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Bereavement through substance use: findings from an interview study with adults in England and Scotland

Background

There is considerable global evidence of how people can be negatively affected by the problematic substance use of a relative or significant other (Orford et al., 2005, 2013; Templeton, 2013), experiences which have been likened to living with other stressful situations such as chronic illness, disability, mental illness or a suicidal family member (McLaughlin et al., 2014; Oreo & Ozgul, 2007; Orford et al., 2013). Some family members talk about living with grief and loss and the possibility that their loved one may die through their substance use (Da Silva et al., 2007; Oreo & Ozgul, 2007), something which will become a reality for a significant number. Mortality rates for alcohol- and drug-related deaths are high across the United Kingdom - in 2013 there were nearly 8,500 alcohol-related deaths in the UK, nearly 3,000 drug-related deaths in England and just over 500 drug-related deaths in Scotland (National Records of Scotland, 2014; ONS, 2014, 2015). There are no firm estimates, however, of how many people will be affected by such deaths.

Similarly, there has been little UK or international research about those who have been bereaved in this way (Valentine, Walter & Bauld, 2016). We identified only three qualitative studies, two which focus on drug-related deaths: a Brazilian study with six bereaved family members (Da Silva et al., 2007) and an English study with four bereaved family members (Guy, 2004). The third study focuses on the parental bereavement of four British teenage girls, aged between 14 and 16 years, and includes alcohol-related deaths (Grace, 2012) which otherwise remain unrepresented. These three studies identify both the impact of the stigma associated with these deaths and of the pressures on families of having lived with the

person's substance use. In addition, Feigelman et al., (2012) conducted an exploratory, comparative survey of 571 parents in the United States bereaved by different causes of death, of which 48 were drug related, 462 were suicide, 24 were natural causes and 37 accidental. They concluded that, while both suicide and drug-related deaths were particularly difficult to grieve, the stigmatisation and lack of compassion for parents bereaved by drug-related deaths were greater than for those bereaved by suicide.

Collectively, these studies, along with other research, suggest several ways in which these deaths can bring 'an additional burden for the bereaved' (Chapple et al., 2015: 14). First, they are more likely to be avoidable, sudden, violent, related to overdose or suicide, and premature (Da Silva et al., 2007; Degenhardt et al., 2013; Nambiar et al., 2015).

Additionally, such deaths, particularly where illegal drugs are concerned, are often complicated by stigma (Lloyd, 2010; Orford, 2012). Commonly involving pejorative language, misunderstandings, judgments and negative opinions, stigma can be directed not only to the user and their behaviour but also to relatives and significant others (Adfam, 2012, 2013; Feigelman et al., 2011; Guy, 2004; Guy & Holloway, 2007; Song, Shin & Kim, 2015). Viewed as criminal or deviant in some way, substance users and their families (including those bereaved in this way) are often seen to be complicit or at fault (Chapple et al., 2015; Guy, 2004; Guy & Holloway, 2007). All of this can lead to increased feelings of blame and shame by those who are bereaved (Chapple et al., 2015; Corrigan, Watson & Miller, 2006; Feigelman et al., 2011), a sense they have somehow failed the deceased (felt particularly keenly by parents: Guy, 2004), and strained relationships with others (kin and non-kin). Stigma can be reinforced by the responses of others including the media, professionals and communities (Guy, 2004).

Guy & Holloway (2007) have therefore proposed that such deaths belong to a category of 'special' deaths which also include, for example, suicide, murder, AIDS, the death of a child, or deaths associated with war/conflict, hostage crises or terrorism (Gall, Henneberry & Eyre, 2014; Guy & Holloway, 2007; Maple et al., 2012; Riches & Dawson, 1998). These deaths have been categorised as such because they, in one or more ways, pose a threat to individual, family and societal ontological security (Chapple et al., 2015; Guy & Holloway, 2007). Moreover, they have been linked with increased rates of post-traumatic stress disorder, major depressive disorder and complicated grief among the bereaved (Feigelman et al., 2009, 2011; Kristensen, Weisaeth & Heir, 2012; Stroebe et al., 2007).

Guy & Holloway (2007) suggested that there are three reasons why a drug-related death is a 'special' death. These are the often traumatic circumstances of the death, stigma towards both the deceased and the bereaved, and disenfranchised grief (Doka, 2002) - grief which is not deemed legitimate because the bereaved feel, and/or are given the impression by others, that they do not have the right to grieve or receive sympathy from others (Chapple et al., 2015; Guy, 2004). Some even feel that, in order to grieve and to avoid tarnishing the identity of either themselves or those they are mourning, they must misrepresent or hide the truth about the death (and about the deceased before they died) (Feigelman et al., 2011; Guy, 2004). Furthermore, the substance use and its impact on relationships between the deceased and those who are bereaved, and the subsequent death, can affect how people remember and construct continuing bonds with the person who died (Gall, Henneberry & Eyre, 2014; Guy, 2004; Hall, 2014; Riches & Dawson, 1998).

The misuse of alcohol and illegal drugs, and associated mortality, are significant public health concerns. They attract widespread public attention and debate, often reinforced by polarising and stigmatising views from the media and others. Yet, the experiences, grief and

support needs of those who are bereaved have hitherto been poorly understood. Given the dearth of previous research in this area this paper reports findings from an interview study, undertaken in Scotland and South West England in 2013, which investigated the experiences of adults bereaved through substance use.

Methodology

The study received ethical approval from the relevant University departments and all participants gave informed consent. A sociologically oriented phenomenological approach was chosen to investigate the lived experiences of adults who have been bereaved in this way and how they have made sense of the death (Valentine, Templeton & Velleman, in press). In order to maximise recruitment 'substance use death' was broadly defined to capture any death which the interviewee believed directly or indirectly involved illegal drugs or alcohol. A number of strategies, including the assistance of a bereaved family member advisor, were used to recruit adults from grassroots organisations and local services in the two study areas. Given the lack of information about the size and demographics of this population, convenience sampling was used although some purposive and snowball sampling guided later recruitment. Participants were not approached directly but either initiated contact with the researchers or had contact facilitated by a third party. All interviewees were given an information sheet and asked to sign a consent form before being interviewed. The majority of interviews were conducted face-to-face (at a neutral location or in the participant's home), with seven conducted by telephone. Interviewers used a semi-structured interview guide to focus on a number of areas of inquiry, including how things were before the death, the death itself, and events, coping and support since the death. Demographic data, about both the interviewee and the deceased, were also collected. Interviews lasted between 40 minutes and

more than two hours, and all were digitally recorded with interviewees' permission and then transcribed.

Thematic analysis, which ran parallel to the latter stages of data collection, combined a grounded theory approach with interpretive phenomenological analysis in order to understand the participants' lived experience (Charmaz, 2003; Smith & Osborn, 2003). The data were organised and coded using QSR Nvivo 10, with several stages to the development of the coding framework. Four members of the research team independently reviewed a sample of initial transcripts to identify emerging themes, following which a first draft of the coding framework was developed. This was piloted with a subset of 10 interviews (coded independently by the researchers), and team discussions led to revisions and additions being made, following which the coding framework was piloted again (with the same subset of interviews), finalised and applied to all interviews. Analysis was supported by memos which summarised individual interviews or key themes.

Description of the sample

INSERT TABLE 1 ABOUT HERE

One hundred interviews (Table 1) were completed with 106 adults (including six couples) who talked about the deaths of 102 significant others (some interviewees talked about the same person, or more than one death). The majority of interviewees were female (and mainly mothers, particularly in Scotland), while the deceased individuals were more likely to be male (particularly in Scotland where they were usually sons). The vast majority of interviewees, and the deceased people they talked about, were White British. One fifth of

interviewees were in treatment for, or recovery from, their own problems with alcohol/drugs at the time of interview. There was wide variation in the time between the death and the interview, from a matter of weeks to more than thirty years. Interviewees described a wide range of causes of death and of the direct or contributory role of alcohol and/or drugs (predominantly heroin) in the deaths. It is hard to quantify exactly the causes of death for a number of reasons: in some cases the interviewee did not know the exact cause of death while in other cases there were differences between the official cause of death and what the interviewee believed to be the cause of death – for example, a drowning which the mother believed to be murder, a narrative verdict at one inquest because it was unclear whether the death was a suicide or an accident, and the exclusion of alcohol/drugs from the official cause of death. Nevertheless, the data suggest that approximately one third of deaths involved a drugs’ overdose, usually involving heroin (see Templeton et al., 2016 forthcoming), roughly one quarter of deaths could be directly attributed to alcohol and approximately 15 deaths were classed as suicides. Other causes of death included two murders and one manslaughter, illnesses (including cancer, pneumonia, tuberculosis, hepatitis C, food poisoning and sudden adult death syndrome), and accidents (a fire, a road traffic accident, misadventure and drowning). The remainder of the deaths were in some way associated with complications of drugs or drugs/alcohol use combined.

Results

Five themes illustrate how substance use deaths are ‘special deaths’ which can adversely affect grief and bereavement: living with the possibility of death; official processes; stigma;

grief; and support¹. However, it is not possible to extrapolate the prevalence of these themes beyond this qualitative and not entirely representative sample.

Living with the possibility of death

Addicted families have been bereaved for a very long [time], they lost that person a long time ago (MotherS)

Most interviewees talked at length about what it was like to live with the substance use of their relative or friend. In many cases the substance use was longstanding and chronic; there were fewer instances where the use was occasional or experimental, or associated with a lapse/relapse. Very few of the deceased were in treatment at the time of their death. Some interviewees, usually parents of drug users, were unaware of the severity of the problem or that the person had lapsed/relapsed. Interviewees described a number of ways in which the substance use had a deleterious effect, covering physical and psychological health, fractured relationships and family life, the ripple effect on the wider family and social networks, and the cumulative impact when the substance use co-existed with other problems, particularly mental illness and offending. Many talked about previous overdose or suicide attempts, illnesses or emergencies involving the deceased.

As a result of their experiences, some interviewees felt that they had already lost their relative/friend and had lived, sometimes for many years, with the possibility that the person would die as a result of their substance use. A number likened this to grief or what one mother called a 'living bereavement'.

¹ Any names used in quotes are pseudonyms; 'E' refers to interviewees in England and 'S' refers to interviewees in Scotland.

The day I found out he was on drugs was the day that part of me died. And the day I realised that he would probably not make it....the progressive illness of addiction had really taken hold. There was really no hope any more, he was definitely dying and it would just be a matter of time (MotherS)

[When] she was in the high dependency unit and I thought she was going to die and she didn't.....I felt like that was the point at which I really lost her....I went through a grieving process then which I think is probably more akin to what people would usually experience when they lose somebody, compared with what I went through when she actually died, which was completely different (DaughterE)

Some attempted to talk to their substance using relative about their concerns, what one son called the 'elephant in the room', but reflected on their understanding of addiction to acknowledge how futile such conversations often were.

The deaths themselves varied in a number of ways, including their cause and the immediate role of alcohol/drugs, whether the death was sudden or expected, how and when the deceased was discovered, and whether others were involved with or present at the death. In some cases, more commonly with deaths involving alcohol, interviewees had time to prepare for the death (for example, because the person had been ill for some time and/or was in hospital) and hence to be with them or say goodbye. However, where the relationship had been damaged this was not always easy. In other cases, more common with deaths involving illegal drugs, the death was sudden and some interviewees faced the additional distress of knowing that their loved one had died alone, was not found for some time, or was (or was believed to be by the interviewee) the victim of murder or manslaughter. A number of interviewees, mainly parents where a child had overdosed, were the ones who discovered the

deceased, usually at home - an experience they found extremely traumatic, in some cases exacerbated by attempts to resuscitate the person.

The thought of him being there so long and no one having found him was quite hard
(SisterE)

He died lying on my settee in the living room. I will never forget that day when I went in and found him (MotherS)

I phoned 999....and the woman told me how to do mouth to mouth resuscitation and everything, and I kept doing that until the ambulance came (MotherE)

In summary, many interviewees experienced grief and loss before the death occurred, and had faced the possibility that their loved one would die as a result of their substance use. Coupled with the nature of the death itself, these experiences and emotions often amplified their grief.

Official processes

We were just part of the process, we weren't a bereaved family (FatherS)

Many interviewees got caught up with officialdom and officials, particularly paramedics, pathologists and mortuary staff, police, coroners/coroners officers in England, and the procurator fiscal (PF) in Scotland. This included being told about the death and how the body was managed. Across the board interviewee experiences were very mixed.

Being told about the death

Despite the significance of this moment, interviewees described mixed experiences of being told of the death of their relative or friend. Table 2 illustrates this range of experience, providing details and examples of how interviewees found out about the death.

INSERT TABLE 2 ABOUT HERE

The data suggest that poor experiences were particularly associated with the police, and that finding the deceased could be particularly traumatic. On the other hand, supportive and kind experiences from others, or being able to be with the deceased when they died, could provide some reassurance at a difficult time.

Legal processes

It is hard to quantify involvement with these processes with any precision because, for example, some interviewees did not know whether there had been a post mortem or official investigation. However, the data suggest that in about three quarters of cases there was a post-mortem, often followed by an inquest in England or investigation by the PF in Scotland. In nearly half of cases there was some level of police investigation. While there were some positive experiences generally, interviewees found the involvement of the police upsetting, intrusive and inappropriate. For example, procedures were poorly explained and families were not kept informed, or families were left feeling somehow to blame or that they and/or the deceased were criminal in some way.

How do you expect me to answer questions when I've just been told my son has died...it doesn't matter what kind of person she is or what kind of person he was, you

try and show a bit of compassion. You don't just go in as if it is an ordinary run of the mill thing (MotherS)

Similarly, a number of interviewees raised practical issues about post mortems, inquests and inquiries, including how long such processes took, uncertainty about the remit of an inquest and what their own role could be, understanding jargon and paperwork, communication and the approach of the officials involved. One mother was not told that there had been a post mortem.

Her [PF] manner was terrible, there was no warmth in her. And I felt as if we were the wrong ones (MotherS)

As will be discussed under the support theme the approach of all of these officials was important. As seen above, while some found officials unsupportive, describing them as distant, and lacking in compassion and warmth, others found them sympathetic, comforting and respectful.

The inquest was incredibly professionally and sensitively done....it was conducted by a woman who was gentle, sensitive, unrushed (MotherE)

They [detectives] were very nice. I didn't feel they were being judgemental or anything towards me or [him], they were very sorry about [his] death (MotherS)

Interviewees described their reactions to the decisions reached by pathologists, coroners/PFs and the police, particularly around the inclusion or not of alcohol/drugs in the official cause of death. While some were satisfied with such outcomes others were not or reported conflict

with others. Some interviewees were affected when the outcome of official investigations meant that those they believed to be involved with the death did not face criminal charges. Some said that they had hoped the inquest or inquiry would provide answers, and for a small number this was the case and therefore helpful. However, this was the exception rather than the rule.

Viewing the body

INSERT TABLE 3 ABOUT HERE

Again, this theme reflects the diversity in the sample, as shown in Table 3, although in about one third of cases (N=36) whether or not the interviewee viewed the body, and the basis for this, was unclear or not explored in the interview.

Interviewees expressed a range of views as to whether they chose to view the deceased or not, and then reflected on whether they had done the right thing. Their decisions were often tied up with the nature of the death, the condition of the body, and their relationship with the deceased before they died. A number of interviewees considered viewing the body as an opportunity to say goodbye, or to see the deceased at peace given the problems they had experienced.

However, some interviewees did not have a say or experienced difficulties in viewing the body, for example, due to official investigations being ongoing, viewing being delayed over a weekend or bank holiday, decisions being made for younger children, or the condition of

the body, that is, in some cases interviewees being advised, or told, that they could not see or touch the deceased. Again, the approach taken by others, particularly professionals, could make a significant difference to experiences at this time. For example, a couple were distressed to find out that their son's body was not embalmed or dressed because he was an intravenous drug user and there was a risk of the transfer of infection. On the other hand, three mothers in Scotland took comfort from being able to view the body through a glass screen or on a television monitor, the policy in that area of Scotland for drug-related deaths, while others described positive experiences of the chapel of rest or when they were able to be involved with preparing or dressing the body.

Overall, interviewees were often caught up in a complicated, confusing and often protracted web of procedures and services, which could have a knock-on effect on other processes such as releasing the body, returning the deceased's belongings and holding the funeral. These experiences were often strongly influenced by the approach and attitude of the professionals who interviewees came into contact with, as will be further explored through themes of stigma and support.

Stigma

I've always talked about [my son's] drug problem, I have never shoved it under the carpet....it's in our life, it's part of who we are now (FatherS)

INSERT TABLE 4 ABOUT HERE

Stigma was one of the most prevalent themes, discussed in approximately three quarters of the interviews, and interviewees gave examples of both direct, and perceived or self-stigma. As shown in Table 4 stigma came from all corners, including officials, the media (the death, including in some cases the funeral, inquest or a court case, was reported in the media in about one fifth of cases), relatives, colleagues and friends.

However, while interviewees were less likely to discuss stigma if they had not experienced it, a small number did cite instances where they had not felt that they (or the deceased) were judged or stigmatised in any way, or where the expectation of stigma had not been realised.

There were two policewomen who came and they stayed and they made us tea and they comforted us.....he was known to the police because he had been an addict....that's awful as a mother.....you feel like society looks down on you.....I didn't get that sense this time. [The police] couldn't have been more helpful (ParentsE)

Well to be honest not really, a lot of people in this town knew my mum, knew my mum and dad and they were very liked. And no I wouldn't say, I didn't no [experience any stigma] (DaughterS).

My biggest fear [was that] nobody will come. It will be a miserable, sad, little funeral...because of the circumstances of his death...I thought people would be judgemental and shocked, but as we drove up I thought there are an awful lot of cars....people milling about. And somebody said they're for [your son]....it's the old stigma again, isn't it? There's real stigma, but there's also perceived stigma (MotherE)

Some interviewees experienced greater stigma when, for example, the death was a suicide or involved illegal drugs (specifically intravenous heroin use). Similarly, some spoke of others who had compared their loss with a non-substance related death, suggesting that this would

be harder to grieve given it was not 'self-inflicted'. A small number of interviewees made comparisons (often based on direct experience) with being bereaved by cancer, highlighting that such deaths are treated very differently to deaths involving drugs or alcohol.

You're sort of envious of people dying of cancer....it isn't the only horrible death in the world, why is that the only death that people want to help a family with (WifeE)

Sometimes I feel that [if] somebody died in an accident or somebody dies of cancer, there is so much support and everybody thinks that's so terrible, that's awful. But somebody died of drugs, oh well that was their own fault (MotherS)

Responding to stigma

INSERT TABLE 5 ABOUT HERE

Interviewees described several ways in which they responded to experiencing stigma. These included efforts to protect the deceased's memory (this is also discussed under 'remembering the deceased' below), attempting to influence or work with others including the media, openly telling the truth about the death or somehow hiding the truth (see Table 5).

One interviewee emphasised the importance of disregarding stigma in all its forms.

[People] shouldn't, like I did.....stigmatise themselves, they shouldn't put themselves down or worry about what other people are going to think..... It's so important to be able to talk about how you're feeling and....not worry that you're going to be judged for how you're feeling, or that your loved ones are going to be judged (BrotherS)

Others gave examples of the complexities of tackling stigma when others did not wish the true nature of the death to be acknowledged, or the true nature of the death was or was not acknowledged in 'official' paperwork.

I remember at the funeral I wanted any proceeds to go to Nacoa².....[but my] brother-in-law didn't want the funeral to have any mention of alcohol. So I thought, this is what killed him but we're not to mention it (Ex-wifeE)

It's hard to take something that said methadone and alcohol around various places that needed evidence of his death, just felt it would have been worse I think....I had to go to the bank with his [interim] death certificate to close his accounts and so it felt a wee bit easier somehow (MotherS)

There's nothing on [the death certificate] about his drug use. And that makes me annoyed because....he will be a [drug death] statistic that is missed (MotherE)

To summarise, this is a group of deaths where stigma, directed to both the deceased and their loved ones, was widespread. This led to a number of personal and practical dilemmas, with many interviewees demonstrating courage in how they responded to stigma.

Grief

² National Association for the Children of Alcoholics

I didn't want her death to be defined by her addiction (BrotherE)

This theme covers emotional impact, remembering the deceased, and understanding substance use.

Emotional impact

The majority of interviewees experienced a range of emotional reactions to the death, often influenced by much of what has been discussed above. Complicated and strong emotions were common, including coming to terms with the waste of life and potential, managing feelings towards others who they believed to be responsible for the death, and feeling relief because both they and the deceased are at peace.

I felt really sad, what a waste of life, I felt really really sad for him (SonE)

I needed someone to hate and he got my focus because of what he done.....[as time went on] I started to let the anger go (FatherS)

Every day was a battle with him. His addiction was...way too powerful for him...I just sometimes think maybe now he's at peace and he's not at war anymore, maybe he's a lot happier (NieceE)

However, some interviewees recognised that their reactions did not necessarily conform to societal norms around grieving which meant that they questioned the legitimacy of their grief. Others questioned their grief in the light of societal norms tending to devalue these deaths.

When she first died it was a relief that that was over...it is difficult because you feel guilty for feeling like that...you think it's wrong to have feelings like that and

therefore you feel that perhaps you don't have the right to grieve and be so upset...it took me a while to realise that I had the right to be upset (DaughterE)

Remembering the deceased

Interviewees described mixed experiences in terms of how they remembered the deceased. Experiences with the person before they died, and then the nature of the death itself, could aggravate this process. While some were able to focus on good memories or 'putting the record straight', others found this extremely difficult because of the dominance of mixed or disturbed memories or a lack of good memories.

I remember him....I think of him smiling, having a good time. We did have like good times together, we always had a laugh (SonE)

There are so many bad memories that you actually forget any good memories....it's twice as bad when somebody is an addict of some kind (MotherS)

Many interviewees talked about creative ways in which they remembered the deceased³. Examples included writing (books, songs, letters, poetry), contributing to memorial quilts and events, making films, raising money for related charities, volunteering/working in related areas, and setting up support/services including bereavement groups. Some talked about the, sometimes unexpected, value of meeting (substance using) peers at the funeral, describing how this gave them the opportunity to learn more about their loved one. Overall, the funeral often provided an opportunity for many to realise how much the person was loved, and to celebrate the life of a much loved person rather than a 'drug addict' or an 'alcoholic'.

³ See Valentine & Walter (forthcoming).

There was some laughter, there were some nice stories that were told and that made a big difference because you were remembering how good a guy he was so you weren't thinking about the tragic circumstances that led to him dying....we were celebrating him as a person and his life (BrotherS)

I didn't want anyone to think just because he was an alcoholic and just because he died young doesn't make him a bad dad, he was a fantastic father....and I wanted people [at the funeral] to know how special he was to us (SonE)

Understanding substance use

Interviewees had mixed understandings of alcohol and drugs, and problems associated with their use, and this could influence their processing of the death. Several were proactive after the death in finding out more about substance use and addiction (including reading or working/volunteering in the area) because they wanted to better understand the deceased and their problems both before and after death. One daughter explained how recognising her mother's alcohol problem as a disease helped her, while others said that their learning helped them to realise that they could not have helped their loved one.

I think that was the first time in my life when I was helped to realise it wasn't my fault, it wasn't my fault that she drank, to see alcoholism as a disease (DaughterE)

In summary, interviewees talked about a number of ways in which they managed their grief, and of the challenges which could influence this.

Support

I noticed how lost the family were after this death. And we just didn't have any support (NieceE)

Interviewee narratives illustrated the distress associated with a death that was often traumatic and stigmatised and which led to additional challenges for grieving. There is a clear need for support and the final theme explores interviewee experiences and needs in this regard.

Interviewees highlighted the range of support available (from officials, bereavement services, substance use treatment services, work, family and friends [including the deceased's networks] and the community) and the way in which support is given. All gave examples of positive and negative experiences of support from a wide range of individuals and services.

Examples of positive support included a priest who stayed with the body the night before the funeral, a coroner who helped a mother to organise a memorial event, professionals known to the deceased (such as prison or hostel staff) who marked the funeral in their own way, police who attended the funeral, and bereavement support groups. Negative experiences were equally varied, and included a lack of support to those who were in prison, poor experiences with counselling (including delays/waiting lists, and counsellors who did not understand this type of bereavement), and not being given contact details of who to call (e.g. during official investigations). Overall, interviewees reported feeling lost and isolated after the death, with some emphasising that they were not considered at all, or commenting on how much harder things are when support is unavailable or poorly joined up.

If it's a murder then there would be a family liaison officer, if it was an accident then there might be victim support. But there was nothing at all. Nobody who made contact or that I was put in contact with. And somehow you don't fit anywhere either...you feel like you fall between everything (MotherS)

A number thought that there needed to be greater recognition that this is a bereavement which requires a particular response.

Some acknowledgement that this was a different kind of death...there is a need not to make presumptions about how people might be....it is really, really important that you pay attention to how they are rather than how you think they should be (MotherS)

Bereavement is a difficult thing for people to deal with, or death is a difficult thing for people to deal with anyway. But the fact that it is death through an addiction I think emphasises that (DaughterE)

A critical factor in whether someone's response was deemed supportive and helpful was how it was given, and this seems particularly important where the death is marginalised and stigmatised⁴. Negative experiences were more common when there was a lack of understanding and empathy, a lack of recognition of the needs of the family, and a cold approach.

The [police] seemed to have a significant lack of awareness of what it must be like for a family (FatherE)

I thought there is no emotion or anything with you....I just felt her [the PF] mannerism wasn't somebody with compassion and empathy, it was just this is my job (MotherS)

Characteristics of a 'good' response can be listed as proactive, responsive, holistic, non-stigmatising and non-judgmental, person centred, flexible (i.e. not time limited or formulaic),

⁴ See Walter et al. (forthcoming).

immediate, respectful and compassionate, what one daughter described as ‘small acts of kindness’. It was especially significant for interviewees when professionals took the care to personalise the deceased or not make judgments, such as the mother who appreciated a doctor referring to her son as a ‘gentleman’ rather than a ‘drug addict’.

I found a very sympathetic, very lovely [undertaker] who was wonderful and who took care of everything. He was just incredibly empathetic and softly spoken and didn’t make any assumptions about the situation....[he] talked about her like she was a person still and I felt comfortable telling him about her (DaughterE)

‘I’m so sorry for your loss in these circumstances. I’ve only heard about the bad things in Paul’s life and the very tragic circumstances of his death, but there will be another Paul and I hope that is a Paul you will all take with you today’ (MotherE – reading what the coroner said from the transcript of the inquest)

I saw her body but not until it had been delivered to the funeral parlour, who actually were great, they gave her a room, we could visit her and people could visit her at any time and they were absolutely amazing (MotherE)

Discussion

This paper has described a unique and large sample, relating to a group of bereaved people about whom there is little research-based knowledge. Interviewee narratives have extended knowledge about both living with, and being bereaved by, the substance use of a close other in a number of ways. The sample’s inclusion of not only spouses, parents and children but also lesser studied groups, such as siblings, nieces, friends, and those who were also alcohol/drug users, has added to this knowledge base. While further analysis is needed to better understand the experiences of these groups and how they may differ from those of

more immediate family members, there are indications that differences do exist – for example, the strength of friendship or sibling bonds and how this can impact upon grief, feeling that grief is secondary to that of immediate family members such as parents, lesser involvement with official processes, exclusion from important decisions such as aspects of the funeral, and feeling that support is even less likely than that given to closer family members.

Before death, how interviewees described living with a close other's substance use, and with the possibility of death, mirrors other work in this area which has considered the stressful impacts of such situations, including the possibility that the person might die as a result of their alcohol/drug use and that families and close others may experience loss and grief before death occurs, their lack of knowledge and understanding about substance misuse, the coping and support dilemmas which many face, and the ways in which both users and their families can be stigmatised (Orford et al., 2005, 2010; Oreo & Ozgul, 2007).

After death the data highlight how, for many, these experiences can continue and significantly compound grieving, suggesting that alcohol- and drug-related deaths should belong to a category of 'special deaths' (Guy and Holloway, 2007), akin to other deaths that have been similarly described as particularly difficult to mourn. The themes summarised in this paper both align with the three features identified by Guy & Holloway (2007) as defining drug-related deaths as a special death, and also build upon these ideas to offer greater understanding as to what might be unique to this type of bereavement, including where deaths are associated with alcohol misuse (Guy & Holloway's work focused on illegal drugs). First, the circumstances before death and the nature of the death itself, which often required involvement with official processes, highlight the traumatic nature of many of these deaths. Our data show that there are parallels with those bereaved by murder or manslaughter whose

experiences highlighted how the judicial process can negatively affect grief, because they believed their grief to be ‘subordinate to justice’ (Riches & Dawson, 1998: 153; Guy, 2004). There were also similarities because of the poor experiences which many interviewees reported when describing their interactions with such processes.

Second, experiences of actual and perceived stigma were widespread (Chapple et al., 2015; Guy, 2004; Guy & Holloway; Maple et al., 2012; Riches & Dawson, 1998). Our data expand on what is already known about stigma to highlight the many ways in which interviewees can be stigmatised and the wide range of people who may propagate this stigma. The data also highlight how stigma impacts upon bereavement, including grieving, seeking support, remembering the deceased, and interactions with others including about the true nature of the death. Moreover, some interviewees indicated that they and their loved ones could be further stigmatised when the deceased died alone (Seale, 2004) or in a public place, when the police and other officials were involved, when the death involved suicide, murder or illegal drugs (particularly intravenous heroin use and where the nature of the death affected the handling of the body, issues similar to those seen in the USA when responding to deaths through HIV/AIDS e.g. Troyer, 2010), or when the death was reported by the media (Beccaria et al., 2015; Guy, 2004). One aspect of stigma which must be carefully considered is the language which is often used to talk about substance use and addiction. While a new finding from our research is that some of those who have been bereaved in this way can find elements of some theoretical models helpful and even comforting (for example, because they view the problem as an illness or disease which thereby removes blame from the person who dies or those who are bereaved), it is important to recognise that some of these models include words and phrases which suggest blame, judgment and the pathologising of those who died and their families (Broyles et al., 2014; Kelly & Westerhoff, 2009; Lloyd, 2010). A final new finding

to comment on here is that a sizeable number of interviewees described their attempts to respond to stigma and the often creative nature of such responses, with many doing this through their own initiative and without the support of others (Valentine & Walter, forthcoming); it is possible therefore that such ideas could be part of support options for this group of bereaved people.

Third, how interviewees manage deaths which are often traumatic and stigmatised illustrates several ways in which their grief is often disenfranchised and complicated, and how this can affect support. For many, this can seriously affect their sense of ‘legitimacy’ to grieve, and therefore remembering and constructing continuing bonds with the deceased (Maple et al., 2012; Root & Exline, 2014) and accessing support. This is similar to those bereaved by suicide who have described being ‘silenced and isolated’ by the death (Maple et al., 2012: 15).

A further finding which adds to our understanding of bereavement in this population is that those bereaved by substance use may experience grief *before* the death occurred and describe how this could impact upon grief after death. The idea of ‘anticipatory grief’ is not new, having been particularly recognised in studies of caregivers of people with cognitive impairment and dementia (e.g. Collins et al., 1993; Garand et al., 2012; Holley & Mast, 2009). An Australian study with 49 parents with a (living) adult child’s substance use also highlighted the presence of grief experiences and the impact this had on their own well-being (Oreo & Ozgul, 2007). Our data expands this concept to include anticipatory grief in those who have been bereaved through substance use, suggesting how aspects of this (for example, loss of familiarity and intimacy, loss of hope, grief before death, expectancy of death, postdeath relief and postdeath reflections – see Collins et al., 1993) might be similar or different to anticipatory grief in other bereaved populations, and how these grieving

experiences before death can influence post-death grief. It is possible that this idea of anticipatory grief, or a living bereavement, could be added to Guy & Holloway's framework about what makes drug deaths 'special', and this is worth further investigation.

While these themes were clearly widespread in our material, we cannot emphasise enough how diverse our interviewees' experiences were. There is no standard, single response to this kind of bereavement, and it would be inappropriate for practitioners and others to assume that everyone necessarily experiences trauma, anticipatory grief, stigma and disenfranchised grief – though these are possible experiences we strongly advise practitioners to be alert to. This leads us finally to the question of appropriate support for this group.

We have learnt much about what this group of bereaved people find helpful and unhelpful from whom and why. There are overlaps with research with families of substance users, which suggests that listening actively and non-judgmentally, providing information, exploring coping, and improving positive social support are core components of the response required to minimise stress and strain and improve well-being (Copello et al., 2010a, b; Velleman et al., 2011). The findings from the interview study reported here subsequently informed six practitioner focus groups to further explore how to best respond and support the needs of this group of bereaved people. A working group then developed practice guidelines centred on five key messages, namely to show kindness and compassion, consider language, treat every bereaved person as an individual, understand the contribution each person can make to supporting the bereaved, and work together (Cartwright, 2015; Walter et al., 2015). The practice guidelines are generic, aiming to be relevant for the very wide range of professionals who may come in to contact with this group of bereaved people including, for example, paramedics, hospital and mortuary staff, funeral directors and the clergy, coroners

or the procurator fiscal and their staff, the police, the media, and those working in substance use or bereavement services.

Overall, there is a need for greater understanding of this group's experiences (before and after death), and of the specific training and support needs which a range of professional groups might have (Gall, Henneberry & Eyre, 2014; Jones, 2013; Riches & Dawson, 1998). Support should also consider the needs of specific groups such those who are also alcohol/drug users, or who are bereaved by a substance-related suicide or murder. Moreover, a considerable number of interviewees spoke about the impact of the death on children, and while this is not considered in detail here, their support must also be addressed. Finally, many interviewees highlighted the need for practical support in several areas, including paying for the funeral (Woodthorpe, Rumble & Valentine, 2013) and negotiating official processes like coroner, PF or police investigations.

There are several strengths and gaps in our sample. Strengths include the size of the sample and the detail contained within the narratives. Together, these highlight both the core elements of such bereavements as well as the diversity of experience. Experiences and needs can differ according to, for example, whether the bereaved is a drug/alcohol user themselves, differences between England and Scotland, the relationship of bereaved to deceased, and whether the death involved alcohol or illegal drug use. With the latter, those who die tend to be younger and to die more suddenly, and the illegal nature of drug use may stimulate greater stigma and moral censure which may continue after death (Guy, 2004). Gaps in our sample indicate the need for further research to explore the experiences and needs of, for example, black and minority ethnic groups, children and young people, those who have been bereaved by a wider range of drugs, including novel psychoactive substances which increasingly

characterise drug use in the UK (EMCDDA, 2015), and to consider how experiences and needs may vary according to gender and socio-economic status.

Concluding remarks

This study provides new evidence that the experience of being bereaved by substance use may be a very particular one, with clear implications for supporting this group. However, our findings also highlight the diversity of how people experience bereavement and services, including diversity within each interviewee's story, a key feature that any attempt to quantify their experience would only obscure. As such, there is no 'one-size fits all' response and it is important that all those who are in a position to support this group of bereaved people do not simply base their response on the most common experience. Instead, the implication of our work is that the response needs to be person-centred and joined up, which throws up a number of challenges in an era of cuts, tick boxes and standardisation. Nevertheless, our Guidelines provide general principles which have been welcomed by practitioners/professionals and we hope that this study will prompt further research in a largely neglected area along with greater recognition within policy and practice.

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Table 1: Profile of Sample (N=100 interviews)

	England (N=66) Interviewees = 71 Deceased = 66	Scotland (N=34) Interviewees = 35 Deceased = 36
Gender of interviewee	Female = 49 Male = 22	Female = 30 Male = 5
Mean age (years) of interviewee at interview	51 (range 22-75)	54 (range 23-75)
Gender of deceased	Male = 48 Female = 18	Male = 31 Female = 5
Mean age of deceased (years)	41 (range 16-84)	33 (range 16-80)
Relationship of interviewee to deceased	Parent = 30 Child = 19 (includes 1 adopted child) Spouses/partners = 9 (includes 1 ex-spouse/partner and 1 LGB partner) Sibling = 9 (includes 2 step-siblings) Friend = 5 Niece = 2	Parent = 26 Partner or ex-partner/spouse = 4 Sibling = 4 Child = 2 Niece = 1 Friend = 1

Table 2: How interviewees found out about the death

	N=106	Positive experiences	Poor experiences
Told by other relatives	40	And he made the right decision, he phoned my husband who then got straight in the car, it would have been about 9-10pm and drove two and a half hours to where I was (MotherE)	I think I felt a bit annoyed because I had answered the phone that night and the person on the phone asked to speak to....my husband....as I say we've been together quite a few years, asked to speak to him and told him (Ex-wifeS)
Told by the police	25	They were lovely, I mean she was quite concerned about me (MotherE) The police were great, they couldn't have been any nicer (MotherS)	They just came in, stood in the middle of the room, told me, stayed for two minutes and then went (MotherE) The police weren't brilliant, the way they told my mum. She has a post office [and they told her] in the shop with customers there (SisterE)
Were with the person when they died	18	Yes at his bedside when he died, which I was so grateful for, glad I was there (DaughterE) I think we possibly were on the better end of the spectrum because we were there with him (DaughterE)	So we all went to the hospital then instead of going out in the evening for a knees up [after my wedding], we were all sat round his hospital and saying goodbye and, you know, even then I felt so angry with him as I always did whenever I saw him

			<p>(DaughterE)</p> <p>I feel like [I had] so much to talk to her about, that I had to get out, just leading up to it and I wanted to say certain things to her, just couldn't get the words out (SonE)</p>
Told by other professionals	12	<p>And I mean I know the doctors, my son was about sixteen they had been our doctor since then (MotherS)</p> <p>The coroner, he was very sympathetic (DaughterE)</p>	<p>I think they did it wrong, because I think personally they should have got a vicar to come to me, take me to the chapel and then break the news, but they never, three prison officers took me into a room (BrotherE)</p>
Found the body	6	<p><i>There were no positive experiences reported</i></p>	<p>You phoned 999 while I tried to resuscitate him (ParentsE)</p> <p>I screamed that much the girl up the stair[s] came down, she burst the door open to come in and see what was the matter (MotherS)</p>
Told by other acquaintances	5	<p>We get the call from his best friend saying he'd just [been] found (ParentsE)</p>	<p>There was a little anger towards the guy that come round (FriendE)</p>

Table 3: Experiences with viewing the deceased's body

	N=106 (unstated in 36 cases)	Positive experiences	Poor experiences
Decided to see the deceased	44	<p>I went to see his body, well while he was in A&E just after he had died and he looked absolutely beautiful, strange to say but you know he just looked so at peace (MotherS)</p> <p>In all honesty I had to see her, if only to believe that she was dead....I really needed to know in a very...real and physical sense that she had gone (DaughterE)</p>	<p>Seeing him dead was just, it was just awful but the other thing is that he didn't look dead (MotherE)</p> <p>Well that was totally wrong and that really upset my wife as well that he wasn't dressed, we didn't get to dress him (FatherS)</p>
Not able to see the deceased – professional input	13	<p>I am glad I didn't, I am really, really glad I didn't (FatherS)</p>	<p>They advised me not to look at him because by that time the body is not in a fit state, so I just feel I never got to say goodbye to him properly (MotherE)</p> <p>I never got to see her at all, they stopped me from seeing her (MotherS)</p>
Decided not to see	11	I wanted to mind her the	I know enough about

<p>the deceased – personal decision</p>		<p>way she was (MotherS) But half of me doesn't regret it because I don't think I would have been able to cope seeing him like that (NieceE)</p>	<p>medical matters to know it's not a pleasant sight when someone has died from carbon dioxide poisoning, it's not good and also he's ravaged by his alcoholism (WifeE)</p>
<p>Decided not to see the deceased – related to input from others</p>	<p>2</p>	<p>No I was told not, I wouldn't, well I can't deal with her in hospital let alone (NieceE)</p>	<p>No I didn't, none of this was really offered to me or occurred to me (DaughterE)</p>

Table 4: Experiences of stigma

Source of stigma	Examples of stigma
Police	<p>And it's just a horrible stigma, you get a label on you, you are labelled, especially by the police.....it's as if when she died 'Oh another one bites the dust'. That's the impression we got when it all happened, it was just horrible (MotherS)</p> <p>When [son] died....the police attitude at the time, I did feel like, do they think I am a criminal, do they think I am worthless, you can't help but have that go through your mind (MotherE)</p>
Media	<p>[Newspaper headline] 'Unemployed Man Dies of Drug Overdose'.... You're not getting the chance to go out and say to them, 'look that's not really how it was' (CoupleE)</p> <p>It was like heroin addict killed....stabbed to death....once people read that they just think oh well, it's only one more gone (BrotherE)</p>
Other professionals or officials	<p>[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 you know. 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)</p> <p>I got the impression that they [health care professionals] just wanted shot of him basically because he was a nuisance....he was on a normal ward....and he probably did manipulate them...I think they just thought, 'Oh Christ, just another addict, let's get rid of him,' (SisterE)</p>
Relatives	<p>She [deceased's grandmother] told everybody he had a brain tumour...at the funeral one of the friends came and she said it's so sad to hear about [son] and I went, yes, yes. And she said 'brain tumour'. I said, 'pardon?'....for my mum's sake I didn't correct her, and I was so cross with her for it. And I told my sister who said 'I think she was only protecting [her son]'; I said 'I think she was protecting herself' (ParentsE)</p> <p>My aunt didn't want to tell anyone how my mum died, she wanted to</p>

	say that she'd had a heart attack, she's so ashamed (DaughterE)
Other such as friends, work or wider networks	<p>I had a struggle with a lady I've known...her son died as an 8 year old of measles....she told me 'well [losing a child to drugs] it's obviously not the same as losing a child through innocent [means]... ' (ParentsE)</p> <p>One incident that I was aware of was my uncle [who] was in a taxi a couple of days after it happened...and the taxi driver said 'oh did you hear about that junkie that overdosed in [area of city], that's at least another one off the streets' (BrotherS)</p>
Wider society	<p>It's like modern day leprosy....it carries that stigma because...it's been criminalised, rather than seen as what it actually is, an illness....(MotherE)</p> <p>You are a second class citizen (MotherS)</p> <p>You feel like society looks down on you (MotherE)</p>

Table 5: Responding to stigma

Nature of response to stigma	Examples
Protecting the deceased's memory	<p>I wrote to the editor of the paper, I explained the type of person [my son] was and I don't think the main point about him was that he was unemployed, there was more to [him] than an unemployed man (ParentsE) We actually gave the eulogy because we thought [that] this is our only time to put the record straight because even at school one of my best friends had said 'Oh, you know we all know your dad is a drunk' (DaughterE)</p>
Influencing or working with others	<p>[She said] 'I'm going to report it anyway. Could we work together on this as opposed to me just writing the story up and disappearing back to the office?'....She wrote it up and e-mailed it to me [to] have a look. 'Is this okay? This will be the actual wording. Are you happy with it? Is there anything you want to change?' (FatherE)</p> <p>[I used] film to try to gather all these stories together and make this film [to try and] tackle those kind of stereotypes and ignorance and stuff in society (BrotherS)</p>
Being open about the death	<p>I've always talked about [son's] drug problem....we don't let it die down now because it's there, it's in our life it's part of who we are now and we are certainly never going to shove it under the carpet (FatherS)</p> <p>The guy that was doing the [funeral] service had said to me what do you want me to say about [your son] and I said.....I am proud of my son and who he was, I am sorry for what he suffered and I am not proud that he was a drug addict but I am not going to pretend it didn't happen and I am not going to pretend that it didn't happen to my family because I think it's important that people know that it happens to ordinary families and to good families (MotherS)</p>

<p>Avoiding the true nature of the death</p>	<p>I only ever say to people he actually died as a result of a road accident, I never ever say it (MotherE)</p> <p>I think some people tried to ask but my mum had just taken an attitude that actually it's nothing to do with youBut I think in some ways she is quite, not embarrassed, but she doesn't want people to think of him like that (SisterE)</p>
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