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The Experiences of Affected Family Members: a Summary of Two Decades of Qualitative Research

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ABSTRACT

This chapter is based upon the collective findings of a number of studies conducted in a number of countries during the last twenty years. Each study involved semi-structured interviews with family members affected by the problem drinking or drug use of a close relative. Female partners and mothers are the family members who have been most represented in the study samples, but the latter also included sizeable numbers of male partners, fathers, sisters, brothers, and adult sons and daughters. The chapter provides a distillation of the findings of those qualitative studies. It does so under the four headings – stress, strain, coping and social support – which are the main elements of the SSCS model described in Orford et al (2010a, this volume). Citing examples taken from the studies, the chapter describes some of the most prominent elements of the stressful experience of living with a relative who is drinking or taking drugs excessively, notably: the relationship with a relative becoming disagreeable and sometimes aggressive; conflict over money and possessions; the experience of uncertainty; worry about the relative; and home and family life being threatened. The reasons why family members may put up with the substance misuse are described, and the ways in which family members may either withdraw and gain independence or stand up to the substance misuse, as alternative ways of coping, are outlined. Examples of the strain experienced by family members are given. The kinds of social support valued by family members are explained, as is

the finding that good quality social support for family members is often lacking. The chapter concludes by offering an integrated view of the experience of being an affected family member, which highlights the disempowered position in which family members usually find themselves and the importance of good social support for family members in their coping efforts. Although the picture is coloured by factors such as socio-cultural group, and the ages and genders of family members and their relatives, we believe the core experience for affected family members, described in this chapter, to be universal.

Introduction

The aim of the present chapter is to put flesh on the bones of the theoretical skeleton presented in the previous chapter. It tries in just a few pages to describe what it is like for family members living in close association with a relative with an addiction problem, thereby bringing to life this very common set of experiences. This chapter reports only qualitative findings. We also routinely ask sets of standard questions for quantitative analysis (see Orford et al, 2010b, and Copello et al, 2010a, both in this volume).

Table 1 about here

Table 1 lists the studies that our group has carried out, each of which contained a substantial qualitative component and which collectively produced the set of data which this chapter draws on. In total over 800 family members have been interviewed. Considerably more women than men were included in all the studies and wives/female partners and mothers were the two groups most commonly represented. But the studies all included a diverse range of relationships, including substantial numbers of husbands/male partners, fathers, sisters and mothers, sons and daughters, and sometimes aunts, uncles, cousins and others. Studies were confined to adults but see Templeton (2010, this volume) for a consideration of the relevance of the programme of research for children).

Living with a relative who is drinking or taking drugs excessively is highly stressful

Over and over again family members have confirmed how very stressful it is living with this problem. There are many strands to these stories but near the centre of family members' accounts has been the deteriorated nature of the close family relationship between family member and relative which should be, and usually had previously been, a loving one. If only one aspect had to be chosen to explain why the experience is so stressful it would be that: a key relationship in which the family member had invested so much, or on which so many hopes had been pinned, had gone badly wrong. There are several elements to this, of which the following are amongst the most salient.

The relationship has become disagreeable, and sometimes aggressive

The unpleasantness of the relative's behaviour toward the family member being interviewed, and often toward other members of the family as well, was described as taking a number of different forms. Sometimes the relative was described as isolating himself or herself, not communicating, and taking little part in family life. There were many references to unexplained changes in the relative's mood. Although physical violence was not universal, some form of aggressiveness was very common and was variously described as: irritability, verbal abuse, rudeness, criticism, and domineering behaviour. Sometimes it was worse: threatening, pushing, punching and hitting, or breaking furniture or other objects. To these forms of direct aggression

were added deceitfulness and lying and sometimes the making of false accusations about the family member to other people.

There is conflict over money and possessions

One aspect of the deteriorated relationship about which family members regularly spoke, and which was a source of great discomfort, was conflict over money. Disagreeable events involving money and possessions were quite varied, including: buying things for the relative which the relative then sold; borrowing without asking; taking objects from the home including things of sentimental as well as financial value; failing to pay rent as expected or to contribute to family finances; or the substance misusing relative controlling finances and leaving the main homemaker short of money for necessities. A common scenario was one in which the family member felt pressured by the relative to give or lend money. The request was often accompanied by an accusation or reproach, a threat or actual violence, such that family members had often in the end given in to such requests or demands. A mother, for example, described how her drug misusing son would 'hound' her and his grandmother for money. Such requests always put family members in a quandary about how to respond. They were often seen as putting family members on the spot, 'black-mailing', or drawing in other issues or other people and hence making a decision about what to do even more difficult. An episode of being hounded in this way brings out in acute form the disagreeable nature of the relationship between family member and relative, as well as the family member's fears and uncertainties. At the same time, it brings into sharp relief the coping dilemmas that a family member faces. It makes for a complicated and confused set of events with much room for

disagreement about rights and wrongs and for self-castigation and conflict among family members (see How family members cope, below).

Family members experience uncertainty

Family members live with a great deal of uncertainty. There is very often uncertainty because of the unreliability of the relative's presence in the home. There were frequent references in the interviews to relatives 'coming and going', being absent when they were expected at home, and arriving home at uncertain times and in uncertain states. The female partner of a man with a drinking problem, for example, said:

'He'd leave home in the morning saying he'd be back at 6 o'clock and then turn up at 9.30 p.m. or at closing time, or would phone from the pub around 7.00 p.m. and say "I'll be home in an hour" and then he wouldn't be. You wonder why he bothers ringing'.

More generally, family members were often having to cope with very imperfect knowledge of exactly what was going on, why it had happened, who or what was to blame, and whether things would get better. The following, from the report of an interview with a father of a drug misuser, nicely captures this element of uncertainty:

He was not sure of the current nature of her [the relative's] drug use. He turned to his wife and said, 'Is she still taking heroin... the awful thing is we

don't know... She's off at the moment I assume'. He was not sure if she was taking methadone but thought it likely.

Family members are worried about their relatives

Worry is a central element of the core experience. Family members are not only subject to personal stress or abuse, but they are also worried and concerned about their relatives whom they see as having become the victims of the drink or drugs. For example, one adult daughter said of her father, 'When I know he is out drinking I just can't settle. I'm just worried about him the whole time'. A mother and father explained how they had first become worried about their daughter when she 'switched off from school' and failed to get the exam grades she needed, and later was given work for a trial period after her father had a word on her behalf, but subsequently had trouble with punctuality and was sacked. They were very concerned about her future prospects. Another mother cried when she told the interviewer that her 30 year-old problem drinking son was very yellow in colour and how worried she was about the possibility of him suffering from liver failure. Relatives gave family members cause for concern on any one or more of a large number of counts. Family members worried, not just about the frequency, quantity or form of their relatives' drinking or drug taking and about the company they were keeping, but also about their relatives' physical and mental health, their financial affairs, their safety, whether their relatives were neglecting themselves, and whether their education, work or sporting performance was failing.

Table 3 about here

Home and family life are threatened

The threat posed is not only to an individual relationship but also to the very life of the family itself as an entity and the home as a place. One obvious way in which family life may be adversely affected is the serious depletion of its financial resources. Accounts of financially damaging effects included both the loss of considerable assets as well as already poor families made poorer by the relative's diversion of funds and failure to contribute to the family economically. Other family members, very often women, had to support the family economically to an extent that they had not expected or wished for.

Equally of concern were the harmful effects on the whole family atmosphere. Sometimes there were disagreements about how to handle the relative – for example, disagreements about whether to give the relative money. The problem was often said to have created strain on marriages where the drinking or drug-using relative was a son or daughter. One mother, not untypically, said that when there was trouble she dealt with it and her husband made himself scarce; on other occasions she had had to stand between her husband and their son because she was 'afraid they were going to kill each other, and that's unheard of'. But the greatest weight of concern was about effects on children. There was worry about children being exposed to violence or neglect. There was also a more general worry about interference with the upbringing

of children. As one mother said, 'I'm no longer going to put the girls through this trauma'.

The physical integrity and security of the home could also be affected, on account of damage or neglect by the relative or by invasion of the home by others. Drug use sometimes took place in the home itself with consequences that family members found objectionable: for example, drug-using paraphernalia being left around the home or drugs being used in front of children. When consumption happened elsewhere, there were often effects on home life in the form of noise late at night when the relative returned intoxicated, or when relatives kept hours that did not fit with the rest of the family. Particularly invasive was the unwanted presence of other excessive drinkers or drug users, and sometimes family members were worried about unexplained calls to the home, presumed to be connected with drug use. Many examples of distressing family contact with the police were described.

Normal social life, on the other hand, was often restricted. Entertaining others in the home, or going to parties, cinema or theatre, or even just family walks in the locality, were often curtailed. Family members were often worried about how the relative would behave, and therefore did not relish the thought of such social occasions. Some were concerned that neighbours or other family or community members should not see the relative intoxicated, fearing shame and even criticism from others. One female partner of a drug misuser said that her social life had been restricted, explaining that he did not like socialising with friends of hers who were not drug users, or going to places where he couldn't use. Parents were cautious about going

away on holiday and leaving young adult children at home for fear of what might take place in their absence or what might be missing when they returned.

Signs of strain for family members

When asked how the experience of having a close relative who had been drinking or taking drugs excessively had made them feel, family members regularly described one or more – and very often a whole gamut – of the following emotions: feeling worried and anxious, helpless and despairing, low and depressed, guilty and devalued, angry and resentful, sometimes frightened, and very often feeling alone. Sometimes anger and resentment was directed clearly towards the substance misusing relative, but even then family members felt badly about feeling that way. For example the sister of a drug misusing brother said, ‘I hardly ever speak to him, he scares me. It’s horrible, he’s my own brother and I actually hate him’; and the mother of a drug misuser said, ‘At times you feel sorry for them for what they are going through, then you get annoyed, then you feel guilty, then you end up hating them but they can’t see what they’re doing. You go through it all’.

Family members’ self-image and self-confidence were often badly dented by their experiences. Sometimes this was attributed to self-blame for what had happened. In other instances it was explained as the result of verbal attacks by the relative, or as a consequence of what neighbours or others had said or might be thinking about the family member. For example, the father of two young adult sons, both taking heroin, described the impact of his sons’ heroin use on his own well-being and described how he had approached his GP for help for depression and sleeplessness, which were

related to his anxieties about his sons. He described his feelings of guilt in relation to both his sons taking heroin while they were in his care, commenting ‘I’ve brought them up... I feel guilty – have I done wrong, is it me?’.

Not surprisingly, family members very commonly described to their interviewers symptoms of physical or psychological ill-health which they either attributed to the stress of living with the substance misuse or at least questioned whether it might be attributed to it. For example, the wife of an alcohol misusing husband described how she had been having panic attacks every couple of weeks until she took part in one of our projects in which the 5-Step Method was offered. Another wife had felt very stressed when she had entered the same project: she had been experiencing chest pains and was sleeping very badly, and when she saw her GP her blood pressure was found to be very high: ‘I knew my health was being affected’, she said. A husband said, ‘You feel hopeful one week and then let down the next. I felt depressed, hopeless about it, certainly very run down and exhausted with it all’. Table 2 indicates some of the more common signs and symptoms of ill-health that family members have described.

Table 2 about here

Mothers often showed signs of severe strain. One described herself as constantly ‘upset, crying and depressed... [sitting in her] dark, prison like house... [not wanting to] clean it or do anything’. Another felt the strain of the problems surrounding her son’s drug use and felt the situation was ‘hopeless... [I am] dragged in all directions’. At a low point, she had thought of suicide. Another said, ‘sometimes I just want to lie

on the settee all day – someone could have come and sat on me... I'd think twice about spending a couple of pounds on myself – I never used to have the money 'cos he used to come and take it'.

Family members who were interviewed were very often worried, not just about the problem drinking or drug-taking relative, or their own mental or physical health, but also about the health and well-being of other family members. The latter included parents, grandparents, brothers and sisters, but it was when the family included children of the problem drinking or drug-taking relative that family members showed most concern (see Barnard, 2007; and Templeton, 2010, this volume). The extent and exact nature of family members' concerns about family health and well-being, and whether those concerns focused upon themselves or upon children or other members of the family, varied from one family to another. What was universal, however, was an appreciation by family members that problem drinking or drug taking had affected the family's health and well-being adversely in one way or another.

How family members cope

Family members affected by a relative's excessive drinking or drug taking are worried and they have good cause to be. They are worried about what is happening to the relative, to themselves and to other members of the family. As responsible family members they want to find the best way of dealing with the situation they find themselves in. But that is no easy matter. The circumstances they face are not ones that people expect or have been taught how to deal with. They are faced with demands that create acute dilemmas: whether to lend the relative money for example.

Sometimes family members have the experience of trying a number of different ways of coping, but none seem to work. ‘What can we do for the best?’ is the question that affected family members often ask. Indeed it would not be too far wrong to say that that question, and trying to find an answer to it, lies at the heart of the programme of work that is described in this supplement.

Figure 1 about here

Figure 1 represents one way of depicting the diversity of ways of coping that family members have told us about. First, it shows that, broadly speaking, there are three positions that someone who is very concerned about another person’s excessive behaviour 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. Secondly, the diagram shows that each broad position can be broken down into a larger number of more specific ways of responding – we suggest it is useful to think of the eight ways shown in the figure, although those eight could of course be broken down still further. A third point is perhaps one of the most important: each of the ways of coping shades into others and there are no clearly distinct boundaries between them. That has a number of implications, one being that a particular family member is quite likely to be coping in a way that stands at the boundary between one way of coping and another or which mixes two or more ways of coping. Another way of thinking of the same thing is to imagine the boundaries between ways of coping as being zones of conflict or areas associated with acute dilemmas about how to respond. These may be the very areas that cause family members most confusion and may constitute the most productive topics for useful discussion (see Copello et al, 2010b, this volume). For example,

going out of one's way to help a relative may stand on the boundary between behaviour which is self-sacrificing and behaviour which is supportive of the relative: family members may be acutely aware of that dilemma. Similarly, when does being assertive become controlling? And, does deciding not to worry imply lack of support for the relative or even rejection? Let us consider in turn each of the three broad ways of coping.

Putting up with it

This constituted a large category of actions reported by family members in the interviews and it has a number of distinguishable facets. Some statements of this position referred to resignation or inaction in the face of the problem, whilst others had a flavour of accepting things as they are, and others of self-sacrifice by restricting oneself or putting oneself out in some way to accommodate the relative drinking or taking drugs. A sister of a brother with a drinking problem expressed resignation when she said:

'I don't want him to die. I'd like to see him old and grey. I'd like to see that we'd spend another Christmas together. I just guess I want it all to go away, to share – you know, to have that sort of sharing in the family. I wish there was a way that I could help him... but he's chosen not to have it'.

The husband of a wife with a drinking problem said:

‘The thing takes you over. It’s the last thing you think of before you go into a fitful sleep and the first thing you think of when you wake up. You just come to the end of your tether, you don’t know which way to turn’.

Family members had often attempted to resolve the dilemma of trying to stand up to a relative’s behaviour whilst at the same time trying to be supportive and not rejecting, by finding a compromise solution. This was often felt by the family members to be unsatisfactory. The mother of a drug misuser provided a good example. She said, ‘I show him I’m not happy if I think he’s been smoking it, but I do what I can to help him’. Asked for money, she would refuse him, but on the other hand she would buy him shoes and, although she had advised him against getting a car which she felt he could not afford, she had agreed to pay the road tax and would fill up his car with petrol. One can imagine her concern that her son was without good shoes and why she might decide to buy them for him despite the money that he would have been spending on his drug use. In fact she was doing a lot that it is difficult for a mother to do in the face of requests from her son about whom she was concerned: she was being assertive by making clear her unhappiness with his drug use and by not trusting him with money. Even so, she felt unhappy that she was giving in to demands – being ‘blackmailed’, as she put it. Another mother was concerned about two of her sons who were both using drugs. She often found herself giving her sons money through fear that otherwise they would commit crimes. She felt trapped, on the one hand feeling that she was funding their drug habits and on the other hand not knowing what else to do. This had put her under considerable financial strain and she often had to go without things that she needed herself. Family members were often worried, as

she was, that without their actions – which, like her, they often recognised as involving putting up with the substance misuse – something worse would happen.

Figure 2 about here

It is often asked by other people who do not appreciate the stressful circumstances to which family members are exposed, why they put up with the inconvenience, hassle, stress and often abuse to which they are subject. The interviews showed that there are in fact many reasons why family members might do so, some of which are shown in Figure 2. Without understanding the circumstances, it is only too easy to label family members as ‘codependent’ or resistant to change. Our conclusion is that, while family members everywhere, much of the time, and in different ways, put up with their relatives’ excessive drinking or drug taking, these ways of coping are fully understandable when the circumstances are appreciated. They are best thought of as the very natural responses of ordinary people to a set of very difficult circumstances. Far from being complacent or uncritical about the ways they are trying to cope, family members are usually very uncertain and uncomfortable about what to do and welcome help and advice.

Withdrawing and gaining independence

One way of avoiding self-sacrifice and putting up with the substance misuse was to respond with actions which involved gaining more independence from the relative and the latter’s problems, or of moving away from the relative, or putting distance, physical, emotional or both, between the relative and the family member. Such action

took many forms, varying from small-scale and time-limited actions, such as hiding in a bedroom or locking oneself in the shower or another room, to larger scale and potentially longer-term solutions, such as living apart in the same home, leaving home or asking the relative to do so. The emphasis of some withdrawing actions was on avoiding the problem drinking or drug-using relative while others placed a greater emphasis upon the family member's own quality of life. A typical example of the latter, independent type of withdrawal coping was that of the mother of a drug misuser who explained how she and her husband had come to realise that they could give up the whole of their lives to their son's drug problem. She had taken a job which had made her feel more confident and she and her husband had agreed that they could bring a freshness to the problem and could be more objective, and get less rattled at home, by being engaged in their jobs. As she put it, '... you can get swallowed up in the problem living in it... we moved on'. Others described similar actions using terms such as 'doing what I want to do', 'getting involved in other activities', 'getting away', 'sorting myself out', 'stopped feeling submissive, I can do many things', 'getting a new and better life'.

Standing up to it

Many affected family members had found ways of responding other than simply putting up with the substance misuse or disengaging from it. By standing up to the relative's excessive drinking or drug-taking by one means or another, they had tried to regain some of the control over family and home life that had been lost. Another way of putting it is to say that family members were attempting, in one way or another, to change the rules of engagement which governed their lives with their relatives. We

have identified a number of ways which family members use to try and do that, and the main ones which recur time and time again are those shown in the centre of Figure 1. They are at least conceptually distinct but, as explained earlier, in practice they blend into one another and it is often some combination of them that the family member is using or has used in the past.

Standing up to the misuse requires family members to invest a great deal of time and effort. Sometimes family members had concluded that such time and effort had not been well spent. But often family members were coping in the way they were either because they were hopeful of helping to bring about constructive change or because their circumstances made withdrawal impossible or inappropriate. One of our conclusions is that all the forms of coping that we have been discussing have points in their favour, and points against, the balance depending on family circumstances (see Copello et al, 2010b, in this volume, for further discussion of this point). While the uniqueness of family circumstances means that the statement, 'there may be no universally good or bad coping processes' (Lazarus, 1993, p.235), may therefore be broadly true, certain ways of responding were generally considered by family members to be counter-productive. The clearest example consisted of ways of confronting the relative that were hostile or aggressive. Family members would commonly describe responding in such ways at an early stage of the process of facing up to the drinking or drug problem. Although it might allow a family member to vent her or his feelings, the general view was that this yielded poor results, since angry feelings would escalate, sometimes leading to fights. Women family members sometimes feared for their safety and even thought that their lives could be at risk. Male partners were more likely to report having responded aggressively and were

equally negative about coping in that way. As one husband said, ‘My behaviour at that time was completely wrong. I was handling the situation completely wrongly’; and as another put it, ‘Getting blatantly angry is the least useful way to react. If I do that she denies the problem and my blood pressure just goes right up’.

Also disfavoured, more often than not, were ways of attempting to exercise control by such tactics as closely watching the relative’s movements, and searching for or destroying the means of drinking or taking drugs. Sometimes family members expressed the fear that their relatives would be angered by such methods, and it was common for family members to acknowledge that they did not produce positive results. One wife summed it up by saying, ‘It’s absurd because if they want to continue drinking they find the way to do it anyway’.

The support family members get (or don’t get) from other people

Social support for affected family members plays an important part in the stress-strain-coping-support model (see Orford et al, 2010a, this volume) and it is something that we have always asked about in detail in our projects. The overall conclusion about social support that has been forced upon us is that good social support, when it occurs, is highly valued, but that, unfortunately, the kind of social support that family members value is very often denied them.

Let us start with the positive. Emotional support in one form or another was the type of support mentioned most often. Simply having someone to talk to and who listened to the family member was the most common form. Family members consistently said

that they appreciated other people making themselves available in a way that allowed the family member to talk openly about the problem in an atmosphere of acceptance and support. For example, the daughter of a father with a drinking problem said:

‘I feel I can share a lot with... [friend] because she knows my dad... I feel I can talk to her a lot more and a lot more openly than I can do to my own family... I feel as long as I have... [friend] to winge and bitch to I will be able to cope. We just sit there and talk’.

Often particularly valued was the support of other people who had ‘been through it themselves’, who were likely to be ‘on the same wave length’ and who could help you feel that you were not on your own. A mother also said that she found it especially helpful talking to people who themselves had had alcohol problems as she felt it gave her insight into what her problem drinking son was feeling.

Practical material support was also much appreciated as was the provision of accurate information. Professional people were prominent among sources of informational support, although it could come from a number of sources both formal and informal. As one father of a daughter with a drinking problem put it:

‘You need somebody who you can go to and discuss overall strategies – how to handle it in the long term, how you handle the umpteen crises which invariably crop up... someone who’d have at their fingertips all the information’.

Emotional, material and informational support are familiar categories to be found in the general literature on social support. But we have found there to be two kinds of support which family members affected by addiction problems mention so frequently that they are worth separating out as distinct categories. The first is what we have termed *coping support* or *feeling backed up*. We found family members to be particularly appreciative of other people who supported their own coping efforts rather than criticising or opposing them. Family members often sensed disapproval from others about the ways they were coping, or received direct criticism about the ways they were responding; hence being backed-up in the position they were taking was valued. For example the father of a drug misusing daughter said, 'I thank God that we're [he and his wife] in tune... if we weren't together I think I'd bugger off, I don't think you'd cope with it on your own'.

The other special category of positive social support was being *positive about the relative*. Consistently positive things were said about family members, friends, neighbours or professionals who interacted positively with the substance misusing relative or who expressed positive sentiments about the relative as someone who deserved to be helped and supported and who potentially could change.

Why support for family members so often fails

In the course of our research we have learned of the many reasons why support can fail. For a start there are a number of reasons why family members themselves may be reluctant to open the problem up to anyone other than those living in the immediate household. For example the brother of a drug misuser said, 'We've never sought help

because these are family problems and I don't want others to know'. The mother of a drug misusing son said:

'I haven't even told the family because they wouldn't support me, they'd just criticise me, they are so self-centred... I told my sister, and she gave me encouraging words and tried to help me, but it's so difficult because she has a problem with her husband... I don't like to mention the problems to anyone... I don't have women friends, they are a bunch of old gossips'.

Sometimes reluctance to seek support was related to strongly held feelings about what it meant to be a good parent or a good wife, and the shame that the family member might feel if it was known outside the family that the partner, son, daughter or other close relative was drinking or taking drugs excessively. Sometimes it was the substance misusing relatives who had convinced family members not to seek outside support because, for example, it was normal for a man to drink, the drug use was not so problematic, or because the relative didn't need anyone else to help stop drinking. Indeed some family members had been dissuaded from seeking support under threat from their relatives.

Very often it was a matter of other people not being available or choosing not to get involved – it might be said that withdrawal (of the avoiding contact kind) in the face of an addiction problem is a way of coping that is much more available to people who are not related to the substance misusing person, or who do not live under the same roof, than it is to the partners, parents and others who make up the large part of our research samples. In many other cases it was a matter of family members finding that

what they received from other people did not match up to their ideas of positive support. Other people sometimes gave unsympathetic and unhelpful advice such as, 'I would have left him' or 'You should have got rid of him', when that was not in line with the family member's plans. Even close relations could be critical. For example, daughters and sons could be critical of a parent who was a family member trying to cope with the drinking or drug use of the other parent. A daughter of a problem drinking father said, 'My mother is less concerned about her own happiness and more concerned about what people will say if she left him. Occasionally she agrees to leave him but she never goes through with it'.

A different kind of misunderstanding or disagreement with a potentially supportive other person arose when a family member was looking for support in either standing up strongly against the alcohol or drug misuse or support in withdrawing or separating from the misusing relative. We have heard many examples of other members of a family acting as a restraint on a family member's search for some distance or independence. For example some family members had been criticised for trying to gain independence by moving away or studying. Some had been described by others as 'cold', 'hard' or even 'cruel'. Some feared rebukes from parents, parents-in-law or others if they responded to their substance misusing relatives in ways that broke with traditional customs and values associated with family and religion.

Nor were professional people always as helpful as might be hoped. For example, the inability or unwillingness of professionals to talk through strategies for dealing with problems had sometimes left family members feeling that they had received inadequate information or support. The feeling of being cut off from information that

might be helpful was exacerbated when family members felt they needed information about the relative and the relative's problem, but professional people were unable to give that information out of respect for the relative's confidentiality. Sometimes family members had felt a professional was implying that the problem was partly the family member's fault.

It was certainly not the case that family members were usually isolated. Far from it; they were usually surrounded by people who could potentially be of great support. Some of them were, but most family members' social networks were mixed in that respect and often largely consisted of people who, for one reason or another, were unsupportive or unhelpful.

An integrated view of the experience of being an affected family member

Figure 3 attempts to summarise what has been discussed in this chapter. Family members find themselves in a very disempowered position as a consequence of the undermining of control that they feel over their own lives and that of their families. This is made worse by the lack of understanding and sometimes outright blame or criticism that they receive from others. The kinds of social support which are empowering for family members are therefore those that recognise the multi-layered nature of the stress that a family member is likely to be under, the complexity of the coping dilemmas that the family member faces, the competing needs and obligations

that a family member needs to bear in mind, and the mixed feelings that she or he is likely to have towards the relative.

Figure 3 about here

How the core experience is modified by socio-cultural and other differences

Our view is that there is much about the experience of living closely with a relative with an addiction problem that is the same irrespective of material, social and cultural differences. Most of what has been described in this chapter, and most of the elements shown in Figure 3, are universal. On the other hand, our data from different countries and from different socio-cultural groups in Britain suggests that certain aspects of the common picture take on greater prominence in certain groups. The experience of being an affected family member is therefore what in cross-cultural studies has sometimes been called a ‘variform universal’ (Lonner, 1980). For example, the work in Mexico drew our attention to the particular importance of: the threat to family financial stability caused by excessive drinking or by drug misuse when families are already living in poverty; the gendered nature of coping, for example the self-sacrificing nature of women’s coping and the greater polarisation of mothers’ and fathers’ positions in relation to their offsprings’ substance problems in a country with relatively traditional norms for men and women’s family roles; and the dominance of kin, and relative absence of friends’ support in a country that is sometimes described as being characterised by ‘familial collectivism’. In the much more individualistic culture of white English family members, it was the threat which substance misuse posed for the family members’ individual autonomy which was

more prominent than in other groups. Amongst first generation British Sikh wives what was impressive was their success in finding ways of standing up to their husbands' problems whilst at the same time being true to their obligations to remain loyal wives to their husbands. Amongst wives and mothers in the Pakistani-Kashmiri community it was the large, close knit family and community networks, offering great potential for social support but at the same time threatening greater exposure and dishonour, which was a dominant feature. In the work with Australian Aboriginal families we were struck by: the way in which alcohol misuse was as much a public matter for indigenous communities as it was a personal or private one for individuals and families; the way in which the link between excessive drinking and violence was at the forefront of family and community concern; and the way in which extended family reciprocity norms placed obligations on people in a way that sometimes made it difficult to stand up to a relative's substance misuse.

Other factors which modify the core family member experience include the nature of the substance that is being misused, and the pattern of its use – for example whether use of the substance is traditional or novel in the community; or whether it takes place mainly at home or out-of-home (Jacob and Seilhamer, 1987). The core experience is of course affected by the relationship of family member to substance misusing relative and the ages of each. Coping with a teenage son's or daughter's problem is not exactly the same as coping if the son or daughter is an adult, and neither is the same as coping with a partner's or spouse's problem. A partner's options for coping are different if the relationship is a relatively new one compared to a marriage of several decades.

Gender is a factor that provides one of the greatest challenges. Much of the previous research in this field had centred on women who were concerned about their husbands' drinking. They had been seen as the ones who must live up to an image of the respectable and self-sacrificing wife, the submissive partner in an unequal relationship, charged with the responsibility for taming and controlling their men's drinking, and even held to blame if they did not succeed in that task (e.g. Holmila, 1988; Ussher, 1998). Our research has certainly provided further evidence of the disempowerment experienced by wives or female partners, and mothers, who constituted the largest groups in our research. The samples of family members included in our research are almost unique, however, in including men as well as women. The findings have shown the ways in which male partners may also feel undermined by their relatives' behaviour, and may feel isolated in their attempts to cope, in much the same way as is described by female partners of male relatives. Men were also represented in the research as fathers, and less often as brothers or uncles. Although there is much still to be learned, our hypothesis is that there exists a core to family members' experience whatever their sex or relationship to the relative. According to that hypothesis, being female or male, wife or husband, mother or father, sister or brother, may colour that experience but does not alter its essence.

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Table 1: Qualitative studies of affected family members carried out by our group

Sample	N	References
Family members of drug misusers in SW England	50	1, 2
Family members of alcohol or drug misusing relatives in Mexico City	129	3, 4, 5, 6, 7
Family members of alcohol or drug misusing relatives in SW England	121	3, 4, 5, 6, 7
Detailed biographical studies of women with alcohol misusing husbands	6	8
Aboriginal family members of alcohol misusing relatives in Northern Territory, Australia	47	7, 9
Wives and daughters of British Sikh men with alcohol problems	31	10
Family members of alcohol and drug misusing relatives in three centres in Italy	103	11, 12
Pakistani-Kashmiri and African Caribbean family members of alcohol or drug misusing relatives in the West Midlands, England	40	13
Family members of alcohol or drug misusing relatives, recruited for 5-Step Method intervention studies in primary and specialist health care settings	~300	14, 15, 16, 17, 18, 19

Table 2: Signs and symptoms of family members' ill-health

Poor sleep, tiredness

e.g. sleep affected, up at night; sleep more; insomnia; spend more time in bed as an escape; lay awake the whole night; wake early; up at night talking with the relative; sometimes sleep for two days; tired; fatigued; weary with it all; difficulty sleeping; waking in a cold sweat.

Substance use

e.g. smoking, drinking or drug taking or prescribed medication, going up, or fluctuating more.

Eating, weight

e.g. eat a lot when nervous; neglect eating; loss of appetite; weight change; have over-eaten under stress; some days eat a lot others not at all; eat less because the relative doesn't eat; weight reduction.

Psychological symptoms

e.g. poor concentration; anxiety and panic; depression; suicidal thoughts.

Physical symptoms

e.g. sickness; anemia; headaches; neuralgia; back pain; 'pains'; hypertension; asthma; hair loss; change in pattern of bowel movements; gall bladder trouble; shortness of breath; palpitations; diarrhoea; migraines; 'minor ailments'; itching.

General poor health

e.g. health poor; weak; in decline; felt ill; health 'went'; put years on me; in bad health; felt fragile; neglected self.

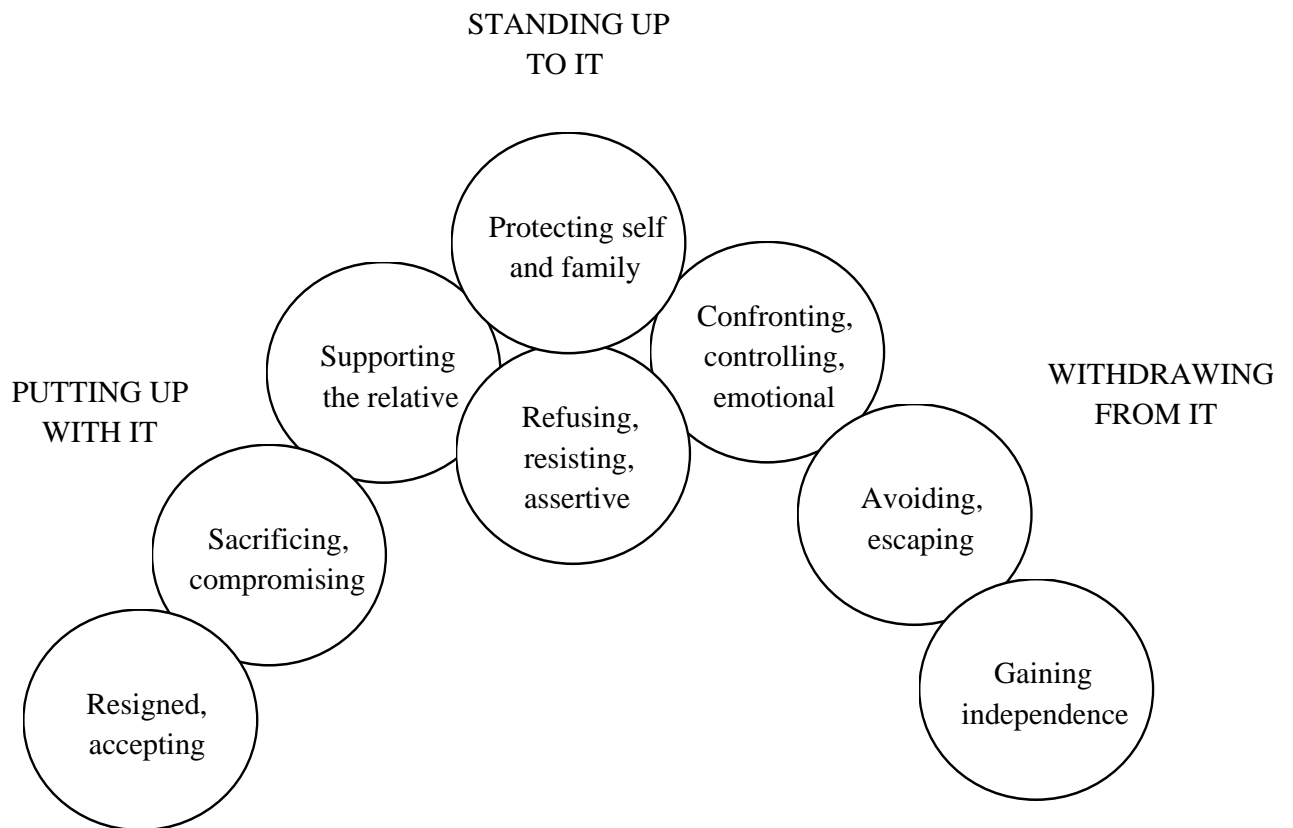
Legends for figures

Figure 1: three positions a family member can take towards a relative's excessive alcohol or drug use, and eight specific ways of coping

Figure 2: several reasons why family members may put up with a relative's excessive drinking or drug use

Figure 3: an integrated view of the experience of being a family member affected by a relative's problem drinking or drug taking

Figure 1



WITHDRAWING FROM IT

Gaining independence

Avoiding, escaping

STANDING UP TO IT

PUTTING UP WITH IT

Supporting the relative

Sacrificing, compromising

Resigned, accepting

Protecting self and family

Confronting, controlling, emotional

Refusing, resisting, assertive

Figure 2

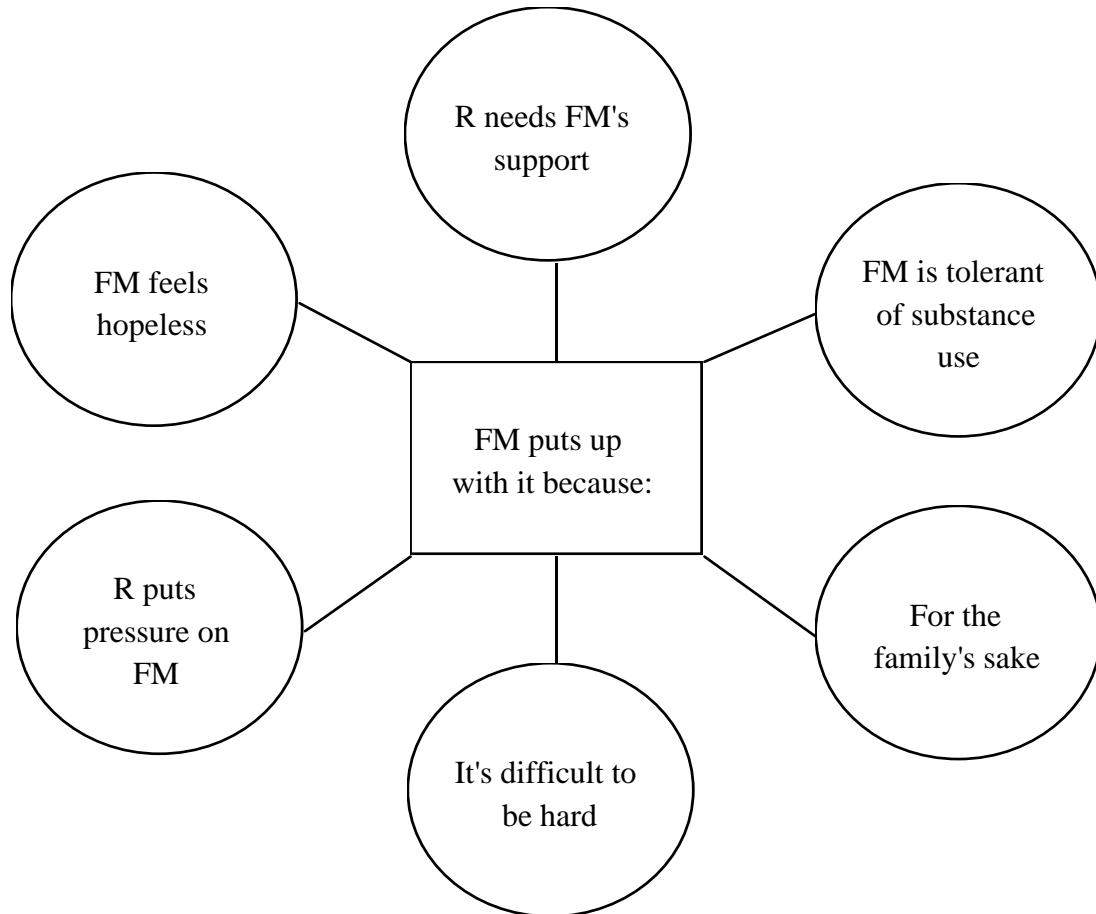


Figure 3

