Chapter 1: Families living with and bereaved by substance use

Lorna Templeton and Richard Velleman

Introduction

Having a relative or friend[i] who uses alcohol or drugs problematically is often extremely difficult, and usually highly stressful. And it is not rare: it has been very conservatively estimated that globally 100 million adults are likely to be affected by their relatives' substance use problems (Orford et al., 2013). Considerable research has been undertaken, in a range of countries, on what this experience is like for affected family members (AFMs). A lot of this research has been undertaken by a research group based in the UK (AFINet-UK, formerly the Alcohol, Drugs and the Family Research Group, of which the authors of this chapter are members[ii]), but many other researchers have also examined this issue (e.g. Barnard, 2007; Casswell et al., 2011; Philpott & Christie, 2008; Ray et al., 2009; Wiseman, 1991). Large numbers of detailed interviews have been conducted (in the research conducted by AFINet more than 800 AFMs have been interviewed) and a considerable amount of quantitative questionnaire data has also been collected. Most of these research participants have been close relatives, and considerably more women than men have participated: for example, wives/female partners and mothers are the two groups most commonly represented in our research. But, overall, the studies which have been completed have included a diverse range of relationships, including husbands/male partners, fathers, siblings, sons and daughters, and sometimes extended family members like aunts, uncles and cousins.

The results of this research has been the development of a clear picture, relatively consistent across geography, socio-cultural groups and type of AFM, showing that AFMs experience multiple stresses, coping dilemmas, and an overall lack of information and support. As a

result, AFMs are at significantly heightened risk for ill-health and other problems, which prove very costly both personally and for public services (Copello, Templeton & Powell, 2010c; Templeton, 2013; Ray et al., 2009).

Based on our many years' experience of undertaking research across the UK and a wide range of other countries and socio-cultural groups (e.g. Arcidiacono et al., 2009, 2010; Orford et al., 2005a, 2010b; Velleman & Templeton, 2003), we and our colleagues have developed a model which summarises our understanding of how a close other's substance problems can affect AFMs so negatively. This is the Stress-Strain-Coping-Support (SSCS) model (Orford et al., 2010a, 2013), which, unlike many other approaches (described in Orford et al., 2010a), offers a non-pathological way of understanding their circumstances. The SSCS model, and the research underpinning it, suggests that:

1) Living in a family where someone misuses alcohol or drugs is commonly very **stressful**, both for the person misusing the substances and for anyone close to them. Substance misuse can and often does have a significantly negative effect on family life in general, and on individual family members;
2) AFMs who are affected by and concerned about a drinking or drug problem in the family are likely to show signs of **strain** including forms of physical and psychological ill-health;
3) AFMs in this situation are often faced with a difficult life task in trying to understand what is going wrong and what to do about it (we refer to these ways of understanding and responding as '**coping**'); this cv cause great dilemmas over what to do for the best;
4) A further issue facing AFMs is understanding both what is happening to their substance-using relative and why it is happening. This understanding may also

influence what sort of stance they feel they ought to take towards both the substance and the relative, which relates to the previous point about how they cope. Part of gaining a better **understanding** is receiving good, accurate **information**. Sometimes this is of a purely factual kind; for example, the names of types of illicit drug, the means of their administration and some of their effects, or information about the strength of different alcoholic beverages. But many AFMs also often find it useful to discuss the nature of addiction or dependence and the difficulties their relatives have in overcoming it, and how treatment works. AFMs may also require information and understanding about a range of other areas too, such as mental health problems, domestic abuse, and social welfare or other financial issues.

5) AFMs can be helped or hindered in how well they respond and how well they understand the problem by how other people react and interact. This is the '**support**' component, and the other people include other family members, friends, neighbours, colleagues and professionals; and
6) The stress describes the impact of the problem drinking or drug use on the other members of the family, and this stress leads to strain. But for any given amount of stress, the amount of strain that is caused is influenced by the positive or negative effects of these three other factors: the information they receive; the method(s) of coping used; and the level and quality of social support

The general conclusion of our research has been that there is a 'common core' to AFMs' experience, consisting of high levels of stress, a set of common coping dilemmas, difficulties in obtaining good quality social support, and high levels of strain usually manifested through physical and psychological symptoms. We may term this as the 'burden' borne by AFMs

(Orford et al., 2013). It has also been concluded that this common core pertains largely independently of the relative's addiction (alcohol or illicit drugs or gambling[iii]) and independently of factors such as the affected family member's sex and relationship to the substance misusing relative.

Having stated that this common core is largely independent of a range of factors, this must not be over-stated. The reality seems more to be that there *is* a core experience but also that some differences, albeit more minor ones, do emerge (e.g. Orford et al., 2016, 2005). These include how socio-cultural factors influence coping; gender roles in different countries and cultures which impact on the ways that AFMs both experience stress and demonstrate strain; whether or not AFMs express (or even recognise) feelings of resentment and anger at how the drinking or drug problem has restricted family members' lives. Furthermore, the predominance of women in our research means that the universality with respect to men is not so clear; and the predominance of partners (usually female) and parents means that universality with respect to other forms of close family (and friend) relationships is also not so clear.

The focus of our study on bereavement through substance use provided an interesting opportunity for us to extend our programme of research by reflecting on the possible application of the SSCS model to bereavement. The first part of our semi-structured interview asked interviewees about their relative or friend's substance use, and the impact that this had on them (the interviewee), others in the family, and on the relationship between interviewees, wider families and the deceased. These often very lengthy accounts, along with the other areas covered in the interviews, provided a valuable opportunity to better understand the experiences of our bereaved interviewees before death and the impact which

those experiences often continued to have after the death. In the following sections of this chapter we will discuss how the SSCS model can be applied to AFMs experiences both before and after death.

Findings – applying the SSCS model before death

Analysis of our data on how the SSCS model can be applied to our interviewees accounts of living with their relative or friend's substance use, in the majority of cases for considerable periods of time, before that person died. Reflecting the SSCS model, our interviewees described the stresses which they were often under, and the resulting strain this brought for themselves and their families.

> *Fights were on a daily basis in the house when I was going through school....and he would always be shouting at my mum....You could see it gradually falling apart, getting worse and worse as the years went on....it was horrible to see that happen to someone you love....It obviously did affect me.....I remember finding school very difficult, finding socialising with people very difficult....[I] didn't have a normal life like most other people did and I had panic attacks and things like that....I felt quite scared of him really, quite intimidated.....Me and my mum....we were just desperate really. We'd cry together sometimes....We were depressed really....because it just used to be the same thing every day.* (SisterE)

Some interviewees also explained that they found it hard to understand why their loved one was using alcohol or drugs so destructively.

> *But to actually be told that he had a drug addiction I was like how come, he is working....how can you hold up a full time job and be a drug addict. It didn't make*

sense to me....maybe I was a bit naïve because I had never really had a lot of experience of [that]....I didn't really understand the ins and outs of a drug addict and what it involved and I wasn't as knowledgeable as probably I could have been (FriendS)

Following on from this, interviewees also explained the difficulties they faced in working out how to cope with the stresses and strains that they faced.

I took to treading [on] eggshells, pussyfooting around [my son], so then we weren't really having a real relationship, because I knew it was going on and he knew that I knew it was going on, but I wasn't prepared to tackle him about it. So I took the coward's way out, so [my son] would go to his room. I knew he was taking a drink up there with him and whatever else he might be doing. And then I just let him stay in his room and then I would just check on him every now and again, make sure he was eating, make sure he was alive. I didn't know what to do.....And what we didn't know....he was moving into harder drugs.....and we kept him short of money (MotherE)

It was because of his drinking that I started to challenge him on it and then we had a very, very, very difficult relationship, because I don't know if the two just coincided as a coincidence, but his drinking then started getting worse, which then made me even more – I think I was just angry at him, like why – you know, who does he think he is that he can just do this to a family? (DaughterE)

Finally, it was clear that a significant number of our interviewees lacked formal and informal support in dealing with the problems that they faced, with some able to reflect on how hard it can be to seek help.

I didn't know there was such a thing until I went in and found out there was family support... we have had the drug worker in the house working with [our son] and he never even mentioned family support" (FatherS)

At that stage it was all out in the open, but his family refused to believe that he had a problem, absolutely refused to believe it. So I found that very difficult doing it all on my own.... I didn't have a soul, I've got some very good friends who I'd known for years and one in particular who I've known for 45 years and she said, 'Why didn't you tell us?'" (WifeE)

I would say there probably wasn't a lot of support around but I do think that I and an awful lot of people in the situation that I was in isolate ourselves. There is a lot of shame in it and guilt I think and that feeling of it's all my fault kind of thing....I don't actually know how much help I could have accessed even if it had been there at the time (WifeS)

Overall, much of what our interviewees said mirrors the findings from our broader programme of research (described above), and from the wider UK and international literature (e.g. Bortolon et al., 2016; Esser et al., 2016; Fereidouni et al., 2014; Orford et al., 2005), about what it is like to live with someone who uses substances problematically or harmfully. However, while our interviewee accounts of how they were affected by the pre-death substance use were largely the 'back story' to our primary focus on their experiences and needs following the death, their stories offer useful additional insights into the stress and coping aspects of our model. These are things which have not previously emerged as dominant in our other research, mainly because the majority of participants in our previous studies had not been affected by the death of their loved one. Figure 1:1 depicts the original

SSCS model (Orford et al., 2013) with our suggested additions (which appear in bold text or shaded ovals) which we summarise below.

Stress

Our data suggest that there are potentially three additions to make to this aspect of our model. First, a sizeable number of the sample talked about their experience of previous overdose or suicide attempts (related to the person who later died), with some directly involved in responding to these incidents (e.g. resuscitating the person or calling the emergency services), demonstrating how close they had come to death before it actually occurred (see also Templeton et al., 2016b).

> *He had a history of overdosing, getting clean, overdosing, getting clean.* (MotherS)
>
> *Mum opened the back door and she heard the engine running in the garage, and he [Dad, an 'alcoholic'] had tried to commit suicide.* (DaughterE)

Overlapping with this, many interviewees, when telling us about the impact of their loved one's substance use on them suggested that that they had already 'lost' the person that they knew before they died, what one mother called a *"living bereavement"*. Some were also anticipating the person's death, and the grief that this would bring for them (see also, for example, Da Silva et al., 2007; Templeton et al., 2016a, 2016b).

> *I was sad... [but]...I don't think I shed any tears for him though. I think I had done all that before.* (Ex-wifeS)
>
> *I really knew six months before she died she'd totally given up, that she'd accepted her fate.* (HusbandE)

> *I lost my mum when this* (i.e. alcohol use) *started. I always hoped I would have my mum back. So I grieved the loss of my mum [and then] I have a second grief for the person she became with her addiction.* (DaughterE)

Second, in the research discussed in this book, stigma emerges important, although different categories of relative appear to experience different levels of stigma (see Chapter 3). Many AFMs felt stigmatised 'by association' as family members of someone who misused substances while their relative was alive, and many also felt this stigma after the death, in how both the deceased person, and they as AFMs, were treated by a range of authorities and others. Stigma has not hitherto been a central part of the SSCS model. This may be because, when it arose as an issue in interviews or discussions, it was simply considered to be one of many variations of 'stress', and that is where we have placed it in our revised model. Indeed, whether or not to place stigma more centrally is still under discussion – it is not clear that the experience of stigma in the ways that an AFM is treated is a more harmful experience than (say) domestic violence from someone within the close family. On the other hand, it may have emerged as more central in the interviews for this present project because it was more openly and specifically asked about as part of experiences after death. Overall, it is clear that we need to carefully consider how to best include stigma in our SSCS model and to further explore the impact that it may have on AFMs experiences, and on the other components of our model such as support and coping.

Overall, our interviewees talked less about their experiences of stigma before the person's death, probably because the focus of the interviews was the death and experiences thereafter. Nevertheless, when it was discussed, what interviewees had to say mirrors other research

which has investigated stigma in substance users and their families (e.g. Adfam, 2012; Lloyd, 2010).

> *When he was alive I did keep a lot of it a secret from my friends.* (SisterE)
>
> *Some of our neighbours, I'm sure they used to look at us and think, oh, that family, because there was lots of yelling and screaming at [our son] as he's going out of the door and he's telling us to eff off and all sorts of things. So we always had the police at our door. So you just create your own little opinion about somebody in their family, but you don't know really what goes on.* (MotherE)
>
> *I was embarrassed when I found out she was a drug addict because I thought it was only me in this world who had a drug addict for a daughter.* (MotherS)

Third, the stressors which AFMS are exposed to may vary in other ways. One is the extent to which AFMs are aware of the person's substance use, an issue highlighted in one of the few other studies which has been conducted in the area of bereavement through substance use (Da Silva et al., 2007). In our study interviewees were usually aware of the person's substance use, but the levels of stress varied. For example, many of those affected by alcohol use had high levels of awareness of the extent of the problem, having been exposed to the drinking and its effects often for many years.

> *I've never known him to be sober, apart from the short stints in rehab. He was always drinking.* (NieceE)
>
> *I would have been probably four or five when she really started to use alcohol regularly, because I remember her being drunk at a time when I didn't understand that's what the problem was.... it was while I was at primary school that she started drinking much more heavily habitually during the day. And certainly by the time I*

was in junior school...I was coming home [and] I could tell just by looking at her that she was drunk.... as time went on and I went up to secondary school, it gradually got worse.(DaughterE)

On the other hand, some of those exposed to drug problems had lower levels of awareness of the problem, either by not knowing for some time that the person was using drugs, or being unaware that their death had been preceded by relapse.

She started taking drugs when she was eleven and I never knew because I was one of these mothers that said 'Oh no my daughter won't take drugs'. When I realised, I ate my words. (MotherS)

"Not only did we find [our son] dead, we found out as well that he was back on heroin. (FatherS)

Another factor influencing AFMs' stress levels was whether or not the AFM was also using alcohol and/or drugs problematically themselves, either independent of or with the person who died. It is perhaps unsurprising that those who were themselves alcohol or drug users, and who might have used alongside the person who later died, experienced lower levels of stress about their relative or friend's substance use than those where this was not the case. Nevertheless, this had not featured in our previous research samples, either because family members' substance use did not feature prominently in these studies or it was an exclusion criterion for our intervention evaluation studies; it is worth considering as an additional feature of our model. However, we did not press interviewees about the impact on them of the other person's substance use when they were themselves a user. We cannot therefore say definitively that stress was absent for them, only that it appears to be a less important feature

of their experiences when compared with AFMs who do not themselves have problems with alcohol or drugs.

Influence of diversity

We indicated earlier in this chapter that there are a number of dimensions along which the experiences of AFMs may vary, although there has been little global research which has examined these differences in depth. Our study offers the opportunity to consider variations for AFMs along some of these dimensions. Given the focus of our study and the scope of this chapter we cannot examine this in detail so what we present are some ideas on what some of these variations might be for two of these dimensions, namely how the bereaved adult was related to the deceased, and whether the bereaved interviewee was themselves in treatment or recovery because of an alcohol or drug problem.

Although our previous research has included participants who represent a wide range of relationships with the problem substance user, parents, spouses/partners and now-adult children have predominated. The present sample has a greater representation of a range of other relationships which can be examined: we interviewed 12 siblings, six friends and three nieces, and so it is on these groups that we will focus here. While it is unknown whether or not these experiences are representative, they are nonetheless an important starting point given that these groups have rarely been included in such research.

Although there was some variation in how strongly affected the 12 siblings were, many of them talked about quite major stresses and effects on them and on others in the family.

I began to notice that he was obviously using again....I was getting calls from phone boxes in those days to say that he'd overdosed in a phone box somewhere and I had no idea.... he was just an absolute nightmare. It had a really big impact on the whole of the family for a long time....twenty odd years really. So yes, we had years of his drug abuse and him stealing off of us and the things that addicts do. (SisterE)

There were times where he stayed with us and we would have the Police at the door....they arrive at your home at five in the morning saying we've got your brother locked up. That caused problems between my husband and I.... I actually hadn't seen [my brother] for quite a while before he died. He had been in touch to get money....he said he had needed to leave [town] that it was trouble, there was people out to get him. And I had lent money and he hadn't left [town] and I suspect he had spent it on drugs. (SisterS)

Many of the siblings also reinforced the themes of living bereavement and anticipatory grief discussed earlier.

I always knew that she was going to come to an end just because of my history with her....I had always been waiting, I'd been waiting for years for the phone call. (BrotherE)

I was always convinced he would either completely end up with a complete irretrievable breakdown or that he would end up dead" (SisterS)

"I just felt like I lost my brother really. (SisterE)

Although the three nieces all stated that the impact on them was less intense, in fact their descriptions show that the substance use of their uncle or aunt did have a significant impact.

Stress.....worrying about what was going to happen next....helpless....anger....guilt" (NieceS)

"*When he relapsed you would feel really disappointed in him. But because I was so young as well, I would get really angry at him for it....I understood he had a difficult life. It's not....you know, addiction isn't something that you can just get over. And I think that's what my family found hard to deal with is that it's no easy fix*. (NieceE)

Compared with the other sub-groups in our sample, the six friends (five males and one female) said very little about impact of their friend's substance use on them. Possible reasons for this include the fact that four of them had a history of taking (and in two cases also dealing) drugs with their friend, and described the strong relationship that existed between the drug use and their bond as friends, while another (the female friend) knew almost nothing about the drug use until a few months before death, and in the sixth case the friend died suddenly as a result of an alcohol-related accident when both friend and interviewee were in their teens. Nevertheless, this group gave some insights into some of the struggles which they faced as a result of their friend's substance use. Two male friends were trying to come off drugs when the death occurred while a third male friend expressed frustration at his friend for not being in recovery like he had been for the last few years.

I was angry with him because he didn't get into recovery. I felt disloyal....and I couldn't help him. (FriendE)

The female friend talked of how she had struggled to understand her friend's addiction and him not conforming to her stereotypes of people with alcohol or drug problems.

Finally, when considering the 21 participants who were in treatment or recovery from their own substance use when they were interviewed, there was variation in how much this group talked about the impact of their relative or friend's substance misuse, and the nature of the stresses that they experienced. These narratives were particularly influenced by whether or not the interviewee had themselves used substances with the person who died and/or whether they were using when the death occurred. For those who were not in either of those categories the nature of how they were affected mirrors that of the wider sample and the literature.

> *All of a sudden addict behaviour was there....if I'm truly honest I chose to ignore it.....things weren't making sense, there were a few lies and this, and that and the other, so it was all those sorts of behaviours and again it caused friction in the relationship. I found that I was getting very stressed when normally I'm not a stress person really, things were getting on top of me.... every night, I knew she was out drinking, is this going to be the night I am going to have a phone call.* (PartnerE)

Those who had used substances with the deceased still alluded to a range of possible stressors related to the other person's substance use, such as mental health problems, violence, prison, removal of children to the care system (all types of stress which AFMs often mention as being associated with substance use). However, this group of bereaved people talked less about the impact which these experiences had on them than did other bereaved family members who had not used substances with the deceased. Further, some in this group through themselves being in treatment or recovery, became more aware of the impact that substance use can have on others.

I've been on both sides now and I know the difficult side is being with somebody who drinks, not being the drinker, the drinking side is the easy side because you believe you are not doing anything wrong. (Ex-wifeS)

I think that's why I cut down and got on top of myself because I didn't want my dad to go through the grief of having to worry about me drinking as well. (NieceE)

In summary, a preliminary investigation of how our interviewees talked about the impact on them of their relative or friend's substance use, before that person died, supports the application of our SSCS theoretical model to AFMs who are subsequently bereaved; some modifications to the model can incorporate these additional aspects to their experiences. We will now move on to applying the model to bereavement through substance use.

Findings – applying the SSCS model after death

Our study has provided a valuable opportunity for us to start to understand how the SSCS model might apply to what interviewees said about how their family member's substance use and subsequent death continued to affect them. Figure 1. 2 shows a second version of the model, and below we unpick what some of the components of each aspect of the model might be when focusing on the specific experience of bereavement through substance use.

Stress

Our data suggest three broad ways that the death affects the stress, and hence grief, experienced by AFMs. First, through a range of circumstances present before death can continue to have a negative impact after death. These include the nature and impact of the substance use, the relationship between the bereaved and the deceased (see below, and

Chapter 5), and the bereaved's own problem substance use. One daughter explained the close association between experiences before death and the death itself saying, *"you can't just look at the death, because there's so much more build up to it"*.

In terms of the substance use itself, influencing factors include the duration and severity of the problem, the substance[s] being used (with perhaps greater stress attached to intravenous drug use and/or polydrug use), and whether other problems are also present such as mental health difficulties, unemployment or criminal activity. Any of these on their own or in combination can increase stress for the AFM after death, for example because of the need to adjust to life after years of being exposed to substance use (and any additional problems as well), or because the stigma attached to substance use may shape conversations with other people about the death, among other aspects of grieving.

Grief could also be influenced by the relationship between our bereaved interviewees and their relative or friend while they were alive. Some spoke of close relationships, and of how those relationships remained close despite substance-related stresses.

> *Our relationship is that she was my best friend....no-one knew her like me, certainly no-one knew me like her.* (BrotherE)
>
> *I was really, really close to [my uncle].....Especially as I hadn't had the best childhood myself, so he seemed to be the one that understood me the most....I lived about five minutes' away from him....I could pop in whenever I wanted. He could pop round whenever he wanted to. It was always really close.* (NieceE)

Others talked about very difficult longstanding relationships, or relationships which became fractured as a result of the substance use.

> *I was really, really close to my dad....we used to do everything together.... [but]…. at one point we did cut him out of our lives because he was just too much to cope with.... I kept my distance from him and eventually I slowly let him back in, but I had to keep him at arm's length..... my relationship with my dad [was] very changed.... [then] we started to rebuild our relationship with him, and unfortunately it was around about then that he started to get really ill.* (DaughterE)
>
> *There wasn't really much of a relationship to be honest....it was quite turbulent, because of his drug use. He used to steal off me.... quite expensive things from my room....but also his moods were all over the place because of the drugs.* (SisterE)

Finally, some of those who themselves had problems with substances described continued or escalated levels of use after the death, which, for many, impacted upon their experience of occasions like the funeral and affected their grieving.

> *[I] just used drugs to block everything out.....and never really talked about it..... I took drugs before I went [to view the body]….I got upset a bit [at the funeral], but because I took loads of drugs it just blocked it out for me so I was just able to get through it, put a front on and make out to my mum I was okay.* (BrotherE)
>
> *My problem was that on the day of the funeral....I just lost it, really. I thought I just can't get through the day. So I went to the fruit market, bought the stuff for the shop, and I stopped at a friend's shop on the way back and got him to give me half a bottle of gin. And I thought, well, I'll just drink this just to get me through the day. And then after that I'll stop. And I didn't. So I carried on drinking with the view [that]….if your*

dad had just died, you would be drinking. And it took me nearly two years to stop drinking. And it was probably the worst two years of my life. (SonE)

Second, stress could also be influenced by a number of factors associated with the death itself. This includes how the death occurred, including end of life care, whether others were implicated or believed to be implicated in some way - this was most common with fatal overdose (Templeton et al., 2016b) and is explored elsewhere - and the extent to which the death required involvement of the authorities and official processes. In one case the interviewee believed their relative had been murdered through a contract killing and fought for some years to get a proper inquest.

The manner of the death could exacerbate stress in several ways, including knowing that the person died alone or in distress, finding out that the person was not found for some time (up to a few weeks in some cases), watching the person deteriorate and die in hospital, or knowing that the person was murdered or had committed suicide.

The neighbours alerted that nobody had seen her for a few days....so the police broke in and found her....I still feel really bad that she died on her own" (DaughterE)

"And then over the seven days you saw him degrade literally. It was just taking over his body to the point where the last time I saw him his breathing was so far in between it was really, really scary. Like literally I thought at any second he was going to die. He was very, very yellow. He had a colostomy bag as well. (NieceE)

Related to the manner of death was the presence or absence of good quality end of life care and whether or not the relative or friend had died with dignity and at peace.

They got him breathing and took him in to the intensive care unit, and he was on a life support machine.....eventually the consultant said we need to turn the machine off.....So we agreed to having the machine turned off. And he died I think it was a day later....it was absolutely shocking – absolutely awful.....he didn't slip away peacefully" (MotherE)

"I just thought this is so undignified.....I definitely remember thinking that she was denied that because she was an alcoholic.... regardless of anything, everybody deserves the right to die with dignity and I don't feel that my mum was given that. (DaughterE)

We have reported elsewhere (Templeton et al., 2016a) that a sizeable number of the deaths required police involvement, a post mortem and inquiries by the coroner (England) or procurator fiscal (Scotland). There were several ways in which these processes could add to or reduce our interviewees' stress, including how officials interacted with them (to be discussed below, under Support), delays with post mortems and inquests and the impact of this on, for example, viewing the body, arranging the funeral, or managing grief.

They kept her body for eight weeks.....and we couldn't see her because of decomposing circumstances.....I phoned them very day for eight weeks and they said 'No, I am sorry'. (MotherS)

And that was painful, it took eight weeks before they released the body because it was deemed a suspicious death at first. (PartnerE)

I think it was over a year [before the inquest]...I think I was quite surprised how much I as fretting....I think the suicide was bad but the fact you can't then move on until the inquest....I lost more weight coming up to the inquest then I did immediately after [my

ex-husband] died....I wanted it to happen, I wanted some answers, I wanted resolution. (WifeE)

Third, our analysis has highlighted that stigma, what one mother called a *"contaminated legacy"*, is central to our interviewees' experiences and the associated stresses they faced. Stigma has been explored in detail elsewhere (Chapter 3; Walter et al., 2016) but, in summary, it covers stigmatisation - direct and perceived by the organisations and people our interviewees' came into contact with.

I was thinking 'What are everybody in my work going to think of me? What are they going to think about my family? And what are they going to think of him?'....I was worried, what are they going to think of him as a person, thinking that he'd died of an overdose..... it was in an area where we know a lot of people, so again that stigma issue came up for me, because I was worried about what people would think, I felt I had to justify his death to people; I had to explain what had happened and that, you know 'he wasn't a drug user' and all the things that came with that. (BrotherS)

Stigma is a significant part of understanding the experiences of adults bereaved by substance use, and needs to be included in the adapted version of our theoretical model.

Strain

Our data indicate how the strain, which can manifest itself through a range of physical and psychological health problems, which AFMs may feel following the death of their relative or friend, can be exacerbated or lessened. This includes whether or not interviewees perceived their grief to be disenfranchised (Doka, 2002); how far the involvement of alcohol/drugs in

the death was acknowledged, and whether this caused conflict with others; and the impact of the death on others including younger children.

First, particularly when interviewees experienced or perceived stigma towards themselves and/or their loved one, some felt they could not grieve openly, or that the complicated emotions which they often experienced did not conform to what was expected of them.

> *Sometimes I feel like I'm trying to protect my friends, I feel like it's something people don't want to hear about or they're going to think bad of me or they're going to think oh your brother was a junkie – and I don't want to feel ashamed, I want to be able to just talk about it, but I think I do feel a sense of shame.* (SisterE)
>
> *I think the biggest thing with the way [our son] died was we didn't really feel entitled to grieve. Nobody said I couldn't, but because of the way he died, I felt that people felt, well, he was doing drugs. What are they upset about? And nobody ever suggested this for a minute. It was my perception.* (ParentsE)

Second, there was variation in how far interviewees felt able to acknowledge to themselves and others, both inside and outside the family, that the death was associated with alcohol or drugs. Direct or perceived stigma, or differences of opinion about how open to be about the death, could influence this.

> *To start off with I was embarrassed. The way he died.....now, I am not, and that's because it's now the fact that he's died than how he died.* (MotherS)
>
> *I don't think anybody wanted to stand up and say anything. Because of the awkwardness and the circumstances.....I don't think people wanted to address the situation even on his funeral day.* (DaughterE)

My aunt didn't want to tell anyone how my mum died, she wanted to say that she'd had a heart attack, she's so ashamed. I said why are we ashamed of this? (DaughterE)

Third, bereaved AFMs could have heightened levels of strain if they had to deal with the impact of the death on others. For example, interviewees talked about a range of ways in which children, usually the deceased's siblings or children, were affected. This included their own grief, their lack of understanding about the death, including feeling that they were somehow to blame, and the cumulative impact of having been affected by the substance use before the death coupled with the effect of the death itself.

I still think my youngest son might be a sort of time bomb in a way because he's never really grieved at all. (Ex-wifeE)

And (youngest son) had seen a needle and he kicked it under the drawers in the bedroom... and he thought that because he's kicked that under there (older son) had got it again and that's how he died.....he thought it was ***that*** *needle... He thought he was to blame for killing [his brother].* (MotherS)

..And that has been really difficult that the two eldest haven't wanted to remember him and neither have I.... I don't remember his birthday and there's no anniversaries. (Youngest daughter) has wanted to keep anniversaries and things, and I found that really difficult.... Just (youngest daughter) finds it difficult to find ways to remember him. (PartnerE)

Information and understanding

Interviewee narratives suggest several ways that the availability or absence of information and understanding in a range of areas can impact upon bereavement and grief. These include

the relative or friend's substance use and the nature of 'addiction' generally; retrospectively finding out more about the person's life before they died and gaining a better understanding of substance use to help come to terms with the death; the official processes with which many were involved; and wanting to have a clear picture about the death such as its cause, whether others were present or involved, and whether the person died peacefully or not.

> *I suppose when your mum on her death certificate has an alcohol related death it confirms to you that you really did have an alcoholic mother and so I guess it enabled me to feel I had the right to read books on alcoholic families, search the internet.....for me I wanted to understand....why she drank I think. And I don't have the answer to that but I think [it's] helped [me] to understand a bit more about my family dynamic and why things are as they are.* (DaughterE)
>
> *The Coroner started summing up and I [wanted to ask a question but].... he said that is outside the remit of this Court.... I thought inquest means having the answers....I mean you might have more realistic expectations, but it's partly because I didn't get given any information.* (WifeE)
>
> *I said to the [pathologist] he didn't suffer did he? I wouldn't like to think he was lying there gasping for breath and he was paralysed and he couldn't move. She said no.....he would have slipped away.* (MotherS)

Coping

Our research about how AFMs cope with the substance use of a significant other has suggested three broad ways in which they endeavour to respond, namely putting up with it, standing up to it, and withdrawing from it (Orford et al., 2010a, 2013). However, AFMs never fit neatly into any one box but fluctuate between styles of coping depending on the circumstances and resources available to them. Moreover, some AFMs may interpret a

coping response in one way (putting up with it) but others interpret the same response another way (withdrawing). In considering what coping might mean after death, we need to think differently because many of the coping responses in our research involve some kind of interaction between an AFM and the person using substances, but this will obviously no longer apply after the death. We therefore now consider whether the three broad categories of coping can apply to the experiences of AFMs after death.

Our first broad category of coping, *putting up with it*, entails AFMs tolerating what they were dealing with, often out of fear that disrupting or changing the status quo might be even more stressful, or sometimes out of fear of what would happen if they attempted to respond differently or more assertively. When bereaved through substance, *putting up with it* could cover feeling powerless to grieve, or going along with others who want to hide the truth of the death or not talk about it (although for some this could be seen as a form of coping by withdrawal – see below).

> *You feel reticent to say my son died of a drug overdose because it tells people so much. They think it's telling them everything about that person and it's not.* (ParentsE)

> *When [my brother] was actually using and doing these things, [my mother] would talk about it to a certain extent, but since his death she doesn't, it's as if it never happened and he just died. I don't think she's dealt with it really....at her age, I'm not really going to bring up those feelings again....if that's her way of coping with it.* (SisterE)

The second coping strategy is *standing up to it*. Before death this covers AFMs' attempts to engage emotionally or assertively with the substance user in the hope of getting them to

change their behaviour through realising its impact on those round them. After death we suggest that this way of coping can manifest itself through, for example, interviewees fighting for the good memory of their loved one and not wanting them to be remembered solely as an alcohol or drug user, finding a comfortable balance between good and bad memories, and acknowledging the truth about the death (particularly if others were believed to be somehow involved with the death).

> *My sister and I wrote the eulogy together....it was our chance just to say to them 'This is the kind of person he was'....and that we were really, really proud of him.....we were able to put all those things to show who he was really.* (DaughterE)
>
> *As time goes on I suppose I remember him more rather than less with the passage of time....You know at first I just blot[ted] him out.....It was just too painful"* (WifeE)
>
> *It was the only thing I could do at that point to honour [my son], I couldn't let it go. It would almost be like saying it didn't matter.* (MotherS)
>
> *I wanted it published, I didn't want to hide the fact that [he] died with drugs. Because the way I looked at it, if I could save somebody else, even one, then I think it's all worthwhile.* (FatherS)

The third form of coping is *withdrawing from it*, and before death this covers AFMs removing themselves from the problem or endeavouring to have some independence from it. After death, this might mean the bereaved adult finding their own way to move on with their life, perhaps by responding positively to their bereavement either for themselves or in memory of the one who died, trying to put behind them the death, their grief and the bad memories connected with the substance use (see also Valentine and Walter, 2015; Chapter 4), or using substances themselves (which, for some, might overlap with the *putting up with it* category discussed above).

The fact that you could say, well, it's better that they're dead than have somebody that uses in society…..that really affected me to the point where that's what really made me want to explore drug use further and understand it better and help....I was doing a lot of work on drug-related deaths....speaking to police and practitioners and people that are still using and as many people as I could....to try to gather all these stories together and make this film [to] tackle....those kind of stereotypes and ignorance and stuff in society. (BrotherS)

The first probably three years after he died were just awful, because anything that reminded me of him all it brought back was like these bad memories and stuff.....whereas it doesn't do that so much now. (DaughterE)

I was stupid after he died with blocking everything out through all the drug abuse.....I wasn't interested [in counselling], I just wanted to get out of my face. (PartnerS)

Though we have stuck with the typology developed from our earlier programme of research, it is possible that the three broad categories of coping do not so easily apply to AFMs after the person has died. This is because our work has focused on the dilemmas facing AFMs while their loved one is actively using substances. Our data suggest that bereaved AFMs face a new set of coping dilemmas after the substance-using person has died, but dilemmas which are still majorly related to having to deal with the substance use and its related effects, such as managing feelings and emotions, communicating with others about how the person died, and remembering the deceased, and the stresses and strains associated with them and their life. Our view is that such dilemmas of coping can persist after the person has died; but it is possible that our typology needs further adaptation to better reflect coping following such a bereavement.

Support

As has been discussed elsewhere (Chapter 6; Templeton et al., 2016a) our interviewees painted a very mixed picture of the support which was offered to them or which they accessed after death, and of what they found helpful or unhelpful in the response of others both formally and informally. These experiences lead us to make three suggestions related to the support part of our adapted SSCS model for those bereaved through substance use.

First is the response of authorities and officials, particularly the police, coroner and coroner's officers, and the procurator fiscal. A poor response which lacked compassion or consideration for the bereaved, or which lacked information about the necessity of following official protocol, could increase stress (Chapter 2).

> *The police basically just said, 'We've found your daughter, she's dead, 'phone that number the morra [tomorrow]' and left.* (MotherS)
>
> *The coroner was on another planet really – as in he was sitting there doing his job and it was almost like watching a play because he had a script he was following really.* (FatherE)

On the other hand a more considered approach, where officials explained what was going on or showed some empathy with or compassion for the bereaved, could be comforting at this incredibly difficult time.

> *[The coroner] explained how long the post mortem would take and when we would get the results and that he would ring me and that the best thing I could do would be to just stay at home and not do anything until that process had gone through. And that was helpful, because otherwise I might have gone into a complete flap unnecessarily* (DaughterE)

And the whole time the police stayed with me, they wouldn't go away....I said you must be busy and they said no we'll stay, I said would you like some tea, no would you like some tea, that's what they asked me...some time later one of the WPC's came back to the house....it was about three weeks after the event... [she] very kindly asked after, she said well how are you all coping? And how's your daughter? So the Police do give you a bit of support. (ParentsE)

Second, is the response of other practitioners, including for example funeral directors and specific bereavement counselling services which interviewees accessed or tried to access.

I went to see a bereavement counsellor, I spent about a year working with her.....[it] was enormously helpful....I think that was the first time in my life when I was helped to realise it wasn't my fault that she drank. (DaughterE)

[The bereavement counsellor] asked me what had happened and I said what had happened to [my son] and he said to me I don't know much about drugs. And I said to him but I am not here about drugs, I am here about loss, but he just didn't seem to understand….I never went back, I just thought he stigmatised me right away because of the drugs. (MotherS)

Third, a number of interviewees talked about the informal support which they received from the friends of the deceased's (including, for some, drug using peers), who could fill in gaps in their relative's life and confirm how much they were loved.

When I got to the crematorium I was absolutely blown away by how many people were there. There was probably a good 200 people there..... I was so proud that they loved my boy so much. As a mum my heart was bursting because the love that came

from those young people was extraordinary.... it was just all these lovely young people all relating stories about him and laughing and joking. (MotherE)

Diversity

We have explored elsewhere (Chapter 5) how aspects of interviewees' bereavement may be different for, or more prominent for, a number of sub-groups within our sample. Considering our findings in this way suggests the importance of the relationship of the bereaved person to the person who died, whether the death involved alcohol or drugs, where the bereaved lives, and whether the bereaved themselves experience problems with substances. Similarly, while not prominent in our study, other forms of diversity must also be considered, including ethnicity, which illegal drug[s] are involved, and sexual or gender identity. As such, diversity should be included within each component of the SSCS model.

In summary, the data indicate that the SSCS model can be applied to adults bereaved through substance use, both to capture their experiences after the death but also to understand that these post-death experiences often continue the stress, strain, confusion, coping dilemmas and isolation they often faced when the person was alive. All aspects of our model seem to be relevant. In other words, AFMs feel stress as a result of the death and the bereavement processes which follow, and this stress can result in strain which can take make forms. Additionally, information and understanding, coping, support, and (new to our model) stigma, all seem to influence (in either direction) the experiences of AFMs after death.

Discussion

This chapter set out to extend our understanding of AFMs' experience when there is an alcohol- or drug-related death, by extending a theoretical model of how people can be affected by the substance use of a close other, the SSCS model, to those who are bereaved through substance use.

We first considered how the SSCS model aligns with what our bereaved interviewees said about the impact on them before death of their relative or friends' substance use. The vast majority of what they said mirrors other UK and international research in this area. However, in subsequently occurred, some additions to our model may be needed. Most notably, in terms of stress and strain, is the sense that many of our interviewees had anticipated or come close to experiencing (through suicide attempts or non-fatal overdoses), the death before it occurred. Related to this, several interviewees described grieving for their relative or friend before they died because of how the hold substances had over them had changed them. We have also added stigma to the stress arm of the model.

We then moved on to think about how the SSCS model could be applied to what our interviewees said about how the subsequent death affected them. While our preliminary ideas require further investigation, we have demonstrated that all five core elements of the SSCS model are relevant. Hence, the death itself can be very stressful not least due to direct or perceived stigma. Levels of stress and strain can be influenced positively or negatively by the bereaved's understanding of the substance use, the death (and subsequent official processes), how they cope; and by the availability and quality of support. We have also shown that AFMs still have major coping dilemmas related to the substance using person, and we have shown that our broad typology of three ways of coping can be applied to the

coping dilemmas which AFMs experience when they are bereaved. Nevertheless, we also think that this area of our proposed new version of the SSCS model requires most further investigation both empirically and theoretically by synthesising with existing theories of coping in bereavement, for example, Nadeau (1998), Stroebe, Stroebe and Hansson (2000).

One thing which our SSCS analysis has confirmed is that stress, strain, coping and support after death often comprise a natural and inevitable extension of the challenging circumstances faced by the family before the death. Many of the interviewees made clear associations between how difficult things were for them before the death and the impact of the death itself. Furthermore, for many it was important that after the death they processed both what had gone before the death, which often included gaining a better understanding of the person's 'addiction', as well as the death itself, in order better to manage their grief. This mirrors the work of others (e.g. Holland and Neimeyer, 2011), which has suggested the importance of both the 'event story' and the 'back story' in meaning making and processing grief. Alongside this, many interviewees wanted to find some way to remember the person in which alcohol or drug use did not dominate (see Chapter 4). This need to minimise the dissonance between the person the bereaved knew and how the deceased was perceived by others was also highlighted in Wertheimer's study of those bereaved by suicide (2001).

In conclusion, our previous work in developing this model has proposed that:

> *...The experience of living with a relative with a drinking or drug problem is a very particular experience. It brings together in some combination elements of stress, threat, and even abuse, often simultaneously affecting different family functions and different members of the family. Worry about the loved relative is a core*

> *characteristic. It is bad for the health of family members and for the health of the family as a whole. There is no simple name for that kind of experience….* (Orford et al., 2005, p117)

The ideas explored in this chapter suggest that the above quote could equally apply to the present study's bereaved participants' experiences both before and after the death. For both versions of the SSCS model which we have presented in this chapter, stigma and diversity are central variables which can influence experiences positively or negatively. This new understanding is critical in considering what support is needed by those who are bereaved through substance use. For people affected by a family member's substance use we used the SSCS model as the basis of a brief intervention, called the 5-Step Method (Copello et al., 2010a, b). While the 5-Step Method does not consider those bereaved through substance use, the application of the model which we have presented here suggests that such a development might well be possible, and could offer a useful addition to existing interventions.

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Figure 1: Stress-strain-coping-support model with consideration of adults bereaved by substance use and the impact before death (new additions in bold text or shaded boxes)

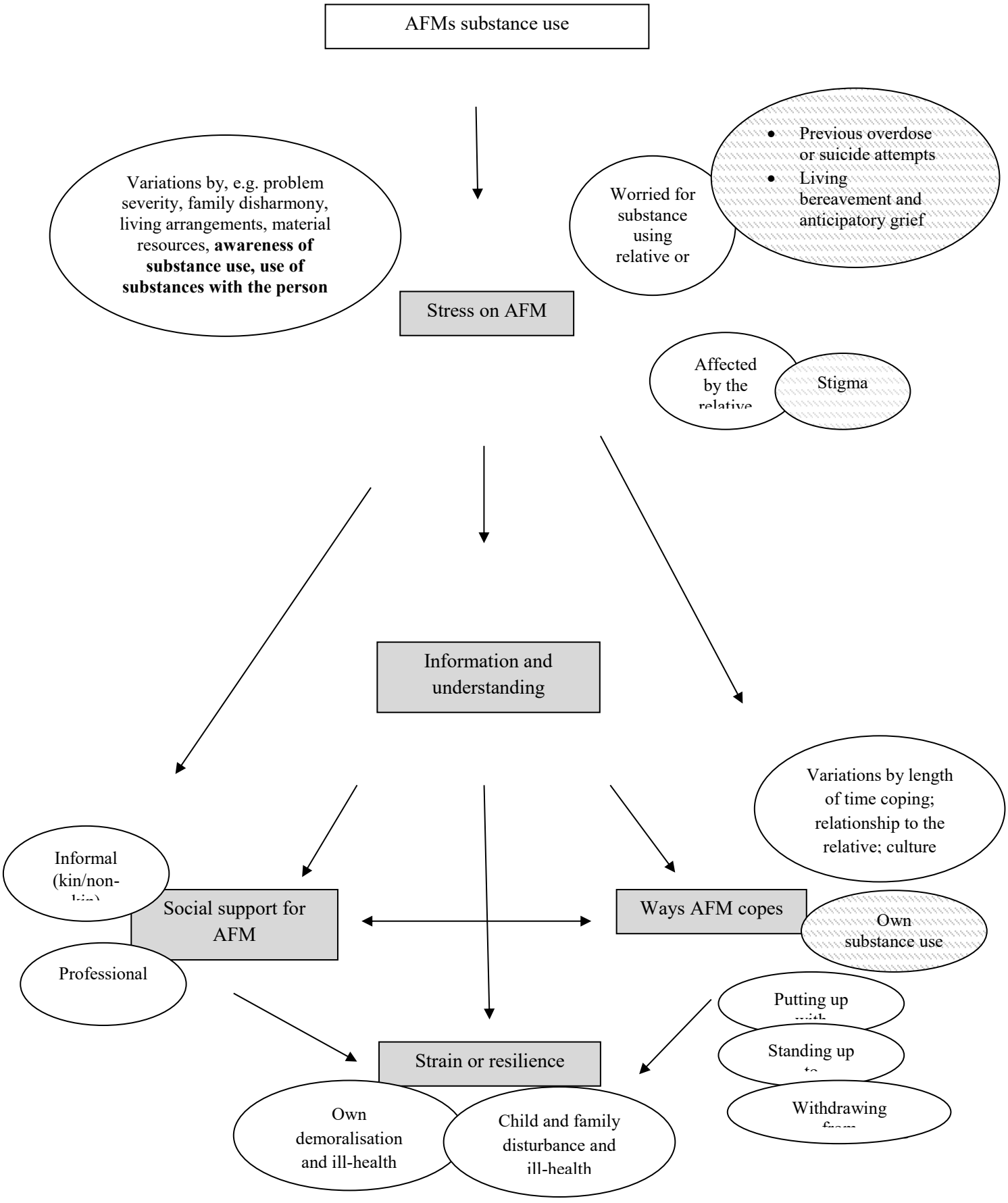
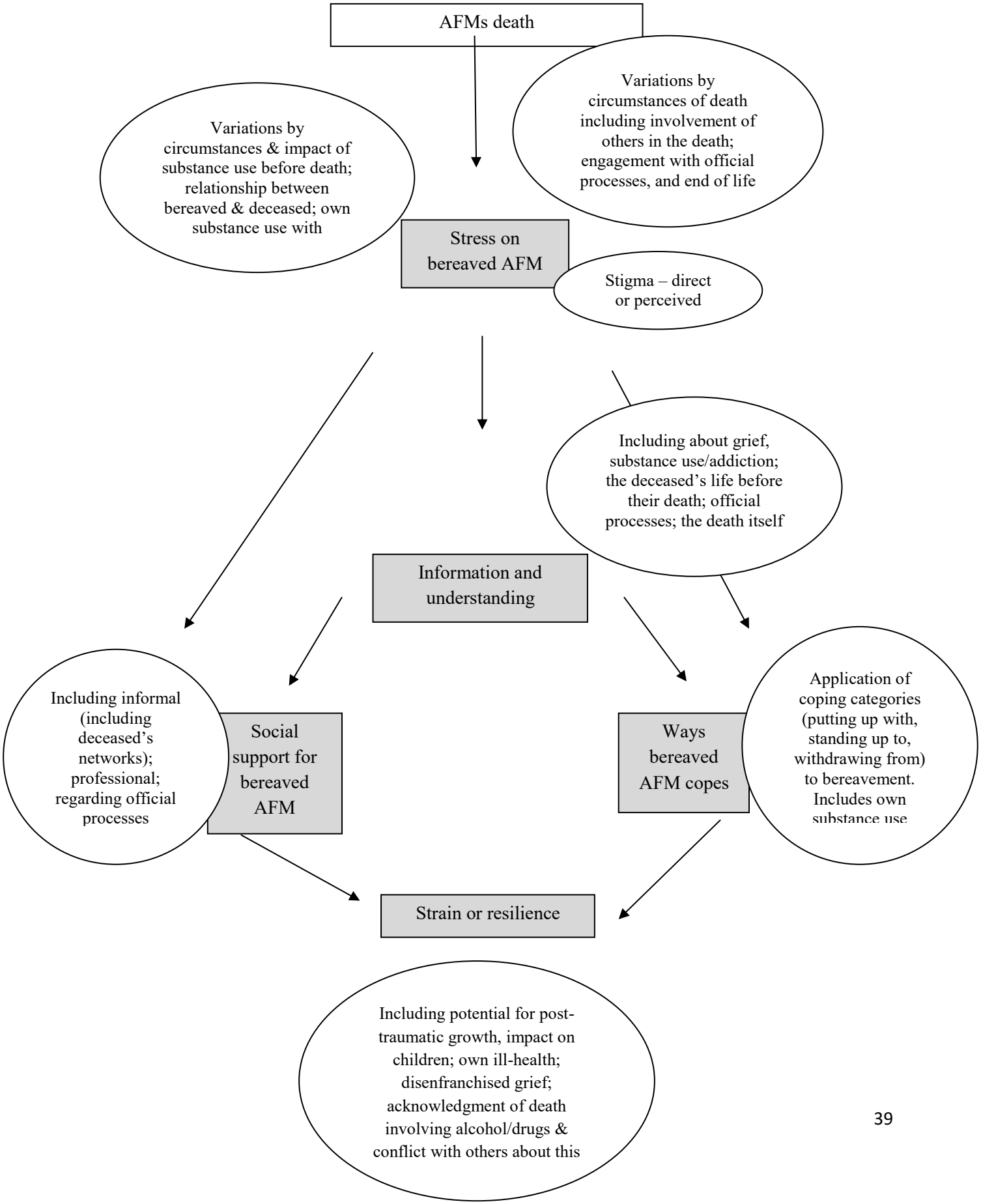


Figure 2: Stress-strain-coping-support model with consideration of adults bereaved by substance use and the impact after death



[i] For brevity in this chapter we will refer to the group of people affected by someone else's substance use as Affected Family Members (AFMs), even though the range of people affected (and who we are writing about) extends to others as well, including friends.

[ii] See www.afinetwork.info

[iii] In recent years the work of AFINet-UK has extended to include AFMs of problem gamblers (e.g. Velleman, Cousins and Orford, 2015).