to social sciences, medicine and humanities. Scopus holds the largest database of peer-reviewed abstracts and citation, while EBSCO-host web is an aggregator database, which entails content from several publishers, including different journals and other databases. Similarly, Taylor and Francis is an accredited database that provides access to an array of articles pertaining to the social sciences, behavioural sciences and healthcare. To ensure that the review was systematic, the same keywords were used across the three databases in the following way:

- Search 1: Family policy AND substance use OR substance abuse OR drug use OR drug abuse OR dependence OR addiction.
- Search 2: Family policy AND alcoholism OR alcohol dependence OR alcohol abuse OR alcoholic OR alcohol addiction.

Only articles with the respective keywords in the abstracts were included in the review. Apart from the keywords, only those articles that were (1) directly interested in AFMs (in their own right) and (2) offered policy implications for AFMs were included in the review. Articles that focused on the family but simply as part of the rehabilitation journey for the person with substance use problems were not included in this review. These strict search parameters were applied to identify articles that closely align with our aim and, in this way, avoid articles that only refer to our keywords in the body of the text. In the next section of this chapter, we describe the findings of our review.

13.2.2 How Can Alcohol and/or Drug Policy Documents Be Strengthened to Prioritize the Support Needs of AFMs?

An important, but somewhat unsurprising, finding that emerged even before drawing insights from the literature in this review was the paucity of papers that explicate the impact of a relative's substance misuse or addiction on family members and the support needs of AFMs. Within this already scant database, even fewer papers offered specific directions on how policies can be strengthened to not only recognize but also prioritize formal support for AFMs. The final number of articles that were included in this review is listed in Appendix (n = 9). A close inspection of this literature showed two types of articles. The first type includes *research papers* (n = 6) that outline the policy implications of their research or intervention studies pertaining to AFMs. The second set of articles, *policy papers* (n = 3), directly focus on the policy landscape and the place of AFMs in drug and/or alcohol policies. Both sets of papers were reviewed with the same question in mind: how can (relevant) policies be strengthened to prioritize the support needs of AFMs?

13.2.2.1 Insights from 'Research Papers'

Notably, the research papers presented here are not exhaustive and therefore do not reflect the breadth of AFMs research. However, these were the only articles that met our search criteria within the selected databases and were thus included in the review. The AFMs in these studies represent different contexts including Canada [3], India [4], Mexico [5, 6], Myanmar [7] and Scotland [8]. The majority of the articles used

[1]For a variety of reasons, problem gambling was not included in this review (see limitations for more details).

qualitative methods with one article [6] conducting a literature review.

The six articles identified here offered valuable insights into the experiences of AFMs. These studies covered various issues pertaining to AFM experiences including: addiction-related stigma and discrimination at treatment centres [5], the role of stigma in caring for a relative with an alcohol use problem [4], the relationships between health care providers and family members of persons with addiction problems [3], families' perspectives on drug consumption rooms and its impact [8], the coping experiences of caring for a relative with a drug use disorder [7] and AFM focused intervention strategies [6].

Our review found that although the authors emphasized the need for targeted support for AFMs, the policy implications listed in the articles were generally vague. For example, authors such as Mora-Rios et al. [5] recommended that governments should 'develop public policy that is more responsive to the specific needs of this population' but did not describe what directives such policies could entail. Similarly, Thein et al. [7] described the burdens associated with caring for persons with drug use problems in Myanmar, often with inadequate support for AFMs. They also emphasized the harsh and punitive drug laws that further increase stigma, making mental health support for the relative and AFMs largely inaccessible. In this regard, the authors recommended that '[d]ecriminalizing drug users would help promote human rights, reduce stigma and social exclusion, and thereby ease caregivers' burden', but did not go into detail on how policies could be strengthened to prioritize the needs of AFMs [7].

However, two papers offered thoughts on how policy and programmes can be strengthened to better support AFMs. Natera et al. (2010), for example, argued for the importance of specialist training on AFMs and described how they hosted training sessions with counsellors across Mexico who subsequently 'incorporated the study of families under this paradigm in national programmes related to addictions' [6]. However, pertaining to policies, the authors maintained that 'a short-term vision about family problems still prevails, which puts the ball squarely in the family's court' [6]. In this regard, the authors argued that the primary focus remains on individual aspects of addiction and that 'the family remains absent from care policies' [6]. Similarly, Kumar et al. [4] identify the implications of their work for policymaking and services in Goa. They prioritized mental health literacy campaigns for nurses and doctors who are typically the first point of care for persons with substance use problems. Further, pertaining to policies, they recommended that psychosocial treatment interventions and mental health care explicitly for AFMs should be a priority within the public health system [4].

13.2.2.2 Insights from 'Policy Papers'

The three articles that formed part of this collection were published between 2010 and 2017. All three articles were policy reviews that primarily considered the place of AFMs in drug and/or alcohol policies. Briefly, Velleman [9] reviewed several policy documents relevant to the UK context that focused on drug and/or alcohol misuse, also considering the progression of targeted attention to the needs of AFMs over a 10-year period. Groenewald and Bhana [10] focused their policy review on the South African landscape, evaluating the extent to which two national substance misuse policies and one family policy prioritize the impact of a relative's substance misuse and addiction on AFMs. Like Velleman [9], Devaney [11] examined eight policy documents focused on Ireland. Here, Devaney [11] specifically reviewed Irish drug policies, focusing on the problematization of families in treatment and rehabilitation.

A number of themes arose from these three policy reviews.

Growing Recognition of AFMs, but Limited Priorities

Across the three papers, mention was made of the growing attention given to families across the different policy documents that were reviewed by authors. For example, referring to the primary drug policy in Britain, Velleman (2010) welcomed the refocusing of the drugs: protecting families and communities (2008) document to centre the family, evident in the title, on drug

issues [9]. This increased interest in the family, Velleman noted, was also observed in other UK policies reflecting that governments and agencies are 'starting to recognize both the needs of, and the positive possibilities of using, affected adult family members, [and that] this needs to be encouraged and developed' [9]. This said, he further cautioned that recognizing family impacts is not enough and might not necessarily translate into the implementation of family-focused interventions for AFMs.

Similar sentiments were offered by Groenewald and Bhana who found that the South African policies made some reference to the family impacts of substance abuse. However, families were often considered as part of the treatment trajectory of the person with substance misuse problems rather than offering targeted support for AFMs [10]. Vague directives aligned with the notion that *families are negatively affected by substance abuse and need support* were observed, but no mention of what such support interventions or programmes need to entail. The authors thus concluded that 'South Africa still has a long way to go in order to embed families of substance abusers more centrally in these policy documents' [10].

Daveney [11] reported a significant silence on the AFM experience. Daveney explained that families have been considered as being part of the problem and solution pertaining to drug use, reflecting 'a construction of affected families as pathological and "dysfunctional", requiring professional intervention to improve relationships, functioning and communication' [11]. This latter finding was also observed in the other two articles [9, 10], creating a context in which family dysfunction is blamed for the development of substance use problems, the family is required to cope without effective support with the challenges they face as a result of the relative's substance misuse behaviours and the family has a shared responsibility for the relative's rehabilitation. Thus, while the family has been more present in policy discourses over the past two decades, these recognitions are not enough to create policy priorities to address the needs of AFMs.

Expanded Perspectives on AFMs Required to Prioritize the Needs of Different Family Members

Representations of AFMs differed across the various policy documents, which means that, apart from a focus on children, there was very little consideration for how different family members may be impacted, and will need to be supported, when a relative has a substance misuse problem. Velleman [9] draws attention to the importance of child protection priorities that consider the devastating effects that living with a parent or caregiver who has a substance misuse problem has on minors. Recognizing this as an immediate priority, he adds that priority setting for adult AFMs is often overlooked. Expanding this further, Daveney [11] points to the importance of an intersectional lens to prioritize the complexities of AFMs' experiences and support needs. Specifically, Daveney asserts that:

> [t]he behavioural focus of the proposed solutions and the lacunae in drug policy around factors that impact on and mediate experiences of drug use in the family—such as class, gender, family position, place, stigma, marginalization and access to material and political resources—individualise complex social issues such as drug use and its consequences [11].

Groenewald and Bhana [10] also maintained this view, arguing that in socio-cultural diverse contexts like South Africa, policies need to address issues of gender, race and service availability and accessibility when setting policy directives for AFMs. There is thus an urgent call for better efforts to integrate an informed and 'whole family' perspective into relevant policies [9] that considers, for example, how children's experiences and needs differ from that of parents, siblings, wives, husbands, grandparents and other caregivers.

Additional Policy Evaluations Required

The third issue that the authors discussed related to the development of a global policy agenda for AFMs. This was particularly evident in Velleman [9] and Groenewald and Bhana's [10] articles where the need to examine other drug and alcohol, and family policy documents across the

global landscape emerged as an imperative. In both articles [9, 10], the authors argue that there is tremendous value in learning from other contexts about how families, in their complexities, can be prioritized as AFMs in respective policies. This is part of what the current chapter aims to address in section B; to consider how, if at all, AFMs are prioritized, where the gaps are and what can be gleaned and adapted from different contexts.

More Research on AFMs and Their Support Needs

The value of additional research that exemplifies the support needs of AFMs in different contexts cannot be overemphasized. As indicated earlier in this chapter, and as other chapters in this book show, there is a scarcity of studies on the experiences and support needs of AFMs. This is particularly true in low-and-middle-income countries (LMICs) where a stronger focus has been placed on the aetiology and prevalence of drug and/or alcohol misuse and addiction, prioritizing an individual, rather than family perspective, on substance misuse. This is, of course, important, but to advocate for AFMs, we must build an evidence base that unpacks how different family members are affected and the applicability of different support initiatives for AFMs. As Velleman (2010) states, 'it is important to underline the fact that policy cannot be developed and implemented on its own, but needs to go hand in hand with research [and], practice' [9]. Likewise, reflecting on a LMIC, Groenewald and Bhana (2016) called for more research in diverse settings within South Africa and other LMICs to expand the database on AFMs' experiences within these spaces [10].

Notably, research, in itself, is a valuable commodity to drive the policy agenda, but what is further needed is the identification of evidence-based interventions to help AFMs cope effectively. In a later section of this book, several chapters have been dedicated to describing different interventions for AFMs. Drawing on conclusions set by Velleman and Groenewald and Bhana [9, 10], evaluation research is necessary to assess the applicability of such interventions for different AFMs and across different contexts. Indeed, policies and programmes are not mutually exclusive but need to work hand-in-hand to address the needs of AFMs and decrease the burden of disease on family members. In this regard, Groenewald and Bhana indicate that '[p]olicies should address what needs to be done and why, while practitioners and researchers promote the implementation of these strategies […] it is imperative that policies rely on evidence-informed policy directives to help create an enabling framework for implementation strategies' [10].

13.3 Document Reviews

13.3.1 Overview

In this section, we report first indications from an ongoing project entitled 'Country policies and practices regarding affected family members (AFMs)'. This project was carried out by members of the Addiction and the Family International Network (AFINet: www.afinetwork.info). As implied, AFINet includes members who have a shared interest in AFM research and interventions and has members from many different countries (now numbering 55 countries). Members were invited to partake in this project by purposively sharing policy documents that have implications for AFMs. A number of documents (n = 36) from eight countries[2] were included in the review, which primarily entailed government policy documents and documents produced by government bodies on alcohol and/or drugs and/or gambling. Also, candidates for inclusion were documents produced by bodies set up by government to advise on regulation, research or treatment in the areas of substances or gambling. These documents were subsequently reviewed, guided by the question: do governments recognize the needs of affected family members? Analysis revealed two findings:

[2]Members from these countries responded to the invitation: Brazil, Germany, India, Irish Republic, Mexico, Netherlands, South Africa, and the UK.

1. There is limited recognition of AFMs.
2. There do exist a small number of exemplary cases of documents that show how AFMs can be well represented in policy.

13.3.1.1 Limited Recognition of AFMs

This finding corroborates the literature previously presented: that policies do not adequately recognize or address the needs of AFMs. Limited recognition was evident, including (1) no or only vague mentions of AFMs, (2) focus on families but AFMs remain peripheral, (3) mention of AFMs but no priority setting and (4) mention of AFMs with a focus on children only.

No or Only Vague Mentions of AFMs

Some policies, such as the *2015 Brazilian document from the Ministry of Justice and Public Security—National Secretariat for Drug Policy*, did not mention AFMs at all, while other documents merely mentioned families through repetitive phrases like 'and their families'. An example of this is found in the *2016–17 annual report of the Department of Social Justice and Empowerment, Government of India*. The remit of the Ministry of SJ&E is to empower various socially and economically marginalized groups including the 'victims of alcoholism and substance abuse', which 'generally includes the immediate family also'. Although there are statements to the effect that it is best to take 'a family/community-based approach', AFMs are nowhere a focus in the document.

A Focus on Families but AFMs Remain Peripheral

Limited recognition of AFMs was also found in documents where families are mentioned, but AFMs generally remained largely peripheral to the document's main concerns with no mention of their needs for help or advice in their own right. We offer three such examples. First, the *UK Government Alcohol Strategy 2012* includes several quite specific family-relevant statements. Although encouraging, these statements mostly consider families and family members in the context of already identified high priority policy areas such as domestic violence, 'troubled families', heavy drinking and hospital accident and emergency admissions, or foetal alcohol syndrome. There is lack of a general awareness of 'affected family members' as a group of stakeholders or of alcohol's harm to others in general.

A second example here is found in the 10 *Mexican national documents* that were examined. Across these documents the family was mentioned 57 times; 24 times as a means of prevention, 12 times as a means of accessing treatment, 7 times as support for adherence to treatment and only 7 times as a system that has its own needs in the face of problems related to consumption. State documents were found to be similar. References to the family are specific in some cases about the family's role in prevention and help for the relative with a substance use problem, but not when it comes to family members' own needs as people affected physically and emotionally by such consumption.

The final example we offer here is a document from the *Provincial Government, Western Cape, in South Africa*, which includes a section on: *Prioritising the role of families in relatives' treatment*. While the title of this document is hopeful, families are not clearly identified as needing help or advice in their own right. The document indicates that Drug Intervention Teams can be set up to conduct community outreach activities (i.e. can be deployed to police stations, schools and courts, for example) and that office-based workers can engage with drug users 'and their families'. The intention here is to motivate the using relative to seek treatment as well as provide advice on how to reduce the harms caused by drugs. Drug Assessment Teams would work with all clients, even those who are not yet ready to stop using drugs, and *if necessary*, develop a care plan for them and their families. Here, again we observe the repetitive 'and their families' statements, and although the family is mentioned, the support needs of AFMs are not well addressed.

AFMs Are Mentioned but No Priorities Are Set

This set of policy documents generally mentions families or AFMs but does not follow through with directed assessments, costing or reviewing

whether set objectives have been met. For example, a *2013 Dutch document by the National Institute for Public Health and Environmental Protection* notes under a paragraph on harms to others in society ('victims'):

> An important cost item, which has not been discussed previously, concerns the loss of quality of life of family members of alcoholics, for example, through fear for domestic violence, or by having to take care of their alcoholic family member… As there is no quantitative data available, these costs have been stated solely as 'to be determined.

Another example is found in the *Responsible Gambling Strategy Board (RGSB) (UK) National Responsible Gambling Strategy 2016–17 to 2018–19*, which appears to show commendable recognition of affected families. They are mentioned in the Executive Summary and in no less than 11 separate places in the main document. Like UK Government alcohol and drug strategies, this document recognizes harms to families as a general category of harm, and not confined to certain sub-categories such as children, pregnant women or foetuses. On the other hand, these mentions of family harm are brief and very general. This oversight is seen again in an analysis of their report the following year. In this report, called *One year on: progress delivering the National Responsible Gambling Strategy*, June 2017, a 20-page document with 56 sub-sections, affected families are mentioned only once and then indirectly. It seems that affected families have been lost sight of between the writing of the strategy document and the first-year progress report.

Mention of AFMs with a Focus on Children Only

The final theme pertaining to the limited recognition of AFMs relates to policy documents that primarily focus on children and do not recognize the diverse experiences and needs for support of AFMs more generally. Examples here include the *German National Strategy on Drug and Addiction Policy 2012*, which focuses on addiction in general including gambling. Another example is the *UK Government 2017 Drug Strategy*, focusing specifically on the work of Public Health England (PHE). It is stated that PHE will be expected to work with Family Drug and Alcohol Courts and local public health teams to help them to work together to improve outcomes for families and children. PHE will also review the evidence and provide advice on the estimated number of children likely to be affected by the drug and/or alcohol use of their parents, and provide advice to national and local government on where action could have the greatest impact on improving children's outcomes. It will also develop a toolkit for local authorities to support local responses to parental substance misuse, which will include local prevalence data on parental/carer use, the associated harms and likely costs, guidance and information on effective interventions.

As mentioned in the previous section of this chapter, a targeted focus on children protection is undoubtedly important in the context of substance and gambling misuse and addiction. However, a 'whole families' approach to AFMs would ensure an expanded reach to support both adult and child AFMs.

13.3.1.2 Exemplary Cases of Documents Showing How AFMs Can Be Well Represented In Policy

Apart from the various documents mentioned thus far, we now present two examples where supporting family members emerged as a priority. The *Substance Misuse Strategy for Wales 2008–18* was structured around four Priority Action Areas of which '*Supporting and protecting families*' is the third. A figure shown in the introductory section of the Executive Summary shows 'Support for Families and Carers' as a main element of relevance to all points on a continuum from education/prevention to harm minimization to treatment to aftercare to recovery. It is also inclusive where adults as well as children are covered although children are still the biggest priority. The good coverage of AFMs appears to follow from the use of the general concept of 'harm', which is a central idea in this document, appearing in the title and repeated often.

The second example is found in the *Reducing Harm, Supporting Recovery—A health-led*

response to drug and alcohol use in Ireland 2017–2025. The most recent *Irish National Drugs Strategy* had considerable input from the *National Family Support Network*, a peer led organization supporting family members living with drug and alcohol use. From the outset the impact on families and the involvement of family members in the design and delivery of services is given precedence. This is seen in both the vision statement and in each of the five main objectives of this strategy. Throughout the document the importance of family involvement in supporting the rehabilitation of a service user and the impact on family members when a relative is engaged in problematic substance use is acknowledged.

13.4 Discussion

Families play a crucial role in the promotion of individual and collective health and well-being [12]. Apart from being a space of care and intervention, family members themselves require support to be well, and to be a space of support to others. This is particularly important when a relative faces significant challenges that may compromise their own well-being and the well-being of those closest to them, as is the case with substance use or gambling problems. In this regard, obtaining support for both the relative and the AFM are complementary urgencies. Although the establishment of programmes and services that provide targeted interventions to promote effective coping mechanisms and enhance the well-being of AFMs are important priorities, the adoption of policies that advocate for such support services will advance these priorities. As Groenewald and Bhana (2016) assert, 'carefully designed policies that magnify rather than minimise support of the family can help lessen the burden of substance abuse on families' [10].

The findings of this current chapter, however, suggest that the policy landscape still has a long way to go to meaningfully incorporate the experiences and support needs of AFMs in the global priority setting. Collectively, the scoping and document reviews highlight patterns with regard to the representation of AFM in policy and service delivery models. Although there were some notable exceptions, we found that AFMs were often vaguely mentioned or completely neglected in policy documents. While there has been growing attention given to families in some policy documents, these policies do not adequately address the needs of AFMs. When AFMs were considered, there was a stronger focus on children (which is most certainly important) as opposed to the needs of the entire family or of particular categories of AFM such as parents or spouses/partners or grandparents [13–15]. Further, policy statements, while sometimes advocating that the family be involved in the treatment trajectory of the person with a substance use or gambling problem, are less likely to emphasize the support needs of AFMs themselves during the treatment process.

In view of these findings, we continue to advocate for a stronger, and more expanded, AFM focus in policy, service delivery and research to understand, describe and address the needs of AFMs worldwide. To support Bogenschneider et al.'s (2012) perspective pertaining to how families affected by a variety of different issues might be involved in policy development, 'how families are affected by an issue, if families contribute to an issue, and […] involving families in the response, would result in more effective and efficient solutions' [16]. Thus, collaborative approaches that enhance and integrate the voices of AFMs should be research priorities to ensure a 'family first' and 'family informed' perspective in the development of formal support initiatives. Continuous, open and meaningful communication between various stakeholders including policymakers, government, family researchers, practitioners, service providers and AFMs themselves would ensure the development and operationalization of unified actions plans for AFM support.

13.5 Limitations

While this chapter provides valuable insights into the policy implications for AFM research, it is not without limitations. The chapter reflects

on papers published within selected databases and covers a specified timeline. Relevant publications beyond this scope therefore may have been excluded. Also, as mentioned earlier in the chapter, two separate review studies were merged for this paper: the review of policy documents covered both substance misuse (drugs and/or alcohol) and gambling, whereas the systematic review solely looked at AFMs of persons with substance problems and did not search for AFMs of those with gambling problems. Future review studies could expand this work by replicating the systematic review with a specific focus on AFMs of persons with gambling problems, recognizing that AFMs' experiences when a relative has a gambling might be different to AFMs of persons with substance use problems. Further, although a large set of policy documents were reviewed as part of the document review, the included documents are not exhaustive but rather include a purposive collection of policies. In this regard, the generalizability of the document review findings is restricted and do not represent different contexts, particularly in the Global South. Again, future reviews could expand this work by systematically considering the differences (if any) in how AFMs are prioritized in policies across the Global North as opposed to the Global South, enabling a move towards a greater understanding of what contextually relevant and culturally sensitive policy responses should entail. This said, we expect similar findings to those that were presented in this chapter, given the widespread recognition of the globally limited research and policy formulations available related to AFMs.

Appendix: Scoping Review Articles

Devaney E. The emergence of the affected adult family member in drug policy discourse: a Foucauldian perspective. Drugs Educ Prev Policy. 2017;24(4):359–67. https://doi.org/10.1080/09687637.2017.1340433

Groenewald C, Bhana A. Substance abuse and the family: an examination of the South African policy context. Drugs Educ Prev Policy. 2018;25(2):148–55. https://doi.org/10.1080/09687637.2016.1236072

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Thein KZ, Herberholz C, Sandar WP, Yadanar. Caring for persons with drug use disorders in the Yangon Region, Myanmar: socioeconomic and psychological burden, coping strategies and barriers to coping. PLoS One. 2021;16(10):e025818. https://doi.org/10.1371/journal.pone.0258183

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14 How to Sensitize Health and Social Workers and the Community to the Needs of AFMs

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14.1 Introduction

Affected family members (AFMs) endure significant suffering due to their relative's addiction and its repercussions, contributing significantly to the global burden of ill-health in adults [1–3]. While AFMs may seek both formal and informal help, professionals may lack the specialized competencies required. Competence in dealing with the impact of addiction on families necessitates social networks involving professionals, institutions, and informal groups.

The heuristics of judgement, as described by Kahneman and Tversky [4], often lead professionals to overlook AFMs, rendering them invisible despite growing evidence of their struggles. Family members hide their issues, do not perceive themselves as needing help, and professionals may feel helpless when confronted with these challenges, perpetuating the invisibility of AFMs.

While professional skills are crucial, they are insufficient in isolation. Networking with the community and addressing hidden, complex issues requires collective efforts. Building and maintaining these networks necessitate sensitizing both practitioners and communities.

Engaging with AFMs is a complex, multilevel process, starting with recognizing them as caregivers. However, solely addressing their support for the relative with the addiction is insufficient. Changing cultural perceptions and attributions is essential. Guided networks between various community actors can sensitize health and social workers, enabling them to develop sensitive "mind maps" and support AFMs without judgment and in their own right, i.e., regardless of whether the relative recovers or stops substance abuse or gambling behavior [5–9].

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The predominant medicalization of addiction issues in the Western world contrasts with the insufficient evidence in developing countries [10–12]. Our proposed approach involves community training to foster empathy, understanding imperfections, and embracing differences.

This chapter draws on experiences in gambling addiction in Italy, the fourth country globally for absolute gambling-related losses. At least 3% of the Italian adult population are problem gamblers [13], and AFMs are obviously a much larger percentage [7, 14–16]. Sensitizing social and health workers and the community aims to create awareness that encountering an AFM is not uncommon, fostering a supportive environment.

For over 15 years in Lombardy and Emilia-Romagna, thousands have been sensitized, contributing to the international network of practices, reflections, and research. This chapter represents an initial step in promoting the global practice of sensitizing social and health workers and communities.

14.2 Systems Thinking, Design, Welfare Strategies, Generativity, and Reprocessing

The narratives and experiences shared by practitioners in the following pages serve as a conduit, guiding us toward new reflective avenues to establish foundations for future work.

In envisioning the future, "Systems Thinking" underscores the imperative to comprehend numerous elements as interconnected systems be it products, services, processes, family dynamics, or organizational structures. This approach is rooted in addressing specific real-world problems, mapping the intricacies of a dynamic, multidimensional reality, and delineating clear goals. Considering the diverse experiences we have lived and contemplated, our proposition is to pinpoint a noteworthy practice for comparative analysis with counterparts in different regions and countries.

The methodological framework intertwines three essential areas crucial for sensitization: design, welfare strategies, and redesign.

Design is conceived here as the lever to prelude changes in both work and cultural paradigms. Design, in this context, surmounts the cause–effect outlook and the automaticity of problem–response. It introduces fresh perspectives to scrutinize human actions and suggests alternative solutions to address challenges. This departure from the recurring treatment of problems as novel arises from the yet-to-be-identified working processes. Design responds aptly to the imperative of unveiling and training practitioners to address latent issues.

Welfare strategies constitute the other pillar. Welfare assumes the role of community generativity, activated when a community collectively shoulders the responsibility for issues that may impact only a few. This does not imply uniform problems but rather emphasizes cultivating an observant mindset and fostering connections within the community. The cultural shift from individualism to community is crucial, imparting meaning to actions and making practitioners' work purposeful. Cultural transformations within a community unfold at a gradual pace. Thus, looking forward involves perceiving today to instigate future changes.

The final focal point revolves around the imperative of reprocessing, emphasizing continual cross-referencing between teams. Reprocessing allows for the evaluation of intervention impact, the identification of requisite skills, and the activation of optimal work processes.

14.3 Theories and Good Practices

Our work in sensitization is grounded in theoretical principles primarily acquired through our association with and insights from media education [17, 18]. In addiction prevention, we have come to understand that while information is essential, it can become ineffective or even harmful due to normalization [19]. Media education has taught us that involving individuals in mes-

sage construction can sensitize them in ways few other experiences can, a phenomenon we have observed with both students and adults.

We advocate for the active participation of youth and adult groups in the creation of sensitization messages. By encouraging them to assist in constructing messages, we believe that messages originating from within communities can become highly effective and beneficial. Engaging people in the process of crafting messages allows for a more profound sensitization compared to conventional communication methods.

14.4 Good Practices in Lombardy

To effectively shift perspectives on AFMs, a comprehensive and sustained effort is required to modify perceptions and attributions.

Formal legitimization to operate is a primary requirement, compelling administrations to implement measures and support interventions. Scientific prerequisites involve the presence of reliable psycho-socio-medical experts, well-versed in the subject matter, who continuously track political and social proposals. This ongoing involvement enables them to substantiate interventions based on clinical research evidence, creating a circular process of monitoring, and evaluating implemented actions. It is essential for the success of the model to provide continuous, diverse, and differentiated actions that persist beyond the cessation of funding.

One notable experience within the framework of this theoretical approach is the work conducted by the AND-Azzardo e Nuove Dipendenze APS association, particularly focusing on the theme of gambling. Collaborating with CCOGA (Coordinamento dei Comuni Contro l'Overdose da Gioco d'Azzardo), supervised by media educator Michele Marangi, the association identified key awareness messages (#azzardotivinco). These messages were disseminated through a planned, multichannel, and multilevel communication strategy, actively involving various recipients of interventions, such as family members, gamblers, and adolescents.

This integrated approach successfully reached a population of nearly 400,000 people, aligning with the target of the target area, especially toward the project's conclusion, showing a consistent upward trend over 5 years.

In conclusion, addressing the complexity of AFMs requires specific actions, summarized by key principles: competence, specialization, consistency, constancy over time, longitudinal planning, leveraging network resources, assuming clear roles based on actual skills, and verifying and monitoring results regularly and progressively. This approach leads to articulated, multidisciplinary, and multilevel actions, embedded within an overarching project that acknowledges the inherently fragmented, highly complex, and multifactorial nature of the addiction phenomenon [20].

14.5 Sensitization Experiences in Emilia Romagna

Cooperativa L'Arco and Associazione La Ricerca of Piacenza have collaborated with the Addiction Service to raise awareness among both practitioners and the community regarding the impact of problem gambling on individuals, families, workplaces, and institutions. While pathological gambling is often perceived as a niche issue, the plight of family members is largely overlooked, such as the submerged part of an iceberg [1].

The challenge lies in conveying the suffering of family members, and it is precisely why we persist in experimenting with ways to engage and sensitize both professionals and the community. In both sensitization and prevention efforts, despite the apparent contradiction, information alone proves insufficient. In fact, it runs the risk of leaving individuals feeling powerless and compelled to avoid addressing the issue.

Here are some practices we have implemented, with some primarily focusing on the community and others on practitioners, often bridging both spheres.

14.5.1 Networking

Networking stands out as the foremost and arguably most crucial practice [21, 22]. It is a practice that involves both the community and practitioners, constituting a continuous effort that we undertake whenever possible, despite occasional frustrations and seemingly unyielding outcomes.

Project Iceberg's primary objective is to directly support family members affected by gambling issues, employing the 5-Step Method [6] and Couple Therapy. Additionally, the project is committed to indirect support through awareness-building and preventive measures. We have embraced invitations of various kinds (350 events) from both formal and informal groups, engaging nearly 3000 individuals of diverse ages and cultures. Our outreach extends to voluntary associations, churches, schools, various institutions, and even entrepreneurs and trade unions. Every entity plays a vital role and can contribute meaningfully.

While conferences may not always yield direct benefits, we never decline invitations. Instead, we view them as opportunities to foster networking, connect with other networks, and explore potential collaborations. These occasions provide a platform to understand and share opportunities for cooperation.

14.5.2 Sensitizing Social Workers

Social workers often prioritize information and request it during meetings, where we typically provide information and some operational guidance. However, the impact of these suggestions, as good advice often proves, can be limited. We have observed that those who immediately apply the questions and frameworks we propose after a seminar are often impressed because they work well in identifying problems and assisting families. Unfortunately, if there is a delay between the seminar and the application of these ideas, they tend to be forgotten. Workers sometimes fail to identify potential families affected by gambling issues among their patients.

In seminars and meetings (almost 50) requested by social and health workers and their services, we manage to grab their interest and occasionally surprise them. However, building the network we envision with them, characterized by discussions on concrete situations and mutual support, seems challenging and utopian.

To address this, we actively engage health and social workers in concrete projects and invite them to Iceberg creative groups, where their presence is invaluable. The "Flea in the Ear" initiative, for instance, resulted from a creative group involving practitioners and family members, primarily from various addiction backgrounds. We aim to transform informational moments into opportunities for involvement and communication. An example is inviting social and health workers from the addiction service we collaborate with to participate in a World Café [23] on the Iceberg Project.

Another sensitization experience for social workers involved lectures for students of the Social Service degree course and the Policy and Family Welfare course of the Specialist Degree in Social Service Design at Parma University. Over a decade of sharing experiences in a university context, dozens of social workers were sensitized to the challenges faced by family members of addicts, the complexities of sensitization, and the benefits of working within networks.

Social workers frequently ask: what should be done? As they begin to understand, their questions shift to: how can we become aware of hidden problems? Specifically, they inquire about "the warning signs… the alarm bells." Our responses are nuanced, especially in gambling cases, where numerous signals are indicative of diverse situations. We propose that social workers, with any client:

Notice: Pay attention to intuition and pick up on strange signals.

Listen: Listen carefully and deeply to what people are saying. Ask for clarification, pose questions, and reflect with interest, respect, and sensitivity.

Accompany: Guide individuals to an awareness of the implications of problematic situations, encouraging them to seek support and help

for all the challenges arising from addiction in the family. Build trust and develop solutions within the social network. Always instill hope that things can improve.

For the first two points, we present the SSICS Model [6], fostering a different understanding of the situations practitioners may encounter. To address the third point, we propose using Step 4 diagrams, illustrating types and possible dimensions of support: emotional, social, informational, practical, financial, legal, physical, spiritual, housing, and work.

Social services and social workers often express a need for training on these issues. Our goal is to train them in Noticing–Listening–Accompanying, particularly by working with them on specific cases and providing supervision for the various steps of a pathway they may find challenging to initiate.

Recently, we have been experimenting with social workers, educators, and teachers with the use of cards that we have prepared using specifically selected pictures: one set of cards contains all the possible family members in a family with gambling and another deck is made up of pictures and words on the possible impact of gambling on families. The practitioners choose in the first case what a family with problems might look like and in the second case what impact there might be on health, finances, relationships, etc. Both experiences generated immediate understanding in the practitioners and teachers, especially since they were conducted in groups and this allowed amplification and mirroring through the sharing of experiences by group members.

Figures 14.1, 14.2 and 14.3 show some of the cards that we use.

The first step is acknowledging the existence of AFMs, followed by recognizing that they suffer and are victims of related diseases, requiring care themselves. The third step is understanding that they form a large, neglected, and often voiceless group. To sensitize health and social workers, as well as the community, to the needs of AFMs, it is crucial to begin with the epidemiological situation of individuals struggling with psychoactive substances or gambling. Despite being a significant number, only a few are identified and treated by physicians and nurses.

According to the Italian National Health Institute (ISS), problem gamblers constitute 3% of the population, totaling 1.5 million [13], but only 40,000 seek treatment from health services. In the case of alcohol, there were 7.7 million at-risk consumers and 750,000 harmful consumers in 2021, yet only about 63,400 received care from alcohol-related services [24].

Fig. 14.1 The pictures among practitioners are invited to chose the Family Members of a family with gambling problems. After everyone in the group has chosen, we discuss about roles in the family, age of AFMs, and so on

Figs. 14.2 and 14.3 There are some of the cards of the impacts of problem gambling on AFMs: among them, closure of social life, lies, debts, selling goods, thefts, asking salary's earnest, shame, separations and divorces, tiredness, absent-mindedness, difficulty to focus, fights in the family, economic violence, losing house, threating suicide, negligence, and so on

AFMs are often the ones expressing the need for help, and their numbers are significant in relation to each patient with an addiction. General practitioners might initially be concerned about an additional workload, but identifying addicts and their families could result in more efficient and effective healthcare. These patients often visit GPs for health problems resulting from their or their relatives' addiction (e.g., depression, insomnia, headaches, anxiety, stress, suicidal ideation, hypertension) [14] without mentioning the addiction.

Overcoming the fear of extra work is a major obstacle to sensitization. To address this, it is not only important to know where to direct individuals with problems and their families but also to foster collaboration with services and patients. Goals, both therapeutic and supportive, should be shared and tailored to individual needs. Additionally, education and awareness campaigns can play a crucial role in dispelling misconceptions and promoting understanding among healthcare professionals.

Pediatricians hold privileged and crucial perspectives, particularly as children often suffer significantly from their parents' dependence. This reflects negatively on the child's caring abilities and is certain to affect his or her psychophysical development, highlighting the importance of recognizing the impact on children.

Neurologists, too, offer valuable insights due to the well-established comorbidity between Parkinson's disease and behavioral issues like

gambling disorder, often induced by the use of dopaminergic drugs in some patients. In Emilia-Romagna, a protocol of understanding and collaboration has been instituted between the Servizio per le Dipendenze (SerDs) and Neurology Departments to facilitate early screening for those using these drugs. The involvement of family members is central to the protocol.

Despite these insights, there remains a need to afford family members proper recognition, not solely as caregivers but as AFMs [25]. However, individuals aware of addiction problems in the population might mistakenly assume that others share the same awareness—a common misconception. The necessity for broader awareness campaigns to recognize and support AFMs becomes evident in ensuring a comprehensive understanding of the challenges faced by families affected by addiction. This includes building awareness amongst policy makers, that external restrictions that reduce access to gambling, limits the economic, psychological and relational damage AFMs of problem gamblers, as demonstrated in a study we conducted during the COVID-19 pandemic [26].

14.5.3 Involving People in Communication Projects

When it comes to sensitization, relying solely on words and information often falls short. Recognizing this, we have drawn inspiration from media education, discovering that an effective way to engage people is to invite them to participate in building communication projects directed at their own communities. Involvement in such projects proves intriguing, fostering a sense of creativity, usefulness, and contributing to the cultural improvement of the community.

In our approach, particularly within the Iceberg Project aimed at supporting AFMs of problem gamblers, we actively employ participatory communication projects in two key contexts: school and community. The focus of message production in schools revolves around gambling and new technologies (video games, social media, etc.), which often mimic aspects of gambling behavior. While themes related to family members are included in our proposals, young people tend to opt for other topics in their message production. In the community, we encourage citizens, both adults and young people, to engage in the "Creative Groups (Tavoli creativi)" of the Iceberg Project. Here, the central themes of communication projects are the experiences and needs of family members. We intentionally seek help from the community to sensitize them to the challenges faced by AFMs of gamblers. The Creative Groups bring together a diverse mix of individuals, including ordinary citizens, practitioners, various professionals, volunteers, and family members (of gamblers or other addicts). This collaborative environment is not only interesting but also highly sensitive, as it allows for a rich exchange of perspectives.

In essence, our approach invites diverse individuals to collaboratively create communication projects within contexts they are familiar with, facilitating their contribution.

14.6 La Pulce nell'orecchio: Arousing Doubts

A notable result stemming from the Creative Groups is "La Pulce nell'orecchio," literally translating to "The Flea in the Ear." The phrase signifies arousing doubts, and this communication product offers a versatile tool applicable in various contexts.

The idea emerged from a fundamental question: "What signals do you need to pay attention to…?" La Pulce serves as a kind of test for family members, friends, and individuals familiar with someone dealing with gambling issues, helping them assess if the situation has taken a potentially dangerous turn.

Creative Groups chose to adapt Lie Bet, the self-administered gambler's test, to create La Pulce. The text underwent drafting, critique, and revision within the Creative Table, involving

family members through focus groups. The drawings were crafted by a graphic designer attuned to social issues, contributing to a visually engaging and effective communication tool.

14.7 The Flea in Your Ear (Figs. 14.4, 14.5, and 14.6)

A flea speaks into an ear: "Is there something bothering you, but you don't know what?"

Do you have a family member (or friend) who gambles, buys scratch cards, plays slot machines or online casinos?

Then here are two questions for you:

1. Do you have any doubt that he/she is overdoing it?
2. Do you think he/she is hiding something from you?

If you answered yes to at least one of the two questions, your family member may have a gambling problem. You are not alone. For more information turn the sheet over.

Fig. 14.4 Exterior

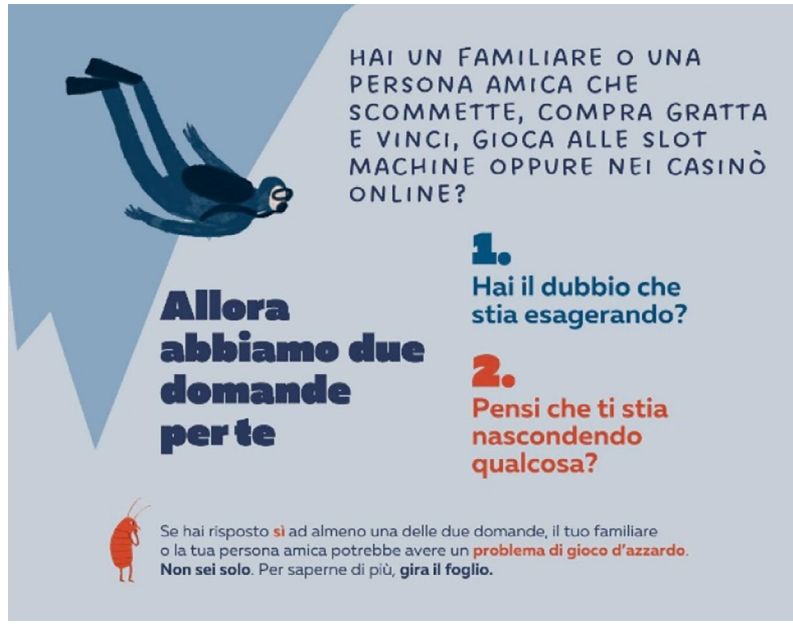

Fig. 14.5 Interior

Fig. 14.6 Pulce flyers

14.8 Iceberg

If you need support, if you want to know more, if you need advice contact us.

Fausta Fagnoni Associazione La Ricerca
Alessandra Bassi Cooperativa L'Arco

Iceberg: Associazione La Ricerca and Cooperativa sociale L'Arco supporting gamblers AFMs (Figs. 14.4, 14.5 and 14.6).

14.9 Conclusion

Raising awareness among practitioners, stakeholders, and the community about the needs of AFMs is a complex yet imperative task. AFMs are not only affected themselves, but their often-overlooked status presents a broader public health and social cohesion challenge. Given that acknowledging the problem can often evoke feelings of shame and guilt, it is crucial to guide practitioners and communities toward a heightened sensitivity and inclusivity. Creating environments where these emotions can be addressed and normalized is essential. Therefore, it is paramount to begin this journey by understanding the experiences, ideas, and emotions of practitioners and the community themselves. Only by deeply listening to their perspectives can we effectively engage them in various forms of support, whether through creative initiatives, educational endeavors, or other means. This collaborative approach allows us to embark on a shared journey—one that we have navigated ourselves and now seek to undertake alongside them.

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15 Stigma as a Barrier to Care as Experienced by Affected Family Members

Urvita Bhatia and Yashi Gandhi

15.1 Introduction: Conceptualising Stigma

Stigma occurs when the identity and reputation of particular groups are identified as deviant; stigma often occurs alongside negative stereotypes, prejudiced attitudes and discriminatory behaviours. More broadly speaking, stigma is a complex interplay of one's attitudes, beliefs and behaviours with societal norms, laws and regulations and media portrayals. Typically, four forms of stigma exist: self-stigma (i.e. internalised shame), public/societal (negative or discriminatory attitudes towards groups, held by people in the community), stigma by association (as experienced by family members of people living with SUDs) and structural (systemic stigma propagated in terms of policies, laws, etc.).

A World Health Organization (WHO) study conducted in 14 countries examined 18 of the most stigmatised conditions (e.g. being a criminal, HIV-positive, being homeless) and found that drug addiction (other than alcohol) was ranked as the most stigmatised condition, with alcohol addiction being ranked as the fourth most stigmatised [1]. Substance users are stigmatised not only for their substance use but also for their comorbid health conditions like HIV. The survey also highlighted that stigma varies along a gradient of social distance, i.e. almost 60% of people indicated that they would experience social rejection if they married someone with a mental health problem as opposed to if that person was physically more distant (e.g. a neighbour) [1]. A USA-wide national survey found that public stigma towards family members of people with substance use problems is greater than other health conditions, with family members often blamed for both the onset and resolution of their relative's substance use [2]. This chapter focusses on the experience of stigma for family members of people with substance use disorders (SUDs), which includes both alcohol and illicit drugs. We have not focussed on gambling in this chapter due to the paucity of literature on stigma faced by family members of people with gambling problems.

15.2 Experiences of Stigma Against Affected Family Members

Stigma against family members is often described as stigma by association, wherein the person is stigmatised by virtue of being connected with another individual who is viewed in stigmatised

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ways. Due to stereotypical representations of people living with SUDs (including stigmatised language used in policies), families often report experiencing social distance and exclusion, blame (in the form of nasty comments) and shame. This in turn leads to family members having lower self-esteem, internalised stigma (self-stigma) and disrupted social relationships with the person living with SUD as well as with others in the community.

Another common explanation for stigma against family members is related to cultural explanations for mental health problems. Previous research suggests that people are more likely to attach negative attitudes towards family members if they hold biogenetic, environmental (e.g. poor parenting) and/or supernatural explanations for SUD. A qualitative study showed how children often experienced 'contamination' stigma, i.e. the wider society perceives them in a negative way when their parents are living with a mental health problem: 'As a child, I used to feel alone a lot, because you always have to hide something. Your parents are drug addicts, you can't say that to anyone. You feel humiliated [pause]. In many ways' (Saraï, 36 years old) [3].

A study from Singapore (N = 940) showed that half of the participants would be embarrassed if they were diagnosed with a mental health problem, and half of those said that they would not want others to know if their relative were experiencing a mental health problem [4]. Given that SUD is even more stigmatising, one can extrapolate that it would be even worse for family members of those with SUD. Thus, family members often cope with the stigma by concealing the mental health problem from others or by reducing contact with others to avoid being confronted with stigmatising reactions. In collectivistic cultures (such as many across Asia) wherein family members are actively involved in decision-making and choices relating to help-seeking, this wish to conceal has a direct impact on the help-seeking intention and behaviour of the person living with a mental health problem and, by analogy, living with a SUD.

Stigma is also a common experience among families experiencing disenfranchised grief (see Chap. 10). Because of the shame, self-blame and guilt associated with the loss of their loved one (due to the use of substances), they experience interactions and responses which end up making the bereavement process more complicated and isolating, and delay help-seeking, as illustrated in the quote below: 'Penelope: Somebody told us about [a grief group] for people who have lost a child. But we were afraid. I remember talking to our counselor [who] said, "you could go to a meeting and be the only [parent] that lost somebody to drug addiction." I don't know that I ever would say that people look down on you… Patrick: [They may believe that those who died from an overdose] did it to [themselves]. Penelope: They did it to themselves. It's not like we lost our child to cancer or an accident… I think that's what kept me from going through' [5]. Lastly, the experience of stigma is also intertwined with one's social positioning in the community, i.e. one's race, sexual orientation, gender, age, religion, financial standing, etc., which directly affects how people perceive them.

15.3 Evidence on the Nature and Impact of Stigma

It is becoming more evident that the use of appropriate language and terminology is essential for people to dissociate from the stigmatising label they are otherwise associated with. Policies often refer to individuals as 'substance abusers' (instead of a person living with substance use problems), leading to attributions of culpability and it being a personal choice. In other words, referring to an individual as a 'substance abuser' may lead to perceptions of a greater need for punishment, whereas referring to an individual as having a 'substance use disorder' may increase perceptions of a need for treatment [6]. Early policy developments predominantly in the developed world suggested that the needs of parents and carers and the recognition of the impact of stigma may have become more widely recognised. A 2-year anti-stigma campaign was announced by the British Government in October of 2003. It aimed to 'take away the shame faced

by relatives of drug abusers' [7] and to encourage them to seek advice and assistance. However, in more recent times, the topic has neither received much traction nor been prioritised by policymakers and clinicians, despite recent estimates that the impacts of stigma on SUD treatment services may have increased and exacerbated during and after the COVID-19 pandemic [8]. While this chapter attempts to highlight the experience and impacts of stigma from the perspective of family members, it is important to note that given the paucity of relevant literature, we attempt to extrapolate where relevant, from the experiences of users themselves, which presumably would be shared experiences of family members as well.

15.3.1 Evidence on Stigma and Substance Use Disorders in Health-Care Contexts

During the help-seeking process as well, family members may experience stigma from health-care professionals. The experience of stigma in health-care settings takes various forms. First, quality of care is often compromised due to health professionals' bias against mental health problems, lack of cultural competencies [9] and stereotypes around people from specific cultures [10]. For instance, although high remission rates for alcohol dependence have been found in population-based studies [11], many health professionals continue to view 'alcoholism' as incurable. A 2013 review synthesised the evidence for health-care provider attitudes and its consequences for substance use treatments [12]. The review found that negative attitudes towards patients with SUDs among health-care providers were common. Major contributing factors to negative attitudes included perceived poor motivation and negative behaviours such as violence [12]. Interestingly, the 2013 review also found that health-care providers who had more contact time, or frequent interactions, with patients with SUDs tended to have more positive attitudes towards patients. Similar findings were reported by Boekel et al. [13] which compared attitudes of general physicians, general psychiatrists and addiction specialists. They found that the latter had more positive attitudes and higher regard for patients with SUDs. Positive attitudes were found to be linked with familiarity and understanding of substance use (and related problems), more frequent working with patients with SUDs and greater confidence in the role of treatments.

Second, from a patient perspective, there have been reports of this negative influence of stigma (across a range of health-care settings), including special populations (e.g. pregnant women with alcohol use-related problems), on help-seeking behaviours and quality of care provided, leading to patients preferring to not openly speak of their substance use history [14–16]. The issue of perceived lack of confidentiality and anonymity can be major barriers to accessing formal care [17]. Qualitative inquiries of the experiences of families affected by substance use have indicated that family members are often judged or blamed for their relative's substance use and experience feelings of shame and hopelessness, which may deter help-seeking for affected family members (AFMs). Their experiences and needs are often not taken into account, and instead care planning and support are focussed exclusively on the user [18]. Families also undergo intensified isolation in their attempts to deal with stigma including not disclosing and sharing about the substance use and minimising their interactions with others [17]. When we consider other types of substances, among adult family members of individuals who have misused opioids, greater self-stigma has been associated with higher levels of criticism towards the person with opioid use disorders and emotional over-involvement [19].

It is important to note that the impact of stigma on treatment-seeking and mental health of families has been documented less in non-high-income country settings. In a qualitative study from India with people using alcohol, their caregivers and doctors, which explored stigma and its role on caregiving [20], stigma was reported to function both as a barrier to treatment and a contributor to poor mental health and impaired decision-making in caregivers. As a result of stigma (and other factors, such as an over-

individualised perception of SUDs), health-care providers may not pay attention to or exclude the role of family members in the treatment process. This lack of support, particularly mental health-related support, in turn may exacerbate the issues faced by family members, increase caregiver burden and negatively impact treatment outcomes.

15.3.2 Evidence on Stigma and Mental Health Problems in Health-Care Contexts

Much of the evidence on stigma experienced by families in health-care contexts has focussed on a range of serious mental health problems, including but not limited to SUDs. The impact of structural stigma and discrimination on children of parents with a mental health problem has been highlighted in a recent review [21]. While structural discrimination is a form of stigma that is experienced through various types of institutions, health-care systems are a primary source of structural discrimination for families affected by mental health problems. The review highlighted negative and uncomfortable experiences of children seeking help from the health-care system, particularly alluding to the overall lack of care of patients and families affected by mental health problems and the negative atmosphere in these settings. These negative experiences were also extended to the interactions with doctors and support staff, with children reporting being ignored, distanced and isolated and being treated without empathy. Further, children have also reported having to taking care of their parents when the hospital system failed in that responsibility. Another consequence of structural discrimination is the lack of information and education directed at family members, leading to further difficulties over how to cope with the problem and seek appropriate support [21].

In summary, family members experience a number of forms of stigma, from institutions, from health-care providers, from the public and from themselves. It is important to note that the extent and level of stigma experienced by family members (affected by mental health problems including SUDs) may differ based on factors including gender, type of relationship with the person with mental health problems, caregiver status (e.g. earning vs non-earning member of the family), etc. All of the forms of stigma either cause or have the potential to cause serious deleterious effects on these family members; hence, the next section of this chapter will examine what research has been conducted on ways to reduce such stigma, specifically in health-care settings.

15.4 Strategies to Reduce Stigma

Addressing stigma in health-care settings requires a multipronged approach involving a range of stakeholders including policymakers, programme planners, delivery agents and support staff working in health-care settings. It is important to note that though mental health professionals working in the addictions sector may be in direct contact with families and hence are in a strong position to support the needs of AFMs, the countering of stigma will need to entail the involvement of all types of health-care professionals who interact with patients and families. Professionals and support staff working with families need to be trained in fundamental concepts of substance misuse aetiology [with a greater emphasis on psychological approaches and a wider understanding of addictions (vs a biogenetic understanding)] and treatment, particularly the stages of change approach and motivational interviewing. The former would help in understanding the difficulties faced by families affected by substance use and the decisions they may make and the latter in eliciting commitment to change. There are a number of evidence-based family-focussed psychosocial interventions for a more tailored response for family members' needs, including the Community Reinforcement and Family Training (CRAFT), the 5-Step Method or Behavioural Couples Therapy, all of which help families in their own right.

There are several ways in which policies and programmes can integrate a stigma-reduction focus. Mental health literacy directed not only at patients and family members, but also the larger

health-care system can play a positive role in ensuring care for affected family members. In addition to education about 'mental illnesses', mental health literacy should also highlight how support networks can play a role in the well-being and care of affected families [21]. Mental health literacy is known to help as it addresses myths and misconceptions, and related fears that people may have, about a stigmatised condition such as substance misuse. In addition to mental health literacy, the training of health-care staff on soft skills, i.e. responding sensitively to the needs of affected families, particularly children [21], is also crucial. Social contact interventions, where mental health problems are more normalised by openly interacting with a person with lived experience, is one of the most effective strategies that has been used in anti-stigma efforts across health and community settings. Such interventions are likely to be more impactful when combined with education and informational strategies [22].

Finally, there is some evidence to suggest that while families may address stigma differently (e.g. by challenging it, accepting it, disclosing their family's experiences), they need to be supported in identifying the strategies to reduce stigma that they consider would work best for them. These strategies may change over time and need to be reinforced based on the social context [23].

15.5 Discussion

Given the dearth of literature around stigma-reduction interventions for families affected by substance misuse, the discussion focusses on drawing learnings from interventions that are found to be effective for families and caregivers affected by other stigmatised conditions such as HIV, severe mental health conditions (e.g. psychosis, bipolar disorder) and other types of disabilities (e.g. physical disabilities, epilepsy).

The key strategies that aid in stigma reduction for family members include (1) psycho-education and skills building at the personal level; (2) contact-based and social support, including sharing and disclosure at the interpersonal level; and (3) transformative education and structural interventions at the societal level.

15.5.1 Psychoeducation and Skill-Building for Family Members

Psychoeducation includes providing useful and practical information about SUDs and its treatment, common comorbidities with SUDs, the role of family in taking care of people living with SUDs (e.g. improving help-seeking behaviours and adherence to treatment) and on resilience and coping skills like communication, problem-solving and conflict resolution. It has been found that specific modules on coping and well-being in addition to literacy education significantly alleviated stress and burden of care for family members.

These sessions can happen in different formats: face to face involving communication between a speaker and a small audience of family members, on social media platforms such as Facebook and WhatsApp groups and using other modalities such as video and telephonic-based interactions. There is merit in conducting a combination of psychoeducation sessions wherein some are attended by family members only and some are conducted in the presence of the person living with SUDs (e.g. parent–child dyad). It is essential to note that the delivery method plays an important role: face to face are most often used, preferred and more effective than telephonic [24]. Moreover, the delivery agent plays an equally crucial role; different interventions may use one or more from a range of agents, including primary or specialist health workers, community health workers and peer-led (e.g. family members of people living with the condition). A study highlighted that an intervention which involved video-based education followed by discussions with peers (i.e. a combination of psychoeducation and contact-based interventions, explained below) was found to significantly reduce stigma among caregivers when compared to health worker-delivered intervention [24, 25]. Another point of consideration is that delivery agents must be chosen based on the local context. For

instance, in certain settings, employing community health workers may lead to unintended consequences such as increased fear of stigma and discrimination in the community due to increased visits made by community health workers [24, 26].

Psychoeducation can lead to a greater acceptance of the member living with the condition within the family environment and can improve the inner feelings of the families towards both that member and themselves, positively impacting one's stigma by association [27]. A study on stigma relating to bipolar disorder showed that, post-psychoeducation, parents did not blame themselves for their child's condition and also viewed the child more favourably [28]. However, existing literature also suggests that psychoeducation rarely has explicit modules on stigma reduction: there is an urgent need to design such modules in order for the caregivers to play their role in the recovery of their family member [24]. Previous studies suggest that this has implications for the treatment uptake and completion rates of the relative with the SUD, especially when these are caregiver-imposed [29], which is often the case in collectivistic cultures like Southeast and South Asia.

15.5.2 Contact-Based and Social Support

Contact-based interventions are based on Allport's theory (1954) that suggested increasing social contact with a person with lived experience would decrease stigma, especially one that is internalised. A growing body of research shows that positive and direct personal contact is an effective anti-stigma strategy. A meta-analysis of 79 programmes representing findings from 14 countries concluded that contact-based interventions were more effective than psychoeducation or literacy building in reducing stigma among adults [2].

Other types of contact-based interventions that have been found to reduce stigma among family members of people with conditions such as dementia and intellectual disabilities as well as children with other disabilities include intergenerational storytelling, film screenings about people living with the condition and their family members and an inclusive sports, music or visual arts programme that demonstrate that people are both capable and more than just how their condition defines them [30, 31].

Social sharing and support can exist in multiple forms: formal or informal peer support groups (e.g. Al-Anon or Nar-Anon, a programme for the family and friends of people living with alcohol and drug misuse, and Families Anonymous, where they explore the nature of addiction as a family disease), disclosure or sharing of experiences and counselling. In one study, peer support groups, where content was chosen by the participants who had the condition (in this case, epilepsy), were successful in targeting internalised stigma and non-disclosure [30]. Similarly, in another instance, visits by community health workers to assist trained professionals in supporting family members reduced exclusion and negative attitudes. Finally, counselling is also considered to be beneficial in disclosure and better understanding of both the condition and their own self-stigma [32].

15.5.3 Transformative Education and Other Structural Interventions

As discussed above, psychoeducation is immensely helpful in overcoming misconceptions and reducing stigma among family members themselves. However, often family members who live with people with these different conditions experience social exclusion and public stigma, which often leads to feelings of loneliness and fear. Transformative education (or mental health literacy programmes) is similar to psychoeducation in principle, but it is directed to the wider community (e.g. in schools, hospitals, etc.) and targets the common fears that family members hold about how they are perceived. Education-related interventions that are often found to be effective include theatre-style plays, curriculum-based interventions and/or films on

struggles of caregivers, with a specific focus on cultural sensitivity and misconceptions widely held by the community. A key driver in the success of the intervention is that each of these educational elements should be followed by group discussions [32].

However, most of the research includes short-term education programmes, and there is a need to conduct more longitudinal efficacy studies and/or trials to determine if they can effectively reduce stigma in family members in the long term. Apart from these recommendations, there is a paucity of broad governmental-level policies and interventions to comprehensively address the negative attitudes towards families. For example, decriminalisation could potentially shift the negative perspectives towards substance use issues and reframe such problems as health conditions impacting individuals and families, rather than criminal offenses that need punishment. It is evident from previous literature that there is a need for multi-level and/or multi-component interventions to create meaningful change in stigma and perceptions, as family members are affected by both public and internalised stigma. A review highlighted that the interventions that led to significant reductions in stigma among family members of people with HIV and schizophrenia, in countries as varied as Vietnam, South Africa, Canada, Haiti and Kenya, included a combination of interventions (e.g. education-based along with contact-based or contact-based with counselling) [33]. Another review on stigma reduction interventions towards people living with 'mental illness' supported these findings [34]. Figure 15.1 below is a conceptual model summarising the experience of stigma and ways in which it can be addressed.

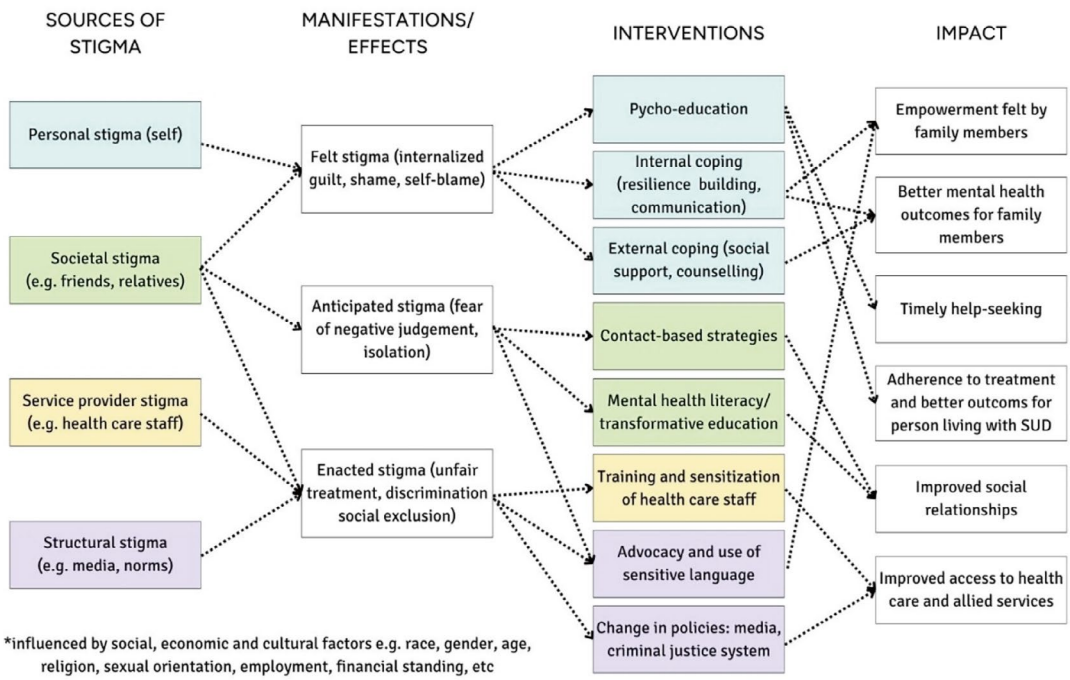

Fig. 15.1 Understanding and addressing stigma experienced by affected family members

15.5.4 Summary of Specific Stigma Reduction Recommendations for Two Key Stakeholder Groups

What can policymakers and programme planners do to address stigma towards affected family members in health-care settings?

1. Focus on integrating stigma reduction in the training of the specialist and non-specialist workforce, particularly on challenging negative attitudes and improving communication and support provided to families.
2. Recognise the wider context within which substance use and misuse occurs, and reflect a more nuanced and systemic understanding in policies.
3. Plan for a well-trained workforce to work sensitively with individuals and families, with a focus on continued training and ongoing support.
4. Prioritise the identification of systemic barriers to care, including stigma; and collaborate with patients, family members, providers and lay public to plan responses.
5. Emphasise the need for data-driven decisions in reconceptualising care for people affected by substance use-related problems: both those who use substances and their affected family members.
6. Endorse the use of stigma-free language in policies and services.
7. Endorse that support services need to think of ways to avoid excluding family members on the grounds of confidentiality (which further perpetuates stigma) and, instead, plan for and adopt family-sensitive approaches to care.

What can health-care professionals do? Practising clinicians and support staff can use a number of strategies to be mindful of and limit the role of stigma, including:

1. Using language that shifts from identity-first (e.g. an addict's relative) to person-first (parent of a teenager with substance use problems): this helps because the problem is not used to define the whole identity of the person or the family.
2. Recognising and appreciating the role that family members play in treatment, either for themselves or for their relative.
3. Using active listening and responding to family members, which may help engage both the family members and the relative who uses substances; both may benefit from treatment.
4. Focussing on strengths that families bring to the table; this is likely to help instil hope and belief in change.
5. Helping families understand how the wider system interacts and influences substance use behaviours and its consequences and using concrete strategies that may be of help to them (e.g. providing information, referrals to services).
6. Using evidence-based treatments models to address their concerns (e.g. the CRAFT or 5-Step Method approaches).
7. Engaging in further capacity-building and sharing of best practices for family-centred care, through credible organisations and networks (e.g. the Addiction and the Family International Network).

15.5.5 Limitations

Most of the literature on the experience of stigma experienced by affected family members has been focussed on public attitudes towards 'mental illnesses' [35]. The small body of literature on substance use-related stigma in health-care settings is predominantly concentrated on the perspectives of substance users [12] and public attitudes and stigma [36]. Though this is a limitation, one can extrapolate from these findings which will likely impact family members as they share treatment experiences with users. Further, the majority of the studies that have explored stigma in health-care settings are situated in the Global North, limiting the generalisability of the findings to other contexts.

A further limitation is that this chapter has focussed primarily on stigma towards affected family members within health-care settings,

whereas, in fact, stigma needs to be reduced in all settings and across society as a whole. However, it is the case that the majority of suggestions and recommendations made will be generalisable across all settings.

15.5.6 Future Directions

Policies and programmes need to more adequately acknowledge the role of stigma and recommend strategies for its reduction. At the health-system level, programmes (e.g. educational programmes) aimed at preventing stigma, with a focus on the delivery of more inclusive and sensitive services, are likely to help and ultimately improve treatment outcomes and engagement of both users and caregivers. Efforts to address stigma in health-care contexts should also involve capacity-building and raising awareness among health-care professionals, because health-care professionals may be the first point of contact for families affected by substance use. It is imperative that health-care professionals understand and acknowledge the diverse impacts that substance use may have on families and involve them as crucial partners in setting treatment goals and in the recovery process. The wider health system, including decision-makers, practitioners and allied staff, needs to ensure an inclusive, non-judgemental and empathic environment, where families feel comfortable and supported in their own right. Finally, there needs to be increased attention and efforts towards understanding complex forms of stigma that may arise in situations where family members are affected by multiple conditions, bereavement and grief and the compounding impacts it may have [37].

15.5.7 Conclusions

Some major challenges in the field include the lack of rigorous research exploring how stigma impacts family members affected by addictions. Further, more work is needed to understand how stigma-reduction interventions can be optimised in specific contexts by uncovering what works, for whom and in which settings. More consolidated efforts are needed at a multi-sectoral level, with service providers, programme planners and policymakers coming together to shift the focus towards system-level approaches to addressing stigma in health-care settings.

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16 Working with Affected Family Members: The Impact on Professionals

Evdokia Missouridou and Jim Orford

16.1 Introduction

The present volume includes a number of chapters devoted to understanding the experiences of addiction-affected family members (AFMs) and the help they need (see Chaps. 1–12), with other chapters detailing the forms of help that have been developed to try and meet those needs (see Chaps. 17–25). This chapter addresses an equally important question which might otherwise easily be overlooked: what are the special difficulties of working with AFMs, experienced by individual professionals and by the organisations they work for, which might explain why AFMs are not more often engaged by services offering treatment for addiction?

We attempt here to start examining this issue by summarising the results of two relevant programmes of research carried out by AFINet members. Although the basic question posed is the same, the two programmes approached it in different ways. The first to be described was carried out in Greece, in a specialised addiction service, and the conceptual framework employed was that of the potential harmful personal impact on individual practitioners, due to their exposure to the traumatic experiences of AFMs. The programme was carried out by the first author who is a mental health nurse with a systemic and group analytic background and her colleagues. They have a commitment to trauma-informed recovery and the reduction of coercive care. The second programme of work took place in England, involved a number of both specialised addiction and general health services, and used a conceptual framework that focused on the extent to which practitioners' attitudes to working with AFMs, as well as the conditions in the groups and organisations in which they worked, facilitated or inhibited engaging AFMs. It was conducted by the second author and colleagues, trained in clinical psychology or social science and committed to the Stress–Strain-Information-Coping-Support model [1].

16.2 Programme 1

The studies which comprised our first research programme were conducted at the drug and alcohol treatment unit of a psychiatric hospital in Greece which has in-patient and specialised family, adolescent, mother, and out-patient units. Most patients were male (83%) and in the age range of 20–39. Families were offered multi-family group sessions throughout the treatment. In addition, the alcohol treatment unit offered

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brief couple-therapy treatment and long-term family support groups; and the family unit offered psychoeducational seminars, family groups focusing on motivation/rehabilitation, drama therapy groups, and family and couple therapy.

This research programme comprised three studies. The first involved 5 focus groups, involving in total 27 professionals, all working at 1 of the in-patient centres. Participants within each separate group worked at the same unit and knew each other well. Involvement in work with AFMs varied [2, 3]. The second study used 42 written case vignettes based on work with AFMs, submitted by 21 professionals, most of whom were psychologists [4]. The third was a study of compassion fatigue in addiction nurses [5]. Semi-structured interviews, focused on experiences of working with individuals, including AFMs, who had suffered from trauma, were held with a total of 59 nurses, most (88%) working in the addictions for more than 10 years. A qualitative, thematic analysis [6] using open coding, creating categories and abstraction, was used for the data analysis for each study.

The findings from the three studies have been integrated here into a single model, shown in Table 16.1, of professionals' personal responses and how those responses had changed, as their experience of working with AFMs grew. The model's overarching theme was that of an often long journey towards greater satisfaction in engaging in family work: moving from feeling overwhelmed and inadequate during their earlier years in their career, through gradual realisation of the position of family members, to a stage termed 'compassion–satisfaction' and enhanced understanding for both clients and family members. That core theme was underpinned by three main stages and seven sub-themes regarding the impact of working with AFMs and the ethical issues faced. Illustrative example quotes from family members, mainly from parents, are provided to illustrate each of the stages and sub-themes.

16.2.1 Stage 1: Reluctance/ Inadequacy in Dealing with AFMs' Intrusion

16.2.1.1 Feeling Overwhelmed by Intense Emotions

For most participants, AFMs' involvement in treatment was described as most distressing because it evoked feelings of anger and resentment. Participants used the term 'intrusion' to denote AFMs' persistent overinvolvement in the therapist-client therapeutic alliance; AFMs contacted the therapist too often, became very demanding, and insisted on taking up time from the client's therapeutic session. The following example is illustrative:

> At first, I found myself entering into a competitive relationship with family members, and I was angry with them, for the attitude they had towards clients. In retrospect, I realized through my own personal work that this attitude I had was not helpful: neither for me nor for the client and (not) for the family obviously. Family members come in deep despair looking for a saviour…

Table 16.1 Programme 1: an integrated model

Overarching theme			Sub-themes
The transition into family work: the long journey from feeling overwhelmed and inadequate to compassion satisfaction	Stage 1	Reluctance/inadequacy in dealing with AFMs' 'intrusion'	• Feeling overwhelmed by intense emotions • Being pulled in different directions
	Stage 2	Realising the dynamics of trauma and family members' abuse by professionals	• Being aggressive/abusive towards AFMs • Reflecting on trauma dynamics/power issues—ethical dilemmas
	Stage 3	Compassion satisfaction Over compassion fatigue	• Being able to listen • Personal/professional growth and self-care

16.2.1.2 Being Pulled in Different Directions

For many participants, maintaining balance in their alliances with the client and with the AFMs was a major challenge, which was often described as a demanding, complex, and exhaustive task, as the following example shows:

> What is most difficult for me is to remain neutral when you work with both (family and client). How can you be objective? With whom do you finally ally? I have a hard time when the dynamics are explosive during the session, and one pulls you on one side and the other on another. Where do you go? How do you remain neutral in this intense triangle that is being formed at that moment?

Some participants reported working with either the family or the client; others did not involve family members in treatment unless they had first built a strong alliance with the client and asked for his or her consent; still others referred family members to a colleague to avoid jeopardising their alliance with their client. Finally, some participants noted that despite the clients' conflict with their families, several would not be satisfied if their families were excluded from the treatment context.

16.2.2 Stage 2: Realising the Dynamics of Trauma and Family Members' Abuse by Professionals

16.2.2.1 Being Aggressive/Abusive Towards AFMs

As professionals grew more confident in their work in the field, they started recognising aggressive and sometimes abusing behaviours towards family members (both in their own behaviour and those of other professionals) which sometimes resulted in family members leaving the centre feeling more guilty and distressed than before. Overall, these aggressive feelings were attributed by professionals as being a result of their own unrealistic expectations, which were quite common at the beginning of their career, and propelled them to identify with the client against one or more family members or related with their own personal history and unresolved family conflicts. Initially such feelings and behaviours were more commonly attributed to younger colleagues' difficulty to recognize and work through feelings of hopelessness and helpnessness which they experience in the landscape of addiction and trauma. However, with the help of supervision or peer consultation, their colleagues were often said to be able to contain the feelings that gave rise to such behaviours. With greater experience, many professionals also started to 'own' these negative feelings and behaviours themselves, as in the following example:

> I also agree that it often happens to me to vent my anger, a momentary relief to get all this out… the family's feelings are very difficult anyway, I appreciate that our workload and the fact that we are several times left without supervision, this does not help us because it is like we are left with very difficult things in our hands, so it is natural that we also sometimes act-out on our feelings during our interactions, mainly anger, depending on the professional's temperament… consciously it is certainly done with the purpose of inducing change by saying something intensely, to feel that family members understood and heard what the professional said, but I think that this is more useful to relieve the professional temporarily, to relieve the professionals' anger or anxiety…

16.2.2.2 Reflecting on Trauma Dynamics/Power Issues—Ethical Dilemmas

Professionals realised that masked trauma, pain, and guilt were behind family members' difficulties in achieving change. They realised that the dynamics of trauma created intense feelings of anger. The following is just one example:

> After the first meeting with the parents, I understood that I have to work with two people who are burdened with serious traumas. The mother had developed anorexia and the father was lost, asking for answers. A parallel intervention was necessary on many levels. Then I realized that parents may not cooperate, they may attend the program without implementing what is recommended to them or even appear resistant, due to their inability to cope with the demands of supporting their child's treatment. Their guilt, their resistance, unprocessed emotions in the intergenerational course of the family, and their problems in the present time may significantly limit their ability to meet the demands of the therapeutic framework.

Some participants reported experiencing high distress when faced with ethical dilemmas and

power issues associated with the dissemination of information and family secrets (e.g. about prior abuse, incest, addiction).

16.2.3 Stage 3: Compassion–Satisfaction Outweighs Compassion Fatigue

16.2.3.1 Being Able to Listen

With practice, professionals developed a more realistic view of their limitations. They progressively gave up their sense of omnipotence and redefined their expectations of family members. Having been exposed to family tragedies, professionals reported having changed in how they perceived their interactions with AFMs and clients. Some began to identify the family's strengths, rather than any pathology, and began interpreting family members' communication patterns in a more positive light. Participants reported becoming more accepting of AFMs, less judgmental, and increasingly able to listen to their stories. These are two examples:

> In my role as a therapist, I now have less expectations of family… I am more realistic, in other words, I am acceptant of whatever they can manage. Some can do many things, others very little, yet all can do something.

> At the beginning I was attending only to the client's story, while family meetings were very distressing to me. With increasing experience, my listening skills improved and I managed to hear more clearly both the person in therapy, and what parents were sharing with me, in general and with regard to their expectations. In my interactions with them, I am now not as insecure since my attitude has changed, and I facilitate communication by listening to them, rather than being concerned over whether they will follow my advice or not.

16.2.3.2 Personal/Professional Growth and Self-care

Professionals reported progressive success in avoiding becoming overwhelmed by the AFMs' needs, fears, anxieties, and expectations. They also recognised that even though their own emotional reactions were occasionally intense, they were more able to contain them and experience them for a shorter duration. Variables that were described as facilitating the professionals' change and growth included (a) clinical experience; (b) specialised training in addictions, as well as in a theoretical and psychotherapeutic approach; (c) supervision; (d) personal psychotherapy; and (e) becoming a parent, which contributed to an increased sensitivity to the family's feelings, responses, and concerns. Some felt they had now achieved this change, while others thought change was still incomplete:

> As time passed, I realised how important small everyday victories are and I felt good when they achieved them… This is why this job is magical! Because even if you take back the least of what you gave, you feel that you really did your job well or that you did the best you could!

> I am undergoing a phase during which I have more concerns and see things that I couldn't see before. For example, parents' guilt. We shouldn't render them more guilty; recently, this has been a lot on my mind, and has become a concern to me. I try, I am in a process, but haven't moved forward yet. I try to perceive the situation more holistically.

16.2.4 Discussion of Research Programme 1

Overall, professionals described the transition into family work as a long journey from feeling overwhelmed and inadequate during the earlier years of their careers to a stage of compassion, satisfaction, and enhanced understanding for both clients and their families. Initially, AFMs' presence in treatment centres was described as an 'intrusion', a word also employed to depict the impact of addiction on families in a recent meta-ethnographic review [7]. It can be seen how addiction is so distressing that it is experienced as an 'intrusion' and how, in turn, family members, carrying all the stress as a result of this 'intrusion', themselves become 'intruders' in treatment settings, intruding into the therapeutic relationship between the professional and client. The 'intrusion' is the fact that these family members bring their overwhelming concern over the stress of preventing the death of their relative, alongside other intense feelings such as betrayal, loss, and anger; but the fact that it is seen as an

'intrusion' is also a mark of the initial lack of understanding and empathy on the part of professionals: in the early years of their careers, many professionals appeared to have difficulty understanding the reasons behind AFMs' feelings and behaviours, with this lack of understanding evoking negative reactions from professionals, similar to other descriptions in the literature of negative and blaming reactions which carers and family members experience [8]. Nonetheless, with time, as professionals became more experienced and were more able to both understand family members' positions and be more capable of containing their own emotional reactions, these negative emotions were reported to be less intense and to last for a briefer time. Instead, professionals came to perceive their emotional reactions as clues for a deeper understanding of the family members' being in the world.

16.3 Programme 2

The aim of our second programme of work was to work with teams and organisations to move their practice towards more positive attitudes in engaging with affected family members [9, 10]. The work required the agreement of a whole team or practice to work towards that end, making sure that there existed sufficient support at all levels of the organisation. All members of each team were provided with training about the Stress–Strain-Information-Coping-Support (SSICS) model and the 5-Step Method of family intervention (see Chap. 18). In contrast to the Greek studies, the perspective was therefore one of organisational change rather than one with a focus on individual staff members' experiences.

Table 16.2 lists the five service teams involved. Exactly how the organisational-change research group worked varied from team to team. For example, work with the NHS drug and alcohol unit and with the non-statutory alcohol team involved regular visits of one or more members of the research team, at least every 2 months and often monthly, for a period of 2 years. Two-day training or progress workshops were held at the beginning, half-way through, and at the end of that 2-year period. In the other cases, the time available for this type of work was necessarily more limited. For example, work with the NHS primary care health centre lasted for a total of 30 months. Contact was maintained by regular visits of the research team to the practice, supplemented in the final 9 months by basing a member of the research team in the practice for 2 days a week.

Table 16.2 Programme 2: service units involved in the research

• A National Health Service (NHS) drug and alcohol treatment unit
• One team of a non-statutory organisation serving clients with alcohol problems
• An NHS primary care health centre
• One branch of a Muslim family-oriented foundation
• A non-statutory drug service

16.3.1 Changes in Attitudes Towards Working with Family Members

In the work with teams 1, 2, and 3, a standard attitude measure was administered at the beginning and again at the end of the project. The Attitudes to Addiction-Related Family Problems Questionnaire (AAFPQ) is an adaptation of one designed by Cartwright [11] to measure aspects of the attitudes of different groups of practitioners towards working with people with alcohol problems. The AAFPQ is an adaptation which refers to working with *family members* of people with alcohol or drug problems. It consists of 28 questions with 7 response options (strongly agree to strongly disagree). The AAFPQ is scored in terms of seven interpretable factors: knowledge; confidence; support from the service; legitimacy; motivation; self-belief; and impact on the substance user [12]. As might be expected, attitudes were more positive at the outset amongst staff of the specialist services than amongst medical and nursing staff in primary care, but positive change occurred for both groups. The main changes were in terms of knowledge (e.g. *I know enough about*

the relationship between alcohol or drug misuse and family problems to work with relatives of misusers), confidence (e.g. *I feel confident when working with relatives of alcohol or drug misusers*), and support (e.g. *I feel adequately supported within my team/practice to work with relatives of alcohol or drug misusers*).

An analysis of detailed notes from all project meetings, events, and focus group or individual interviews with team members provided more insight into why attitudes might need to change and what might underlie the change when it occurs. In teams 1, 2, and 3, working with family members was not the norm at the outset, and progress in the early months of the project was slow and frustrating. There was difficulty in each team about identifying family members to engage with, and it was up to a year into the project before sufficient experience had accumulated for teams to recognise the benefits of involving family members. However, from a slow start, by the end of the project, the two specialist teams believed there had been a 'cultural shift', that the approach the project had aimed to foster had now 'permeated' the whole team and had become firmly 'embedded'. From having been services with an individualistic orientation, based on one-to-one counselling or therapy for individual alcohol or drug misusers, and probably discouraging of family members, it had 'become the norm' to welcome family members, and teams had become more 'network minded' and 'family friendly'. At the non-statutory drug service, and in the Muslim service, it was the case that much of the initiative for the work had come from the teams themselves. They were already committed to some form of family work, and it took less time for the 5-Step Method to be incorporated into their work. In the primary care health centre, all practice members recognised the consequences of ill-health from having a close relative with an alcohol or drug problem, and nearly all, when asked whether they thought the primary care general practice setting was the right one for this kind of work, answered positively.

In the first year of our work with the alcohol and drug specialist teams, it became clearer why many of those working in substance misuse treatment services might be reluctant to engage family members. Table 16.3 illustrates some of the concerns about involving family members which surfaced during the first year of the project. Some of these were concerns about resources. In the primary care team, it was lack of time that was most commonly mentioned and the need for additional help in order to take on what was often seen as a new line of psychological treatment. Although such concerns were also expressed in the specialist teams, it was more often uncertainties of other kinds that were mentioned. One set of concerns was about the potentially disruptive effects of including family members, for example, that they might bring unhelpful attitudes, might dominate sessions, or have needs and goals which were incompatible with those of the substance-misusing clients. A further set of anxieties had more to do with a lack of confidence on the part of the practitioner, for example, about handling confidentiality questions or managing conflicts which might arise. It will be seen that many of these issues are similar to those described in our first example above, from Greece.

Table 16.3 Programme 2: some initial concerns

• I do not feel confident about handling open conflicts between users and family
• It is often inappropriate to ask users about involving their family members
• Family members just want to have the drink or drug problem fixed
• I have concerns about confidentiality if family members are included
• Involving family members will require more time which we do not have
• Won't it open a Pandora's box of marital and family problems?

As the project progressed, and teams gained more experience working with family members, some of these worries diminished. Equally, if not more important, was the growing realisation of the rewards of involving family members. Table 16.4 illustrates the kinds of statements that team members increasingly made about the benefits of family work. Although it was recognised that the teams now had a powerful method for helping family members in their own right, there was also increased acknowledgement that involv-

Table 16.4 Programme 2: seeing the benefits of working with family members

• I get a clearer picture of the problem when I involve family members
• Making sure the family is well informed is an essential part of good treatment
• Encouraging open communication between the user and their family is important
• I believe that involving family members should be the norm
• I am now responding to the needs of family members in their own right
• Clients can be discharged more easily knowing that they have support

ing family members aided rather than hindered substance misuse treatment goals, for example, by enabling fuller information to be obtained, being able to helpfully work through conflict, giving family members greater understanding of what the service was trying to do, and even experiencing some relief that dealing with the problem was being shared with family members.

16.3.2 Changes in Teams' Working Practices

A quasi-experimental design was employed, comparing project teams 1 and 2 with two comparison teams in the same organisations who had not taken part in the project. The results showed that family members were being seen three to five times as often in the project teams compared to the control teams (15–17% of sessions versus 3–5%). It was now the case that the majority of team members were seeing family members at least sometimes, whereas that was true of only a minority of team members in the comparison teams. In addition, project teams were now carrying out considerable amounts of family work informally, for example, on the telephone, during home visits, or in the waiting room. In the primary care practice, over a period of 18 months, 32 adult patients were identified as suitable for the project, and 13 were recruited for the project. In the Muslim service, 29 affected family members were recruited over a period of 18 months. In the non-statutory drug service, 12 family members attended a themed carer group programme and were assessed before and after.

There was also some success in encouraging teams to introduce new family-oriented procedures. Changes to initial appointment letters and assessment forms were thought to have been particularly effective in some teams. In one team noticeable improvements had been made to the 'family-friendliness' of the team building: the waiting room had been improved, now including family-welcoming notices and a game for children to play; and one of the counselling rooms had been designated as a family room, with space to accommodate children.

16.3.3 Issues Remaining and Lessons Learned

A number of issues remained. One was the need to recognise the differing levels of experience and confidence for doing family work possessed by different team members. The emphasis on training and supporting whole teams may have given insufficient recognition to variation in training needs. Some team members, for example, social workers and community psychiatric nurses, were more comfortable working with family members because of their professional training and/or previous practice. Other team members had had no such experience. We may also have underestimated how different from their normal practice it would be for some primary care health workers to work in a counselling or psychological way.

As was the case in our first example, from Greece, one frequently discussed question was how to strike the right balance between seeing an affected family member and the focal client (the one whose alcohol or drug use was of concern) separately or together jointly. Preferred practices differed, and a family's circumstances needed to be taken into account. A related and much debated issue was whether it was more difficult, or even sometimes appropriate at all, to include affected family members when cases appeared particularly complex, for example,

involving child-protection issues, domestic violence, or when other agencies were involved in the case.

16.3.4 Discussion of Research Programme 2

Despite the existence of remaining issues, of which the foregoing mentions only a few, we believe this work provided some promising evidence that substantial changes can be made in the direction of promoting work with addiction-affected family members in a range of healthcare settings. However, the work is not easy or straightforward, and a number of difficulties were encountered and lessons learned. For one thing, it was not easy to recruit teams to take part. As a result, those that did become involved were a highly selected sample. Furthermore, the amount of input necessary, over a period of several months, was very considerable. The results were encouraging but might be seen as modest. Whether changes would be sustainable remains an open question. In this regard, support at the levels of management, service procurement, and both local and national government policy levels (see Chap. 13) will be required. At the time, we said:

> We are much more conscious now of how strong and pervasive is the focus of most services on individual patients or clients and how difficult it is to change that focus, however motivated individual practitioners may be to move their practice in the direction of greater involvement of affected family members (Orford et al., 2010, p 162).

16.4 General Discussion

We have described two very different sets of studies, carried out in two different European cultural settings, with differing theoretical guiding frameworks, and different research foci and methods. Yet the conclusions complement each other and in certain ways are the same. Both conclude that, if health and care services aspire to include family members affected by a close relative's addiction and to help them humanely and effectively, they face very significant challenges and barriers. The English programme of research, focusing on the attitudes of service organisations and their staff towards working with affected family members, found that it was common for staff to hold misgivings about involving AFMs and that they often lacked confidence in doing so. The Greek studies, informed by a trauma-response conceptual framework, found evidence of staff responses which were uncomfortable and emotional, when trying to work with AFMs. Despite the evident differences in approach, there were some notable commonalities. Although couched in different language, examples depicted in the Greek studies were the feelings of inadequacy in working with family members, resentment at what was seen as the intrusion of a family member into the therapeutic work being undertaken by the professional and the person with the addictive problem, and, similarly, in the English work, the lack of confidence, as well as concerns about the appropriateness of involving an AFM in work with the person with the addictive problem and what might happen in practice. In light of these findings, the scarcity of AFM-accepting practice in the addiction field should come as no surprise.

Our most important conclusion from the findings in both programmes of research, however, was a very positive one: that professionals faced with such challenges can and do move their practice in a more AFM-accepting direction, given help and supervision from more experienced colleagues, further specialist training, and greater experience at work and in life generally. This, it seems, is not a quick or easy journey. Our results point to the need to provide training and supervision to support the development of therapeutic skills in addiction professionals, in their attempt to engage family members in treatment. If the challenging and demanding nature of family involvement is not recognised, and no policies exist for adequate staff training and supervision, then the invaluable contribution of family engagement in addiction treatment will remain limited. Family work is not, and should not be, an individual affair or a field of specialist work, but

rather a collective pursuit that promotes mutual support in times of distress and the sharing of rewarding experiences that derive from our encounters with families.

Finally, an important limitation of both sets of studies needs to be noted. They took place in services where the primary focus was the treatment of patients who themselves were experiencing addiction problems (or, in one of the English studies, in a general healthcare service). Involving and responding to the needs of AFMs was a secondary consideration. It is tempting to conclude that the situation will not change and that improving the service response to AFMs will remain hard to achieve until services are set up, managed, and monitored in such a way that accepting and working effectively with AFMs is mandatory.

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Part IV

Interventions for AFMs

17 A Review of the Leading Forms of Interventions for, or Involving, AFMs

Ruth McGovern, Gallus Bischof, and Cassey Muir

17.1 Introduction

Addictive behaviours, including alcohol misuse, drug misuse and problem gambling, are common in families around the world [1]. Previous estimates have suggested that over 100 million people are affected by a family member's addiction [2]. More recently, however, studies have suggested a much higher prevalence (see this volume: Chap. 2). Within the current chapter, an 'affected family member' is used to describe a significant other and may include a parent, partner, adult or dependent-age child, sibling or other relative/caregiver. 'Addiction' or 'addictive behaviours' will be used to describe the problematic use of alcohol and/or drugs as well as gambling. Many affected family members suffer significant stress, which may cause psychological, social and physical problems [2, 3]. Despite clear evidence of harm to the close family members, interventions aiming to reduce the harm caused by addiction have primarily focused on the individual with the addictive behaviours [4]. Inherent within this approach is the assumption that if 'addictive behaviours' are reduced, the harm will also be reduced. Where family members have been involved in the treatment of persons with addiction problems, this has been informed by the belief that the family may in some way be part of the problem or offer part of the solution. However, such an approach can led to the perception of a shared responsibility for the behaviours of the person who has addiction problems and has been widely criticised for pathologising the family. More recently there has been a growing recognition that family members affected by a relative's addiction may benefit from treatment 'in their own right' [5]. Such approaches recognise that there may be an enduring impact upon the affected family member beyond the initial exposure to addiction. Reducing the addictive behaviours prevents ongoing, repeat exposure, but it will not resolve the trauma that has often been experienced by affected family members. Moreover, recovery from addiction is rarely linear, and affected families may experience an increase in stress relating to fear of relapse following periods of abstention. Therefore, interventions focused on the needs of the affected family members typically aim to address this impact and provide ongoing support and/or strategies to the family member as to how to cope.

Whilst there is a 'common core' of harm, affected family members are far from a homogenous group [6]. As shown in other chapters within this handbook, differences in impact have been reported based on the gender of the affected family member [6, 7], relationship type [6, 8] and socio-economic status [6, 7], with accumulative

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stress increasing the strain experienced [6]. Parents of adult children who have addiction problems have been reported to experience high levels of worry, difficulties coping and a grief response [9]. Within intimate relationships, affected spouses often experience mental health problems and social problems such as financial and housing instability. Moreover, there is established evidence of an association between addiction and intimate partner violence and abuse both in the perpetrator and the victim [10]. Dependent-age children are highly vulnerable to the effects of a family member's addiction, particularly when the person with addiction is their parent (see this volume: Chap. 5). Research has shown an association between parental addiction and a wide range of harms, including abuse and neglect [11]. These varying impacts are suggestive of the heterogeneous nature of families affected by an adult relative's addiction and their need for different interventions. Moreover, affected family members may have greater or lesser need for intervention depending upon the extent and quality of social support available to them informally. For affected children, this may include the presence of a parent/caregiver who does not have addiction problems. Similarly, adult affected family members may experience some protection from impact if they have the support of other family members or friends or if they are involved in activities they consider meaningful.

17.1.1 Types of Interventions for the Affected Family

Interventions that involve affected family members tend to be psychosocial in nature. They differ in their aim and can largely be categorised as interventions that (1) work with the family to address problems within the family, (2) are focused on the person who has addiction problems and include conjoint sessions that may also provide some support to the affected family member or (3) intervene directly with the affected family member only [12]. These interventions are likely to work in quite different ways, and each is underpinned by different theoretical positions. As will be explained in more detail below, interventions that work with the family to address family problems such as through family therapy typically view the family as 'part of the problem'. These interventions assume that addiction is a product of, or at least a problem that is compounded by, those family problems and dynamics. As such, addressing family dynamics and improving family relationships and communication are believed to bring about positive change in the person who has addiction problems as well as the wider family. Conversely, interventions that are focused on the person who has addiction problems but include conjoint sessions with family members perceive the family as largely 'part of the solution'. They often follow traditional individualistic addiction treatment approaches and introduce specific content focused on how the affected user (usually the partner) can better support the person with addiction, within their efforts to achieve change. This may include how the affected other can positively acknowledge the addictive behaviours family members' efforts to change and increase shared activities and constructive communication, all with the view to supporting the person who has addiction problems. Interventions that directly intervene with the affected family member often work in one of two ways: (1) intervene with the affected family member to influence change in the person who has addiction problems and/or (2) provide intervention to the affected family member in response to their own needs, typically with the aim of enhancing their ability to cope, alleviate stress or address trauma.

17.1.2 Interventions that Work with the Family to Address Problems Within the Family

Family therapy perceives the family as a system, wherein each part is connected to another. Addiction, from this standpoint, is perceived as a manifestation of serious dysfunctional relationships and interactions within the family. As these approaches view addiction as a product of the family system, the family receives treatment as a 'whole'. The aim is to improve family function-

ing and the health and wellbeing of the family, not just the person who experiences addiction. There are many different types of family therapy available, each informed by its own theoretical positioning. However, many share a belief that families may engage in behaviours that support the addictive behaviours. These include problems with communication, conflict, parenting skills, family cohesion, and family attitudes about substance use. Within family therapy, these behaviours are sometimes referred to as 'enabling behaviours', wherein the affected family member is perceived to be complicit in *enabling* the person experiencing the addiction to continue in their addictive behaviours, and therefore in some way responsible for them. By working with the family and agreeing family goals it is believed that family therapy can create an environment that supports recovery for the family, including the person who has addiction problems. Family therapy with families affected by addiction is discussed in detail in Chap. 20.

There have been a number of randomised controlled trials (RCTs) examining the effectiveness of systemic family therapy at improving the wellbeing of the affected family member, which have found significant effects. Family members receiving this intervention have reported significant improvements in family functioning [13] and family member mental health [14]. Studies have reported reductions in depression [13] and 'co-dependency' between family members [15]. Whilst family therapy has previously been recommended for vulnerable children and young people under 25 years, more recent evidence for the involvement of family members has been mixed and reported not to be cost effective [16].

17.1.3 Involvement of Family in the Addiction Treatment

Some addiction interventions involve other family members in the treatment of the person who has addiction problems, usually because their involvement is perceived to be supportive to the treatment aims. These approaches often include an addiction treatment component with adjunct conjoint sessions with a family member. However, the specific content of the conjoint sessions varies, depending upon which affected family member is involved in the intervention and the theoretical approach underpinning the intervention.

Couple's therapy typically includes between 10 and 32 sessions, which aim to support addiction recovery through improved communication and positive support for the person who has addiction problems. In addition to a reduction in addictive behaviours, couple's therapy may also result in positive outcomes for the affected family member, particularly relating to improved relationship adjustment and family functioning, and a reduction in intimate partner violence if that is occurring [17]. Further examination of the approach can be found in Chap. 21.

A family-centred empowerment approach assumes that the family, along with the person who has addiction problems, requires empowerment to support the individual to reduce their addictive behaviours. The approach aims to enhance motivational, psychological (such as self-esteem) and self-problem (such as knowledge and attitude) characteristics of the family (including the person who has addiction problems). A trial of the family-centred model found the approach improved social support and quality of life in family members of methamphetamine users post-intervention when compared to no intervention [18].

Similarly, parent skills training is typically focused on how the parent who has addiction problems may minimise the impact of their behaviours upon the child; and sessions may include affected children directly or indirectly. When these interventions are combined with addiction treatment, they have been found to result in significant reductions in parental addictive behaviours [19]. In general, they have also been associated with positive outcomes for both the parent and the affected child by (1) providing opportunities for positive parent–child interactions; (2) including supportive peer-to-peer relationships for family members; (3) harnessing the power of knowledge, especially regarding addiction; and (4) using strategies that are responsive

to socio-economic needs and matching services to lived experience. A systematic review of interventions for affected families members found that children whose families received parenting skills intervention in addition to problematic substance use treatment reported significantly more parental involvement and activities with their parent and significant improvement on parental discipline scales (laxness and over-reactivity) than children whose parents received substance use treatment only [17]. Further to these indirect outcomes, these children have been found to be less likely to use substances as they grow older, including alcohol [20], tobacco [21] and marijuana [20]. However, a recent systematic review of reviews reported mixed evidence as to whether parenting interventions for parents who misuse substances resulted in improved child outcomes [22]. There is a paucity of studies that have examined parenting skills training with parents who gamble problematically. Further discussion of parental skills training can be found in Chap. 22.

17.1.4 Interventions Provided Directly to the Affected Family Member

As highlighted above, interventions that are provided solely to the affected family member can be categorised as interventions that either aim to work with the affected family member to influence change in the person who has addiction problems or intervene with the affected family member in their 'own right'. There are a range of interventions delivered directly to the affected family member with one or other of these foci: readers are directed to the recommended readings listed at the end of this chapter, which includes wider references to other interventions. This chapter will outline one example of each of these.

Community Reinforcement and Family Training (CRAFT) is an adaptation of the Community Reinforcement Approach (a cognitive behavioural approach to working with people who have addiction problems). This intervention approach is described in more detail in Chap. 19. Within CRAFT, the therapist works with the families of 'unmotivated' or treatment-refusing people, in an attempt to change their environment to achieve three main goals: (1) decrease the addictive behaviours, (2) get the person experiencing addiction into treatment and (3) increase the affected family member's wellbeing. The intervention begins by building the affected family members' motivation to engage in the approach, before conducting a functional analysis of common episodes of addictive behaviours. The affected family member is supported to consider how they might better respond within the episode, particularly how to respond to early triggers for problematic substance use or gambling. The family member is taught positive communication skills which are used within episodes of addicted behaviour as well as within the ultimate invitation to the person experiencing addiction to access treatment. In addition, they are trained in how to positively reinforce non-use and introduce negative consequences (removal of rewards) for use. Whilst there is a large evidence base from RCTs finding CRAFT to be effective at enabling family members to influence the family member who has addiction problems to reduce their addictive behaviours or increase treatment engagement, the effects of CRAFT on family members affected by addiction are less conclusive. Furthermore, whilst improvement in the wellbeing of the family members was observed in all studies, no superiority was found compared to other active controls like Al-Anon or the Johnson Institute Intervention. Exploratory analysis suggests that treatment engagement of the individual with addiction problems through CRAFT is more likely if family members engaged in CRAFT strongly endorse this as a motive for participating at the beginning of the intervention, whilst family members putting less emphasis on this goal revealed lower engagement rates [23].

One intervention that focuses on the affected other is the 5-Step Method, which is a brief semi-structured psychosocial intervention. This method is based on the stress–strain-information-coping-support model, which recognises and seeks to respond to the impact of a family member's addiction on affected family members. The

approach does not view family members as contributing to addiction but instead focuses upon supporting family members to cope with its impact. The 5-Step Method consists of the following steps:

1. Getting to know the family member and the problem
2. Providing relevant information
3. Exploring and discussing coping behaviours
4. Exploring and enhancing social support
5. Reviewing previous steps and exploring further needs

The 5-Step Method benefits from high levels of flexibility and has been adapted to a range of settings and populations, including affected children, and is one of the few interventions that has been adapted for families from low- to middle-income countries. The method has been found to be a promising intervention for family members, with some evidence suggesting an improvement in coping behaviour in family members [24] in pre-post studies for problematic substance use and gambling [25]. The one RCT conducted so far showed both personally conducted 5-Step sessions and self-help material based on the method had positive effects for the affected other [26, 27]. For further discussion of the 5-Step Method, please see Chap. 18.

SMART Family and Friends has adapted the four principles of SMART recovery for affected family (and others). Whilst SMART Family and Friends includes some examination of how best to help their family member to reduce their addictive behaviours, which is similar to CRAFT, at its core is a concern to train the affected family member to take better care of themselves and their own goals (as opposed to influencing the person who has addiction problems). The SMART Family and Friends approach recognises that affected family members may have neglected their own needs whilst prioritising the needs of the relative who has addiction problems; therefore, they may require support to refocus on their own life goals and concerns. It aims to (1) promote motivation to change, (2) encourage the family member to engage in self-care, (3) challenge the family member's thinking and (4) teach assertive communication. The approach is delivered within both in-person groups and online wherein other affected family members and friends share their experiences. A recently completed pilot feasibility study has reported improvements in psychological distress and family impact post-treatment [28].

This peer support shares similarities with other mutual aid and self-help approaches such as Al-Anon. Al-Anon, formally known as Al-Anon Family Groups, is a 12-step mutual-help programme for affected family members and is a widely used approach in the USA. Social processes including bonding over shared experiences and provision of role models have been found to mediate between participation in Al-Anon and positive outcomes. Al-Anon has been reported to be associated with better quality of life, better coping and improved positive symptoms [e.g. increased self-esteem and reduced negative symptoms (e.g. depression)] in pre-post studies and has shown similar effects on the wellbeing of family members compared to CRAFT interventions [29]. For further discussion of self-help approaches, the reader is directed to Chap. 25.

Low-intensity interventions are brief, time-limited interventions that include affected family members. Whilst there is no agreed definition of a low-intensity intervention, these are typically six sessions and often take a structured approach, wherein affected family members complete a brief training programme of progress through steps or stages. A number of established more intensive interventions have been adapted for lower-intensity, brief formats. Such approaches have the benefit of enabling integration within a wider range of settings and, in doing so, may reach more affected family members. Examples include single-session adaptations of the 5-Step Method for delivery in structured carers groups [30] and in primary care [27]. More recently there has been the development and evaluation of a low-intensity mobile app to provide information to friends of adult substance users and empower affected oth-

ers to influence addictive behaviours [31]. Low-intensity interventions are discussed in more detail in Chap. 24.

There are a limited number of interventions that are provided directly to affected children, all of which focus upon parental problematic substance use. Most interventions aimed at younger children utilise cognitive behavioural therapy, psychoeducational or skills training approaches. A small number of school-based interventions have been developed to try and improve outcomes for children whose parents use substances problematically. These have largely been developed within the USA, adopting a peer support model rather than involving family members. However, these interventions showed low-quality evidence of effect [17]. The 5-Step Method, mentioned previously, has also been adapted for children, called 'Steps to Cope', which aims to build resilience by targeting known protective factors, including ensuring young people have a supportive adult they can trust, and by enhancing their self-esteem. A pre-post study found some significant improvements in resilience measures, but further work is needed to ensure barriers to implementation are overcome [32]. In Germany, a RCT found that a community-based psychoeducational intervention called 'Trampoline' for children aged 8–12 years had some effect on reducing feelings of social isolation and improving parent–child relationships [17]. Trampoline includes nine group-based modules (e.g. one on enhancing self-worth and another on providing knowledge on addiction), utilising role-play and fun activities. Interventions for adult children mostly consist of self-help interventions to improve wellbeing. These interventions typically consist of regular group meetings wherein family member's share experiences of living with parental alcohol use, with mental health benefits reported [33], although self-help approaches have more recently been adapted for online delivery. Other intervention approaches have included forgiveness therapy and coping skills training. For further discussion on interventions for children, please see Chap. 23.

17.2 Responding to the Needs of the Affected Family: Is It Enough?

This chapter has discussed a wide range of interventions involving affected family members. However, as illustrated within this overview chapter, when families are involved in interventions, this is often as a means of affecting change in the focal user. Family interventions such as family therapy see the family as part of the problem and therefore needing to change before addiction can be addressed. Conjoint interventions see the family member in some way as part of the solution, wherein they are intervened with as a means of encouraging change and contributing to the success of the addiction treatment. Similarly, interventions such as CRAFT empower family members to take an active role in changing the behaviour of their relative who has addiction problems and encouraging treatment entry. Many of these interventions have been found to be effective at reducing the addictive behaviours of the individual and are therefore important in alleviating the acute stress and strain family members often experience when affected by a relative's addiction. However, the traumatic impacts of addiction upon affected family members are well documented [2, 3, 34]. These impacts may be long lasting and compounded by accumulative burden experienced by many families [6] and require direct intervention to the family member in their own right. In order to meet the needs of the affected family, it is likely that interventions that focus on the family member in their own right are required.

17.3 Gaps in the Evidence

Although a number of studies have analysed the effects of interventions for or involving family members, to date, no long-term effects of interventions have been reported. Study quality on average is at best modest and often restricted to pre-post studies that likely overestimate treatment effects (e.g. when family members seek help at specific critical situations), without

consideration of aspects such as chronicity of the relative's substance use. Furthermore, many studies have restricted their assessment on outcomes for the focal relative who uses substances (especially in studies on conjoint treatments) or the affected family member (without taking relationship and/or user into account). This makes a comparison of changes obtained through specific interventions difficult. In addition, most studies relied on self-selected samples, and generalisability to the population of family members is questionable. Future studies should consult affected family members on their intervention preferences, co-producing interventions informed by the specific needs of different subgroups of affected family members. Much of the available evidence currently is focused on female affected family members, with very little research developing or evaluating interventions for affected male family members. As a result, we know very little about how best to intervene with affected male family members. It is likely that male family members will have both different impacts from their exposure to their relative's substance use and varying support needs. Most of the interventions available to families affected by a relative's substance use are from high-income countries, with a paucity of approaches and evidence focused on low- and middle-income countries [35]. There is a need for further research to examine how best to respond to the needs of these populations, including how to culturally adapt promising interventions and implement them within countries that may have limited reliance upon state-provided health and social care provision.

17.4 Conclusions

There are a wide range of interventions involving affected family members with differing mechanisms of impact and outcomes. This increasing recognition of the importance of the family within the context of addiction is welcomed. However, many of the interventions which include affected family members maintain a primary focus on the person who demonstrates addiction behaviours, with little examination of family outcomes. These interventions do not go far enough to address the needs often experienced within addiction-affected families. There is a need for research which develops and evaluates interventions which seek to address the complex multidimensional adversities experienced by many families affected by addiction. Further research is needed to determine the effect of multi-component psychosocial interventions, which seek to support both the relative exhibiting addiction behaviours *and* the affected family member, with equal focus on their needs.

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The 5-Step Method: Evidence and Implementation

18

Lorna Templeton

18.1 Introduction

There is clear global evidence of the complex, extensive and long-term ways in which people can be negatively affected by the alcohol, other drug or gambling behaviours of a relative or close other [1, 2] (see also Parts 1 and 2 of this volume). Despite this, there continues to be insufficient attention paid to the development and implementation of evidence-based interventions for these individuals in their own right [3–5]. In 2022, the EMCDDA named the 5-Step Method as one such intervention [4]. The 5-Step Method is a brief, structured, psychosocial evidence-based intervention for adult 'affected family members' (AFMs). It is important for four main reasons: its central focus on AFMs, worthy of support in their own right and regardless of whether the person who is using alcohol or other drugs, or gambling, is in treatment or recovery; the evidence-based foundations related to both its original development and its ongoing implementation and evaluation; its measurement of AFM-focused outcomes; and its careful attention to language and terminology.[1]

This chapter will summarise the three core components of the international 5-Step Method programme of work, namely, the development of the original intervention and early evidence of efficacy and effectiveness, ongoing evidence of effectiveness and global implementation including attention to context and ensuring fidelity. The chapter will end with some reflections on the successes and ongoing challenges related to the 5-Step Method.

18.2 The Development of the 5-Step Method Intervention and Early Evidence of Efficacy and Effectiveness

The 5-Step Method was first developed in the 1990s, following many years of international mixed methods research in the UK, Mexico City, Aboriginal communities in the Northern Territory of Australia and Italy [6]. The wealth of data thus collected provided valuable and, at that time, innovative evidence to understand and describe in-depth the 'variform universal' experience of AFMs. In other words, there is a core experience for AFMs, best summarised with the 'Stress–Strain-Information-Coping-Support' (SSICS) model (Fig. 18.1) [5]. Collectively, stress and strain describe how AFMs are affected,

[1] See also http://afinetwork.info/5-step-method-resources-introduction (free membership is required to access some materials).

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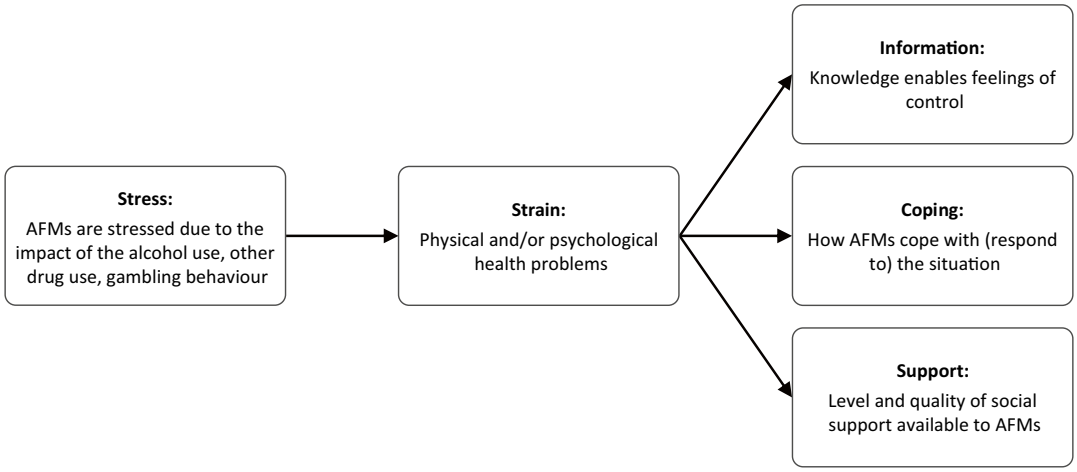

Fig. 18.1 The Stress–Strain-Information-Coping-Support model

with information, coping and support acting as mediators of their experiences, thereby being open to influence through intervention. Within this core experience, there can be variation and nuance according to, for example, country; relationship; whether the situation involves alcohol, other drugs or gambling; familial structure and hierarchy; and cultural norms including faith and religion [6, 7] (see also Part 2 of this volume). The SSICS model forms the building blocks of the 5-Step Method itself, and the 5 Steps are as follows:

Step 1: Listen, reassure and explore concerns.
Step 2: Provide relevant, specific and targeted information.
Step 3: Explore coping responses.
Step 4: Discuss support.
Step 5: Discuss and explore further needs.

In the UK, initial testing of the 5-Step Method found that it was feasible to train primary health-care practitioners (doctors, nurses and health visitors) to use the intervention, with data from AFMs showing a significant reduction in physical and psychological symptoms and similarly significant changes in coping responses [8]. A further randomised controlled trial in primary care compared the intervention as delivered by practitioners, supported by a self-help version of the handbook, with the self-help handbook only [9]. Both forms of the intervention led to improvements in impact, health and coping, changes which were maintained and/or improved at 12 months, with no significant differences between the two arms of the trial [9, 10]. Qualitative data from AFMs and primary health-care practitioners helped to further understand the opportunities and limitations of the intervention and the potential for delivery in primary care [11, 12]. Further small-scale research studies at this time successfully explored the feasibility for the intervention to be delivered in a statutory substance use treatment service and in a group format [13, 14].

Early research also tested the 5-Step Method in Mexico and Italy, supported by translation of materials and accounting for sociocultural characteristics. These included alcohol and other drug problems being viewed as private problems for internal resolution by families rather than as issues of public health concern and the tendency for women to be viewed as responsible for such problems [15, 16]. In Mexico, research with 60 indigenous female AFMs from a rural area known for both its poverty and ancestral alcohol drinking practices compared those who received the 5-Step Method with a control group who chose not to engage with the intervention. This study found that the former experienced a reduction in health symptoms (symptoms increased in the control group) and changes in coping behaviour that were not seen in the control group [17].

In Italy, a feasibility study in primary care and specialist addiction services found that staff could be trained to use the intervention with fidelity, with similarly positive outcomes for AFMs in impact, health and coping [18, 19]. Considering all the early international evidence of efficacy and effectiveness, it was concluded that [20]:

> When all strands of evidence are considered together, the 5-Step Method emerges as a very promising approach to reduce addiction family-related harm…. a strong platform from which to roll-out the 5-Step Method in routine practice" (Copello et al., 2010: 100)

Subsequent work in the UK explored whether it was possible for a range of services (a primary care team, a National Health Service substance use treatment service, two non-statutory substance use treatment services and a Muslim family-oriented service) to become more family-focused in their response to alcohol and other drug use, including the use of the 5-Step Method, and outside of the rigorous requirements of research studies [21]. Successes included improved knowledge, confidence and attitudes of staff in working with AFMs, as well as improved family-focused working practices, such as increased engagement of AFMs. Challenges included the time needed to make the required changes and undertaking the work in the context of broader service pressures. Concluding reflections from this work were summarised as follows [21]:

> Change takes times but ….a 'cultural change' can take place…..[however] sustainability of change remains an issue…. the capacity of services to take on work with family members affected by substance misuse of close relatives varies greatly (Orford et al., 2010: 154)

18.3 Ongoing Evidence of Effectiveness: The Family Member Questionnaire

The primary way in which the effectiveness of the 5-Step Method is measured is through the Short Questionnaire for Family Members Affected by Addiction (SQFM-AA: commonly referred to as the FMQ [Family Member Questionnaire]). Developed from the four measures that were used in many of the research studies described above, the FMQ consists of 33 items covering the core elements of the SSICS model [22, 23]. So, there are 11 sub-scales covering Stress (e.g. 'Has your relative upset family occasions'), Strain (e.g. 'Worrying'; 'Cannot concentrate'), Coping (e.g. 'Watched his/her every move or checked up on him/her or kept a close eye on him/her?'; 'Got on with your own things or acted as if he/she wasn't there?') and Support (e.g. 'I have confided in my health/social care worker about my situation'; 'Friends/relations have said things about my relative that I do NOT agree with'). Additionally, 18 items (all stress items, all strain items, emotionally engaged coping and tolerant inactive coping) are combined to calculate total family burden [23].

The FMQ is completed before and after a 5-Step Method intervention (the time frame between timepoints can vary). Based on pre- and post-intervention matched data from 871 AFMs from 16 different services across 8 countries,[2] statistically significant positive change occurs across all domains measured by the FMQ (Table 18.1, Fig. 18.2) [23]. Of particular note is the 98% improvement in formal Helpful Support, along with 29–38% reductions in Overall Impact, total symptoms, engaged emotional coping and total family burden [23].

Based on data from six of the eight countries, there are no statistically significant between-country differences, for example, to account for gender or cultural norms [23]. While there are insufficient data currently to assess the longer-term impact of the 5-Step Method, there are indications from individual studies that the positive

[2]Unpublished data, presented by Professor Richard Velleman at the 4th AFINet International Conference, Rotterdam, June 2023. The FMQ data come from 16 organisations (covering alcohol, other drugs and gambling) in 8 countries (Australia, England, Hong Kong, Ireland, the Netherlands, New Zealand, Northern Ireland and Scotland). However, for one country (Australia), there is matched FMQ data from one AFM, and for another (Hong Kong), there are matched FMQ data from eight AFMs, so the analyses reported here are based on FMQ returns from the other six countries.

Table 18.1 International Family Member Questionnaire data

	Before intervention Mean (SD)	After intervention Mean (SD)	*t*-Test (statistical significance)
Impact worrying behaviour (*N* = 868)	5.52 (2.44)	3.77 (2.52)	20.508 (<0.0005)
Impact active disturbance (*N* = 871)	3.79 (2.69)	2.21 (2.18)	19.003 (<0.0005)
Total impact (*N* = 868)	9.31 (4.39)	5.98 (4.12)	23.514 (<0.0005)
Psychological symptoms (*N* = 866)	5.19 (1.51)	3.78 (1.86)	22.647 (<0.0005)
Physical symptoms (*N* = 865)	3.88 (2.01)	2.65 (1.91)	18.050 (<0.0005)
Total symptoms (*N* = 863)	9.07 (3.21)	6.47 (3.36)	23.332 (<0.0005)
Engaged emotional coping (*N* = 866)	5.56 (2.48)	3.42 (2.42)	24.795 (<0.0005)
Engaged assertive coping (*N* = 869)	5.44 (2.80)	4.27 (2.81)	12.108 (<0.0005)
Tolerant inactive coping (*N* = 867)	3.52 (2.60)	1.80 (2.09)	19.754 (<0.0005)
Withdrawal coping (*N* = 865)	4.37 (2.64)	5.37 (2.60)	−10.918 (<0.0005)
Helpful informal support (*N* = 864)	6.04 (2.81)	6.30 (2.61)	−2.900 (<0.002)
Helpful formal support (*N* = 853)	3.24 (2.95)	6.43 (3.01)	−26.332 (<0.0005)
Unhelpful informal support (*N* = 859)	2.36 (2.47)	1.90 (2.28)	5.897 (<0.0005)
Total family burden (*N* = 853)	27.44 (9.47)	17.68 (9.40)	29.184 (<0.0005)

In all but three areas, a reduction in score indicates positive change; for three areas (withdrawal coping, helpful informal support, helpful formal support), an increase in score indicates positive change

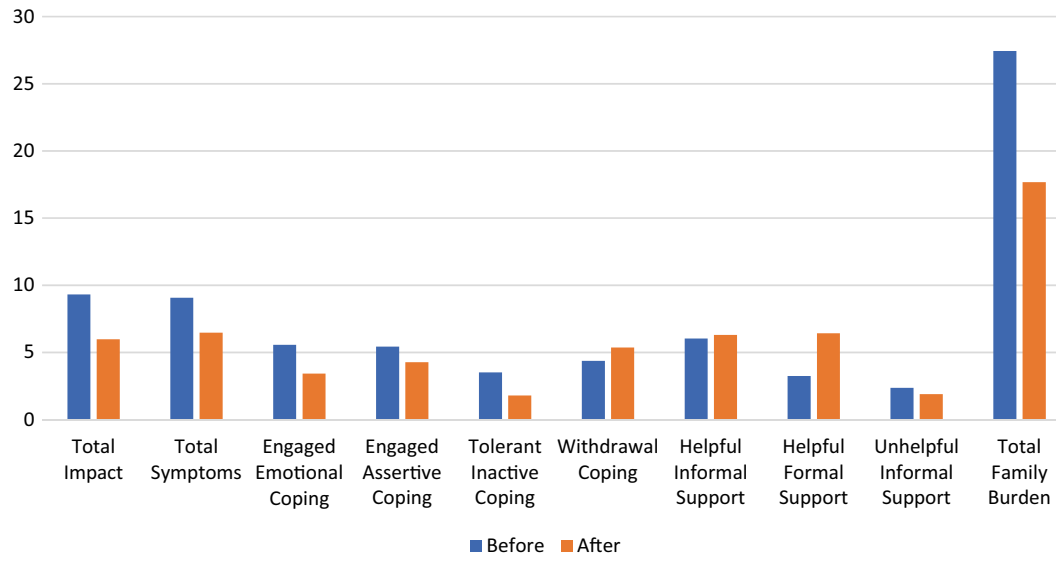

Fig. 18.2 5-Step Method outcomes—impact, symptoms, coping, support, and total family burden (*N* = 853–871)*. *In all but three areas, a reduction in score indicates positive change; for three areas (withdrawal coping, helpful informal support, helpful formal support), an increase in score indicates positive change

outcomes seen at the end of the intervention can be sustained and/or improved in the longer term [10, 22, 24]. Finally, while there is no standardised way to collect qualitative feedback from AFMs, some services do collect such data through their own research and evaluation or service-based processes like a satisfaction questionnaire. By way of example, this AFM from New Zealand explains how the intervention helped them:

> You are encouraged to realise that you are not alone….It shows you three key, coping mechanisms and reinforces to you that regardless of whichever one you utilise, there is no wrong answer because each way has its own positive and negative aspects and you will find yourself using different ones at varying times depending on the need. I also found that the non-judgemental approach, geared towards helping you to gain insight, resilience and strength, helps you to find confidence in yourself and to hold your head up high during what is often a very long and at the very least challenging journey, where the propensity to give up is not unusual….[there were] quite a few eureka moments….[before] I felt shellshocked, humiliated, afraid, confused, deflated, exhausted and alone. Now I feel armed with a significant amount of knowledge and information from various perspectives and I feel so much better prepared than I otherwise would have been for what still lies ahead (AFM, New Zealand)

18.4 Evidence of Global Implementation Including Attention to Context and Ensuring Fidelity

Four overlapping components of the international 5-Step Method programme of work will be summarised, namely, the reach of the intervention including who uses it and with whom it has been used, ways of using the intervention including remote delivery and organisational and country-wide schemes, adaptations of the original intervention and supporting delivery and implementation fidelity.

18.4.1 Who Uses the 5-Step Method and with Whom Has It Been Used?

In 2023, the 5-Step Method is used in 11 countries: Australia, Canada, England, Hong Kong, India, Italy, Mexico, the Netherlands, New Zealand, Northern Ireland and the Republic of Ireland, although there is variation in the levels of implementation. Training is compulsory for all those who wish to use the 5-Step Method, although there is some flexibility in the length and mode of training, with increasing use of online training largely because of the Covid-19 pandemic. Generally, training is up to 2 days supported by a requirement to engage in self-guided learning using reading and video materials that are primarily available online. Skills practice, observed by the trainers and guided by the competency framework (see below), is crucial and a significant part of the training. However, some countries deliver training differently, such as in Mexico where it is part of a Master's psychology degree programme. Supplementary sessions can be run for managers and supervisors to provide an overview of the intervention and to ensure that the various essential components of delivery (such as data recording and supervision) are in place.

In total, approximately 2500 practitioners have been trained globally, although it is not known how many of these proceed to regularly use the intervention or are still using it after a reasonable period of time.[3] Despite the focus of the original testing of the intervention in primary care, those trained most commonly come from statutory or non-statutory alcohol/drug/gambling treatment services and specialist services for AFMs/carers or are counsellors in a range of settings. In some locations increasing numbers of people with 'lived experience', who can be either

[3]The number is probably larger than this as data have been more consistently collected from ~2012. The number also includes those who have been trained to use Steps to Cope (see later in Chapter).

volunteers (e.g. peer mentors) or salaried workers, are being trained.

Alongside the use of the FMQ (see above), services are asked to record basic demographic information about all AFMs with whom they work and where possible agreements are put in place for anonymised data to be shared with AFINet. Data for 945 AFMs (the exact *N* for each variable varies) indicate that the majority (81%) of AFMs are female (33% mothers and 23% spouses), with an average age of 51 years (range 16–90 years); are concerned about male relatives (73%), with an average age of 35 years (range 13–81 years); and have been living with the situation for an average of 9.4 years [23]. Over one third (38%) were concerned about another's alcohol use, a similar proportion (38%) were concerned about another's drug use, with the rest concerned about either polydrug use (15%) or gambling (9%) behaviours. AFMs from the UK, Ireland and the Netherlands are predominantly White, while in New Zealand 16% of AFMs are indigenous Māori or Pasifika (which mirrors national population data), and in Australia 6% of AFMs are Aboriginal or Torres Strait Islanders [23].

18.4.2 Ways of Using the 5-Step Method

Originally, the 5-Step Method was developed as an individual in-person intervention, but, over the years, how the intervention is delivered has become more varied. It continues to be used mainly as an individual intervention between a trained practitioner and an AFM—in-person, over the phone or, increasingly in recent years, by remote computer sessions—with the self-help handbook often used to support this work. Recent years have seen an increase in the use of the 5-Step Method with groups of AFMs.

Delivery via video-conferencing, using a range of platforms, has significantly increased, largely due to the Covid-19 pandemic. Guidelines to support this have been developed,[4] and research has started to explore whether there are differences in outcomes for AFMs when the intervention is delivered via video-conferencing. For example, a study in the Netherlands with 145 AFMs who engaged with the 5-Step Method via group work, half of whom attended intervention groups via video-conferencing, reported no significant differences in outcomes between the two groups [24].

As part of the initial research phase of the 5-Step Method programme, Ibanga reported encouraging results from a web-based self-help version based on the self-help handbook [25]. This exploratory study identified a number of challenges with online delivery, such as maintaining the website, recruiting AFMs and ensuring that digital interventions can keep up with advances in digital technology. Unfortunately, there has been limited work subsequently to progress web-based versions of the 5-Step Method. One exception is a non-statutory substance use treatment service in England, where the 5-Step Method is now available as an online intervention as part of a broader suite of digital interventions and resources available to AFMs (evaluation of this is ongoing). Also, in Mexico a Spanish language web-based self-help version of the intervention is being evaluated.

Generally, services commission AFINet to deliver training. In some countries the 5-Step Method has been introduced across a whole organisation, to services that are part of a larger organisation, or across a service at a national level. Examples are Turning Point in England (Box 18.1), Family Drug Support Aotearoa in New Zealand (Box 18.2), Family Support Network in the Republic of Ireland (now C&F Training), Jellinek Foundation in the Netherlands and primary care centres for addiction (CAPA) across Mexico.

[4] See, for example, the guidelines developed by colleagues in New Zealand on the AFINet website.

Box 18.1 Introducing the 5-Step Method Across Treatment Services: Jan Larkin, Head of Psychology, Turning Point, UK

Turning Point is a publicly commissioned health and social care charitable organisation in England providing substance use, public health, mental health and intellectual disability services. We have a strong commitment to offer evidence-based support to those affected by others' substance use and have been developing our psychosocial model in this regard since 2010, when we began to offer the 5-Step Method to AFMs in our substance use services. Over the last 12 years, we have integrated the approach by increasing our numbers of dedicated family workers and offering specific training to family members with lived experience to facilitate the approach as peer mentors. Our family model currently includes the 5-Step Method in a range of modalities: individual and group-based, face to face and virtual by phone or computer. We have recently launched a digital version of the 5-Step Method, developed in conjunction with AFINet, which can be used as a self-guided or guided resource. Additionally, we offer less structured regular carers groups in each substance use service for longer-term support and have linked up with Talking Therapies in a number of areas to offer mental health interventions either alongside or after our 5-Step Method and carers support groups. Currently, the 5-Step Method is being used in services across eight English counties and five London boroughs.

In response to positive clinical outcomes as measured by the FMQ (currently before and after data from over 100 AFMs and a great deal of positive feedback about the 5-Step Method from affected others and staff), we have developed an adapted a version of the approach to support those affected by others' mental health problems. Our intention is to pilot this adapted version in some of our mental health services to reach those people who are currently not being offered dedicated support in their own right.

Box 18.2 Introducing the 5-Step Method Across a Family Support Service: Pauline Stewart, Executive Officer and Founder, Family Drug Support Aotearoa New Zealand (FDS)

FDS, a not-for-profit organisation formed in 2018 by Dr. Stewart, has offered the 5-Step Method across rural, town and city areas since 2020, with 95% of AFMs receiving support via Telehealth (Zoom). To date, FDS has trained around 35 accredited practitioners, 4 accredited trainers and 4 accredited assessors (see elsewhere in this chapter for more information on accreditation). Training is delivered in-person twice yearly in New Zealand, with all those trained expected to subsequently complete the accreditation process. Practitioners are primarily volunteers, although four are employed part-time to provide the intervention via Zoom. Many are already counsellors, psychologists, social workers or people with considerable experience working professionally with families. Those selected for training are provided with the training and accreditation free, in return for volunteering with FDS to use the 5-Step Method for at least 2 years. This team is supported by administration, supervision and ongoing professional development.

AFMs apply for the 5-Step Method programme online via the FDS website (www.fds.org.nz) or via the FDS support line. While AFMs are diverse demographically, the majority (79%) are female with an average age of 52 and have been an AFM for an average of 10 years. One quarter of AFMs are indigenous Māori or Pasifika.

(continued)

Box 18.2 (continued)

Two thirds of those who they are concerned about are male (66%) with an average age of 33 and generally using alcohol (30%), methamphetamine (24%) or cannabis (22%). Telehealth delivery is usually on a one-to-one basis with a practitioner, although sometimes two AFMs, such as couples or siblings, engage (sometimes because they are in different areas of New Zealand). Before and after FMQ data from approximately 300 AFMs indicates that 92% experience reduced total family burden, with improvements seen across all areas measured by the FMQ. Clinical evidence suggests that the outcomes in reduced family burden are as good as, and in some cases greater, for Māori/Pasifika AFMs. Three-month follow-up data (available from about three quarters of AFMs) show that improvements in coping and well-being are maintained.

FDS has now introduced a Youth 5-Step Method intervention for young people aged 16–24 years (supported by the University of Quebec), and a special version of the 5-Step Method for AFMs whose loved one has died during the intervention. One challenge of introducing the 5-Step Method has been balancing the number of accredited practitioners trained to the number of AFMs seeking help so that AFMs can receive support within 1–2 weeks of contacting FDS. The success of the 5-Step Method across FDS has now attracted government funding to supplement grants and donations, ensuring sustainability for the organisation.

18.4.3 Adaptations to the Original Intervention

In some countries (such as Hong Kong, India, Italy, Mexico, New Zealand), the introduction of the 5-Step Method has considered cultural relevance (such as for Māori or Pasifika people in New Zealand), including language translations (e.g. Chinese, Dutch, Italian, Indian languages, Spanish/Portuguese) and other cultural adaptations such as the use of imagery. With regard to gambling, while a separate version of the intervention was originally developed and primarily used in England, intervention materials now integrate alcohol, other drugs and gambling. Additionally, two more extensive adaptations to the intervention have been undertaken—one for children and young people and another for adults bereaved by substance use—and these are outlined below.

18.4.4 Steps to Cope: Supporting Children and Young People[5]

Children and young people can be particularly vulnerable to the short- and long-term harms associated with parental substance use [4, 26] (see also Chaps. 5 and 23 of this volume), with Tamutiene and Stumbrys estimating that approximately 9.5 million children were affected by parental problem drinking across 19 European countries in 2015 [27]. Steps to Cope was first developed in 2011 in Northern Ireland in response to calls for evidence-based interventions to be developed, and it aims to build resilience in this population [26, 28]. While Steps to Cope is the same as the adult 5-Step Method in terms of the underlying theoretical SSICS model, the 5 Steps and the key principles of delivery, there are a number of ways in which it is different. These include integrating ideas about building resilience, renaming the 5 Steps, a workbook developed specifically for a young client group, using the READ (Resilience Scale for Adolescents) rather than the FMQ and supporting children and young people affected by parental mental health problems, as well as parental substance use

[5]The Steps to Cope programme of work operates as a partnership between ASCERT, the South Eastern Health and Social Care Trust and AFINet, with the early work also supported by Barnardos.

(currently Steps to Cope is not used with those affected by parental gambling) [29].

Data from one evaluation study illustrated that over two thirds (70%) of 119 young people who started Steps to Cope went on to complete it [30]. Furthermore, matched READ data for 80 individuals show statistically significant improvements in the 5 domains of the READ (covering individual-, family- and social/environmental-level protective factors associated with building resilience) and an overall increase in resilience [30]. While promising, challenges include the initial engagement of young people and of sufficiently embedding the work within appropriate services [29, 30]. The potential of Steps to Cope is summed up by this 14-year-old girl of a mother with alcohol and mental health problems [29]:

> Before I started meeting with [Jane], I didn't like talking about any problems I had and often bottled my issues up, this always ended up in the same result. I would end up breaking down and often didn't realise why I was so upset, as I was used to blocking things out. I found it hard trusting people, including friends, which had quite a negative impact but I [saw] this as a way of protecting myself, as I was always used to people letting me down…..Since I've started working with [Jane] I've become more open. I know that I have to learn to trust people because not everyone is going to let me down. I can talk about my problems more easily and this has had a very positive impact on my life. I have also learnt to sort out my problems because avoiding them does not help the situation.

18.4.5 Supporting Adults Bereaved Through Substance Use

In response to increasing UK (and global) public health concerns about the prevalence of alcohol-, drug- and gambling-related deaths, but insufficient recognition of the support needs of those who are thus bereaved, a small pilot study was undertaken in an English substance treatment service to test an adaptation of the 5-Step Method [31]. Informed by Templeton and Velleman's consideration of the application of the SSICS model to bereavement through substance use [32], only minor revisions to the intervention were made. These included renaming the 5 Steps, reorienting the content of the Steps to support AFMs after such a death, encouraging practitioners to follow 5 key messages for good practice developed by a UK research study with adults bereaved through substance use and not including an outcome measure [31].

Qualitative data suggested that the 5-Step Method can be used within a treatment service to support bereaved adults, with its potential summed up by this bereaved AFM [31]:

> It just makes me know I can do this, I can carry on with my life and I will...I can't give up....[the worker] reiterates 'you're doing fantastic, you're stronger than you think', it gives you the oomph to think you will do this.....gives me confidence, makes me feel positive, [my worker] makes me feel that after this terrible tragedy that I'm strong enough and I can carry on.

While encouraging, there were limitations due to the size of the study and challenges in sustaining the work beyond the study. Further work is now underway in England, with a charity that offers specific support to AFMs (whether the person they are concerned about is alive or has died), to progress this version of the 5-Step Method. Areas that require particular attention are how the coping typology can be better suited to bereaved AFMs, aligning the work with theoretical models of understanding grief and bereavement and identifying a suitable outcome measure.

18.4.6 Supporting Delivery and Implementation Fidelity[6]

An ongoing challenge for global 5-Step Method work is ensuring that those who are trained use the intervention with fidelity, thereby minimising the training dilution effect while offering opportunities for practitioner reflection and professional development including through supervision [33]. Responding to this challenge centres on the Competency Framework and the process of assessing competence.

[6]More details on the Competency Framework and the accreditation certification process can be accessed by AFINet members via the website and the 5-Step Method Resource Hub.

Table 18.2 Sample competencies from the 5-Step Method Competency Framework

Step 1 (1.1)	Beginning of session—warm welcome, set a clear and structured agenda for the session, communicate this to the AFM and ensure that this agenda is followed throughout the session. Introduce the 5-Step Method and relate it to the Stress–Strain-Information-Coping-Support model, confidentiality, the purpose of Step 1, and complete the FMQ (if not already completed)
Step 1 (1.3)	Identify relevant stresses and how the AFM has been affected. As necessary, utilise the results of the FMQ to guide the session
Step 2 (2.3)	Identify/check areas where the AFM needs more general information (about anything not directly addiction related, e.g. anxiety, sleeping and other health issues, housing, debt management, benefits, educational courses), present targeted and relevant information to the AFM and discuss this with the AFM. As necessary, utilise the results of the FMQ to guide the session
Step 3 (3.4)	Facilitate the AFM to see that there is no right or wrong way of coping
Step 4 (4.5)	Discuss how AFMs can support each other and agree on approaches when communicating with the using relative
Step 5 (5.3)	Discuss the AFMs' need for further help and how this can be actioned
Core counselling competency	Careful listening and summarising, the giving of minimal encouragers, the asking of appropriate open and closed questions and probing, reflecting both the verbal and emotional content

The Competency Framework details 35 competencies, covering 5 core counselling competencies and 6 competencies for each of the 5 Steps (see Table 18.2 for sample competencies). Attention is given to key components of delivery such as how to start and end intervention sessions, structuring sessions and time management and ongoing discussion and monitoring of client risk and safety. The Competency Framework is integrated within the handbook, is central to all training courses and is supported by online resources including good practice guidance, demonstration videos and expert panel discussion videos (there is also a Competency Framework, and a range of delivery resources, to support Steps to Cope and the bereavement version of the intervention). It is recommended that the Competency Framework is integrated within supervision practices, and additional resources have been developed to support supervision.

To further support and maximise fidelity, an assessment of competence process has been developed. Using the Competency Framework, supported ideally by the submission of audio recordings (or transcriptions of sessions), an experienced assessor asks a practitioner to reflect on their delivery of the intervention against the competencies, before offering detailed feedback and an action plan for improvement [33]. While there are challenges with this process, particularly the time requirements for practitioners and assessors and the need to record or prepare transcripts of sessions, there are over 120 practitioners globally (mainly from Ireland and New Zealand) who have completed this process for the adult 5-Step Method. A need to develop less time-intensive versions of this process has been identified.

18.5 Discussion

> When I heard about the [5-Step Method] I could have cried with relief. At that point, my brother had been using drugs recreationally for more than 25 years. For all that time I hadn't known where to go for help….I highly recommend this programme for anyone who loves someone struggling with alcohol or other drugs….It represents a very therapeutic, realistic, harm reducing, health and non-judgemental approach to an extremely serious and heart wrenching issue that affects people across all so-called borders regardless of age, race, health, socioeconomic position, job, location…. [it] should be made available to all who need it (AFM, New Zealand).

Taken together, the research-based and the practice-based evidence from a longstanding international programme of work clearly demonstrate increasing global use of the 5-Step Method and significant positive outcomes for AFMs. The high completion rates (for the 5-Step Method and Steps to Cope), reported anecdotally and by a number of studies [24, 30], coupled with encouraging quantitative findings, indicate numerous

benefits associated with a brief, structured interventions for AFMs (who may be adult or young people) who have usually been living for many years with their situation.

The intervention is successfully used in a range of countries and settings, including some low- and middle-income countries, and with indigenous populations, children and young people and bereaved adults. However, an urgent priority is extending the cultural reach of the intervention, particularly in low- and middle-income countries, including further understanding the optimum mode[s] of delivery in any country or cultural setting. This work can be informed by literature on the cultural adaptation of interventions usually developed in high-income countries, enhanced understanding of the experiences of AFMs from indigenous populations and low- and middle-income countries and a more nuanced understanding of how the SSICS model may vary for different cohorts of AFMs such as how different coping styles moderate stress, strain and family burden [34–37]. Further work could also explore the potential for the intervention to be applicable to members of wider social and community networks who can also be harmed by the alcohol or drug use, or gambling behaviours, of others [38, 39]. Finally, there is a need to build on the limited work that has been undertaken thus far to develop web-based versions of the 5-Step Method and Steps to Cope, including how such support could be offered in countries where the capacity for accessing such support may be more limited.

Future work must also increase the use of the FMQ or READ in all settings where either intervention is used, so that the evidence base can continue to grow. In some settings completion of the questionnaires is seen as additional burdensome paperwork, thereby affecting its use and subsequent sharing of data with AFINet. To help overcome this barrier, there needs to be greater emphasis on the differing functions of the FMQ as a therapeutic tool that is relevant throughout an intervention, a useful tool for research and evaluation and, in some countries (such as the UK and Ireland), a necessary tool to support the commissioning of services. In New Zealand FMQ findings have helped to secure government funding for the national Family Drug Support service. Further research involving the various outcome measures could also be conducted to include, for example, longer-term follow-ups, undertaking larger-scale research trials of effectiveness including comparison with other family-focused interventions and comparing different modes of delivery, building on some of the 5-Step Method research reported above.

One aspect of the 5-Step Method/Steps to Cope programme where there has been limited work is understanding the potential cost savings of such an intervention. One cost-effectiveness analysis in Mexico, conducted with indigenous women affected by another's alcohol use, reported that the 5-Step Method was more cost-effective when compared to the provision of pharmacological treatment, both in terms of the cost of treatment in primary mental health care and the reduction of symptoms of depression [40]. Advancing this aspect of the work is important in light of the evidence that there is a high engagement rate of both interventions and positive outcomes such as lowering physical and psychological symptoms, both of which could be associated with a potential reduction of pressure placed on health, social care and other community services. This thread of work can be contextualised by research that has estimated the economic impact that AFMs can place on healthcare services and wider society, both negatively through days lost due to work-related absence and positively because of the 'invisible' care that they provide [41].

Having a structured model that can be implemented with some flexibility is a key strength to the 5-Step Method and Steps to Cope. Yet, there are real challenges, locally and nationally, with introducing and sustaining the intervention in almost any location globally. The key driver to change here is international and national policy (see also Chap. 13 of this volume). Generally, the attention given to AFMs in policy is to be found seriously wanting, although there are encouraging signs of change with a small number of countries, such as Ireland, Scotland, Quebec in Canada, and New Zealand specifying the need to

better support AFMs in their own right in key policy documents [42–45]. In Ireland, this commitment is supported by the addition of data fields about AFMs to the national treatment monitoring system; currently, this is the only European country to collect such data, although it remains voluntary [46]. However, attention is urgently needed to ensure that these policy aspirations are followed through, with the provision of an adequate level of services and interventions to AFMs. Success is more likely if there is commitment to supporting AFMs by all levels of a service or organisation, if AFMs are given equal status to those who are using alcohol or drugs or gambling in treatment services and if there is recognition of the time needed for support to AFMs to be implemented in a way that is sustainable in the long term.

In 2010, reflections on the 5-Step Method programme of work identified a number of 'future directions' [47], namely, ongoing intervention development including evidence of effectiveness and implementation; enhanced theoretical understanding of the SSICS model, testing suitability for particular groups of AFMs and accounting for the increasingly flexible ways in which 'family' is defined around the world; exploring different ways of delivery including digital options; expanding the research evidence to include larger samples and longer-term follow-ups; and cost–benefit work. This chapter has shown that progress has been made with all of these future directions, extensive in some cases, limited in others. There is encouraging international evidence that the 5-Step Method is an appropriate, flexible and culturally adaptable response to a global public health issue, with the potential to offer tangible hope for millions of AFMs. Yet, policy voids are greatly limiting what such work can achieve. There is an urgent need for elevated global policy recognition of the plight of AFMs and the need to adequately support them in their own right. This needs to be fully supported by national and local practice frameworks, and accompanied by sufficient resourcing, to introduce and embed evidence-based interventions such as the 5-Step Method and Steps to Cope, as well as a variety of other ways of supporting AFMs, routinely and sustainably, in a range of health- and social-care settings.

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19 Community Reinforcement Approach and Family Training (CRAFT)

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Community Reinforcement Approach and Family Training (CRAFT) is aimed at offering addiction-affected family members (AFMs) both support and strategies to increase the likelihood that the person with addictive behaviors, such as alcohol, drugs, or gambling, reduces alcohol consumption, drug use, or gambling and/or seeks treatment. The treatment traditions that CRAFT is making use of originate from Motivational Interviewing (MI) and Cognitive Behavioral Therapy (CBT), both of which are central interventions in the treatment of patients suffering from addictive behaviors.

It is a central assumption in CRAFT that behavior is learned through the experience of rewards that result from the behavior [1], either when something that is regarded as valuable increases, for example, feelings of happiness following exercise (positive reinforcement), or when something regarded as negative decreases, for example, feelings of stress when listening to music (negative reinforcement). Positive reinforcement is therefore considered an effective method for stimulating one form of behavior over another [2], assuming that the individual will be more inclined to repeat a behavior that leads to a reward and less likely to engage in a behavior that leads to difficulties or the loss of a reward. This way of understanding behavior and behavior change is supposed to help the AFM regain control in situations that might otherwise be experienced as being completely at the mercy of another person's drinking or drug use.

The CRAFT intervention itself is structured, but it is also flexible and should be adjusted to the needs of the AFM. A CRAFT intervention will typically consist of an initial, 'diagnostic' session with the AFM and several subsequent sessions. During the first conversation with the AFM, it is important to get a sense of what is at stake for the AFM. For many AFMs, meeting with the therapist is the first time they share their experience of being an AFM. During the first conversation, the therapist should examine at least the following: How is the quality of the relationship? Does violent behavior occur in the relationship? How and in what situations does the identified patient (IP) drink, use, or gamble for the time being? What is facilitating the substance use? Are there any appropriate (non-addictive) behavior now? If there is, how are those behaviors supported? How do the

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Table 19.1 Themes in CRAFT

Building up hope	Encourage hope in the AFM
Prevention of violence	Assessing the risk of violence and securing strategies to prevent it
Quality of life	Developing strategies to improve the AFMs' quality of life, in particular installing social support
Functional analysis	Functional analysis is a tool for analyzing behavior and how it is facilitated by context, expectations, and feelings. It is a structured way of identifying aspects that might be an option for change
Communication training	Aimed at installing the ability to perform positive and clear communication
Reinforcement of positive behavior	Development of strategies to reinforce positive behaviors of the IP that does not involve alcohol or drug use
Allowing natural consequences to happen	Identification of AFM's behavior that unintentionally facilitates IP's alcohol or drug use by removing the natural consequences of it and the development of alternative strategies, if wished for
Introducing treatment	Insight in the treatment possibilities and assessing when and how to introduce the option of treatment to the IP

AFM and the IP communicate? Has the substance use been discussed? How did the IP react during discussions? Is there a risk of violence? Most importantly, how burdened does the AFM feel?

During the following sessions, a series of themes will be introduced (Table 19.1), and in connection with them, the tools will be used and trained [1]. The central themes in a CRAFT intervention are building the AFM's hope for change, strengthening the mental health and quality of life of the AFM, gaining insight into what drives behavior, preventing violent behavior, making use of the positive reinforcement strategy and allowing natural negative consequences to occur, and helping to initiate treatment for the IP.

Prevention of violence and abuse implies an ongoing constant focus on the risk of violence throughout the CRAFT intervention and, if relevant, developing a plan together with the AFM on how to deal with and avoid a potentially violent situation. Should a critical situation arise in the interaction between the IP and the AFM despite attempts to predict and prevent it, the AFM should be prepared. The therapist should therefore develop an emergency plan together with the AFM. An emergency plan involves, for example, packing the most necessary things so that the AFM can go away for a few days: some clothes, toiletries, any papers, money or credit cards, etc.

The next theme in CRAFT is ensuring the AFM's quality of life, regardless of what the IP does or does not do. First step is assessing the areas of the AFM's life where improvement may be needed, and the therapist and the AFM together can consider which areas of the AFM's life that need improvement and brainstorm on possibilities and strategies to accomplish a change. When the AFM has chosen which areas need to be improved and the strategies for how this can be achieved, the therapist can anchor the decision by writing up the specific plan together with the AFM, including formulating goals and sub-goals.

Another central theme in CRAFT is the functional analysis, which is used to help the AFM to rationally analyze situations with drinking, use, or gambling, so that the AFM can better influence them. The functional analysis is considered as a tool for the AFM to analyze alternatives to simply reacting spontaneously and emotionally, and instead reacting carefully and constructively, so that the AFM gains more control over the situation. Functional analysis is introduced to the AFM by explaining how behaviors always have a purpose or a function, although not always a well-functioning or an appropriate one. A functional analysis is an attempt to take a step back and examine from a distance what leads to a specific behavior or action; what the behavior or action is supposed to ensure; and what consequences it has in the short and long term [3]. The functional analysis is thus an attempt to understanding what drives behavior related to situations with the addictive behavior. The functional

analysis may also be used to try to understand what drives positive, sober, and non-using behavior or what drives violent behavior. The therapist trains the AFM in analyzing a typical, but specific, situation—a specific day, at a specific time.

Since communication in families or in relationships with persons with addictive behavior is often strained, communication training is a central and well-liked theme in CRAFT. This theme is aimed at training AFM in positive, direct, assertive, and clear communication in general and with the IP. The theme involves a lot of specific training. Small role-plays are used, allowing the therapist and AFM to train communication in specific situations until the AFM feels comfortable and able to use the strategies in real life.

Making use of positive reinforcement for sober or non-using behavior, allowing natural negative consequences of the addictive behavior to occur, and training on how to implement these strategies in daily life are some of the key markers of CRAFT. It might be where CRAFT differs the most from other kinds of interventions for AFMs. These themes imply paying attention to aspects of the AFM's own behavior that may be effective in motivating the IP to change his or her behavior. Positive reinforcement is focused on making the sober or non-using life attractive for the IP—and hopefully also for the AFM. For most AFMs, this theme leads to new insights, involving taking the perspective of the IP into account and in a positive way. An example can be the AFM arranging an activity for both him- or herself and the IP, an activity that the IP finds attractive and that will take place only if the IP is sober, or giving active, positive feedback when the IP shows sober and wished-for behavior.

When the AFM has understood the rationale behind the positive reinforcement of behavior, the AFM can develop a list of sober and wished-for behaviors or activities that may be reinforced. The list of rewards can include anything that the AFM considers the IP will perceive as positive, i.e., a list of things or activities that give the IP so much pleasure that it may motivate the IP to change their behavior. Obviously, it is also important to create a clear link between the wished-for behavior and the rewards. Allowing natural negative consequences of the addicted behavior to occur without mitigating them or removing them often implies a new way of thinking for most AFMs. Natural negative consequences can be, for example, covering for the IP if the IP is drunk or cleaning up if the IP has messed up. It may sound simple, but for many AFMs it can be transgressive and difficult. Whether or not the AFM wishes to allow natural negative consequences to occur is thus—like all the other themes in CRAFT—solely to be decided by the AFM. In fact, it is perhaps the most central aspect of CRAFT not to put pressure on the AFM, but to entirely focus on what is most helpful for the AFM and what he or she wishes support for. If willing, the AFM can develop a list of natural consequences of the addiction that the AFM might decide to allow to happen without mitigating them.

The last theme in CRAFT is how to help the IP with treatment-seeking, including informing the AFM about the treatment options for the IP and how to access them. The aim of this theme is to ensure that the AFM has the ability to advise the IP as best as possible. It includes, for example, very basic information about the address of the treatment institution, when it is open, and what will happen when the IP shows up. In the United States, CRAFT may include direct access for the IP to treatment, if the AFM has signed up for a CRAFT intervention. In most European countries, however, access to treatment is easy and without costs for the IP, which is important information. The theme also includes practical information, insight in what treatment involves, the risk of relapse, and how the AFM can support treatment-seeking. Also of importance, the theme involves exploring how to choose the right moment for introducing treatment-seeking to the IP, for example, not introducing it when the IP is under the influence of alcohol or other substances or when agitated.

Throughout the themes, a series of tools are introduced, in particular brainstorming techniques, problem-solving strategies, and the use of role-plays between the AFM and therapist, in order to try out how to handle specific situations.

It is also recommended that the AFM write a diary as a means to seek relief and document change and progress.

19.1 Evidence on CRAFT

The efficacy of CRAFT has primarily been investigated with AFMs of people suffering from alcohol use disorder (AUD), substance use disorder (SUD), and gambling. Most studies of CRAFT have been performed in the United States [4–13], but there have also been studies on CRAFT conducted in Denmark [14], Germany [15], Sweden [16, 17], Spain [18], and Canada [19–21].

The main goal of CRAFT is to motivate the IP to seek treatment, and thus, treatment-seeking of the IP has been the primary outcome measure in most studies. Most studies have included AFMs of IPs suffering from AUD [4, 5, 13–17]. Slightly fewer have included AFMs of IPs with SUD [6, 8, 10, 11, 18], two of them including AFMs to adolescents [11, 18]. A few studies have included AFMs of IPs where both AUD and/or SUD were allowed [7, 9, 12] or on AFMs to IP with gambling problems [19–21]. CRAFT has been demonstrated to be twice as effective in engaging IPs with AUD/SUD in treatment, compared to other comparison groups, e.g., the Johnson Method or Al-/Nar-Anon, or a control group without an active intervention [22]. The treatment entry rates for IP with AUD/SUD were between 40 and 86%, and the treatment entry rates for IPs with problematic gambling were 12.5–23% [19–22].

Various formats of CRAFT have also been studied. The individual format of CRAFT has been reported to lead to treatment entry rates for IPs with AUD between 39–64% [14, 22] and 59–74% for IPs with SUD [6, 8, 10, 11], 55–63% for IPs with AUD and/or SUD [7, 12], and 12.5% with IPs with gambling problems [21]. The format reported to lead to the highest treatment engagement rates is the individual format combined with group sessions, with IP engagement rates ranging from 77 to 86% [4, 6]. It should though be noted that in these studies, both the AFM and the IP could book treatment appointments directly, which may have affected the outcome.

Group format is considered a cost-effective way of providing CRAFT and may be just as effective as individual CRAFT [9, 14]. Within 6 months, CRAFT offered in a closed-group format has been reported to lead to an IP treatment entry rate of 60% [9], whereas CRAFT offered in an open-group format has a treatment entry rate of 49% [14].

CRAFT delivered in a self-help format may be particularly cost-effective and flexible. Self-help materials offered to AFMs of IPs with AUD and/or SUD have shown treatment entry rates of 32–40% after 6 months, a rate not significantly lower than the individual format or group format [9, 14]. Self-delivered formats aimed at AFMs of IPs with gambling problems showed treatment entry rates ranging between 13 and 23% at 3–6 months follow-up [19–21].

CRAFT in an internet-based format, offered to AFMs of IPs with AUD, showed a treatment entry rate of 21.3%, which is not significantly different from a waitlist control condition [16].

Originally, a CRAFT intervention consisted of 12 sessions, but the efficacy of shorter versions of CRAFT has since been investigated. For example, one study tested a version of CRAFT called TEnT, which focused on treatment entry and communication training only, in four to six sessions. There was no difference in treatment engagement for the AFMs who received full CRAFT (12–14 sessions) and the ones receiving TEnT [7]. In another study, the number of sessions offered in either individual or group format was reduced to six sessions involving all themes of CRAFT and showed a treatment rate of 49% after 6 months [14].

19.1.1 Improvement/Influence of the Well-Being of the AFM

Besides treatment entry, some studies have considered other aims of CRAFT, such as the AFM's quality of life and mental health. Two studies of AFMs of IPs with AUD who received CRAFT in an individual format, one of which was internet-based, found a significant increase in mental health and relationship happiness at the 3-month

follow-up, compared to AFMs randomized to a waitlist condition [15, 16]. In most studies, the quality of life and functioning of the AFMs improved over time when receiving an intervention, but no differences were found between types of interventions, neither between different formats of CRAFT [8, 11, 14] nor between CRAFT and other types of interventions [5, 6]. In a study of parents of adolescent drug users, the parents receiving the CRAFT intervention experienced a significant reduction in negative symptoms, including self-esteem, depression, and anger state, and a decrease in negative moods [18].

Even though several studies have showed improvement in health and quality of life following a CRAFT intervention, some studies have been negative in this respect. A study of AFMs of people with AUD and/or SUD showed that AFMs' symptoms of depression, efficacy, physical symptoms, anger, and anxiety did not decrease significantly from the baseline to the 3- or 6-month follow-up. In this study, AFM reports of family cohesion and family conflict significantly improved from the baseline to the 3- and 6-month follow-up. However, no between-group differences on any of the measures of AFM or family functioning, with the exception of AFM efficacy, were found [9].

Another study with AFMs of people with alcohol and/or drug problems AFM mood and functioning showed no significant between group or interaction effects. However, depression, anxiety, and anger expression decreased over time, indicating improvement in all three groups [7].

In the three studies with AFMs of people with gambling problems, the AFMs' personal functioning and relationship functioning were assessed. The participants displayed significant improvement overall, but there were no differences between the CRAFT group and the control group at the 3-month follow-up [19–21].

19.2 Qualitative Studies

So far, only a few qualitative studies of CRAFT have been performed [23, 24]. The main focus of these studies has been to investigate experiences of CRAFT among participants and therapists, for example, regarding what elements in CRAFT were more or less useful and easy to learn and in what way CRAFT may be improved. Based on interviews with AFMs, it has been found that some of the CRAFT themes seem more relevant to AFMs and are easier to learn than others. "Quality of life," "communication training," and "positive reinforcement" were themes that the AFMs found useful and relatively easy to implement. "Functional analysis" was described as creating an overview useful for applying other CRAFT strategies [23]. The AFMs also described that the knowledge gained from CRAFT made it easier for them to distance themselves from the IP when necessary. When the AFMs learned to separate themselves more from the IP and prioritized their own interests, they experienced improvement in quality of life [23].

Even when AFMs could not motivate their IP to treatment, they considered that their quality of life and their relationship with the IP had improved after participating in CRAFT. Even the ones who had decided to leave the IP, either immediately before, during, or after the CRAFT intervention, found that their relationship with the IP had improved and that their satisfaction with their life had increased after participating in CRAFT [23].

In a Danish study of CRAFT, a self-help book [25] was part of all three interventions (individual, group, and self-help) and the only source of information and help for the AFMs in the self-help group. AFMs from all three groups were pleased with the self-help book. Some AFMs found it helpful to read the material before each session, and other AFMs liked to use the material to brush up on the themes after the sessions [23].

The therapists reported that it was easy to adapt to CRAFT, in particular when the therapist was already trained in MI and CBT. Some therapists even felt that their role as therapists changed after they began working with CRAFT into a more professional role. Before they were trained in CRAFT, they felt they were more on their own and primarily offered support to the AFMs. CRAFT seemed to give the therapists action competences [24]. The therapists considered the self-

help book helpful and possibly even an essential supplement during the intervention. However, the therapists also considered that most AFMs needed more help than a book could give [24].

19.3 Critical Discussion on the Method and Evidence

While there is a consensus among many that CRAFT is beneficial for many AFMs, and by extension also for IPs, several issues have been raised regarding the scientific evidence of the method, as well as regarding the content and administration of CRAFT.

The most commonly raised issue concerns the remarkably large variability in treatment engagement for IPs, which in most studies has been the primary outcome measure [22]. Variability in the effects of interventions is, of course, not something reserved for the CRAFT method and may occur due to many reasons, such as the therapist's compliance with the manual, characteristics of participants, and the context in which the treatment is provided. However, treatment engagement rates vary between 13% and above 80% across CRAFT studies, naturally raising questions about how to better understand in depth the reasons behind this variation.

First, it must be stressed that the scientific quality of many of the studies forming the basis of evidence for CRAFT has been deemed low. For example, in a recent systematic review, Archer et al. [22] concluded that only 2 of the 14 included RCTs reached even a moderate level of quality, while the remaining 12 studies received a low rating, according to the Assessment Tool for Quantitative Studies (EPHPP) [26]. Several studies were identified as having a risk of bias in important domains such as participant selection, blinding, and data collection method. These deficiencies, of course, create a challenge regarding the trustworthiness of the results obtained in the field. It is important that future studies on CRAFT are conducted to ensure good scientific quality and transparency in procedures, for example, through pre-registered study protocols and study data accessible on demand by other researchers.

Several aspects that overall pertain to the contextual factors in which CRAFT is delivered have been pointed out as contributing to the large variability in treatment engagement rates. Contextual factors are probably also a contributing factor to the large differences between studies conducted within versus outside the United States. Many American studies are conducted within an "integrated" treatment approach. These designs imply that it is common that *either* the AFM or the IP can contact a pre-specified treatment center, often the same center in which the CRAFT is delivered to the AFMs [5, 6]. It is not reported in the studies how large the percentage is of either the AFMs or IPs among those who contact the center for an appointment intended for the IP. The integrated treatment approach further in some cases implies that the IP is offered treatment as part of the study, sometimes together with the AFM. It is difficult to regard both of these components of an integrated treatment approach as components of CRAFT, since the same conditions apply also for the control conditions in these studies. Together, there are indications that the integrated design inflates treatment engagement rates also in the control condition. To illustrate, in Meyers 2002, the control condition (Al-Nar), was chosen with the purpose of not including components that actively promoted treatment engagement among IPs. However, the treatment engagement rate for participants in Al-NAR was 29% in the study, which is a figure not particularly lower than the engagement rates of CRAFT interventions in studies conducted without the possibility of a pre-arranged treatment engagement procedure [14, 15, 17]. An even higher proportion of treatment engagement was found in a more recent study [7], where 37% of the control group (Al-Anon) entered treatment.

Other important differences are more general aspects of treatment organization and availability [15]. In Europe, treatment for substance use disorder (SUD) is most often free of charge. This is more seldom the case in the United States. This may create a bias in which the relative benefits of taking part in a research study or receiving treatment free of charge within the context of a study

inflate engagement rates compared to a European context.

Further, actual or perceived availability of treatment varies between countries and regions. This has been suggested as a contributing reason for low treatment-seeking rates in several studies on CRAFT for AFMs of people with gambling disorders [19]. If treatment options are scarce, as has been proposed to be the case for gambling disorder [27], and if treatment may not even be seen as an option even if available, treatment engagement rates may not be expected to be high, even if CRAFT is delivered according to protocol.

Furthermore, in some CRAFT studies, participants have been recruited nationwide [16]. For natural reasons, in these studies it has not been possible to refer participants to specific clinics; instead, participants have been supported in locating treatment options for the IP in their home area. This results in different participants having very different conditions to find good alternatives to treatment for their IPs, even if the IP would be inclined to seek treatment. The strength of studies conducted without connection to a specific addiction treatment clinic is a high level of ecological validity, perhaps providing an indication of the effect of CRAFT alone without the possibility of referring to a certain treatment clinic or integrated treatment.

There is also a lack of studies on treatment components that contributes to the efficacy of CRAFT. In one study [7], a shortened version of CRAFT, including primarily components related to facilitating treatment-seeking, was compared to standard CRAFT and Al-Anon. No difference was found between standard CRAFT and the shortened version, indicating that if treatment-seeking for the IP is the goal of treatment, a specific focus on this aspect may suffice. Another related aspect is the number of sessions provided to the AFM, which has varied between studies, ranging from 4 to 14. The conclusion in the systematic review conducted by Archer et al. was that the number of sessions offered was not related to the rates of treatment entry [22]. To summarize, in-depth studies on which components contribute—and which components perhaps do not contribute—to treatment outcomes are lacking, and more research is warranted to elucidate this question.

There is a lack of knowledge regarding what characterizes AFMs that are successful in engaging the IP in treatment. Few studies have related treatment engagement to either AFM or IP characteristics and pertain at best to secondary analyses in clinical trials. It is safe to propose that individuals affected with SUD, as well as their family members, vary considerably. For example, AFMs may have different reasons for seeking help, and treatment engagement for the IP may not be the most important goal of treatment for all. Other factors such as previous treatment-seeking for IPs, psychiatric comorbidity, age, SUD severity, and stage of change of use may contribute to the inclination to seek treatment.

Lastly, when assessing the studies on CRAFT performed so far, it becomes clear that a few researchers have participated in relatively many studies. Furthermore, some of the researchers are also paid trainers in the method, but conflict of interest is not declared in the papers. Not declaring conflicts of interest despite the researcher having an income stemming from disseminating a particular intervention is not special to CRAFT, but is a usual practice in studies of other psychosocial interventions. Nevertheless, such a potential conflict of interest is concerning, and the practice should be changed.

19.4 Conclusion

To conclude, we propose that future comparisons between studies regarding the efficacy of CRAFT need to take contextual aspects into account. We claim that it is almost like comparing apples and pears to compare studies with very different conditions built into the study design. We do not claim that one design is necessarily better than another, but rather that one should expect different outcomes of CRAFT, depending on different circumstances, and that taking these conditions into account can fruitfully increase knowledge about how to provide the best support to AFMs.

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Family Therapy for Addiction

20

Abhijit Nadkarni

20.1 Introduction

Addiction is a multifaceted disorder characterised by the intricate interplay of neurobiological, psychological, and social elements, leading to the development of persistent maladaptive behaviours that become increasingly resistant to change over time. These behaviours encompass the stimulation of brain systems associated with adaptive motivation, learning, executive control, reinforcement, maladaptive cognitive processing, deficits in self-regulatory capacities, and social influences from family, friends, and extended social networks, all operating within a broader sociocultural context [1]. The convergence of these factors initiates processes that, once activated, become self-sustaining.

This chapter directs its focus towards interventions involving the family as a crucial social factor intersecting with addiction. For the purposes of this chapter, the family is defined as a group of individuals sharing affection and responsibilities. As explained in Chap. 3, addiction can be viewed as a manifestation of dysfunctional relationships and interactions within the family. In such scenarios, the family, with its intricate network of relationships and behavioural interactions, emerges as the most suitable unit for intervention. This approach necessitates an exploration of the nuanced, overt, and complex dynamics of family interactions, shifting attention from merely medical symptoms and individual psychodynamics.

Addiction is not an isolated phenomenon but exists within interactive and dynamic systems, such as the family. On one hand, the family's efforts to adapt to and accommodate the individual's addiction may perpetuate the problem, while on the other hand, the family can play a pivotal role in promoting recovery. The broader family context is associated with various adverse outcomes, including impaired relationship functioning, frequent intimate partner violence, and marital dissolution [2–4]. Children with one or both parents experiencing addiction face an elevated risk of many adverse outcomes, including engaging in substance use themselves and associating with deviant peers due to inadequate parental monitoring ([5, 6], Chap. 5 of this volume).

It is precisely due to these reasons that family therapy situates the individual's addiction within the wider context of the family. This therapeutic approach delves into communication patterns within the family, fosters an understanding of family dynamics, and explores their intersection with the family member's addiction. The objective is to facilitate collaborative problem-solving, mediate conflicts, encourage open communication,

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validate difficult emotions in a safe setting, and empower family members through a deeper understanding of substance use and each other [7]. The theories and concepts of family therapy gained prominence in the 1950s, with the application of research findings to addiction treatment gaining traction from the late 1970s [8].

20.2 Family Therapy: Underlying Theories

As described in the following section, there are a variety of effective interventions that engage family members in the treatment of addiction. Underlying these interventions are a range of theories that define the different ways of modelling or approaching the relationship between addiction and family. The following section summarises the key underlying assumptions of some of the most prominent theories.

20.2.1 Family Systems Theory (FST)

The fundamental principle of family systems theory (FST) is grounded in the idea that each individual is an integral part of a larger whole: the family. The interactions among the individual components (family members) within this holistic system profoundly influence the life of each individual. Consequently, any alteration in one aspect of the system triggers a cascading effect, leading to changes throughout the entire system [9]. Bowen's family systems theory describes the following fundamental principles: (1) undifferentiated fusion of the emotions of the parents leads to marital conflict, polarisation and alienation in the spousal relationship, and psychological impairment in the child; (2) coping strategies, themes, and roles pass from generation to generation; (3) parents transfer their anxiety levels and their levels of emotional differentiation to their children, who are then identified as the source of the family's dysfunction; (4) sibling birth order makes a significant contribution to personality characteristics; and (5) family members may withdraw emotionally from the family to regulate unresolved attachment [10].

20.2.2 Structural Family Theory (SFT)

According to SFT, difficulties within the family system result from an imbalance within the structure of the family, dysfunctional relationships, inappropriate boundaries, and negative communications between parents and children. According to this theory, the three types of families are as follows:

(a) Disengaged family, which is characterised by rigid boundaries and limits; poor communication, cohesion, and relations between the family members; and the lack of support between them.
(b) Enmeshed family, which is characterised by poor boundaries and limits between parents and children, resulting in children being very dependent on their parents and having difficulties in developing their own identity and self-image.
(c) Adaptive family, which lies between the first two types and is characterised by clear boundaries, limits, communication, and relations within the family system. Adaptive families allow children to develop their self-worth and self-image, help them cope with close relationships in their adult years, and have a good ability to deal with the various problems in the lives of individuals and in the family system [11, 12].

20.2.3 Family Disease Model

The core tenet of the family disease model is grounded in the perspective that a substance use disorder is not solely a manifestation of the behaviours and thought patterns of the individual with addiction; rather, it is intricately linked to the dynamics of the entire family system [13]. Consequently, this model posits that treatment is necessary for all family members involved, recognising their roles in the collec-

tive disease. Dysfunctional relationships within the family contribute to the control, nurturing, and perpetuation of connections with the individual experiencing addiction [14]. This dynamic leads to a continuous preoccupation of the individual with their addictive behaviour, while family members, in turn, are persistently preoccupied with the pathological behaviour of the individual.

This ongoing preoccupation often gives rise to the development of defence mechanisms, including the denial of the problem and the displacement of responsibility. In essence, these defence mechanisms serve as coping strategies employed by both the individual with addiction and family members to manage the challenges posed by the addictive behaviour. The family disease model underscores the importance of understanding and addressing the collective impact of addiction on the family unit, recognising it as a shared challenge that necessitates comprehensive intervention.

20.3 Family Therapy for Addiction

Overall, interventions that involve family members in treatment have a significant effect on reducing the severity of the addiction (e.g. approximately three fewer weeks of substance use per year), with consistent impact across different treatment models, participant and study characteristics, and types of comparator treatments [15]. Couple therapies such as alcohol behavioural couple therapy (ABCT) and behavioural couples therapy (BCT) have been demonstrated to be effective in not just reducing substance use but also in improving the partner's skills to facilitate the reduction, enhancing the functioning of the relationship, and reducing maladaptive couple behaviours and intimate partner violence [16, 17]. However, while couple therapies could be conceptualised as a subset of family therapy, they will not be covered in this chapter and have been comprehensively described in Chap. 21. In the following section, we will focus on examining a non-exhaustive list of family therapies for addiction.

20.3.1 Family Systems Approaches

While there is substantial evidence on the effectiveness of family therapy in general for the treatment of addiction, the evidence for family systems approaches is more robust specifically with adolescents who have an addiction [18]. Family systems approaches aim to change the structure and functioning of the family to change dysfunctional behaviours, i.e. addiction. Some major evidence-based family systems approaches are summarised below.

20.3.1.1 Brief Strategic Family Therapy

One of the key advantages of brief treatments is their suitability for short-term programmes and the potential to achieve change over a shorter duration than what would be possible with some of the other models. Brief strategic family therapy (BSFT) is one such brief treatment that can be applied to a variety of settings, including residential treatment and aftercare programmes, and can be used either as a primary intervention or as a supplement to other services. While the length of treatment can be tailored to the specific needs of each individual, the average duration of treatment is 12–16 sessions [19].

The focus of BSFT is on family interactions that reinforce or intensify adolescent substance misuse, and it has three main elements: joining, diagnosing, and restructuring [19]. 'Joining' involves building rapport and forming an alliance with the family, 'diagnosing' entails observing family interactions in order to identify those that will interfere with reducing addictive behaviours (e.g. inappropriate alliances, inadequate boundaries, and maladaptive communication styles), and 'restructuring' focusses on reducing conflict in the family through strategies such as directing, redirecting, or blocking communication; shifting family alliances; helping families develop conflict resolution skills; developing effective behaviour management skills; and fostering parenting and parental leadership skills [19, 20].

BSFT is effective in engaging and retaining adolescents and family members in treatment, reducing both adolescent and parental substance use, improving family functioning, reducing

arrests and incarcerations, and reducing externalising behaviours such as aggression [21, 22]. However, BSFT is a complex treatment with low fidelity in community-based settings and hence has intensive requirements with regard to training and supervision [23].

20.3.1.2 Multidimensional Family Therapy (MDFT)

MDFT is based on the key principle that adolescents are greatly influenced by their support network, and the intervention addresses factors that underlie emotional and behavioural symptoms that coexist with the addiction, for example, family relationship factors, parenting practices, and family conflicts and communications [24]. MDFT consists of three stages: enhancement of treatment motivation, forging of multiple therapeutic alliances, and drafting of the treatment plan (Stage 1); strategies aimed at the adolescent and family to improve family communication and relationships, strengthen competent parental practices, and help the adolescent develop more adaptive and prosocial coping skills (Stage 2); and developing a relapse prevention plan before completing treatment (Stage 3) [25].

While it has been examined in diverse geographies and populations, most participants in MDFT studies have been from low-income, inner-city communities. MDFT has been tested in high-risk early adolescents, older adolescents with multiple problems, adolescents in the juvenile justice system, and adolescents with substance use disorders comorbid with mental disorders. There is substantial evidence indicating that MDFT is superior or equal to other types of established drug misuse treatments such as cognitive behaviour therapy at improving a number of drug use and related outcomes (e.g. problem behaviours, family functioning) [25]. MDFT has also been shown to improve family functioning and can be an effective alternative to residential treatment for some adolescents [22, 26].

20.3.1.3 Multisystemic Therapy (MST)

MST is a behavioural intervention that has no predetermined techniques, with goals being established in consultation with the family members. MST closely explores family features such as conflict, discipline, and parental substance misuse. Importantly, when feasible, the family caregivers are the ones delivering the intervention to the adolescents [27]. While the treatment plan is individualised to address specific needs of the adolescent and their family, a critical component involves working closely with other social systems such as schools and peer groups. Based on individual requirements, the treatment focusses on cognitive and/or behavioural change, communication skills, parenting skills, family relations, peer relations, school performance, and/or social networks [28]. The core steps of MST include a comprehensive assessment of child development, family interactions, and family members' interactions, collective identification of a well-defined set of treatment goals, assignment to family members of tasks required to accomplish the goals, and monitoring of progress in regular and frequent family sessions in the family's home [28].

20.3.1.4 Ecological Interventions

Ecological interventions draw on MST models which focus on the young persons' broader ecology in addition to their family dynamics. One such example is the ecologically based family therapy (EBFT), which is influenced by multisystemic family therapy models as well as family preservation and crisis intervention approaches which focus on helping runaway adolescents reunite with families and reduce their substance misuse and other risky behaviours [29].

The intervention can be delivered in the home and community; and it appears to address many barriers typically presented by the most severe drug-misusing adolescents and their families [30]. As such, the EBFT is a significant advance in potential care options for adolescents who are runaways and homeless, a population that has historically been less amenable to family therapy.

Another example of an ecologically oriented family treatment is the Structural Ecosystems Therapy (SET) [31]. The added benefit of such ecology-focussed models over those that do not go beyond the family is that they intervene

directly within environments most influential in the adolescent's day-to-day life, e.g. home, school, and social services.

20.3.1.5 Functional Family Therapy (FFT)

FFT is a behaviourally based approach focussed on the maladaptive family patterns maintaining the adolescent's problems [32]. It aims to change negative family interactions by reinforcing positive ways of responding and effective problem-solving approaches. The three treatment phases of FFT include engagement and motivation (e.g. reduce blaming interactions through reframing), behaviour change (e.g. help parents implement consequences for substance use behaviours), and generalisation (e.g. teach families how to generalise newly learnt skills to situations beyond initial target behaviours). There is growing evidence supporting the effectiveness of FFT compared to other treatment approaches such as CBT and group counselling for adolescents [33].

20.3.2 Behavioural and Other Therapies

While family systems therapies are concerned with family functioning, behavioural family therapies are based on principles of learning theory and are focussed on altering reinforcement of substance use behaviour. However, we must be mindful that the lines distinguishing different therapeutic modalities are increasingly becoming blurred, as behavioural intervention programmes also focus on interactions, and thus include a systemic perspective.

20.3.2.1 Behavioural Family Therapy (BFT)

BFT applies to the family unit, well-established and evidence-based practices in substance use disorder treatment such as contingency management and communication skills training. BFT is based on social learning and operant conditioning theories that view substance misuse as a learned behaviour that members of the family may reinforce [34]. Hence the focus of the therapy is to support family members to engage in contingency management strategies that reward abstinence, reduce reinforcement of alcohol and drug use, and increase positive behaviours and social interactions incompatible with substance use. Additionally, the family members learn conflict resolution skills and, through cognitive restructuring, are helped by the therapist to replace self-defeating beliefs (e.g. 'He drinks heavily because he doesn't care about us'.) with those that facilitate recovery.

20.3.2.2 Solution-Focussed Brief Therapy (SFBT)

The foundational assumption of SFBT is that identifying the cause of problematic family functioning is not necessary and instead narrowly focusses on generating solutions to specific problems. More specifically, the therapist emphasises when substance use behaviour (the problem) does not occur and helps the family identify achievable solutions to effect behavioural change [35]. The techniques used in SFBT include developing a vision of the future (family members imagine life without substance misuse), asking the miracle question (eliciting each family member's vision of life without substance misuse), envisioning interpersonal change (helping family members set goals, respecting the views and needs of other family members), identifying exceptions to the problem, identifying the sequence of behaviours of all family members that contributes to the problem, and identifying the sequence of family member behaviours during an exception to the problem [36]. Unlike most other approaches, SFBT emphasises solutions for the future (instead of understanding the development of the problem in the past or its maintenance in the present) and a collaborative, solution-seeking relationship between the therapist and the family (instead of a traditional expert-directed approach aimed at correcting pathology). There is promising, but limited, evidence on SFBT's effectiveness in reducing substance use and improving comorbid mental health problems, such as depression and trauma, and reducing school- and work-related behaviour problems [37].

Table 20.1 Evidence base for different modalities of family therapy [39]

Type of intervention	Target group	Well established	Probably efficacious	Experimental
Systemic family therapy				
Brief strategic family therapy	Adolescents		✓	
Ecologically based family therapy	Adults		✓	
	Adolescents		✓	
Functional family therapy	Adolescents	✓		
Multidimensional family therapy	Adolescents	✓		
Behavioural family therapy				
Strengths-oriented family therapy	Adolescents		✓	
Family behaviour therapy	Adults			✓
	Adolescents		✓	
Multiple family therapy	Adults			
	Adolescents			✓
Behavioural family therapy plus other approaches				
Behavioural family therapy + motivational interviewing + cognitive behaviour therapy	Adolescents	✓		
Alcohol behavioural couple therapy + cognitive behaviour therapy	Adults	✓		

Finally, there is emerging evidence of Integrative Family Therapy models that combine core family therapy interventions with other therapeutic approaches to attempt to maximise the effects on youth drug use. While the evidence of such models is promising, more research is needed to test the effectiveness and to define the active ingredients. One example of such an approach is the integrated family and cognitive behavioural therapy (IFCBT) [38].

Table 20.1 summarises the evidence for some modalities of family therapy. Overall, systemic family therapy is well established as a standalone treatment, and while behavioural family therapy and behavioural couple therapy have some evidence of effectiveness as standalone treatments, they are well established as part of a multicomponent treatment [39].

20.4 Other Considerations

20.4.1 Theory of Change

The treatment mechanisms that have been studied in family therapy could broadly be categorised into (a) therapeutic alliance, therapist adherence, and competence, and (b) within-treatment parent and family changes.

Parent and/or adolescent alliance has been linked to less drug use and acting-out among adolescents, reductions in externalising symptoms at 6-month follow-up, reduced drug use up to 6 months posttreatment, improved psychological symptoms up to 3 months posttreatment, and reduced behaviour problems [40–43]. Similarly, adherence to family- and adolescent- focussed techniques and therapist competence is linked to less internalised distress, greater family cohesion, less family conflict, and fewer behaviour problems [44, 45].

Finally, changes in parental monitoring mediate reduction in adolescents' substance use and improvements in parenting practices (e.g. greater follow through with discipline) mediate reduction in antisocial and deviant sexual behaviours in juvenile sex offenders [46, 47]. These latter findings indicate that reducing negative parenting practices and strengthening parenting skills could well be the common factor that mediates positive outcomes in the adolescents.

20.4.2 The Reach of Family Therapy

(a) Low- and middle-income countries (LMICs)

Despite the substantial (and growing) evidence supporting the effectiveness of a variety of family interventions for addiction, their reach remains limited. Almost all the research and rigorously evaluated implementation of different types of family interventions for addiction have happened in the developed world. The evidence base from LMICs is limited. There are some studies from Brazil, Mexico, Vietnam, Iran, and Malaysia which have tested family interventions for addiction in predominantly female participants comprised of parents, spouses, and siblings. Some of the common components across the interventions tested in LMICs include providing information regarding addiction, improving communication, teaching coping skills, and providing support. Preliminary evidence from these studies indicates positive outcomes in family members affected by addiction such as lowering of psychological and physical distress, a better understanding of addictive behaviour, better coping, improvements in self-esteem, and assertive behaviour [48, 49]. However, this evidence needs to be interpreted with caution, considering the methodological limitations of the studies such as small sample sizes.

(b) Ethnic minorities

Based on existing evidence, mostly from the USA, some approaches such as the BSFT appear to be efficacious with some ethnic minorities [50]. However, not many rigorously conducted studies have substantial proportions of ethnic minority sub-samples. Some interventions such as the BSFT, MDFT, and FFT have been validated with Hispanic families in the USA, and MDFT and MST have also demonstrated effects in African American families [22]. Further dedicated research on family therapy approaches in ethnic minorities is a critical area for the future.

20.4.3 Sustainability of Family Therapy Effects on Drug Misuse

While there is consensus on the chronic relapsing nature of drug misuse and the importance of treatment approaches with sustained impact, research on long-term effects of family therapy is limited. Most studies of those with drug misuse generally measure follow-up outcomes up to a year following treatment. The limited research on long-term effects of family therapy approaches, specifically MST, has shown abstinence from marijuana 4 years after receiving the intervention and reduced arrests and days incarcerated 14 years post-intervention [51, 52].

20.4.4 Implementation Challenges

A key barrier to scaling up family-based treatments for addiction is the shortage of trained professionals. Training and supervision of therapists in evidence-based and manualised family therapy protocols is resource-intensive when implemented at scale. Extensive research has been done on the translation of research evidence on MST. Therapist adherence to research-based models has strong effects on outcomes achieved in clinical settings, but maintaining fidelity at scale remains a critical challenge. While high-quality supervision, therapist adherence, and organisational structure and climate all predicted outcomes 1 year after receiving MST, therapist adherence trumped all organisational variables in predicting outcomes at 4-year follow-up [53–55]. Another family therapy approach that was successfully integrated into a comprehensive day treatment programme is MDFT. In this programme, even 1 year after expert supervision was withdrawn, providers continued to deliver MDFT, clients continued showing better outcomes, and the organisational climate sustained positive changes [56].

20.5 Conclusion

In recent decades, there has been a substantial expansion of the knowledge base concerning family- and couples-based approaches and their application in the treatment of addiction. Families play a pivotal role in supporting individuals with addiction by helping them recognise the need for change, motivating their engagement in treatment, providing support throughout the change process, and fostering long-term recovery. The involvement of family members in addiction treatment has been shown to enhance the likelihood of positive outcomes for both individuals with addiction and their families. However, while family therapy has been found to be more effective than other treatments in adolescents with substance use, the evidence base is less clear-cut in adults. This chapter highlights various evidence-based family therapy approaches, emphasising the imperative to enhance providers' skills and increase the adoption of these interventions to enhance accessibility and broaden their reach.

Advancing towards these objectives necessitates heightened collaboration among community partners, researchers, administrators, and clinical providers. Future efforts should prioritise community-based research, multisite randomised controlled trials, implementation research, and a focus on diverse populations, including those in developing countries and ethnic minorities within developed countries. By addressing these areas, we can make significant strides in improving the quality and effectiveness of addiction treatment, ensuring that it is accessible and beneficial to a broader spectrum of individuals and families.

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Couple Treatment for Addiction

21

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21.1 Introduction

Addictions have numerous and serious consequences for the physical, mental, economic and social health of both members of a couple [1, 2] and negatively affect the functioning and quality of the couple's relationship [3]. Recently, various meta-analyses have confirmed that treatment for couples where one or both partners suffer from a substance-related addiction is just as, if not more, effective than interventions that do not include the partners of persons with an addiction (PPA) [4], even in situations of concurrent mental health disorders [5]. Studies have also documented the positive impact of couple treatment for addiction on the couple's children [6] and its positive cost-effectiveness ratio value [7]. The National Institute for Health and Care Excellence, which issues guidelines for health care in the United Kingdom, has recommended behavioural couple interventions in situations involving treatment for not only substance-related addiction but also less severe forms, such as problematic substance use [8]. This chapter focuses on couple treatment for problematic substance/gambling use and addiction.

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21.1.1 Problematic Substance/Gambling Use and Couple Relationships

There seems to be a bidirectional link, or even a circular causality, between couple satisfaction and problematic substance/gambling use. On the one hand, couples presenting with problematic substance/gambling use report more frequent relationship problems than couples without any addictions[1] [1]. Their conflicts are linked to relationship dissatisfaction, sexual dysfunction, communication and problem-solving difficulties, couple violence and a high incidence of separation [6, 9]. On the other hand, couples experiencing relationship distress are three times more likely to develop an addiction [10]. In short, problematic substance/gambling use is associated with an increase in couple problems, which in turn exacerbate use.

The concordance or discordance of partners' substance/gambling use also seems to influence couple satisfaction and plays a role in motivation to change. Among couples, discordance in alcohol use—where one partner drinks more than the other—creates more dissatisfaction and conflict in the couple than concordant use does [11]. The consequences of use seem more apparent and generate tension that facilitates intervention in discordant couples. They may present with more relational wounds (lying, disappearing or not fulfilling their responsibilities when using, etc.) than concordant couples do. Though problematic substance use is linked to dissatisfaction in couples regardless of concordant or discordant use, concordant couples report less relationship distress than discordant couples, particularly when partners use together [12]. In concordant couples, substance/gambling use can sometime become intertwined in positive aspects of a couple's life and be an obstacle to therapeutic work.

[1]Throughout the text, the terms "addiction" and "problematic substance/gambling use" have a generic meaning that refers to both substance use disorder and gambling disorder but also includes problematic use of substances or gambling whose severity is not sufficient to make a diagnosis.

21.1.2 Couple Treatment for SUD

Several couple treatment models have demonstrated their efficacy not only for treating addictions but also for improving couple relationships and reducing both partners' psychological distress. Among the five models identified, *Behavioral Couples Therapy* (BCT) [13] and *Alcohol Behavioral Couple Therapy* (ABCT) [14] are the best established models, having demonstrated their efficacy for alcohol and drug problems. Three other promising models have been developed recently. The first, *Systemic Couple Therapy* [15], was developed for women presenting with a substance use disorder, while the second, *Congruent Couple Therapy* [16], has proven its efficacy for couples presenting with addiction to alcohol and/or gambling. Both of these treatments focus on the couple as a system and on addiction as a symptom of a distressed relationship and/or the repetition of family of origin dysfunctional patterns. This focus on the dyad and the family system has the advantage of preventing professionals from falling into the trap of having an identified patient and of shielding partners from mutual blame.

The last model, *Integrative Couple Treatment for Addiction* (ICT-A) [17], developed by the authors of this chapter, draws largely on the ABCT [14] and was initially adapted for couples presenting with a gambling addiction. Like most addiction couple treatment models, the ICT-A has three objectives: (1) reduce or stop problematic use, (2) improve the couple relationship and (3) improve the psychological well-being of both partners. Using behavioural cognitive treatment, the ICT-A also incorporates aspects of systemic approaches, considering addiction not only as a primary symptom that needs to be treated. The substance use has a function in the relationship and may result to some degree from the couple's dysfunction. The ICT-A also draws on other general and integrative couple treatment models as well as intervention strategies that are recognized as being effective for treating addiction, such as motivational interviewing.

In a randomized clinical trial, the ICT-A proved to be superior to the usual individual

treatment for gambling addiction, improving both individual and couple well-being [18]. A second randomized clinical trial of the ICT-A is currently underway, with enhancement to the treatment model, integrating components of *Emotion Focused Couple Therapy* [19], with couples presenting with a substance and/or gambling addiction.

Lastly, the couple treatment models described above have certain limitations, including the fact that they were developed and evaluated in North America, mainly with white heterosexual couples where the man is the person with an addiction (PA) and usually for alcohol use disorder.

21.1.3 Couple Treatment, Problematic Substance/ Gambling Use and Sociocultural Diversity

There do not seem to be any gender differences in the efficacy of couple treatments when it comes to reducing use, even though women who present with a substance addiction are more likely than men to be in an intimate relationship with a person who has an addiction (PA) [20]. Female substance use and relapse are also triggered more often by conflicts or by their partner's use [1]. However, gender differences are observed with regard to the improvement of relationships. Men are more likely than women to report couple satisfaction following couple treatment for addiction [6]. A larger number of female PA prefer individually based treatment, citing family organization problems and lack of partner support as obstacles to couple treatment [1].

In the case of same-sex couples, those who present with an addiction to substances experience more couple dissatisfaction, conflicts and couple violence than heterosexual couples regardless of gender [9]. However, studies examining adaptations for sexual minority couples are scarce and warranted [21].

Though research has focused on the complex links between culture of origin, substance use and couple violence [22], no studies were identified on cultural adaptations of couple treatments for addiction and their efficacy. A person's culture influences their expectations of their couple relationship, substance/gambling use in general and its role in couple and family interactions. Culture influences a couple's expectations regarding not only the role of the therapist but also the ease with which the couple talks about emotions and problems [23]. Cultural and religious norms and expectations exert social pressure on the couple to comply by either using or maintaining control or abstinence. These norms and expectations will also affect the support given or judgements passed by members of their families.

In the absence of data on the efficacy and sociocultural adaptations of interventions with couples presenting with an addiction, using existing couple treatment models is recommended, while adopting a sensitive approach to diversity and to potential trauma linked to the stigma and discrimination experienced by couples from minority groups.

21.2 Initiating Couple Treatment

21.2.1 Conditions for Initiating Couple Treatment

The main condition for treating couples with addiction is that both partners must be engaged in the relationship, particularly when it comes to working as a team to instil change. If one of the partners is seriously considering separation, they may undermine the user's efforts to change. It is also recommended that the couple be in a relationship for at least 1 year if they do not live together, in order to build on a relationship that will last throughout the treatment. Some conditions should lead to the exclusion of couple treatment. It is not advised if medical supervision of withdrawal or inpatient services are needed or if one of the partners has an unstabilized mental health disorder. Also, when serious intimate partner violence is present, that is, one partner fears for their safety or of reprisals or has had physical injuries requiring medical intervention over the past year, couple treatment is precluded.

21.2.2 Structure of Sessions

Couple treatment for addiction typically comprises 12–20 sessions over 3–6 months, with each session lasting between 75 and 90 min. Most treatments suggest focus on the cessation or stabilization of substance/gambling use within the first half of the treatment. While the couple's strengths emerge when use decreases, new problems or major changes in the couples' dynamics may also arise. Strengthening the relationship is thus the focus of the second half of treatment. The following sections describe certain components of the assessment and the intervention strategies from the ICT-A.

21.2.3 Assessment

Both partners are assessed through joint interviews at treatment onset, and time is taken to discuss their treatment needs and expectations. Each partner also individually completes a series of questionnaires. The PA's assessment focuses on substance/gambling use (e.g. frequency, quantity, scale of the consequences and degree of addiction, reasons for using, motivation to change, history of use). The PPA's assessment focuses on their substance/gambling use, the consequences of the PA's problematic use, the PPA's reinforcing behaviours of substance use/gambling change or involuntarily reinforcement of use (e.g. Coping Questionnaire),[2] the PPA's confidence in the PA's ability to change and the extent to which they are motivated to support the PA. For both partners, the scope of certain emotions, such as discouragement and anger, must be assessed, as they may affect the couple's ability to work together. Both partners' subjective psychological well-being (e.g. WHO-5), general quality of life (e.g. WHOQOL-BREF) and quality of their social support (e.g. Social Provisions Scale) are assessed.

Couple relationship assessment measures include quality of couple satisfaction (e.g. Dyadic Adjustment Scale—Brief Version), marital commitment (e.g. Marital Status Inventory), perpetrated and experienced violent behaviours (e.g. Revised Conflict Tactics Scale – Short Form (CTS2S)), mutual support (Partner Support Questionnaire), communication styles (Communication Patterns Questionnaire) and attachment patterns in couple relationships (e.g. Experiences in Close Relationships—ECR12). Observing how a couple interacts during the sessions also sheds light on several of these aspects.

In addition to conducting assessment at onset, it is recommended that routine outcome monitoring be done. Short questionnaires are administered weekly during sessions to track changes in key components of treatment such as substance/gambling use, couple satisfaction and psychological well-being. Line charts of these measures are shared with the couple and provide an objective view of each person's progress, in addition to centring the discussion around key aspects.

21.3 Intervention Strategies

Table 21.1 shows the different components of the treatment in a temporal sequence and in relation to three intervention targets, namely, working on reducing the PA's substance or gambling use, working with the PPA and working on the relationship. Working on reducing substance/gambling use is done in a classic cognitive behavioural approach that is clearly described in a number of well-known textbooks [24].

21.3.1 Working with Partners

Working with the PA to reduce their use involves asking the PPA to share their view of the problems and to contribute to the solutions proposed. This approach also has an educational purpose for the PPA, as well as a positive impact on the quality of the relationship. Studies conducted with PPAs show that hearing about and gaining a different understanding of what the PA is going through is a positive aspect of the treatment, changing attributions towards the PAs and what

[2]The research protocol for the ICT-A and references for the tests used can be found in Tremblay et al. (2022).

Table 21.1 Therapeutic targets of the sessions in the ICT-A model

Sessions	Person with an addiction	Partner	Couple
1–2	• Sessions for assessing the two partners and the couple • Expectations and objectives of both partners • Treatment goals • Rules/expectations		
3	• Assessment feedback of both partners and their relationship • Weekly report on substance/gambling use and other measures • Ambivalence (if necessary) • Functional analysis of recent use	• Involvement of partner in the work on substance/gambling use • Ambivalence about changes made by the user or about changing one's own behaviours (if necessary)	• Mutual exchange of reinforcements • Initiating identification of the negative cycle of interaction about substance/gambling use
4–12	• Weekly report (*outcome monitoring*)		
	• Work on substance/gambling use • Functional analysis and self-observation – Identification and management of triggers, high-risk situations, underlying needs, erroneous beliefs and expectations • Development of skills and alternatives to using	• Involvement of partner in the work on substance/gambling use • Education on problematic use and the change process • Modification or elimination of behavioural triggers • Reducing addiction reinforcements • Increasing abstinence/reduction reinforcements • Self-care	• Negotiation of a substance/gambling use target • Mutual exchange of reinforcements • Modification of the negative cycle of substance/gambling use • Healing attachment wounds in the couple related to substance/gambling use
13–16	• Continuing work on substance/gambling use • Relapse prevention (aspects not related to the couple)		• Working together against addiction • Relapse prevention: substance/gambling use and negative couple interactions

is causing the addiction. PPAs also often feel excluded from addiction services and cut off from the user's experience [25].

Professionals will work with the PPAs on behaviours that reinforce use or change. Faced with the enormous stress caused by the PA's substance/gambling use, the PPA may adopt a number of coping styles. Some PPAs opt for withdrawal and tolerance strategies towards use, which are associated with more distress. When the PPA opposes substance/gambling use in an affirmative and supportive manner, their distress decreases, and problematic use may subside [1]. Treatment aims to help the PPA develop new skills for coping with the anxiety associated with a possible relapse. The couple will join to determine the role the PPA can play in different high-risk substance/gambling use situations (drink refusal, cravings, relapse, etc.) so that they can learn to deal with these difficult situations together. Finally, substance/gambling use sometimes fulfils certain needs in the relationship (e.g. having fun together) or for one of the partners, which have to be addressed for change to last.

21.3.2 Working on the Relationship

Bringing back positive interactions between the partners is usually the first target of this phase of the treatment. To foster mutual reinforcement of affection, pleasure and intimacy between the partners, the professional asks each one to identify small gestures that might bring joy to the other. Both partners then commit to spontaneously implementing some of these gestures between sessions [14]. Partners are also encour-

aged to resume positive shared activities. This aspect of the treatment is particularly useful for restoring positive exchanges and mutual affection in couples experiencing a great deal of distress. It also makes it possible to develop new loving behaviours and intimacy, so different from that which was associated with substance use. In the case of the PA in particular, rediscovering enjoyable moments that do not involve substance/gambling use can compete with the pleasure and relaxation formerly associated with their problematic use.

Couples in which one of the members presents with problematic substance/gambling use often present communication and problem-solving challenges [11]. PAs tend to avoid talking about their use, and when they do talk about it, both partners tend to display a great deal of emotion and negativity. Though many PAs are afraid of having to reveal hidden aspects of their use, they report that this is an important component of recovery [25]. Therefore, in the ICT-A, developing communication skills is mainly done by discussing situations surrounding substance/gambling use. The underlying assumption is that conflict over use leads to interactions that give rise to fears related to attachment needs (e.g. "Do I matter to you?") and that the communication cycle in that regard needs to be worked on. Such fears are activated easily when a couple argues about substance/gambling use problems. Clinical work will aim to restore a reassuring bond between partners so they can tackle, as a team, the core problem: substance/gambling use. Hence, the expression "Working together against addiction" has become a leitmotif of the ICT-A.

Typically, in the ICT-A, the couple is asked to describe how each partner interacts with regard to an incident of substance/gambling use. Drawing on the *Emotionally Focused Couple Therapy* [19], the professional will help them identify their negative interaction cycle. For example, a couple has fights about lies concerning substance use and broken promises to remain sober. The PA will express what Johnson [19] calls primary emotions, which are related to fears about attachment needs. These primary emotions are in opposition to the more overt secondary emotions of anger, wanting to attack the other person, wanting to withdraw, etc. Typically, the PA will explain how they use lies for fear of creating conflict if they reveal their substance/gambling use behaviours. Since the partners are committed to one another, it is likely that the PA will talk about how they risk being considered inadequate by the PPA and fear being abandoned by them. These are primary emotions. The professional will then turn their attention to the PPA to explore the same concerns. The discussion may help the PPA explain how the PA's lies hurt them, their fear of not mattering to the PA ("you would be honest if you loved me"). Once again, these are primary emotions. In this process, the couple realizes that outside of the treatment sessions, they are not expressing these fundamental messages to each other. Instead, they are expressing withdrawal, anger, criticisms, attempts to control the other person, etc. Throughout the treatment, the professional will invite both partners to do what Johnson calls "enactment", which means sharing their respective primary emotions. However, they must be expressed in a context where the other partner will listen openly. By better identifying this negative interaction cycle and developing the ability to express primary emotions, both partners slowly break free of this interaction cycle. Each partner comes to understand that they matter to the other and that they both want to re-establish a relationship where each person is valued and loved.

Through this process, both partners identify and understand the other person's emotional triggers. Explosions of anger, resentment and deep distress are often associated with fragilities tied to the history of their relationship and to each partners' life history. Without reconstructing their entire life history, both partners benefit greatly from sharing with honesty, openness and understanding how a particular behaviour gives rise to emotions, because it is imbued with an interpretation derived from a past hurtful situation. This mutual expression of emotions helps both partners to change how they explain such intense moments and to become sensitive to each other, taking better care of each other's vulnerabilities. The bond between the partners is rein-

forced when the PPA interprets and expresses their concern as a desire for attachment. The couple thus breaks the negative interaction cycle related to problematic substance/gambling use, so as to restore a relationship of mutual trust. By helping the couple to re-establish this bond, problems related to substance/gambling use do not rekindle fears associated with attachment needs, but instead become an opportunity to work as a team through mutual support.

Though the addiction couple treatment models described previously use strategies to help couples rebuild their trust, the hurt caused by broken promises, lies, absences and commitments not kept during problematic use has overly weakened the attachment bond in some cases [26]. A parallel is often drawn between the magnitude of the hurt and betrayals experienced by these couples and that experienced by couples dealing with infidelity [27]. Thus, there are cases where no progress is made in the relationship because a major attachment wound is blocking the work with the couple or the engagement in treatment of one partner. Relationship repair work, or the forgiveness process, will sometimes have to be carried out before the partners can be mobilized to identify their negative interaction cycle in regard to addiction [27].

21.3.3 Interventions to Maintain Changes Over the Long Term

During the last phase of the treatment, the partners consolidate the skills they have acquired. They learn to support and turn to each other rather than rely on the professional. Typically, treatment is stopped when substance/gambling use or abstinence is stable, cravings are manageable and when the partners can address problematic use together. One progress indicator of this is when the PA can talk spontaneously to the PPA about their urges to use, a constructive conversation ensues and the partners find solutions together to counter substance/gambling use.

The professional pursues two objectives during this phase of the treatment. First, they prepare the couple to cope in the event of a return to problematic substance/gambling use. When substance/gambling use goals set by the couple are not met or there is a relapse after several weeks or months of controlled use, both partners often feel discouraged and may feel like quitting. A relapse also undermines the feeling of trust and confidence in their ability to deal with problems as a team [26]. It is important to encourage the couple to be indulgent and patient and to support their perseverance. The professional's focus is on enabling both partners to break free of a dichotomous view of abstinence versus relapse and come to understand that recovery is a process in which there is gradual increase in the duration of abstinence/controlled use and a gradual reduction in the intensity and length of periods of problematic use. The couple is now able to identify the warning signs or triggers of problematic use. An agreement should be negotiated on the conditions for resuming treatment if needed.

The second objective in this phase of treatment is to prepare the couple for the natural evolution, transitions and crises of a couple relationship. Specifically, how will both partners cope with possible life crises, without resorting to substance/gambling use and without blaming these difficulties on prior use problems? The couple transitions, creating a different, sober relationship. The PPA will give back or let go of certain responsibilities, showing vulnerability and trust. Meanwhile the PA resumes an active role in the life of the family, rebuilding trust by being present, consistent and open. This gradual approach enables some partners to rediscover themselves. This adaptation must be sustained, because it sometimes involves challenges and uncomfortable situations that may undermine the changing process.

Lastly, even though the various addiction couple treatment models propose a time-limited intervention, current knowledge on the importance of maintaining change and preventing a return to problematic use has led researchers and professionals to adopt a more long-term ad hoc follow-up model [5]. After the intensive couple treatment, couples are offered follow-up sessions at interval spreading over several months. In the case of couples with a chronic addiction or

numerous concurrent problems, some researchers suggest that follow-up sessions be spread out over several years [5]. During these sessions, the professional follows up on the couple's substance/gambling use, couple issues that may not have been resolved during the treatment and those that may have emerged since then.

21.4 Some Other Characteristics of Couple Treatment for Addiction and Related Issues

21.4.1 Alliances

Professionals must be careful to avoid creating an imbalance in their alliance with each of the partners. The emphasis placed on reducing substance/gambling use in the early stages of treatment can place the PA in the role of the identified patient while fostering a rapid alliance with the PPA. PAs often take on this role de facto and are thus afraid to come to the sessions [25]. The professional should therefore be particularly sensitive to the creation of an alliance with the PA while also taking care of the alliance with the PPA. Rapidly, the professional shifts from alternating between showing empathy to each partner to using systemic interventions, thereby creating an alliance with the couple. Emphasis on their shared suffering and hopes will strengthen the alliance with the couple and between the partners so that they may pool their efforts and work as a team to counter addiction.

21.4.2 Two Partners with an Addiction

The presence of two PAs does not affect the efficacy of couple treatment for addiction, nor is it contraindicated [5]. Although treating the addiction of both partners may lead to increased clinical complexity (several different addictions and multiple associated problems), it presents more benefits than limits for these couples. Treating two PAs together makes it possible to incorporate aspects of couple dynamics linked to substance/gambling use that would not be addressed in individual treatment of the two partners. In cases where one of the PA relapses, the professional can directly discuss with both PAs the risk that the other might relapse as well. In addition, sharing the changes they make regarding substances/gambling is a source of learning for both partners and enables them to support each other more effectively.

21.4.3 Implications

Couple treatment for addiction, as shown by four decades of research, has proven to be more effective than individual or group interventions. Even though the Substance Abuse and Mental Health Services Administration (SAMHSA) reports that nearly 80% of specialized addiction treatment centres offer couple and family services in the United States, implantation of this structured intervention appears to be spotty, uncoordinated and focused to a greater extent on initiatives by clinicians and to a lesser extent on structured organizational decisions at the national level [28]. This gap between scientific progress in health and implementation problems in practice settings is observed generally in the field of mental health and addictions [29]. Onken et al. [30] note that no matter how efficacious an intervention is, it is useless unless it is implemented for as many people as possible. To that end, they propose that, in all the steps involved in the research process aimed at developing interventions, top priority be given to the goal of making implementation as seamless as possible [30].

Observation of specialized addiction treatment centres that introduced couple interventions by taking part in efficacy studies has revealed that, a few years after the end of the research work, 80% of the centres no longer offered couple treatment [31]. The main difference observed between the centres that had maintained the service and those that had abandoned it was that the former had made it practically compulsory to include the PPA in the assessment process as of the initial meeting [31]. This practice made it

possible to create a relationship of trust by addressing the PA's fears (e.g. the belief that the PPA and the therapist would gang up on the PA). Other obstacles were encountered, including high staff turnover and therefore the loss of qualified professionals convinced of the relevance of this type of intervention. Another persistent myth and obstacle is the belief that couple interventions should be implemented only once abstinence or control has been achieved. From a structural standpoint, our team reached the conclusion that this practice can be sustainable only if it is officially part of a centre's clinical programme and a team responsible for providing the service has been created.

In conclusion, couple treatment for addiction is more effective not only for reducing use but also for improving the well-being of partners and children and for fostering long-term maintenance of these changes for the family. Future research should focus on the specific characteristics that make this approach effective and especially on best practices for implementing and ensuring the sustainability of this practice.

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22 Parenting Training Programmes for Mothers and Fathers Who Have a Substance Use Disorder

Diana Moesgen and Anne Koopmann

22.1 Parenting and Substance Use Disorders

Historically, substance use disorders and parenting have been researched largely on separate trajectories [1]. There has been little integration of theoretical or applied research on the treatment of substance use disorders and parenting intervention development. This gap is still perpetuated in clinical practice, even though it is widely acknowledged (a) that substance use disorders impair parenting a child and (b) that being responsible for child rearing often adds additional stressors and complications for adults with a substance use disorder, who are often struggling with their everyday life already. Additionally, parental substance use is often falsely regarded as a willful act rather than a psychiatric disorder, leading to fatalistic beliefs and punitive attitudes among healthcare providers. It is also often disregarded that most parents affected by a substance use disorder express a strong desire to become better parents and worry about the impact of their substance use on their children. Nevertheless, affected parents still struggle with symptoms of their disorder that often conflict with the needs of their child.

Even though the interdependence between substance use disorders and parenting is complex and not all of its mechanisms and processes have been comprehended entirely, several investigations have focused onto understanding its relationship as well as conceptualizing and evaluating treatments targeting parent-child relationships in the context of parental substance use.

22.1.1 Parental Substance Use and Family Environment

There are numerous studies that have demonstrated the adverse living conditions in substance-involved families. For example, aspects of social marginalization and low socioeconomic status are observed more frequently in affected families than in families without substance use disorders [2]. The interaction of disadvantageous social conditions and a parental substance use disorder often leads to conflicts between parents. According to Templeton et al. [3], children with substance-abusing parents generally experience multiple parental disputes that may even result in domestic violence. It is therefore little surprising that parents with a substance use disorder often

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experience separation or divorce from the other parent. These disruptions, next to (repeated) out-of-home placements of a child by youth welfare services, long-term inpatient treatment(s), imprisonment(s), or even death of the affected parent (e.g. through an overdose), may have negative effects on the parent-child dyad and foster insecure attachment patterns [2].

Parents with a substance use disorder often struggle with an accumulation of stressors, especially if illicit substances are involved. The daily lives of parents who use illicit drugs more often are characterized by low structure, poverty, and illegal activities [4]. Moreover, living circumstances can be shaped by the drug subculture (e.g. prostitution, delinquency, or incarceration) and volatile (intimate) relationships within the substance-using community. Constellations of both parents using illicit substances are frequent. In addition, long-term drug use is often associated with poor physical health of the parent, transmission of blood-borne viruses such as hepatitis C or HIV, and comorbid mental health problems [5]. Generally, there is a higher risk of social isolation and societal marginalization in drug-involved families [2].

22.1.2 Parental Substance Use and Parenting Behaviour

In addition to the challenges described above concerning the family environment, the dyadic relationship between parents with substance use disorder and their children is often strained on multiple levels.

When parents suffer from a substance use disorder, their priorities frequently shift to acquisition and consumption of the substance, while parental responsibilities are neglected. Parental tasks, such as providing basic care for the child, safety, and stimulation of development, offering guidance and boundaries, and fostering emotion regulation, often seem to be impaired in substance-involved parents [6]. Moreover, parents with a substance use disorder have been found to show less emotional engagement, encouragement, and emotional warmth and less responsiveness with their young children [7]. At the same time, negative parenting styles are often predominant, including punitive and harsh practices to discipline and control children, as well as less parental monitoring [8].

Depending on the intoxicating effect of the substance being used, parental mood and behaviour tend to be erratic [3]. This challenges the child's formation of a secure attachment pattern with the parent. The specific effects of the different substances vary and strongly shape parental behaviour: while alcohol, marijuana, or opioids are linked to social withdrawal and depressive moods, stimulants such as cocaine or methamphetamine may lead to agitated, impulsive, and intrusive behaviour [9]. Affected children often become aware of the parent's intoxication because of slurred language, inappropriate communication, switching between physical proximity and rejection, and unpredictable reactions ranging from lax permissiveness to overreactivity. The resulting lack of continuity and age-appropriate boundaries can leave the child disoriented, overwhelmed, and unsettled [10].

Parental substance use disorders also have been associated with different forms of child maltreatment, such as physical and sexual abuse and neglect [11]. Especially neglect has been studied extensively in substance-affected families: Dunn et al. [12], for example, found that children who experience parental neglect (with or without parental substance abuse) are at increased risk of developing substance use disorders. The effects of parental substance abuse on substance abuse outcomes of their children appear to be partly mediated by neglectful parenting. Ghertner et al. [13] have demonstrated that higher substance use prevalence predicts more complex and severe cases of child maltreatment, with more children ending up in foster care.

As soon as dysfunctional parenting becomes chronic in substance-involved families, affected children increasingly need to fulfil duties that the parents themselves can no longer fulfil, e.g. taking care of a younger sibling. This leaves children tremendously overwhelmed in the long term, since they cannot adequately cope with age-inappropriate tasks [14].

22.2 Effects of Parental Substance Use on Their Children

Numerous research findings have been able to demonstrate that parental substance use disorders and the associated living circumstances and behavioural consequences described above as well as the principles of social learning and the lack of functional parental role models can have a detrimental effect on the child on various levels.

Already during pregnancy, the unborn child can be exposed to the harmful influences of maternal substance use that may result in physical, developmental, and/or behavioural impairments [15]. Besides, children from substance-affected families are considered an especially vulnerable group for the development of own substance use disorders [16] or other mental health problems [2]. More detailed information on the effects of parental substance use disorders on their children can be found in Chap. 5.

22.3 Parenting Interventions for Parents with Substance Use Disorders

The illustrated impact of parental substance use on their children calls for systematic approaches to improve the living situations and developmental settings for children involved and to improve parenting skills. Repeating cycles of transgenerational transmissions of maladaptive parenting, adverse family dynamics, and substance use disorders need to be interrupted permanently.

A literature review reveals that there are a few systematic reviews and single articles focusing on the effectiveness of parenting training programmes that have been evaluated with substance-involved parents. Parenting training programmes can be delivered in traditional face-to-face-settings or online. Online interventions have become increasingly important since the COVID-19 pandemic. Nevertheless, to date there is relatively little scientific evidence on the efficacy and feasibility of online interventions.

22.3.1 Face-to-Face Parenting Training Programmes

Primary support for mothers and fathers with substance use disorders generally focuses on the individual her- or himself and prioritizes the treatment of the disorder. As described earlier, enhancing parenting skills usually does not appear to be embedded into the treatment of substance use disorders very often, despite a documented need of tailored services for this target group and a variety of existing parenting training programmes.

Especially in the United States, the range of existing parenting interventions is significantly broader than in other countries. Several systematic reviews have discussed issues of conceptualization, methodology, and outcomes in the context of parental substance use disorders [17–19]. Their findings demonstrate that parenting training programmes can be effective with regard to, for example, reducing substance use, improving parenting practices, decreasing child maladjustment, and improving psychosocial outcomes and parent-child interactions in substance-involved families.

Moreland and McRae-Clark [20] conducted the most recent systematic review on parenting interventions in the context of parental substance use disorders. In their review, they identified 18 studies that specifically evaluated parenting outcomes following engagement in parenting interventions that were embedded in integrated substance use treatment programmes. The outcomes assessed were programme retention, substance use, parenting stress, psychosocial adjustment, depression, child abuse potential, parenting behaviours, and parent-child interaction. However, not all studies assessed all eight outcomes. The authors were able to identify 12 different parenting interventions that were evaluated in at least one study with a pre-post, quasi-experimental, or randomized-controlled trial (RCT) design (see Table 22.1).

As seen in Table 22.1, all parenting training programmes were delivered either individually, in a group setting, or in both individual and group settings. Most programmes were carried out in an

Table 22.1 Parenting interventions that were evaluated in one or more studies with regard to 8 primary parenting outcomes (18 studies in total) (according to [20])

Name of programme	Intervention type	Intervention setting	Intervention length
Project STRIVE	Individual and group	Outpatient and in-home	~1 year
Attachment and biobehavioral catch-up (ABC)	Individual	In-home	10 sessions; 1 h/week
The nurturing programme for parents of children birth to 5 years old	Group	Outpatient	23 weeks; 2.5 h/week
Focus on families (FOF) [now titled: families facing the future (FFF)]	Group	Outpatient	53 h; 5 h retreat, 32 meetings (90 min each)
Emerging moms (EMP)	Individual	Outpatient	Ongoing
Parents under pressure (PuP)	Individual	In-home	10–12 sessions; 1–2 h/week
Family behavior therapy (FBT)	Individual	In-home	20 sessions; 75 min/week
Parent skills with behavioral couples therapy (PSBCT)	Individual	Outpatient	24 sessions; biweekly
Relational psychotherapy mothers' group (RPMG)	Group	Outpatient	24 sessions; 1 h/week
New choices	Individual and group	Outpatient	~4 months; 2× week
Multisystemic therapy-building stronger families (MST-BSF)	Individual and group	Outpatient	~1 year
Mothers and toddlers programme (MTP) (now titled: mothering from the inside out)	Individual	Outpatient	12 sessions; 1 h/week

outpatient setting, some were delivered in the parent's home, and one was provided in a combined outpatient and in-home setting. The length of the parenting interventions ranged from ten sessions to 1 year. Some of these programmes are described in more detail below.

The retention rates in parenting interventions embedded within integrated substance use programmes varied across studies, which is possibly due to the differences in delivery method (e.g. individual, group), setting (e.g. home, treatment setting), and length of intervention. Nonetheless, results indicated that parental substance use significantly decreases following engagement in a parenting intervention in integrated substance use treatment programmes. Studies that evaluated alterations in parenting stress after engaging in a parenting intervention found significant pre-post intervention decreases in parenting stress. The results on the impact of parenting interventions on psychosocial adjustment or depression among parents involved in parenting interventions in substance use treatment, however, were inconclusive: some studies found significant improvements in psychosocial adjustment, whereas other studies failed to find significant differences. Results on child maltreatment potential were mixed as well. Whereas some studies demonstrated significant decreases in child abuse potential, in other studies child maltreatment potential remained the same. With regard to parenting behaviours, few studies reported significant improvement following engagement in the parenting programmes, while one study did not find significant differences. However, findings regarding parent-child interactions indicate improvements after engaging in a parenting intervention integrated in substance use treatment. No study showed any form of deterioration.

While some programmes integrated in this review have been specifically developed or adapted for parents (or mothers only) in substance use treatment (i.e. STRIVE, FOF/FFF, EMP, PSBCT, RPMG, New Choices, MTP/Mothering from the Inside Out), it is important to note that others were not specifically developed or adapted for the use with parents with substance use disorder (i.e. ABC, The Nurturing Programme, PuP, FBT, MST-BSF). Rather, they

are parenting interventions developed for at-risk populations that have been simply implemented with parents in substance use treatment programmes. It must be stated, though, that both types of programmes usually share various commonalities that have proven to be effective (e.g. cognitive-behavioural elements and/or attachment-oriented skills).

An evidence-based parenting training programme that has not been included in the review of Moreland and McRae-Clark [20] but has been researched in the context of parental substance abuse, too, is the "Strengthening Families Programme for Parents and Youth 10–14 (SFP10–14)". SFP also has not been exclusively designed for parents with a substance use disorder but addresses this population next to other vulnerable families with high prevention needs. SFP is a family-based prevention programme that consists of a parent, youth, and family skill-building curriculum and was designed to prevent substance use and other problem behaviours in teenagers, to strengthen parenting skills, and to build family strengths [21]. When researched in families with parental substance abuse, SFP10–14 has demonstrated statistically significant reductions in family and child dysfunctions across several ethnocultural groups when consistently utilized [22].

It can be concluded that the positive parenting outcomes following the inclusion of parenting training programmes in integrated substance use treatment programmes provide evidence that parenting interventions should be tailored for substance-involved parents and provided within substance use treatment programmes [20]. Given the specific needs of substance-involved parents, it seems reasonable to make specific adaptations to evidence-based parenting interventions for use with this population. While some programmes have been specifically developed and adapted for parents (or women) in substance use treatment, it is crucial to further evaluate the use of these interventions so that they can be widely disseminated.

Hence, further research on the efficacy and feasibility of parenting training programmes in the context of parental substance use disorders remains necessary, especially in countries outside the United States. While the existing parenting programmes generally can be transferred to other countries, language barriers, cultural specificities, and organizational and financial structures of different healthcare and/or child welfare systems might challenge adaptations outside North America.

Remarkably, if developed for substance-involved parents, current parenting training programmes primarily aim at mothers with a substance use disorder. Substance-involved fathers are often disregarded even though they may play an essential role in rearing their children [17]. There are only few programmes focusing on the paternal role throughout substance use treatment. One example is "Fathering for Change (FTC)", an individual treatment (with an optional co-parent component and optional father-child component) that addresses the comorbidity of substance use disorders, domestic violence, and poor parenting in fathers of young children [23] (see below for more details about the programme). FTC was able to achieve promising effects regarding emotion regulation, anger and aggression, and co-parenting, and it was highly accepted among participants. Therefore, the involvement of fathers—biological or non-biological—should be considered more strongly in both research and practice.

Moreover, existing evidence-based interventions focus primarily on alcohol and opioids, whereas other (illicit or prescription) drugs remain largely unattended. Thus, there is a need for interventions tailored to the characteristics of parents using cannabis, benzodiazepines, or stimulants, since substance-specific characteristics need to be assumed. Following this approach, the German "SHIFT Parent Training" for mothers and fathers using methamphetamines is worth mentioning. The resource-oriented intervention is unique in its focus on addressing the specificity of one substance while fostering parenting and family resilience at the same time [24]. Future studies should also consider the different severities of parental substance use disorders. With regard to the effects on parenting behaviour and thus on the development of children, it can be

assumed that there is a difference between parents that are in need of substance use disorder treatment and parents that may be at the beginning of demonstrating harmful patterns of substance use (e.g. binge drinking).

Most recent studies focus on so-called wraparound programmes, wherein multiple services (including child welfare, health services (e.g. primary care, public health, and perinatal care), and specialized health services, such as mental health services) are provided at one location [25]. As wraparound programmes are effective in engaging pregnant or parenting women experiencing substance use and other complex challenges while also addressing gaps in services between the health, child welfare, and addiction fields, this promising approach should be studied further, too.

22.3.2 Digital Parenting Training Programmes

In everyday life, parents with a substance use disorder often face the challenge to organize care of their children during treatment sessions in order to participate in specific treatment offers, both in inpatient and long-term outpatient treatment. Since this is often not possible for affected parents, mostly due to insufficient social or family networks, parents are often unable to take part in recommended treatments [26].

This situation was further complicated by limited institutional care options available in kindergartens and schools during the COVID-19 pandemic. This exceptional situation made it more necessary than ever to develop low-threshold, online treatment services for the target population of parents with a substance use disorder that would allow them to partake in treatments while fulfilling their parenting responsibilities. Even though digital and/or web-based interventions are a viable and effective alternative to face-to-face contacts with healthcare providers in substance use treatment facilities [27], there are several reasons that complicate implementing them: First of all, the institutions must have the necessary technical infrastructure on site. This sets enormous technical and financial challenges, especially for smaller institutions. Second, institutions must train their staff in the use of digital applications.

In addition, it requires motivation and willingness on the part of patients/clients in order to engage in novel digital healthcare offerings. Moreover, both the implementing institutions and the patients/clients must have reliable, inexpensive, or free internet access and the technical devices that are needed. This can be a major challenge, especially for families with low incomes, such as substance-involved families. Even in the past years during the COVID-19 pandemic, where face-to-face contacts had to be avoided and web-based services became much more important, these challenges mentioned above led to relatively few digital services being available for affected families in many countries [28].

In contrast, there was an increase in the development of web-based parenting services in the United States prior to the COVID-19 pandemic. This was the result of an initiative of the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Institute on Drug Abuse (NIDA) which was launched due to the national "opioid crisis". The web-based programmes developed within this initiative were originally designed to provide substance-affected mothers and fathers from rural areas with greater access to parent-specific substance use treatment or parenting training programmes [29]. However, the COVID-19 pandemic led to a need for evidence-based digital programmes to be accessible to a much larger number of affected families within a short period of time. This also included that more healthcare providers had to be trained in delivering the programmes on short notice.

At present, web-based versions are available for the following evidence-based parenting training programme: "Mothers and Toddlers Programme (MTP)" [30], "Attachment and Biobehavioral Catch-up (ABC)" [31], "Family Check-Up (FCU)" [32], and "Fathering through Change (FTC)" [23]. All of these programmes were originally designed to be delivered in a face-to-face setting.

The "Mothers and Toddlers Programme (MTP)" [30] was designed for substance-involved mothers of infants aged between 12 and 36 months. MTP is delivered individually and helps mothers develop more balanced representations of their children and improve their capacity for reflective functioning (e.g. by fostering recognition of the intentional nature of children's behaviour). Although an online version of this programme exists, unfortunately there is no specific study data on the efficacy and feasibility of the online version compared to the face-to-face version of MTP.

The "Attachment and Biobehavioral Catch-up (ABC)" programme [31] targets mothers and fathers of infants aged between 0 and 24 months from low-income families affected by neglect, abuse, domestic violence, or precarious living situations. Therefore, it is not a programme that was designed for parents with a substance use disorder only, but it addresses many challenges that affected families may face. In a recent study of Schein et al. [33] on the online version of ABC, 43 families received ABC entirely in a telehealth format, whereas 27 families took part in the programme in a hybrid format (in-person/telehealth). Findings indicate that when parents received ABC through a telehealth or hybrid format, they showed the results suggest that parents who received ABC via a telemedicine or hybrid format were more likely to implement the program's recommendations in a pre-post comparison. These results suggest that ABC can be implemented successfully through a telehealth format.

The "Family Check-Up" programme (FCU; [32]) was designed for lower- or middle-class families with children aged between 2 and 17 years. It is a family-centred intervention that promotes positive family management practices and tries to reduce behavioural problems of children and adolescents. Like ABC [31], FCU was not specifically designed for substance-affected families but focuses on challenges that may be experienced in substance-involved families, too. The efficacy and feasibility of the online version of the FCU were tested in a randomized clinical trial during the COVID-19 pandemic [34]. Participants assigned to the FCU online group showed significant improvements in parental well-being, including reduced anxiety, depression, and perceived stress; adaptive parenting skills (e.g. less negative/coercive parenting, greater proactive parenting); and family-relational functioning (e.g. improved co-parenting) [34].

The "Fathering through Change (FTC)" programme [23] was developed for fathers with children under the age of 12 years who have a history of intimate partner violence. It addresses nine subject areas: four that focus on parenting as a couple and five that specifically address the interaction between father and child. It was developed as an individual treatment with 60-min weekly sessions over 16–24 weeks. The intervention combines elements from attachment theory, systemic family therapy, and cognitive-behavioural therapy to achieve goals such as ending domestic violence and aggression, achieving abstinence, improving co-parenting, and reducing negative parenting behaviour and promoting positive parenting behaviour. Again, this is not a programme specifically aimed at fathers with substance use disorder. However, it does comprise a module that specifically addresses fathers' substance use and, in addition, other modules that address related issues. Cioffi et al. [28] demonstrated in a RCT that participation in the online version of FTC is associated with reductions in total substance use ($d = 0.14$) and drinking ($d = 0.26$) but not with reductions in tobacco smoking and marijuana use. Additionally, a significant indirect effect for FTC through pre-post changes in parenting efficacy was found ($d = 0.36$).

This overview on web-based parenting training programmes suggests that there are still far fewer web-based parenting training programmes than face-to-face programmes specifically designed or suitable for parents with substance use disorder. For the existing online programmes for parents with substance use disorders, there are only few scientific studies on the effectiveness and feasibility, as outlined above. Thus, in practice, programmes are sometimes used, whereas their benefits have not been sufficiently scientifically studied.

However, data on the effectiveness of online programmes for patients with substance use dis-

orders in general have shown that the difference in alcohol use in an internet group was non-inferior to that of a face-to-face group in the intention-to-treat analysis of data from the 6-month follow-up [internet = 12.33 and face-to-face = 11.43, difference = 0.89, 95% confidence interval (CI) = −1.10 to 2.88] [35]. By contrast, the Alcohol Use Disorder Identification Test score failed to show non-inferiority of internet intervention compared with face-to-face intervention in the intention-to-treat analysis at 6-month follow-up (internet = 12.26 and face-to-face = 11.57, d = 0.11, 95% CI = −0.11 to 0.34). Therefore, it could be assumed that internet-delivered treatment was non-inferior to face-to-face treatment in reducing alcohol consumption among help-seeking patients with alcohol use disorder but failed to show non-inferiority on some secondary outcomes.

The COVID-19 pandemic and its related altered societal conditions throughout the world will probably increase the offer of digital interventions—both individual and group interventions—in the long term (not only in the context of substance use disorders). It is to be expected that more web-based interventions are going to be developed, implemented, and evaluated. Hopefully, significantly more evidence-based, specific web-based parenting training programmes for mothers and fathers with substance use disorder are going to be available in the upcoming years. In order to apply them on a large scale, it will be necessary to develop political strategies to improve the technical infrastructure in institutions providing healthcare and social services for substance-involved (and other at-risk) families worldwide. Furthermore, parents affected by a substance use disorder must be provided with low-cost access to an adequate IT infrastructure that is required for participation in web-based interventions.

22.4 Evidence of Parenting Training Programmes

Parenting training programmes are complex interventions as they contain various therapeutic elements. Depending on the structure of the social and healthcare system of the country in which they were developed and evaluated, they are implemented by different types of healthcare and/or social welfare providers. Thus, researching the effects of parenting training programmes can be challenging, as not all institutions are able to conduct studies according to high methodological standards. However, if researched, the methodological designs of the various studies on parenting trainings programmes differ from one another, with some studies using RCTs and others using quasi-experimental designs. In the latter, study participants are free to choose whether to participate in the intervention group receiving the parenting training programme or in the control group with participation in treatment as usual (TAU). This may have led to an overestimation of effect sizes in studies designed in this way, as mothers and fathers with greater motivation to change were more likely to participate in the intervention group than parents with rather low motivation. However, quasi-experimental study designs provide all parents who want to participate in a specific parenting training programme with immediate access. Consequently, quasi-experimental study designs make sense, too, especially regarding ethical reasons. The earlier parents receive treatment, the earlier their children can benefit from it. In addition, not all parenting training programmes can be researched in a RCT. It is very difficult to compare newly developed parenting training programmes, because there is no same TAU or other standardized control intervention with which the programme can be compared. Thus, all programmes are compared to different TAUs or different treatments, leading to impaired comparability between parenting training programmes. In the future, it may be helpful to define one "standard intervention" that will serve as a control intervention for new specific parenting training. Based on the evidence of the existing programmes to date [36], the "Triple P—Positive Parenting Programme" might be considered as an option, as it provides encouraging evidence that families at risk for substance use issues could profit from this programme even when implemented mostly online [37].

Another challenge in assessing the evidence of parenting training programmes is finding the

"best" outcome criterion. As outlined in the review by Moreland and McRae-Clark [20], most evaluation studies of parenting programmes focus predominantly on parenting-associated characteristics such as parenting stress, psychosocial adjustment, depressive symptoms, child abuse potential, parent-child interaction, and other parenting behaviours or on changes in substance use of parents. Furthermore, the studies examined programme retention. For example, the evaluation study on the STRIVE programme focused on the outcome criteria programme retention, depressive symptoms in parents, and child abuse potential. In contrast, the evaluation study of the Attachment and Biobehavioral Catch-up (ABC) programme examined programme retention and parent-child interaction as outcome criteria. The evaluation study of the Nurturing Programme for Parents of Children Birth to Five Years Old had defined child abuse potential and parent-child interaction as outcome criteria. In the evaluation of the Focus on Families (FOF) programme, the outcome criteria chosen were programme retention and parenting stress, whereas in the evaluation study of the Emerging Moms Programme (EMP), the outcome criteria were programme retention, substance use, psychosocial adjustment, and child abuse potential. In the evaluation studies of the Parents Under Pressure (PuP) programme, programme retention, substance use, parenting stress, and child abuse potential were selected. The evaluation study of the Family Behavior Therapy (FBT) used the outcome criteria programme retention, substance use, and child abuse. The Parent Skills with Behavioral Couples Therapy (PSBCT) used the outcome criteria programme retention, substance use, and other parenting outcomes in its evaluation study. In the Relational Psychotherapy Mothers' Group Programme (RPMG) evaluation studies, the outcome criteria were programme retention, substance use, psychosocial adjustment, depressive symptoms, and child abuse potential. In the evaluation study of the New Choices programme, programme retention, substance use, and depressive symptoms were used as outcome criteria. In the evaluation study of the Multisystemic Therapy-Building Stronger Families (MST-BSF), the outcome criteria used were substance use and depressive symptoms, whereas in the evaluation studies of the Mothers and Toddlers Programme (MTP), the outcome criteria used were programme retention, substance use, parenting stress, psychosocial adjustment, depressive symptoms, and parent-child interaction.

The different outcome criteria of the presented evaluation studies on parenting programmes significantly limit the comparability of their results. In addition, the measuring points of the presented studies differed significantly from each other, which in turn affects comparability. In order to improve the comparability of established and new parenting programmes in the future, homogeneous parenting-related outcome criteria and evaluation time points should be defined.

Additionally, it seems useful not only to focus on changes in parenting behaviour, as has been done so far, but also to consider direct effects on children's behaviour including psychosocial health markers. An appropriate instrument for screening changes in children's behaviours can be the Strengths and Difficulties Questionnaire (SDQ; [38]). However, studies assessing children's variables must be conducted in longitudinal study designs with several follow-up measuring points, since the effects of an intervention on a child's behaviour can sometimes only be detected with a longer latency. Ideally, all studies including child assessment are designed and coordinated by multidisciplinary study teams, including experts of child and adolescent psychiatry.

In sum, the evidence base for parenting training programmes for substance-involved mothers and fathers must be improved. Whenever possible, future validation studies should perform RCTs with a standardized TAU or control intervention (e.g. "Triple P"). Outcome criteria should include changes in both parents' and children's symptoms, behaviours, and/or experiences.

22.5 Conclusion

It is widely acknowledged that substance use disorders and parenting interact in a complex manner with each other, as one complicates the other.

Numerous studies have demonstrated the unfavourable living conditions in substance-involved families, which include a negative impact on the family environment and the dyadic parent-child relationship. Both may lead to adverse outcomes for affected children, e.g. the development of substance use disorders at a later age and/or other mental health problems.

Therefore, it seems crucial to integrate parenting training programmes into substance abuse treatment. Most evidence-based parenting training programmes that have been researched in the context of parental substance use disorders can be found in the United States. Adaptations outside the United States seem feasible; however, cultural specificities as well as differences in the healthcare and/or youth welfare systems need to be taken into account. Whereas most parenting training programmes were developed to be delivered and evaluated in face-to-face settings, the COVID-19 pandemic has led to several programmes also being offered digitally.

Even though many parenting training programmes have been proven effective, more research is needed to develop and evaluate programmes that address more specific target groups (e.g. fathers) and/or substances (e.g. other drugs than alcohol or opioids) and that can be delivered in different settings. Web-based interventions will become even more important in the future. The advantages of web-based interventions are that parents do not have to arrange for someone else to look after the child at the time of treatment and that families from rural areas can be reached more easily. However, the prerequisite for this is that affected families are technically equipped accordingly.

In order to ensure the quality of face-to-face and digital interventions in the long term and to facilitate sustainable financing, they should be evaluated according to high methodological standards, ideally within studies with RCT designs, even though this may be challenging in some settings.

Lastly, mandatory networking between institutions from different systems such as substance abuse treatment, other medical and child welfare services seem to be effective measures and should be further expanded.

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Interventions for Children Affected by Parental Substance Misuse

23

Hannah Todman and Hugh McLaughlin

23.1 Introduction

This chapter identifies the needs of children affected by parental substance misuse (PSM) in relation to professional support. The findings from existing literature presented in Chap. 5 illustrated the interconnected risk factors experienced by children living with PSM and of their severe and enduring nature. Chapter 5 stressed the need for children's voices to be heard and the need for trusted adults to act as a buffer against the often-multiple risk factors, to afford children the opportunity to recover from adversity and trauma. As a continuation, this chapter critically engages with existing literature on the current models of intervention for children living with PSM. The purpose of this chapter is not to decipher which model of intervention is best, but to explore through a trauma-informed lens the practice principles needed to effectively respond to children affected by PSM.

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23.2 Exploration of International Models of Intervention

23.2.1 Interventions Aligned to Adult Treatment Services

Much of the research surrounding interventions for children affected by PSM has primarily focussed on two types of intervention: those directed at increasing positive parenting and peer group models aimed at building mutual support for children.

'Trampoline' is a community-based 9-week programme focussed on children aged 8–12 years living with a parent who misused substances [1]. It is an educational intervention programme focussed on 'fun and play' designed to support children with their ability to cope with stress. While the intervention did not demonstrate any changes in self-efficacy, self-perception, physical stress symptoms and in other health-related quality-of-life aspects, it did result in improved 'addiction-related knowledge'.

The Family Competence Programme (FCP) adapted from the Strengthening Families Programme (SFP) is another example of intervention designed to prevent 'adaptation problems' in children and young people at risk of 'delinquency, academic failure and absenteeism at school, drug use' [2]. Delivered over 14 weekly sessions, the FCP was designed to increase parents' 'value of children' to prevent or decrease

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the risk of neglectful parenting alongside 'training children' in life skills, understanding and managing feelings, accepting criticism and praise, problem-solving, communication skills and the 'making and keeping of positive friendships' [2].

The AFP results in improved 'family relationships, family bonds and cohesion', as well as improved parent-child relationships observed through positive play and interaction [2]. However, it is not clear if these positive outcomes are sustained beyond the programme. Furthermore, neither of these programmes were accessible to children whose parents were not engaged in adult treatment services and hence are likely to be more vulnerable (see Chap. 5).

Another example of an intervention for children that is aligned to adult substance misuse treatment services is the Family Behaviour Therapy (FBT) model. The inclusion of children in the FBT model is designed to support children to reinforce positive parenting behaviours, to strengthen the parent and child relationship and to teach children home safety skills [3]. There are significant strengths in the FBT model in relation to a whole family approach. Similar to the Family Competency Model, it brings families together to talk openly about their struggles and to gain advice and guidance to support parents receiving substance misuse treatment. The structured FBT sessions with children appear to focus on the needs and wellbeing of parents and not of the emotional health and wellbeing of the children. FBT sessions with children are centred on teaching children to support their parents with home tasks such as grocery shopping and praise their parents [3]. The rationale for the design of the FBT sessions with children are outlined by Donohue et al. [3]. Along operant conditioning lines, if children are perceived by parents to be reinforcing to them, parents are more likely to reciprocate positive behaviours with their children.

Arguably, the design of this FBT model of intervention, while it seeks to improve family relationships and increase positive parenting behaviours, places an unnecessary and unfair burden on children. It almost suggests that if the children change their behaviour, this would lead to improved parenting and reduced PSM.

Further developments have emerged from studies in Australia in response to PSM and the negative impact on children [4]. The 'Parents Under Pressure' (PuP) programme is an intensive intervention for parents who have been prescribed methadone. PuP is underpinned by the notion that in order for a parent to provide a nurturing and sensitive caregiving environment, a parent needs to manage their substance misuse [4]. Though PuP does not directly support children affected by PSM, there is a positive indirect impact on children—significant reduction in cases of child abuse—as well as positive changes in parents' behaviour and increased engagement in substance misuse treatment [4]. Thus, PuP too responds to the support needs of parents but does not afford children the same right to support, to overcome trauma and the possible neglect and abuse they have suffered.

23.2.2 Time-Limited Models of Intervention

M-PACT (Moving Parents and Children Together) is an example of innovative practice and one of the growing number of interventions in the United Kingdom for children affected by PSM [5]. The 8-week programme combines individual support for children, their parents, family and whole family group sessions. The programme covers topics such as making sense of addiction, family communication, feelings/beliefs and safety [5]. It helps to increase openness and honesty, strengthen family relationships and reduce family conflict [5]. As with other models of intervention explored within this chapter, the support available to children through M-PACT is reliant on their parents' engagement. The structured, time-limited design of the model is highlighted as a limitation by practitioners, parents and children, as it is felt that children and families need support for longer than the programme's duration [5].

A further example of an intervention model for children affected by PSM is the 'Steps to Cope' model in North Ireland [6]. The 'Steps to

Cope' model is adapted from the 5-Step Method that was developed in response to the needs of adult family members affected by substance misuse [7]. Steps to Cope is a short-term intervention for children and young people aged 11–18 years affected by PSM and/or parental mental ill health. The overarching aim of the intervention is to support children affected by PSM and the associated risk of harm (including adverse childhood experiences) 'so that they are better protected from harm, more resilient and more able to deal with the impact caused by these adversities' [8 p. 2]. Sipler et al. suggest that the Steps to Cope intervention can be delivered over five to six sessions, although it is acknowledged that due to the complexity of risk factors and the length of time children have experienced the negative impact of PSM, this intervention may need to be delivered over a longer period of time [8].

It would appear that although time-limited and structured interventions may meet the needs of adults, they do not necessarily meet the needs of children affected by PSM. For the intervention to meet the needs of children affected by PSM, there is a need for more flexibility, especially when children are faced with multiple risk factors and crises, which makes it challenging to work with a structured, sequential and time-limited intervention [6]. Hence, it is recommended that interventions such as the Steps to Cope 'should be part of a range of services and interventions which are available and delivered as part of a stepped care approach' [8].

23.2.3 Interventions Aligned with Statutory Children's Social Work

The limitations of existing models of intervention for children affected by PSM presented within this chapter have included interventions being time limited, being aligned to adults' substance misuse treatment services and/or reliant on parental engagement. These effectively deny children the right to access support in their own right or when their parent is not engaging in adult treatment services. This potentially represents a further exclusion and missed opportunity to respond in a timely fashion to the needs of children affected by PSM.

Option 2 is an 'intensive family preservation' model of intervention in the United Kingdom which is designed to support families at 'crisis point' and where there is a risk of children 'entering care' due to PSM [9, 10]. While this intervention shows positive impact through children being able to talk to their keyworker, improved family relationships and support to reduce substance misuse, this is not sustained beyond the duration of intervention delivery [9]. Additionally, while the intervention does not reduce the 'likelihood of children entering care', it does delay this outcome [9]. Thus, a brief intervention which is only available to children and parents, at 'crisis point' of severity, is not enough to reduce the risk of harm to children and support parents to achieve sustained change [10].

Furthermore, the short-term design of Option 2 leaves many parents with a sense of abandonment when the intervention comes to an end [10]. Finally, there is a feeling from parents that had the intervention been available earlier, before the point at which families are entering care proceedings, then the negative impact of PSM and the complexity of risk factors endured by children could be prevented [10]. Thus, it might be that Option 2 would be better considered as the start of help for these families, and the other supplementary help that the children might benefit from needs to be explored further.

The focus on models of statutory intervention for children living with PSM and who are likely to have suffered and endured significant risk factors (see Chap. 5) can be seen with the development of the Family Drug and Alcohol Court (FDAC) in the United Kingdom. FDAC is an alternative to family court care proceedings and is designed to support parents struggling with their substance misuse, to reduce the risk of harm to their children, through joint working with social care, health, adult substance treatment services and housing and probation teams [11, 12].

The initial indications were promising in that FDAC appeared to be more inclusive and responsive to parents' needs, and positive outcomes

including parent and child reunification, parents remaining in treatment for their substance misuse and a reduction in PSM were achieved [11]. Though FDAC had been found to support positive change, a longitudinal study involving families 5 years after FDAC had ended raised significant concerns. This included the number of families who had been known to children's social care for more than 10 years [12]. Furthermore a quarter of all mothers over the follow-up period had suffered domestic abuse and had continued to misuse substances. Finally, a third of all the children who were reunited with their parents at the end of FDAC had either developed or continued to display anxiety, self-harm, violence, offending behaviour and bed-wetting [12].

This raises the question, as with the Option 2 intervention, regarding what could be done earlier to support children and their parents, how long a child has to endure PSM and the associated risk factors before support is available to them and whether family drug courts only postpone decisions about the best ways to achieve the long-term interests of children [12, 13].

The development of interventions for children affected by PSM is welcomed, but as this chapter has highlighted, there are limitations to existing models, which are often brief, time-limited models of intervention and exclude children whose parents are not accessing adult treatment services. A further significant limitation is the length of time children have to endure a complex web of risk factors before specialist support is available to them. The response to children affected by PSM needs to be meaningful, as Kroll outlines: Children need to be seen, heard and engaged with on a real level if they are to feel confident about being helped. Communication between professionals needs to be made open, and the child's perspective needs to be brought firmly into the entire assessment process so that workers can gain a sense of what children's lives are really like [14].

Interventions that simply focus on reducing risk factors by reducing substance misuse and focussing on the needs of parents neglect the actual needs of children affected by PSM, as interventions are not structured to provide ongoing support that is flexible and responsive to the needs of children [15].

23.3 A Mandate for Systemic Change

23.3.1 Impact of Short-Term Interventions

The findings from research presented in Chap. 5 illustrated the precariousness and complex risk factors experienced by children affected by PSM, which can be long-standing and with little respite [16]. Models of intervention that focus solely on the reduction of risk factors, namely, reduced substance misuse or abstinence, do not take into consideration the long-term emotional health needs of children. Research findings have drawn attention to the needs of children when positive change has been achieved, as children may continue to suffer from emotional turmoil during periods of abstinence; this time of reduced risk factors can lead to children feeling 'unsafe due to the dread of resumption' [15].

Todman and Galvani [17] stress the need for practitioners to understand the long-term impact on children due to exposure to prolonged periods of unpredictable parent behaviour and children's experience of suffering hypervigilance. Hypervigilance is a term adopted to describe the symptoms children experience when anticipating the next domestic abuse incident, including 'exaggerated startle', struggling to fall asleep, thinking about violence and difficulty regulating their emotions [18]. The impact of unpredictability on children's emotional health and of the anticipation of when, or if, their parent may relapse evidences the need to understand the impact of hypervigilance in children affected by PSM [17].

The impact of PSM on children and their need for longer-term support is evidenced in the findings from safeguarding practice reviews, where an investigation has taken place following the significant injury or death of a child in England [19, 20]. The complexity of risk factors endured by children affected by PSM and the increased

stresses experienced by families, exacerbated by poverty, can lead to child neglect, abuse and fatality. As Brandon et al. outlined: 'The links between domestic abuse, substance misuse and poverty are complex and often inter-dependent […]. Substance misuse can result in money needed for food and clothing being diverted to satisfy parental needs. Short-term solutions followed by case closure leaves children at risk. Practitioners need to understand how poverty affects children and, through hearing their voices, seek to safeguard and improve the quality of their lives' [20].

Despite the overwhelming knowledge of the impact of PSM on children and the overrepresentation of PSM in statutory children's social work, training for frontline practitioners on substance use and PSM is still not routine [16]. This failure to provide adequate training for practitioners to understand the needs of children affected by PSM has been known for over 30 years [21]. A lack of training for frontline practitioners, time-limited interventions and the findings from safeguarding practice reviews evidence that children living with PSM continue to suffer the consequences of a fragmented inadequate system; 'in the end it is the children who are paying the price for inadequate policy responses' [22].

23.3.2 Child-Centred Interventions

The findings presented in this chapter have illustrated that there is a clear endeavour to respond to the needs of children living with PSM. However, there are significant limitations to existing models of intervention, including support being time-limited and often dependent on parents' engagement with services rather than the child's own right. Therefore, there is a clear mandate for change in recognizing and responding to the actual needs of children affected by PSM.

In considering what a model of practice/intervention means, Stanley [23] suggests that it is:

> […] a particular way of, or approach to, working with children and families. It is values-based and, when successful, transformative […] When it's done carefully and well, innovation moves social work forward and that leads to better decision-making and more impactful direct work with children and families.

Models of intervention must reflect the presenting challenges for children and their families, and any model of intervention needs to maintain a continuous focus on the needs of children [23]. Further, a model of intervention which responds to the needs of children affected by PSM must align with the key principles of child-centred practice. O'Reilly and Dolan [24] identify these key principles as being:

- A child's right to participate
- Children's need to be listened to
- Practitioners spending time with children and utilizing age-appropriate communication, through playful and creative practice skills
- Providing a child-friendly environment
- Ensuring that the voice of children is central to decision-making

As outlined from the beginning, the purpose of this chapter is not to determine which model of intervention supersedes another but to critically engage with the limitations of existing models. In response to the limitations, including a lack of training for frontline practitioners regarding PSM and the time-limited interventions that are weighted towards the needs of parents and aligned to adult services, the British Association of Social Work [17] has proposed a model of practice to afford a child the opportunity to recover from the web of risk factors they have experienced, many of which will have been severe and enduring. This proposed model of practice outlines the minimum support children affected by PSM need as follows:

- Provision of support that is not time-limited. Care plan tailored to a child's unique needs
- Child-centred, creative and therapeutic support. Hearing the child's voice
- Specialist support for children not dependent on parental engagement
- Reduce social isolation. Involvement in positive activities. Chance to meet other children who live with a parent who uses substances

- Improving understanding and responses in school. Relationship building between child and trusted adult in school
- Increasing support networks. Emergency and longer-term emotional support
- Long-term support for emotional recovery from trauma, access to specialist therapy. Pathways with child mental health services

A mandate for change is needed, and only by addressing the complexity of PSM through the provision of specialist services that respond to the actual needs of children living with PSM can the gap between research and practice be bridged [16].

23.4 Conclusion

This chapter has explored existing models of interventions which seek to support children affected by PSM. The literature presented in Chap. 5 and within this chapter evidence the complex web of risk factors experienced by children, which can be severe, enduring and, as evidenced in the findings from safeguarding practice reviews, even fatal.

The evaluative studies evidence the clear endeavour in policy and practice to respond to the needs of children affected by PSM; however, the limitations explored within this chapter highlight that current models of intervention fall short of responding to children's needs. The limitations include the exclusion of specialist support being available for children whose parents are not engaging in adult treatment services. Worryingly, given the depth of knowledge about the negative impact of PSM on a child's life, many models of intervention are only accessible after children have endured multiple risk factors, which have become so severe that a child is at significant risk of harm. Few preventative services are available, meaning that situations have to become severe before any services are offered.

A theme throughout this chapter has been the time-limited structure of interventions. While structured brief interventions may be appropriate for some adult family members and some children, the voices of parents and children identify the need for longer ongoing support. There is also a major gap in our knowledge of the long-term impact of such interventions and whether positive changes made by parents during brief interventions are sustained. One evaluative study of the Family Drug and Alcohol Court [12] raised significant questions about the impact of brief interventions, which may prolong decisions being made by social workers and the courts about what is in the best interest of the child. Further, despite the long-term impact of childhood adversity, compounded by socio-economic factors including endured poverty, coupled with reduced community resources, it is little wonder that current brief interventions are attractive even though they do not provide clear evidence of having achieved a sustained positive impact for children and their families.

In response to the limitations, including a lack of training for frontline practitioners regarding PSM, short-term interventions aligned with adult treatment services and/or statutory social work, the wider infrastructure within policy and practice needs overhauling to address children's access to support and intervention at the time of need and for as long as necessary.

This chapter has highlighted the overdue need for models of intervention to be designed and delivered through a trauma-informed lens and framed by the key principles of child-centred practice. It is vital that children are afforded equal rights to adults, including the choice and autonomy in decisions made about the level of support they require and, above all, for the support they receive to be meaningful. Children affected by parental substance misuse need and deserve much better. Government, commissioners, researchers and service providers need to understand the lived experience of children and respond to their actual needs, or we will continue to fail them, with negative consequences for all concerned.

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24 Low-Intensity Interventions with AFMs

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24.1 Introduction

For many AFMs, support is not readily available, even though they, like caregivers of adults with other chronic conditions [1], experience a high burden. Barriers to help-seeking still exist, and there is a need for low-threshold support. Shame, embarrassment, stigma, denial and guilt are common barriers to help-seeking [2, 3]. In addition, opening hours, the distance to facilities or a lack of knowledge about possible support, limited coping strategies and misinformation about mental health can be obstacles when seeking help [4, 5]. Those AFMs seeking help appear to favour low-intensity interventions such as self-help, telephone or online support [3]. A recent study shows that AFMs of persons with gambling problems who seek help in German counselling centres averagely take part in three counselling sessions, underlining the value of brief and low-intensity interventions [6].

In 1998, Barber and Gilbertson published their first paper on brief interventions for family members, stating that self-help is a viable way to support AFMs [7]. Up until now there has been very little research on brief or low-intensity interventions for AFMs, with only a few publications on this topic, most of which refer to the 5-Step Method ([8, 9]; see also Chap. XXX). Furthermore, studies comparing group settings versus workbooks showed no significant differences between both interventions [10, 11]. With increasing access to the internet, internet-based interventions for AFMs were also developed and tested [2, 12, 13].

For AFMs, reasons for using internet-based counselling include convenience, privacy and anonymity and a liking for the unique features of the online therapeutic approach [13]. Web-based interventions[1] offer this anonymity and privacy, which is important for highly stigmatized topics [12] and enables the so-called online disinhibition effect, which involves people being more open in sharing their emotions and conflicts in virtual spaces. Therefore, web-based programmes have the potential to overcome existing barriers and offer an entry point to further services [12, 13]. They also have the potential to reach a clientele that is not actively seeking help but merely browsing for information about sensitive or stigmatized topics [12] and searching online for health information on behalf of their family members. A recent study on AFMs of persons with gambling problems shows that the main interest of AFMs in seeking help is often to get information about ways to deal with the per-

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[1] We use the terms web-based interventions, online programs, e-mental health programs and internet interventions interchangeably.

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son with the gambling problem, define boundaries and responsibilities and receive concrete advice [6]. Reasons for seeking assistance online are very similar: AFMs of persons with gambling problems seek ways to encourage their family member to decrease gambling time or money expenditure [14]. They also expressed an interest in enhancing their coping abilities and obtaining personal support; this involved addressing a wide variety of issues related to the person with gambling problems or the repercussions related to gambling problems, e.g. financial management, legal options, crisis management, relationship advice and mental and physical health [15].

Self-directed interventions, such as workbooks or online modules, have been suggested as low-cost, easily accessible minimal treatment options. The current findings imply that low-threshold online interventions, e.g. *EfA* [12] and *Gambling Help Online* [13], may effectively reach new clients and fulfil their needs. As an added advantage, online interventions broaden the reach of existing programmes, making it possible to provide support to individuals who may be unable to attend in-person due to time or travel constraints or restrictions. Considering the impact of addiction on families, it is crucial to make appropriate interventions for AFMs widely available and accessible.

24.2 Digital Media in Psychotherapy and Counselling

Digital media has been used in therapy and prevention for nearly 40 years, with the first programmes for contingency management in alcohol use as well as for the prevention of alcohol and substance misuse in adolescents being tested in 1985. Until the SARS-CoV2 pandemic, many psychotherapists and counsellors were rather critical of the use of online treatment. Due to pandemic-related contact restrictions, their willingness, especially regarding video calls, was drastically increased [16].

There are various ways to integrate digital media into psychotherapy. The approaches differ in terms of the extent of self-monitoring by participants and intensity of care provided by professionals and can also combine online and offline sessions. The most common internet interventions can be described along two dimensions: firstly, the degree of automation, i.e. how much the intervention is automated through self-help programmes or apps versus personally delivered by therapists, and secondly, the ratio of therapy elements that are delivered remotely versus in person (see Table 24.1). The features can be controlled, combined and modified in various ways in order to address clients' specific needs and proved stepped care. Unguided or guided self-help programmes with little support can be used as a starting point and meet the criteria for low-intensity interventions.

While guided self-help programmes are similarly effective as face-to-face psychotherapies, unguided self-help programmes often come with high dropout rates and smaller effects [18]. In blended therapy as well as in video therapy and guided self-help, a good therapeutic relationship can be established via the internet [17]. The main challenges in internet interventions include ensuring the qualification of providers and content, the confidentiality of data and patient safety [17]. Ethical recommendations for the use of mobile

Table 24.1 Categorizations of internet interventions based on the degree of automation and delivery mode according to ([17]; table by the authors)

Therapy delivered	On site	On site and remotely	Remotely
Personally by therapists	Traditional psychotherapy	Blended therapy: face to face and email/chat/video	Video therapy, therapy by chat or email
By therapists and automated	–	Blended therapy: face to face, email/chat and self-help programme	Guided self-help programme with different degrees of support
Automated through programme or app	–	–	Unguided self-help programme

phones or devices in clinical settings, e.g. concerning anonymity and de-identification, third-party data usage, storage and transmission of data and access as well as regulation of e-mental health programmes, must be followed [19].

Often online programmes are developed as part of research projects and discontinued after the funding period ends. At long last, there are some countries, including Australia, the Netherlands, the United Kingdom and the Scandinavian countries, where internet interventions are already an integral part of the care system [17, 20]. In other countries, internet interventions have not yet been implemented into routine practice. Internet interventions yield not only the potential for low-threshold interventions but also the advantage of cost-efficiency [20]. The applications are expected to contribute to the reduction of costs in psychiatric and psychotherapeutic care [20].

24.3 Therapeutic Approaches and Techniques

Looking at web-based interventions for AFMs, there are two questions to consider: First, which therapeutic approach can generally be used for online adaptation? Second, which approaches work best for AFMs? Regarding the first question, both online therapy and blended care approaches are open to any therapeutic school. To date, cognitive-behavioural approaches are often used for online interventions, whereas psychodynamic or systemic approaches are rare. Also, it is known that internet interventions are not beneficial for higher symptom severity [20]. Therefore, these interventions are suitable for mild-to-moderate impairment or harm of AFMs.

As to the second question, a recent scoping review showed that interventions for AFMs emphasize on coping skills, improvement of the family relationships' quality and the rise of AFMs' understanding of addictions through psychoeducation [21]. These results can be seen in different countries and backgrounds, e.g. a review on psychosocial interventions for AFMs in low- and middle-income countries also revealed providing information regarding addiction, teaching coping skills and providing support as common components [15]. In a systematic review [22] of nine AFM interventions (three AFM-directed, four for couples and two low-threshold online interventions), no single intervention emerged as preferable in terms of content. However, a well-defined structure and content make some interventions more attractive for systematic implementation and examining the mechanisms of change. To address the diverse needs and requirements of specific subgroups of AFMs, interventions must be tailored accordingly and encourage adherence where necessary [22].

24.4 Factors for Uptake and Effectiveness

Considering that most people with problems related to addiction do not seek help from addiction services, low-threshold digital treatment options are a way to establish a bridge to local addiction support and enable better care. There is considerable evidence in several systematic reviews for the effectiveness of internet-based interventions targeting substance-related disorders [23, 24].

Keeping in mind that unguided self-help programmes often come with high dropout rates, offering therapeutic guidance could contribute to higher retention rates. All in all, the addition of professional psychological support to web-based interventions has shown beneficial effects. The different needs and experiences of AFMs can be met through tailoring and customization. A multicomponent intervention that incorporates behaviour change techniques like stress management, problem-solving and graded tasks [25] could therefore unfold unrealized potential impacts of web-based interventions.

24.5 Learnings from Support for Caregivers in Other Chronic Conditions

A review of web-based interventions to improve mental health in caregivers classifies web-based interventionsaccordingtotheircomponents[1]:single-

component interventions with information/education versus multicomponent interventions with either information/education combined with peer support and/or professional support and/or monitoring. Studies included in this review show improvements in mastery or self-efficacy, reduced burden and strain and enhanced quality of life, indicating that web-based interventions might lead to enhancements in mental health, general caregiving and general health outcomes [1]. However, based on this review, it remains unclear which type of web-based interventions are most effective and for which individuals [1].

Systematic reviews of web-based interventions for caregivers of individuals with Alzheimer's disease and related dementias have reported that interventions leading to improved AFM health outcomes possess the following characteristics: (1) they allow for individual tailoring by offering choices in various aspects of the intervention, (2) they include multiple components and (3) they are psychoeducational interventions [26]. All in all, the study emphasizes that support for caregivers is important and their confidence in their capacity to achieve a positive future needs to be strengthened [26].

In the following, an internet intervention for caregivers of people with a physical or mental disability is described, the results of which could be useful to transfer to AFMs.

StressLess: A Mobile App-Based, Self-Directed Psychological Intervention for Caregivers of Family/Friends with a Physical and/or Mental Disability [27]

StressLess is a self-guided, 5-week programme rooted in the principles of second- and third-wave cognitive-behavioural therapies (CBTs). The programme is delivered via mobile application and offers psychoeducation through various mediums such as text, video, audio and visuals, along with a sequence of interactive tasks or activities. The content of the five modules can be seen in Fig. 24.1. In addition to the core modules, a troubleshooting tab is provided, offering a range of stress-relieving activities, such as body scan relaxation and breathing techniques to diffuse negative thoughts.

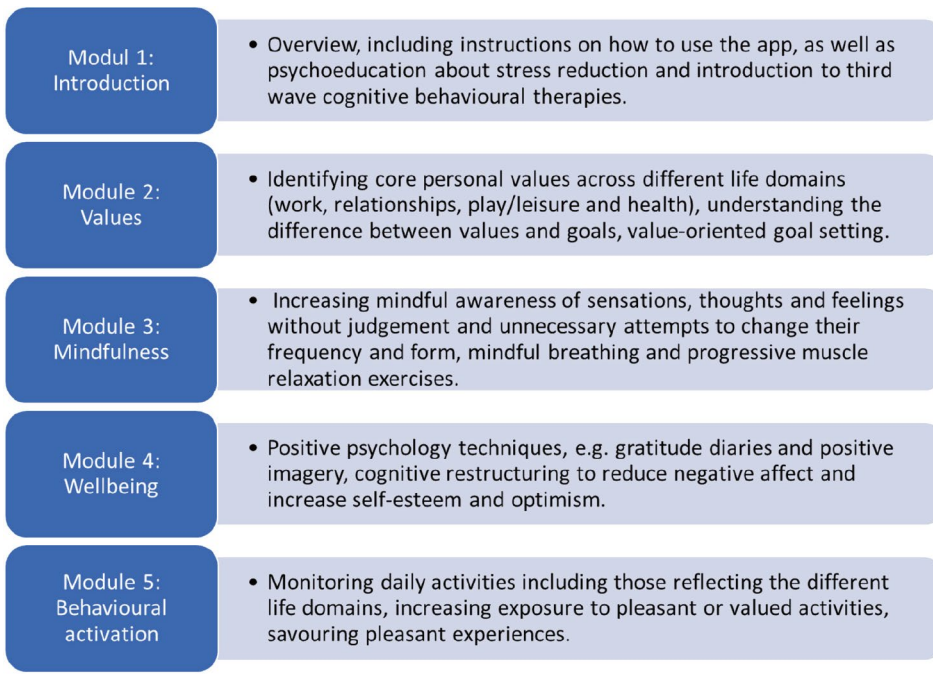

Fig. 24.1 Modules of StressLess according to ([27]; figure by the authors)

The most utilized modules were those focused on psychoeducation and values clarification, while those on mindfulness, well-being and behavioural activation saw less usage. The usage pattern observed in this study suggests that participants selectively engaged with specific modules, potentially reflecting their high-stress and time-constrained circumstances. These findings indicate the importance of designing flexible interventions, particularly for AFM populations, as they allow individuals to customize programmes to suit their unique needs.

Participants rated the overall quality of the app highly. The intervention group saw a decrease in stress and symptoms of depression from the beginning to the end of the intervention. These improvements were even more pronounced from the end to the intervention to the follow-up stage, with the intervention group consistently reporting reduced levels of depression and increased levels of emotional well-being, optimism, self-esteem, familial support, support from significant others and subjective well-being.

Availability The programme is no longer available online.

24.6 Internet Interventions for AFMs: State of Research

Currently, there are different national and international programmes available for AFMs, even though specialized care is still scarce. This also holds true for internet interventions. Programme evaluations show a similar effectiveness of online programmes in comparison with face-to-face settings [28, 29] as well as several benefits of the online format, e.g. easy access, privacy, anonymity, convenience and a non-intimidating character [12, 13, 30]. This format also speaks to people looking for help for the first time and to AFMs, like siblings, who did not feel entitled to help in on-site settings [12, 30]. Internet interventions can lead to an increased self-efficacy expectation and general life satisfaction [12, 31], improved coping skills and satisfaction with the relationship with the affected individual [31], as well as a change in stigmatizing beliefs about addiction [30]. These interventions may reduce AFM burden [28] and contribute to a decrease in depressive symptoms [31, 32] and anger [32].

A narrative review was conducted in April 2023 by searching literature in PubMed and Google Scholar. Both German and English language publications were included, targeting AFMs and discussing online interventions for this clientele. Search terms included *family*, *relatives*, *partner* and *child**, combined with search terms related to *(substance) dependence* or *addiction*, *gambling addiction* and *pathological gambling*, combined with terms for interventions including, e.g. *E-Mental-Health-Intervention*, *Online Program* or *web-based intervention*. Ultimately, 12 articles discussing 9 programmes were included in the analysis. In the following, published internet-based approaches for AFMs are listed, and their effectiveness and implications are highlighted.

Web-Based 5-Step Method for AFMs of Alcohol and/or Drug-Misusing Affected Individuals [29]

This online intervention was adapted from the 5-Step self-help manual and converted into a web format. The programme is organized in five distinct modules (Table 24.2), which correspond to the five steps of the 5-Step Method. The findings demonstrated that presenting the intervention in a self-help book format was an acceptable method of delivery. Moreover, it proved to be as effective as the face-to-face format, which involved up to five sessions with a professional. AFMs who registered to use the programme shared many demographic similarities with those who received assistance through the face-to-face and self-help version of the 5-Step Method. In contrast to the face-to-face format, siblings also took part in the online version. It is possible that siblings did not perceive themselves as eligible for help in face-to-face sessions or as the primary caregivers for their relative with alcohol or drug issues. As a result, they may have lacked opportunities to participate in treatments using

Table 24.2 Modules of the web-based 5-Step intervention according to ([29]; table by the authors)

Module	Content of the module
Module 1	Examines the nature of stress that substance use brought to the Well-being of other family members as well as their health issues
Module 2	Provides information to enhance understanding and thus reduce stress and strain
Module 3	Analysis of how family members responded to past situations and exploration of alternative responses that might lead to more positive outcomes (coping strategies and reactions)
Module 4	Examination of current support networks and ways to improve and expand their positive social support system
Module 5	Provides additional sources of help and treatment if necessary

other formats. In contrast, the web-based programme represented a low-threshold offer, which also gave siblings an easy access to help (Table 24.2).

Availability The programme is no longer available online.

Gambling Help Online [13]

Gambling Help Online provides around-the-clock instant chat support, email assistance, community discussion platforms and self-guided resources through its website. According to Rodda [13], the most frequently viewed pages were those dedicated to providing information to family and friends on how to assist others and those offering practical help advice. Approximately 15% of all individuals who received counselling through the website were family members and friends of people struggling with problem gambling. Five key factors were identified that encompass reasons for AFMs to seek help through the online intervention:

1. Ease of access, the possibility to access the service instantly and without scheduling and without extra cost.
2. Potential for privacy and anonymity, especially when discussing the impact of gambling without the possibility of the person with the gambling problems or others overhearing the conversation.
3. Characteristics of the online therapeutic platform, which made it easier for AFMs to be open and honest about the gambling problem due to the absence of visual or auditory cues in a text-based environment.
4. Easy accessibility of the service system—for more than three quarters, it is the first access point to the professional help system.
5. Perceived helpfulness of online counselling, which was associated with counsellors' ability to listen, provides empathetic and non-judgmental support, along with expert advice and information.

Availability www.gamblinghelponline.org.au

EfA: E-Mental Health Programme for AFMs of Persons with Gambling Problems [12]

EfA is an acronym for the German programme title and roughly translates to 'Don't gamble away my life'—Support for Affected Others (Verspiel nicht mein Leben—Entlastung für Angehörige). The programme was established in 2013 and is based on *ETAPPE*, an on-site group training with a psychoeducational basis, which aims to lower burden and stress in AFMs of persons with gambling problems. *EfA* is designed as an unguided self-help programme with a responsive design. Participation is anonymous and free of charge. It enables low-threshold access to professional help and primarily reaches a clientele that has not yet been connected to support services.

EfA comprises six self-administered modules, beginning with an information module that is freely accessible (see Fig. 24.2). The subsequent five training modules necessitate registration, but no fees are associated with joining the programme. Each module is composed of 18–20 web pages, featuring text and figures that either explain the text's content or display the models used in the text. To ensure accessibility, all information is also available as an audio file.

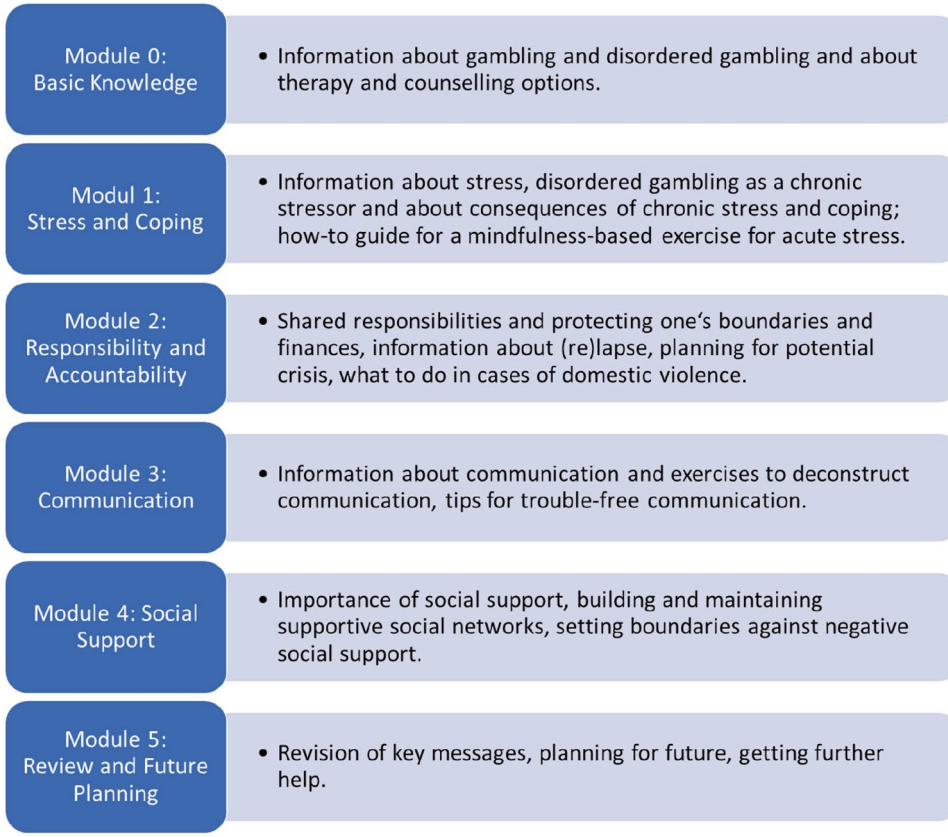

Fig. 24.2 Contents of *EfA* according to ([12]; figure by the authors])

An initial study suggests the feasibility of engaging AFMs via the *EfA* programme [33]. When queried about their *EfA* referral source, roughly one-fourth of participants disclosed discovering the programme through a search engine with search queries predominantly (91.9%) incorporating the programme's name, its leaflet slogan or fragments of both. This underscores the significance of selecting a memorable name and slogan and disseminating this information broadly. Notably, about two thirds of all participants had not pursued any prior professional help or self-help, pointing out the potential of web-based programmes for professional support. All in all, participating in *EfA* positively impacted self-efficacy expectation and general life satisfaction.

Availability http://www.verspiel-nicht-mein-leben.de

Kopstoring: An Online Course for Children of Parents with Mental Health Problems or Addictions [34]

The 8-week online group course under the supervision of two trained psychologists or social workers sought to prevent behavioural and psychological issues in children (aged 16–25 years) whose parents struggled with mental health problems or addictions. Each week, participants explored a different theme and were required to complete homework assignments in preparation for the upcoming meetings. Topics included (1) getting acquainted with the home situation, (2) roles in families, (3) thoughts and feelings, (4) questions about addiction and mental problems, (5) different styles of behaviour, (6) social networks, (7) leading your own life in relation to social networks and (8) what is coming up in the future.

Both participants and providers consider the online intervention to be effective and valuable,

with the protection of anonymity being regarded as a crucial aspect. Participants also appreciated the freedom to choose whether to participate without interference from others.

Availability www.koppsupport.nl

StopSpinningMyWheels.org: A Web-Based Programme for Women with Problem-Drinking Partners [32]

Women married to or living with an alcohol-misusing partner receive a 24-session, self-paced, online skill training called *Internet-based Coping Skills Training (iCST)* on the Website StopSpinningMyWheels.org. The website content, adapted from the face-to-face Coping Skills Training (CST), aimed to alleviate participants' distress. Through videos, instructional narration, animated presentations, quizzes and personal journaling, participants learned to (a) prioritize their own needs, (b) control negative thinking, (c) resolve situations through problem-solving, (d) conduct functional analyses of their own and their partner's behaviour and (e) communicate with increased consistency and clarity.

In relation to a delayed treatment condition, iCST improved coping skills, reduced depressive symptoms and anger and prevented the escalation of depression and anger among individuals who initially exhibited low baseline levels for these indicators.

Availability The programme is no longer available online.

Online Cognitive-Behavioural Therapy for AFMs of Treatment-Refusing Problem Gamblers [2]

The internet-delivered CBT programme consists of nine modules inspired by the gambling adaptation of the CRAFT approach [35] and involves psychoeducation, functional analysis and positive reinforcement. Study counsellors provided support to participants through email and weekly 15-min phone calls. Compared to a wait-list group, the intervention enhanced the psychological well-being of the AFMs at the post-test. Despite overall low adherence to the programme, the results suggest that AFMs who actively engaged with the programme experienced greater benefits.

Availability https://spelfri.se/

iCRAFT: Support Programme for AFMs to Engage Affected Individuals to Treatment and Improve AFM Functioning [31]

iCRAFT represents the internet-based version of CRAFT and was designed based on the original treatment manual. It incorporates the same fundamental components, but the number of modules was decreased to five in order to promote treatment adherence (see Fig. 24.3). iCRAFT consists of 5 weekly therapist-guided modules covering the following topics: (a) enhancing the mental health of AFMs, (b) improving AFMs' skills in encouraging the person with the drinking problem to seek treatment, (c) developing positive communication skills and (d) influencing the affected individuals' drinking behaviour through contingency management. A recent effectiveness study from Sweden found a positive impact of iCRAFT on the mental health of AFMs. Participants displayed reduced scores on depression scales, while the outcomes for anxiety, stress and emotional avoidance were less conclusive. Additionally, iCRAFT participants reported an enhanced quality of life and satisfaction with their relationship with the person with the drinking problem. Overall, results indicate that the iCRAFT programme initially had a beneficial effect on participants' mental health, but these improvements did not persist over an extended period.

Availability The programme is no longer available online

BreakThrough: An Online Addiction Education Programme [30]

Drawing from the Stress-Strain-Coping-Support (SSCS) model, the peer-led online programme *BreakThrough* offers evidence-based and guidance on topics such as substance use, communica-

Fig. 24.3 Contents of iCRAFT according to [32; figure by the authors]

tion, coping tactics, family violence and safety and self-care. It also provides resources to help participants obtain further support. It is offered biweekly, with sessions taking place either at local community centres (Victoria, Australia) or through the online platform *Zoom*. Each session is led by two facilitators, both possessing qualifications in alcohol and/or drug-related fields, with one having personal experience supporting a family member struggling with addiction. The 1-h sessions involve facilitators presenting information and techniques while also giving attendees the opportunity to share and discuss their own experiences if they choose to do so. The sessions cover a range of topics with six topics offered consistently: (1) understanding addiction, (2) mental health, (3) family relationship, (4) boundaries and safety plans, (5) communication and (6) recovery.

Overall, a qualitative analysis of the attending AFMs' experiences showed that participants favoured the accessibility and convenience of the online format. The online environment was perceived as non-intimidating, particularly for newcomers. Participants reported two primary shifts in their thinking related to attending *BreakThrough*: a change in stigmatizing beliefs about addiction and a transformation in their strategies for coping with and managing their loved one's addiction.

Availability www.breakthroughforfamilies.com

Sterk Ernaast: Helping Family Members Affected by a Relative's Substance Use or Gambling [28]

Even though the aim of this study was not to develop an online adaptation of the 5-Step Method in the beginning, parts of the study included testing the 5-Step Method as videoconferencing, due to the pandemic situation. Overall, family burden was significantly reduced by about 20% at the end of the intervention. Also, scores on various coping scales changed considerably in the 3-month follow-up, indicating that

participants learned new skills and developed their coping behaviour further after the end of the programme. Results for face-to-face and video-conferencing were very similar, indicating that the 5-Step Method can readily be adapted for online usage.

Availability www.jellinek.nl/

24.7 Conclusion

Considering the limited research on web-based interventions for AFMs, any subsequent studies will play a crucial role. It is advisable to expand qualitative and mixed-methods research to guarantee that perspectives of AFMs are included in the development of best practices. Furthermore, these perspectives should encompass varied backgrounds of clients and adopt inclusive notions of family, ensuring that interventions are culturally pertinent and adaptable [21].

It may also be beneficial to digitize existing valid offline programmes, as online interventions should incorporate a solid theoretical foundation and integrate techniques to enhance self-efficacy, stress reduction and coping mechanisms [36]. It is suggested to adopt strengths-based, non-pathologizing theoretical frameworks, along with greater emphasis on harm reduction and recovery-centred care [21]. Adopting a tailored approach that concentrates on a select few core skills relevant to individual AFMs may enhance adherence and motivation in the intervention [2]. Moreover, it is important to create brief and low-intensity interventions with a suggested maximum of five modules. In terms of adherence, a combined strategy, in which AFMs can continuously decide which approach they want to pursue, i.e. promoting and supporting changes in gambling behaviours while also concentrating on their own needs, may also be beneficial [14]. Moreover, web-based interventions need to meet ethical standards and ongoing maintenance. Lastly, it is essential that internet interventions receive continuous funding to ensure their availability for AFMs in the long term.

List of useful resources: existing programmes for AFMs

Name of the programme	Target group	Authors	Website
BreakThrough: Families understanding addiction	AFMs of persons with addictive behaviours (unspecified)	Peart et al. (2023)	www.breakthroughforfamilies.com
EfA ('Don't gamble away my life'—Support for Affected Others; 'Verspiel nicht mein Leben'—Entlastung für Angehörige)	AFMs of persons with gambling problems	Buchner et al. (2017)	www.verspiel-nicht-mein-leben.de
Gambling Help Online	AFMs of persons with gambling problems and affected individuals	Rodda et al. (2013)	www.gamblinghelponline.org.au (Might not be working from other countries than Australia)
Kopstoring (nowadays: KOPPsupport)	For young people (16–25) with parents who have mental and/or addiction problems	Woolderink et al. (2015)	www.koppsupport.nl
Online CBT for treatment-refusing problem gamblers (Spelfri)	AFMs of treatment-refusing persons with gambling disor[l]ders and affected individuals	Magnusson et al. (2019)	https://spelfri.se/
Sterk Ernaast	AFMs of persons with substance or gambling disorders	van Beek et al. (2023)	www.jellinek.nl/

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Mutual-Help Groups for Affected Others

25

Christine Timko and Michael Cucciare

25.1 Introduction

An important component of the system of care for Affected Others is mutual-help groups. Mutual-help groups are groups of two or more people who share an experience or life problem and meet regularly to provide problem-specific help and support to one another [1]. The term "mutual-help" is preferred to the traditional term "self-help" by healthcare providers and researchers because it emphasizes the interdependent nature of group processes. Generally, members run mutual-help groups without professional involvement. People can attend mutual-help groups as often and for as long as they choose. Mutual-help organizations provide an adaptive, community-based system of care that is highly responsive to members' risk for personal setbacks [1].

Recovery-oriented mutual-help groups aid recovery from substance use disorders and facilitate personal growth through peer support and self-exploration. They provide a forum and opportunity for individuals seeking or in recovery—both Affected Others and the people they are affected by—to connect with others who have similar experiences and goals, allowing them to build relationships within a supportive network. These groups are typically free, anonymous, and easily accessed (are available in person and/or online) and thus can be of benefit over the long-term trajectory of recovery.

A variety of terms is used for people affected by, or concerned about, a family member or friend's alcohol or other substance use. We usually use the term "Concerned Others" to include people affected by family members and/or friends. Indeed, a sizeable minority of patients in treatment for alcohol use disorders consider a friend to be their primary Concerned Other [2]. However, in keeping with other chapters in this volume, we use the term "Affected Others" in this chapter. In addition, in order to be concise, respectful, and inclusive of persons in treatment

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and persons not in treatment (i.e., patients and non-patients), we use the term "recipient" for the person engaged in alcohol or other substance use. This is consistent with the literature on caregiving in which the term "care recipient" is used. We now turn to describing types of mutual-help groups for Affected Others.

25.2 Major Types of Mutual-Help Groups for Affected Others

Recovery-oriented mutual-help groups are often categorized as 12-step or non-12-step (also known as 12-step alternatives). Twelve-step mutual-help groups are fellowships that follow 12 steps that guide recovery. Twelve-step programs have a general spiritual foundation, but they do not require any specific spiritual or religious background for participation. They usually encourage members to look outside themselves to a higher power, which is defined by each member. Although 12-step groups are spiritual but not religious, some people may be uncomfortable with participating in 12-step groups if they view them to be religiously oriented. Thus, in addition to 12-step programs, alternative mutual-help groups are available.

Twelve-step alternative mutual-help groups are often secular, perhaps making them more acceptable to people who are atheist, agnostic, or of religions that do not share a western, Christian tradition. In addition, in contrast to 12-step programs, alternative mutual-help groups may discourage the emphasis on the recovering individual's powerlessness over substances or behaviors and instead view individuals as having adequate power within themselves to work toward, and learn skills to support, recovery.

25.2.1 12-Step Mutual-Help Groups for Affected Others

Al-Anon Family Groups (Al-Anon) is the recovery-focused mutual-help group for Affected Others with the largest knowledge base and availability and thus is a focus of this chapter. Al-Anon meetings are held in more than 133 countries, with more than 30,000 groups. Al-Anon was cofounded in 1951 by Lois Wilson, the wife of Bill Wilson, who was the cofounder of Alcoholics Anonymous (AA). It is a fellowship of family and friends of people with alcohol problems who share their experience, strength, and hope to solve their common difficulties [3, 4]. Al-Anon is closely allied with Alateen, a peer support group for young people (mainly adolescents) who are affected by someone else's alcohol use. There are more than 2300 Alateen groups worldwide. Alateen helps young people learn about the impact of an alcohol use disorder on the recipient and their family and friends.

Al-Anon's 12 steps were adopted nearly word for word from the Twelve Steps of AA. Three legacies of AA guide Al-Anon: recovery through the 12 Steps, unity through the 12 traditions (which provide principles keeping 12-step programs focused on their primary purpose of fellowship), and service within the Al-Anon program. Al-Anon and Alateen members are encouraged to focus on themselves, rather than on the person drinking, emphasizing that Affected Others did not cause, cannot cure, and cannot control another person's alcohol-related choices and behaviors. Members are encouraged to attend meetings, work the 12 steps, obtain a sponsor (an Al-Anon [or Alateen] member who provides personal support for understanding the program and working the steps), read Al-Anon (or Alateen) literature, and develop spiritual practices such as prayer and meditation. Some meetings are open to attendance by anyone, and others are closed—that is, only for members or prospective members who have a relative or friend with substance use problems. In a typical meeting, participants share and listen to each other on a confidential basis. Often meetings focus on a topic addressed by a lead speaker. Attendees are not required to speak, but when they do, they are encouraged to share about themselves and their experiences without giving direct advice or questioning or interrupting others.

Some information about Al-Anon comes from its triennial survey, the most recent of which was in 2021. Information was collected from 16,486

Al-Anon members who responded in 3 languages. Respondents' average age was 63 years old; most respondents identified as White (90%) and female (87%) and had at least a college degree (79%). In addition, although Al-Anon was founded for Affected Others of people with alcohol-related problems, the survey found that 28% of members first came to Al-Anon because of a relative or friend's drug-related problem. Some of the main reasons Affected Others first attend Al-Anon are their problems with their overall quality of life, problems with their loved one's substance use, stress, and anger [5]. Women are more likely than men to have started attending Al-Anon because of their stress, anxiety, and inability to relax, as well as their feelings of hopelessness and their physical health problems. In contrast, men are more likely than women to have begun attending Al-Anon because they want to learn how to help their loved one with substance use and because they felt they were missing what's important in life [6]. Finally, Affected Others wait a relatively long time before seeking help for themselves. Specifically, Affected Others have known their loved one with alcohol use for an average of 22 years, and the drinking had been a problem for an average of 13 years, before the Affected Other sought help [7].

Whereas Al-Anon participation is often related to another's alcohol use, Nar-Anon Family Groups (Nar-Anon) is primarily for people concerned about another's drug addiction. Nar-Anon filed articles of incorporation in 1971 and established its World Service Office in 1986. It is a worldwide fellowship that is adapted from Narcotics Anonymous and uses its own 12 Steps, 12 traditions, and 12 concepts. Narateen, part of the Nar-Anon program, is for adolescents affected by someone else's addiction.

Gam-Anon is a 12-step fellowship of adults affected by another's gambling problem. Its purposes are to give assistance and comfort to those affected by someone else's gambling; to communicate Gam-Anon's understanding of compulsive gambling and its impact on Affected Others' lives; to share experience, strength, and hope in coping with the gambling problem; and to use the steps and tools of the Gam-Anon program to nurture members' spiritual and emotional growth and recovery.

These three 12-step mutual-help programs for Affected Others are not an exhaustive list of such resources. For example, another is Adult Children of Alcoholics and Dysfunctional Families, which is for adults who grew up in homes with a person with an alcohol use disorder or experienced other dysfunction (e.g., abuse, neglect, trauma). Members of this program recover by identifying and healing core traumas, experiencing freedom from shame and abandonment, and becoming their own loving parents. In addition to 12-step programs such as the ones just described, there are alternative (non-12-step) programs for Affected Others.

25.2.2 12-Step Alternative Mutual-Help Groups for Affected Others

SMART Recovery Family and Friends, for family members of people living with addiction, is described as a secular, science-based alternative to Al-Anon. Its content is based on SMART (Self-Management and Recovery Training) Recovery for people addicted to substances and on CRAFT (Community Reinforcement and Family Training) for Affected Others. The SMART Recovery approach for people addicted to substances enhances and maintains motivation to abstain from substance use; cope with urges; manage thoughts, feelings, and behaviors; and balance momentary and enduring satisfactions. CRAFT trains Affected Others to motivate their loved one who is treatment-resistant to seek help for addiction. Meetings for Affected Others aim to provide tools to support Affected Others' ability to cope and "regain peace of mind" without supporting addiction behaviors.

Another 12-step alterative is Learn to Cope. Learn to Cope is a peer support network that offers meetings, education, and resources for adult family members coping with a loved one addicted to opioids or other drugs. It began in one US state (Massachusetts) in 2004 and has since been expanding to other US states with over

11,000 members. It also has an online forum [8]. During Learn To Cope meetings, attendees share personal experiences and exchange information. In addition, there is explicit professional input through lectures by addiction professionals, members of other recovery support organizations, and persons in long-term recovery. Meetings are also used to distribute intranasal naloxone (Narcan) to members and offer and provide training free of charge on how to use it to reverse opioid overdose. Learn to Cope encourages Affected Others to provide reinforcement to their loved one for behaviors, such as attendance at treatment sessions and medication compliance, and actively facilitates cross-talk and direct feedback among members during meetings. Similar to Al-Anon, Learn to Cope's membership is composed mainly of White, middle-aged, and educated women [8], which suggests the need for outreach to the diverse population of Affected Others. The need for such outreach is supported by evidence, reviewed in the following sections, that participation in mutual-help groups benefits Affected Others.

25.3 Participation in Mutual-Help Groups and Affected Others' Outcomes

Outcomes or consequences of Al-Anon participation that have been studied include Affected Others' understanding of alcohol use disorders, mental health, coping skills, and relationships. Early studies of Al-Anon, conducted mainly in the 1980s and 1990s, found that Al-Anon attendees reported improvements in their understanding of alcohol use disorders, depression, assertiveness, self-acceptance, and relationships [9], greater reductions in personal problems and emotional distress (depression, anxiety, anger), and greater increases in self-esteem, coping behaviors, and relationship happiness [10–14].

More recent studies of Al-Anon agree with these findings. Al-Anon was found to help with the main reasons that Affected Others began attending the program, including improving their overall quality of life, and helped address problems with the loved one with substance use and their own stress and anger [5]. In addition, longer-term Al-Anon members were more likely than Al-Anon newcomers to report more improvement in these domains [5]. For example, in Al-Anon's 2021 survey, 83% of members reported improvement in their mental health within the first year of attendance, and 93% of members with four or more years of attendance did so. Thus, a longer duration of Al-Anon attendance is associated with better outcomes for Affected Others.

Some studies compared CRAFT, which focuses on teaching Affected Others how to motivate their loved one when they are resistant to seek help for their substance use problems, with the Al-Anon or Nar-Anon approach. CRAFT is associated with a higher likelihood of the recipient entering treatment. However, Affected Others showed comparable mental health (e.g., depression, anger, mood), social relationship functioning (e.g., family conflict and cohesion, relationship happiness), physical (e.g., health, symptoms), and other (e.g., financial) improvements whether they were assigned to CRAFT or the other approaches [15]. In a study that compared the full CRAFT intervention (12–14 sessions), a shortened CRAFT intervention (4–6 sessions), and an Al-Anon/Nar-Anon facilitation intervention (12–14 sessions consisting of education about Al-Anon's steps, principles, and philosophy and encouragement to attend), the two CRAFT interventions resulted in greater treatment entry rates compared to the Al-Anon/Nar-Anon facilitation intervention. However, in all three interventions, days of drug use by the recipient decreased, and Affected Others' mood and functioning improved [16].

25.3.1 How Al-Anon Works

Although much is known about mechanisms through which 12-step groups benefit members, little is known about how Al-Anon in particular works. The social or therapeutic processes that likely explain the benefits of Al-Anon are described in Rudolf Moos' model of the active

ingredients of substance use-related mutual-help groups [3, 17]. The social processes that may explain why Al-Anon is helpful include (a) bonding (the group is cohesive and supportive), goal direction (the group encourages personal growth), and structure (the group embodies clear expectations); (b) the group's provision of norms and role models; (c) the group's offer of involvement in rewarding activities; and (d) the group's bolstering of self-efficacy and coping skills. Figure 25.1 outlines the hypothesis that more Al-Anon attendance should lead to more social processes (i.e., bonding, goal direction, and so on), which in turn should lead to better Al-Anon outcomes.

This hypothesis is particularly relevant for "newcomers" to Al-Anon. Social processes significantly mediate associations between newcomers' attendance status (sustained versus terminated) and outcomes such as quality of life, ability to handle problems due to the loved one who uses substances, and positive symptoms (e.g., self-esteem, hope). Sustained Al-Anon attendance is associated with more social processes such as bonding with other members and having structured goals, which in turn is associated with better outcomes. However, among "oldtimers," Al-Anon attendance (number of meetings) is not associated with outcomes. But, importantly, among "oldtimers," more social processes are associated with better outcomes. This means that among "oldtimers," the number of meetings they attend may be less important to their well-being than the social processes they experience when they attend. In summary, bonding, goal direction, and access to peers in recovery and rewarding pursuits help to explain associations between sustained Al-Anon participation among newcomers and improvements on key concerns of Al-Anon attendees [18].

25.3.2 Al-Anon Across Cultures

Still unknown is the extent to which these same mechanisms explain Al-Anon's positive outcomes in different cultures. Most of this chapter focuses on what is known about Al-Anon participation in the USA, where research indicates that Al-Anon is composed mainly of White, middle-aged, and well-educated women. In Iran, where Al-Anon appears to be the sole source of assistance for Affected Others in that country, compared to first-time attendees, sustained Al-Anon attendees reported better quality of life, including better social functioning, fewer limitations due to physical and emotional problems, more vitality, and less pain [19]. A qualitative study conducted in Goa, India, found that Affected Others relied upon Al-Anon as a source of support and that Al-Anon was particularly helpful to them. In Al-Anon meetings, perceived shameful and stigmatized experiences could be shared, and Affected Others could achieve empowerment and acceptance [20].

Although there is universality to the experiences of families and friends affected by addictions, this must be interpreted with caution, as it is accompanied by variations in cultural factors related to these experiences. Such factors are primarily external to the lives of Affected Others (e.g., societal expectations of how families should address their problems, available social support) and may influence their internal lives (e.g., guilt,

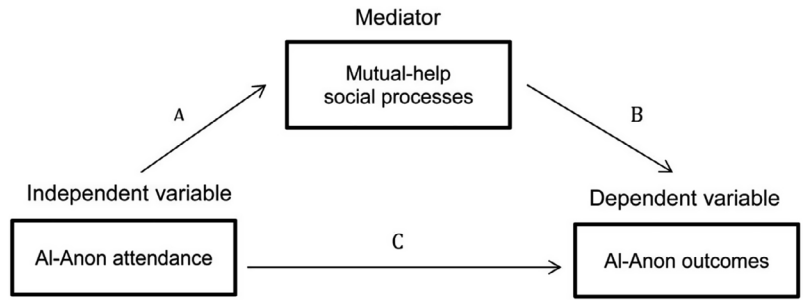

Fig. 25.1 Social processes mediate between Al-Anon attendance and outcomes

blame). As discussed in the following sections, mutual-help groups may help Affected Others with both external factors and their internal lives.

25.4 Affected Others' Mutual-Help Group Participation and Dyadic Outcomes

25.4.1 Early Research Studies

Early studies of Al-Anon also supported the notion that Al-Anon participation is associated with improved functioning by the Affected Other, which in turn is associated with better functioning of the loved one with substance problems. Patients treated for alcohol use disorders were more likely to stay abstinent when their Affected Other participated in Al-Anon [21, 22], and Affected Others attending Al-Anon also had better communication with their loved one's treatment staff [23].

Staying in Al-Anon longer was associated with greater decreases in Affected Others' negative coping (e.g., threaten actions but do not follow through, have emotional outbursts), and decreases in negative coping were associated with their loved one staying abstinent from alcohol longer [24]. Affected Others who stayed in Al-Anon longer were more likely to have a loved one who attended AA for a longer period of time. Further, when Affected Others stayed in Al-Anon longer, they and their loved ones with substance problems were also more likely to report less stress [25]. Affected Others who received psychotherapy focused on Al-Anon facilitation (i.e., therapy that encouraged the Affected Other to try Al-Anon) [13] showed less depression, and their loved one reported a reduction in alcohol use [14]. Together, these findings suggest that active Al-Anon membership that helps an Affected Other is also of benefit to their loved one with substance use problems.

25.4.2 Later Research Studies

Research conducted more recently confirms these early findings. While both those with sustained attendance and those who stop attending Al-Anon report benefits, the former are more likely to report benefits in a number of domains, including learning how to handle problems due to the recipient, general well-being, functioning, and psychological symptoms [26]. Further, those who continue to attend Al-Anon are more likely than those who stop to report increases in daily, in-person contact with the loved one with substance use problems. The last point is important because Affected Others often want to maintain their relationship with their loved one with substance use problems while reducing associated distress [27]. In keeping with Al-Anon's focus, while Affected Others are more likely to report personal gains from attending Al-Anon, more Al-Anon meeting attendance is also significantly associated with reports of the loved one having fewer drinking days, less use of non-prescribed drugs, and fewer substance-related problems [26] (Box 25.1).

Box 25.1 Dyad Study

We conducted a study of 279 dyads comprised of adults entering treatment for an alcohol use disorder and their Affected Others. Dyads were assessed when patients entered treatment (called "baseline") and 3, 6, and 12 months later. Analyses at patients' treatment entry found that when Affected Others had greater readiness for Al-Anon participation, patients had higher scores on a measure of protective factors (e.g., spends time at work or school) for future substance use [2]. Other analyses from the same study examined Affected Others' Al-Anon participation, as well as aspects of their functioning (relationship stressors, use of approach coping, and perceived stigma) as predictors of patients' AA participation, abstinence, and risk of substance use over the full 12 months. Results were that Affected Others' participation in Al-Anon was associated with more AA participation by patients. In addition, more perceived stigma (e.g., needing to hide the patient's drinking) reported by Affected Others was

(continued)

Box 25.1 (continued)

associated with less AA participation by patients. Further, more use of approach coping (i.e., problem-solving or seeking information) by Affected Others was associated with patients' lower risk for alcohol and drug use [28].

Finally, we conducted an analysis to identify subgroups of the same dyads of patients in treatment for alcohol use disorders and their Affected Others [29]. In the analysis, patients were characterized on their AA participation and substance use, and Affected Others were characterized on their Al-Anon involvement, at baseline (i.e., the patient's treatment entry) and the 3-, 6-, and 12-month follow-ups. Three classes (subgroups) of patient-Affected Other dyads were identified. The "Low AA/Low Al-Anon" subgroup (38% of all the dyads) had patients with low AA participation, Affected Others with low Al-Anon participation, and patients with high-to-moderate substance use. The other groups were "High AA/High Al-Anon" (10%; patients' high AA and Affected Others' high Al-Anon participation and patients' moderate-to-low substance use) and "High AA/Low Al-Anon" (52%; patients' high AA and Affected Others' low Al-Anon involvement and patients' moderate-to-low substance use). At follow-up, the Low AA/Low Al-Anon class patients were less likely to have spirituality as recovery support, confidence about staying abstinent, and satisfaction with their recovery progress. The High AA classes' Affected Others had less concern about patients' drinking and scored higher on positive aspects of relationships with patients.

Although AA involvement was high for patients in two of the three classes, combining to make up 62% of the sample, the High AA/High Al-Anon class was small, making up only 10% of the sample. Perhaps due in part to the small size of this group, analyses revealed few different predictors or outcomes associated with membership in the High AA/High Al-Anon class compared to the High AA/Low Al-Anon class. The High AA/High Al-Anon class had the highest proportion of women patients and more "Positive Aspects of stigma" among Affected Others. Positive Aspects of stigma involved personal growth, e.g., "My relationship with someone who has an alcohol use disorder has made me more accepting of other people." Regarding this aspect of stigma, Al-Anon principles contain reminders to be compassionate with others, including the person who is drinking, and to avoid impatience, criticism, resentment, and vengefulness because they harm both the self and others. Possible reasons for low involvement in Al-Anon include the stigmatization of addiction, the lesser availability of Al-Anon meetings relative to AA meetings, Affected Others' perceived lack of need (they believe their well-being is not affected by the recipient or that the recipient's difficulties should resolve once treatment has been initiated), a lack of willingness to do any more to help the patient than the Affected Other already has (even though Al-Anon is for the Affected Other, not the patient), and Affected Others' emotional withdrawal from loved ones with years of active substance use because hope has been lost for the recipient's recovery [29].

The findings from our study of dyads support the conclusion that clinicians should encourage Affected Others (and recipients) to participate in 12-step groups. That more than one-third of dyads had low 12-step group participation suggests that treatment providers may need to facilitate participation in non-12-step mutual-help groups. For example, providers could educate their patients about 12-step alternative

(continued)

Box 25.1 (continued)

groups and help them locate and attend a group meeting. This may be especially needed for Affected Others, of whom the large majority had low participation in Al-Anon. Accordingly, we turn next to the topic of connections between mutual-help groups and treatment for Affected Others (Box 25.2).

Box 25.2 Intervention Study

We conducted a randomized controlled trial to test the effectiveness of an intervention, Al-Anon Intensive Referral (AIR), compared to usual care, to facilitate participation in Al-Anon by Affected Others of patients in treatment for alcohol use disorders [30]. AIR consisted of four sessions over 3 months with an Al-Anon Coach. Usual care was the treatment program's offer of educational sessions for Affected Others. There was no significant effect of AIR on Al-Anon attendance. However, there was a significant effect of AIR on Affected Other-patient relationship resources at follow-ups: Affected Others assigned to the AIR condition had more resources (i.e., a supportive, calm, and fun relationship with the recipient) than Affected Others who were in the usual care condition.

Consistent results were found in a qualitative evaluation of AIR in which substance use treatment providers were interviewed about AIR's usefulness. Treatment providers recommended that to optimize AIR's implementation, AIR should target Affected Others with high readiness for receiving help [31]. Another recommendation was that AIR be fit into existing provider workflows to minimize staff burden, in light of providers' views that AIR was relevant and appropriate for its purpose, consistent with treatment staff values and skills, and would require only minimal staff training to implement in treatment programs. Further, treatment providers perceived Al-Anon (and other 12-step programs) positively; recognized such programs as useful to, and widespread resources for, Affected Others and recipients; and welcomed additional efforts to educate and encourage Affected Others to initiate and engage with these resources.

25.5 Connections Between Mutual-Help Groups and Treatment

In the substance use treatment community, usual care for Affected Others may involve treatment programs offering education or treatment sessions specific to them, which may also include referral to mutual-help groups [32]. However, how Affected Others in various treatment and service settings are referred to help or treatment likely varies. In addition, referral methods often have unknown effectiveness in terms of increasing participation in mutual-help groups and improving Affected Others' and recipients' outcomes. In Al-Anon's 2021 Membership Survey, 66% of respondents reported receiving professional treatment (counseling, therapy, or other treatment) before attending Al-Anon; of these, 41% were referred to Al-Anon by a healthcare provider, and nearly 75% continued professional treatment during Al-Anon attendance. Those attending both Al-Anon meetings and professional treatment together reported a 14% greater improvement in mental health than those who had not received treatment. Another survey of Al-Anon attendees found that the least common source of referral to Al-Anon was the Affected Other's own healthcare provider [5]. However, sustained attendance was more likely among individuals who were referred to Al-Anon by a healthcare provider [33].

Findings that the combination of professional treatment or referral to treatment and Al-Anon participation is helpful to Affected Others suggest that healthcare providers may want to refer

Affected Others to Al-Anon or other mutual-help groups. In addition to focusing on patients who see themselves as in need of help, healthcare providers may be more successful at referring patients to community-based recovery programs when they are knowledgeable about these programs [34]. In addition, because different meetings have different ambiences, providers should encourage patients to attend several different meetings to identify the ones that feel most comfortable for them or the ones in which they find connection with other members [35]. It is helpful to inform patients that each meeting is unique and has its own character. That is, if an Affected Other has a negative experience in a particular meeting, they should try attending different meetings to find the ones that feel right.

25.6 Conclusion

Mutual-help groups are an important component of the system of care for Affected Others. Of all the 12-step and 12-step alternative mutual-help groups for Affected Others, Al-Anon currently has the largest knowledge base and greatest availability. Evidence shows that participation in mutual-help groups benefits Affected Others, such as improving their understanding of their recipient's alcohol use disorder and their own mental health, coping skills, and relationships. In addition, compared to shorter-term attendance, longer-term attendance is associated with more improvement in outcomes for Affected Others. Longer-term Al-Anon attendance is effective because it is associated with the social processes of more bonding with others sharing similar experiences, goal direction, access to peers in recovery, and involvement in rewarding pursuits. In addition, more Al-Anon participation is associated not only with improved functioning by the Affected Other but also with better functioning of their loved one with substance use problems. Based on such research, clinicians should encourage Affected Others' and recipients' 12-step group participation. Indeed, research findings that the combination of professional treatment or referral to treatment and Al-Anon participation is helpful to Affected Others underscore that healthcare providers should refer Affected Others to Al-Anon or another mutual-help group.

Even with this knowledge, the empirical base for mutual-help groups for Affected Others is relatively limited, and there is a need for more research on Affected Others' mutual-help group participation, especially for programs other than Al-Anon. The focus of future research should include the examination of mutual-help groups' active ingredients and outcomes and a better understanding of newcomers to these groups and patterns of participation over time. Conceptual frameworks are helpful to guide the examination of these different areas of research [3, 17]. When the active ingredients of mutual-help groups are identified, it will be possible to examine how well and consistently different groups deliver them and the extent to which they are associated with varying outcomes for individuals with different characteristics, such as those from diverse ethnic and cultural backgrounds.

To fully examine the outcomes of participation in mutual-help groups, we need more comprehensive measures of involvement in these groups. Specifically, meeting attendance (i.e., number, duration, and frequency of meetings attended) is an important indicator of participation, but it may not adequately reflect an individual's level of group involvement, such as engagement in the mutual-help program's practices. Further, methods are needed to facilitate earlier attendance of mutual-help groups, before the accumulation of life stressors becomes too burdensome. It would be helpful for the mutual-help, professional treatment, and research communities to work together to help individuals shorten the delay between recognizing the problems of their friend or family member and obtaining help. We want to facilitate help-seeking before the Affected Other hits rock bottom, viewing life as unmanageable, hopeless, and full of despair. To accomplish the goals of earlier help-seeking as well as increased diversity of mutual-help groups, we should continue to build strong alliances among professional treatment providers, researchers, and mutual-help group leaders

and members, who ultimately serve to provide hope and recovery to Affected Others.

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Part V

Conclusions

26 Recognising and Responding to the Needs of AFMs: The Next Steps (Implications for Policy, Practice and Research)

Gallus Bischof, Richard Velleman, Marcela Tiburcio, Abhijit Nadkarni, and Jim Orford

26.1 Introduction

This book has brought together the work of renowned authors from the global South and the global North to examine the multiple facets of the experiences of family members facing addiction-type problems. The 25 chapters in this volume show us how much we already know, although research on affected family members (AFMs) has been relatively scarce (similar to approaches for supporting AFMs), and many issues need further research. However, these chapters demonstrate that an impressive body of evidence has been accumulated so far:

- Epidemiological data suggests that a large number of individuals are affected by a relative's addiction-type problem and that the effects on AFMs should be viewed as a public health issue (Chap. 2).
- The harm caused by these types of problems affects a wide number of relationships and can be consistently found in different cultures (Chaps. 4–9, 11, 12).
- Although children appear to be among the family members most severely affected (Chap. 5), the harm caused to adult family members has, so far, been largely neglected by research and practice (Chaps. 4, 6–9, 11, 12).
- The degree of ill-health caused to families by addiction-type problems is substantial, with elevated rates of both psychiatric morbidity and somatic illnesses. Health insurance data suggests that this ill-health is causally attributable to family members' exposure with addiction-type problems, since morbidity is significantly reduced once the relative has been successfully treated [1]. Furthermore, there is no evidence that AFMs who reveal elevated morbidity share common pre-morbid characteristics that trigger

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ill-health, although it is likely that the level of resilience (i.e. personal characteristics) of AFMs can contribute to the level of impairment experienced, as is the case in psychiatric disorders in general [2] (Chaps. 4–12).

At the same time, preliminary results suggest that the AFM experience is moderated by a number of factors, including gender, type of relationship, type of attachment and (sub-)cultural and economic background, just to name a few.

As Chap. 3 shows, the ways that researchers and practitioners conceptualise what it means to be an AFM influences the work that they do, be it research, policy development, implementation development or simply how one works to try to help people as a practitioner or clinician. The various chapters examining the barriers to working with AFMs (Chaps. 13–16) and the chapters examining the variety of ways that have been developed to try to support and help AFMs (Chaps. 17–25) all show that the model adopted then largely determines the ways that policies or interventions are either developed or implemented.

Many studies have demonstrated that effective interventions and help for AFMs have been developed, be it by including AFMs in the treatment of their relative (i.e. couple's therapy or family therapy) or by offering treatment only to the AFM, which is highly relevant given that only a minority of individuals with addiction-type problems ever enter treatment [3]. But, in contrast to interventions targeting only AFMs, even in interventions which do include both the relative with the addiction-type problem and the AFM, a substantial proportion of these intervention studies do not assess the outcome or effects on the AFM. It seems clear that future studies on family-based interventions should simultaneously assess all three of the effects on AFMs, the relative and the quality of the relationship.

Many of these evidence-based treatment offers are not regularly implemented in the addiction treatment system (Chaps. 13, 15). There are many reasons for this, including the fact that, in many countries, reimbursement for working with AFMs is difficult or non-existent; and in countries where services are contracted by authorities to work with those with addiction-type problems, work with AFMs is excluded from these contracts. Data from treatment facilities indicate that the treatment gap for AFMs is even bigger than it is with regard to the individuals with addiction-type problems. As well as the structural reasons affecting provision and reimbursement of these services, public stigma and self-stigma seem to substantially contribute to the treatment gap (Chap. 15).

We will close this book by reflecting on some of the main issues and challenges which the preceding chapters have highlighted for the Editorial group, examining such matters through the lenses of policy, practice and research.

26.2 Policy

Regarding policy measures (Chap. 13), it is clear that the ways of offering support and help to AFMs need to be expanded and barriers to treatment reduced. This is the case with all AFMs, but a good starting place would be the offer of support for those with addiction-type problems who are also parents, and where the AFMs are children or sometimes toddlers, related to these parents' parenting behaviour (see Chap. 22). Such offers do exist within some countries, but there is a great need to increase this provision and to ensure that it is offered much more equitably across the world. A second area of need is to offer far more interventions focusing on the needs of juvenile and adult AFMs and, related to this, to routinely offer AFMs the option of participating in the treatment of their relatives (Chap. 16). Furthermore, anti-stigma campaigns regarding addiction-type problems are needed (Chap. 15). Such campaigns have been successful in the field of mental health issues in general [4]. They should also be used to specifically fight stigmatising concepts regarding family members (Chap. 3), such as the concept of co-dependency as a deficient personality trait, and to acknowledge that caring for someone with addiction-type problems is not pathological per se and that many family members are facing coping dilemmas [5].

Furthermore, public health campaigns targeting addictive behaviours need to be carefully

considered and planned (and then evaluated) since such campaigns can often stigmatise individuals (and thus potentially their family members) who show loss of control towards these behaviours [6]. In addition, given that many AFMs are faced with coping dilemmas (i.e. a living situation in which all reactions are facing a serious threat of negative consequences; [5]), campaigns should refrain from providing simple messages such as advising AFMs to distance themselves from the users (often referred to as 'tough love' in popular self-help materials; [7]).

Within the Harm to Others paradigm, structural prevention measures like reducing the availability of psychoactive substances and/or gambling venues have been proposed [8]. Harm to others and to society was an important issue when alcohol was prohibited in the USA in the early twentieth century. However, although such measures can reduce access to addictive substances (and behaviours), criminalisation of addictive behaviours can also have serious drawbacks on AFMs, including the risk of delinquent behaviours, pauperisation and overdoses. To date, it remains unclear what advances and what drawbacks can be predicted depending on the type of measure. What is clear is that, when planning such policy measures to address addiction-type problems, and substance use or gambling in general, their potential effects on family members must be taken into account, and in any evaluation of the effectiveness of such measures, the effects on family members must also be assessed.

What remains a great challenge is the task of raising awareness among policymakers of the needs of AFMs and how these must be incorporated within policy initiatives. Some of the reasons why it is so difficult to make these changes, and the possible ways of raising such awareness, are outlined in Chaps. 13, 15 and 16. Two major areas need to be changed.

First, the attempt to raise the profile of AFMs within policy initiatives aimed at dealing with addiction-type problems. It is the fact that such policies are generally not a high priority for many policymakers, in themselves (never mind related to AFMs). Many countries do not have comprehensive policies to tackle either alcohol or gambling behaviour and misuse, and many policies related to drug use and misuse are strongly oriented towards the criminal justice systems in each country. Given that these policies are themselves not high priorities, it has proved extremely difficult to raise the profile of AFMs within them and in their rare revisions.

Second, AFMs ought to figure much more strongly within policies aimed generally at families and family care. Most countries have policies related to children at risk, and it is well evidenced (e.g. Chap. 5) that the children of those with addiction-type problems are at a far higher risk than are other children; yet it is often the case that there are no or few mentions within such policies of the special risks and circumstances that child AFMs face. Besides child-protection policies, there are a host of other family-related policy areas within which many countries have developed policy initiatives—for example, domestic and interpersonal violence, mental health, education, care of older adults, family strengthening policies and so on. At present, the family members of those with addiction-type problems rarely appear in any of those policies. A challenge is to change things so that those charged with making or updating policies in any of these 'family-oriented' areas incorporate AFMs to a far greater degree.

AFMs themselves have an important part to play, as experts by experience (EbEs), in advocating for the improvements we are seeking and which are so badly needed. Their arguments, as the ones who know first-hand the stresses and dilemmas which AFMs experience, are likely to carry considerable weight with policymakers, provided their voices can be heard. Furthermore, their ideas about the services that are needed for their relatives and for themselves should be listened to very carefully, alongside the ideas brought to the table by health and social care professionals and researchers.

26.3 Practice

The chapters examining the interventions to support or help AFM (17–25) demonstrate that there are a number of such interventions, with emerging

and increasing evidence that many of these are effective in reducing the stress and strain that AFMs experience from living in close proximity to an addiction-type problem. These evidence bases need to be further developed, but a far greater challenge is the lack of uptake of such evidence-based interventions into routine practice. Given that AFMs can be approached in various settings (e.g. primary health care, addiction-related services, counselling centres for psychosocial issues and so on), providing professionals in various settings with adequate skills to approach the issue and refer to specialised services if needed is mandatory for improving support for AFMs. The vast majority of the limited evidence base for all of these interventions comes from funded trials, where the effectiveness of the intervention is tested and potentially demonstrated. But it is always the case that such externally funded trials end, generally with no element of follow-up, and it is rare that the interventions tested in these trials continue to be used or incorporated into routine practice. There are examples of evaluations of interventions that have been incorporated in routine practice [9], but mostly the take-up of any of these developed interventions and their incorporation into routine practice is rare. There are many reasons for this, with some being explored in Chaps. 15 and 16; but a massive challenge for practitioners and those who provide services is to find ways to incorporate such effective ways of working with AFMs into their routine practice.

26.4 Research

Commissioning this book, and writing or editing the chapters, has reminded us that there has been research that has been undertaken on AFMs, and that some of it is good research; but it has reinforced the fact that there is still a great deal which remains to be understood and discovered, as the summaries and discussions in this chapter so far have underlined.

Although a great deal is known about the experiences of AFMs in general, in living with and having to cope with the challenges arising from being in a family where someone has an addiction-type problem, a major percentage of the research undertaken has involved volunteer samples (as opposed to representative cross-sectional samples), often recruited whilst in crisis, and predominantly comprising women (as mothers, partners, children etc.). The area of the epidemiological study of AFMs would be well served by recruiting far more diverse groups (especially recruiting males of all sorts, but also a far wider distribution of ethnic and socio-economic groups). In terms of quantitative work, much more research is needed using population-based samples to start to understand whether or not volunteer samples in crisis are representative of the far larger numbers of AFMs in the wider community. Integrating research on AFMs into large-scale epidemiological studies would be an important starting point to estimate the public health dimension of the problem. Standardised questionnaires based on the Stress-Strain-Coping-Information-Support Model are available [10]. As far as qualitative work is concerned, it is important to discover whether males experience being an AFM in similar or different ways to females, among other questions.

When we move to research into interventions or treatments to help AFMs, there is far less published material (although Chaps. 17–25 summarise the evidence well). There are many reasons for this, but two of them are outlined here. First, the fact that acquiring funding for undertaking research into the experience of AFMs is very difficult: as this book has tried to demonstrate, AFMs are a low priority for most research funders, alongside other groups such as policymakers.

The second reason why there are few published 'high-quality' studies of the effectiveness of interventions or treatments to help AFMs is the fact that many such research trials raise considerable ethical and other difficulties if researchers attempt to use the most common method, the randomised controlled trial (RCT), to test one intervention against another.

Increasingly, many researchers in the intervention field (within substance misuse and within mental health generally—see, [11, 12]) argue that

undertaking RCTs comparing different interventions, with the aim of claiming one intervention's greater effectiveness as a 'method', as compared with some control group, is not the best way forward. Instead some argue that we should espouse methods which have obvious face validity: as humanitarian, common-sense, cost-reducing ways of responding to harms (in this case, the harm which 'addictions' inflict on concerned and affected others). 'Evaluation' would then be in terms of feedback from participants (AFMs, other relatives, professionals), identifying cost savings, making successive improvements on the basis of feedback rather than sticking to a fixed formula or fixed intervention, etc.

RCTs are extremely expensive and time-consuming and difficult to attract funding for (and are too complex to be undertaken without significant funding). Currently, if such trials are not undertaken, suggestions for use of these helpful interventions simply invite rejection: these interventions are seen as forms of treatment which are not sufficiently 'evidence-based'. One opposing position is that instead of pursuing RCT evidence, their acceptance would be better based on the argument for involving and supporting AFMs (as with AFMs where other health and social conditions/problems are involved), using approaches which are both sensible, and have some evidence of feasibility and acceptability to AFMs and others (i.e. that they have already been well received and disseminated in a number of contexts). This view suggests that researchers should put much more emphasis on winning the argument for involving AFMs rather than on inventing (and testing via RCTs) rival therapies which are, in essence, probably indistinguishable [13]. Needless to say, there are competing views, some arguing almost entirely for RCT evidence, others suggesting that RCT evidence is needed, but also arguing that these should not be the only legitimate form of evidence. In the field of psychotherapy studies, much emphasis has been put on process research, indicating the relevance of so-called non-specific factors that especially focus on therapeutic relationship and shared decision-making. Given the heterogeneity of living conditions AFMs are facing, flexible approaches that focus on the client's needs are vital. In addition, all intervention studies should include a measure of potential harm to clients, as research on therapy has also shown negative effects on clients [14].

This is also important for brief and digital interventions that can have the potential to reach wider groups of AFMs (Chap. 24). Such interventions might serve as a first step to more intense treatment, and for some AFMs they can also serve as a sufficient approach to reduce stress and burden. However (and unfortunately), research comparing the efficacy of these approaches to face-to-face interventions is still an under-researched area.

26.5 Summary

Addiction in the family has been described as 'a major but neglected contributor to the global burden of adult ill-health' [15]. Although this is still true, especially in the field of practice and public awareness, this book shows that some major improvements regarding our understanding of the situation of AFMs have been achieved in the last decades. We hope that this handbook is a first step towards closing the ongoing gaps in research, policy and practice.

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