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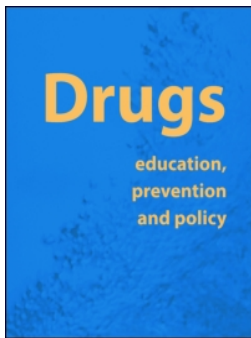
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REVIEW ARTICLE

Bereavement following a fatal overdose: The experiences of adults in England and Scotland

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Abstract

Aims: Overdoses contribute disproportionately to drug-related deaths (DRDs) in the UK, yet little is known about the experiences and needs of those who are bereaved by such deaths, and how their experiences and needs might differ from other bereavements associated with substance use. **Methods:** An interview study with 32 adults in England and Scotland (part of a larger study). **Findings:** Five themes describe the core experiences of this group of bereaved people: drug use, the death, official processes, stigma, and overdose awareness and prevention. Together, these findings offer new insights into the key features of this type of bereavement; for example, living with substance use including previous overdoses, difficult circumstances surrounding the death, having to negotiate the complex procedures involved in processing the death, the stigma such deaths attract, and feelings of guilt, self-blame and an unworthiness to grieve. **Conclusions:** There are ways in which bereavement following an overdose differs from bereavement following other deaths associated with alcohol or drugs. Understanding the experiences and needs of this marginalised group can help improve support for them. Furthermore, this group's experience of witnessing and/or responding to previous overdoses indicates the value in prevention programmes targeting relatives/friends.

Keywords

Bereavement, drugs, families, overdose, qualitative

History

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Introduction

Deaths from overdose (usually involving opiates) are high both in the UK and worldwide (Degenhardt, Larney, Randall, Burns, & Hall, 2013; EMCDDA, 2015; Hecht, Barnsdale, & McAuley, 2014; Strang, Bird, Dietze, & Gerra, 2014). More than half of the nearly 3000 drug-related deaths (DRDs) in England and Wales in 2013, and over 80% of nearly 500 DRDs in Scotland in 2012, involved opioids, and were predominantly overdoses (Hecht et al., 2014; Strang et al., 2014). Risk factors for increased overdose include intravenous use (Hecht et al., 2014), release from prison (Farrell & Marsden, 2007; Merrall et al., 2010; Strang, Bird, & Parmar, 2013), and commencement or cessation of opiate substitution treatment (Cornish, Macleod, Strang, Vickerman, & Hickman, 2010).

There are, however, no UK or global estimates of how many people are bereaved by overdose-related deaths (indeed,

there are no reliable estimates of how many family members are bereaved by any drug- or alcohol-related death). Mortality statistics (e.g. between 6000 and 7000 overdose-related deaths across Europe each year [EMCDDA, 2015]), and the UK figures presented above, suggest that such bereavements are a sizeable problem, but one which has gone largely unnoticed by research, practice and policy, resulting in isolation and a lack of support for those who have been bereaved in this way. As a group which faces many challenges before and after the death, it is important for research to better understand their experiences and needs, and that is the focus of this paper.

While much is known about how families can be affected when a relative has a drug or alcohol problem (Barnard, 2007; Orford et al., 2005), little is known about those who are bereaved through substance use generally or overdose specifically. A Brazilian study interviewed relatives from six families (four parents and two siblings) who were bereaved by an overdose (mostly involving cocaine) (Da Silva, Noto, & Formigoni, 2007). Three of the families were aware of the drug problem and talked about having a 'veiled preparation' for the death (see also Oreo & Ozgul, 2007), and of experiencing both pain and relief when death came. The other three families were unaware of the drug use until after the death and described the anger, guilt, helplessness and shame which they faced along with feeling that they had somehow failed to prevent the death. As a result of such

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experiences, DRDs, and associated bereavement, have been identified as “special deaths” (Guy & Holloway, 2007), because they threaten individual, familial and societal ontological security (Guy & Holloway, 2007), what Da Silva et al. (2007, p. 302) described as an “existential blow of the hardest type”. Rates of post-traumatic stress and complicated grief have been reported as high in those bereaved by such deaths (Da Silva et al., 2007; Fiegelman, Gorman, & Jordan, 2009; Fiegelman, Jordan, & Gorman 2011). Like other deaths which have been similarly defined, such as murder and suicide (Gall, Henneberry, & Eyre, 2014; Riches & Dawson, 1998; Wertheimer, 2001), there are three features which can be particularly difficult for those left behind; namely, stigma, the often traumatic circumstances of the death, and the resulting disenfranchised grief because the bereaved do not feel, and/or are given the impression by others, that they have the right to grieve or receive sympathy from others (Chapple, Ziebland, & Hawton, 2015; Guy, 2004). These features may engender intense and long-lasting feelings of guilt and self-blame which may seriously impede their capacity to grieve.

Stigma is a particular issue for those grieving a substance use death, with drugs being associated with criminal, and therefore unacceptable, behaviour. Such stigma tends to be reinforced by the way in which these deaths are discussed, managed and institutionalised in western societies (Lloyd, 2010). Stigma can extend to family members who may be viewed as, and thus experience being, to blame or complicit in some way (Adfam, 2012; Corrigan, Watson, & Miller, 2006; Guy, 2004; Song, Shin, & Kim, 2015) by, for example, officials, the media and other relatives (Beccaria Rolando, Hellman, Bujalski, & Lemmens, 2015; Chapple et al., 2015; Riches & Dawson, 1998). DRDs can be further stigmatised when other characteristics are also present, including dying alone (Seale, 2004), suicide, a sudden or violent death including murder (Kristensen Weisaeth, & Heir, 2012), the person having a mental illness or a criminal record, or (intravenous) heroin use. It is unclear whether such experiences will be stronger for those who are bereaved following an overdose.

Rates of DRDs, including overdoses, are disproportionately higher than in matched general populations (Nambiar et al., 2015; Strang et al., 2013). In the UK the broad demographic profile of those who die is male, living in deprived areas and aged 25–44 (Hecht et al., 2014; ONS, 2014). Rates of non-fatal overdoses are also high in populations of drug users (54–92%), and it is common (about one third of cases) for an overdose, non-fatal or fatal, to be witnessed by someone else (Best, Man, Gossop, Noble, & Strang, 2000; Strang et al., 1999, 2008b). Guy (2004) commented that high numbers of drug-related overdoses/deaths occur in the home, where they are most likely to be witnessed by parents. A survey of 147 carers attending support groups in England found that 31 had witnessed an overdose (usually opiates). Further, eight carers had experienced the fatal overdose of a loved one (Strang et al., 2008a, b).

This paper focuses on a subset of interviews, undertaken as part of a larger study to explore the experiences and needs of adults bereaved through substance use (Templeton et al., submitted for publication), to provide insight into the

experiences of those bereaved by overdose. In so doing we consider, first, how their experiences differ from those bereaved by other deaths associated with substances and, second, how these insights could contribute towards initiatives, such as take-home naloxone training programmes, to reduce DRDs among drug users and hence the number of those who are bereaved in this way.

Method

One of the most striking findings from the larger interview study was the diversity in interview narratives (Templeton et al., submitted for publication). As a result, we have been looking at subsets of our data to further understand how different groups experience a substance use related bereavement. This paper concentrates on one of the largest subgroups in our sample, 32 adults who experienced bereavement following a fatal overdose. All were participants in the larger qualitative study, conducted in England and Scotland in 2013, which interviewed 106 adults bereaved through substance use. The methodology used to recruit all participants was the same. The study received ethical approval from the Universities of Bath and Stirling and all participants gave informed consent. The 32 participants were recruited from local services and support groups (both bereavement and alcohol/drug services). Initially, convenience sampling guided recruitment but some purposive and snowball sampling guided later recruitment. Participants were not approached directly but either initiated contact with the researchers following seeing project related information or had contact facilitated by a third party. All interviews were conducted face-to-face at a neutral location or in the participant’s home.

Interviews focused on three key areas: how things were before the death; the death itself; and events, coping and support since the death. Interviews lasted between 40 minutes and more than 2 hours, and were digitally recorded and transcribed. Thematic analysis, supported by QSR Nvivo 10, combined an inductive grounded theory approach with interpretive phenomenological analysis in order to understand the participants’ lived experiences. For this paper, analysis has combined a review of the most relevant themes of the analytic framework (e.g. the nature of the death, engagement with official processes and with the media, and stigma) with a close re-reading of the subset of 32 interviews where an overdose-related death occurred to explore the most pertinent issues relating to overdose.

The sample

Thirty interviews (16 in Scotland and 14 in England) from the larger project involved an overdose (Table 1). A total of 32 adults (two couples were interviewed in England) talked about the overdose deaths of 29 people. Three quarters (23) of the interviewees were female and nine were male. Two-thirds (19) were mothers; in addition, there were four fathers, four friends, three siblings and two partners. Five of the interviewees (three friends and two partners) were themselves drug users and had been active users at the time of the death, though they were all in treatment or recovery when interviewed.

Table 1. Information about each death ($N = 30$).

Interview ID number	Demographic summary (E = England and S = Scotland)	Summary of the death
1	Mother whose son died aged 29 in 2011 (S)	Heart attack as a result of a drugs and alcohol overdose, deceased took (or was given) methadone prescribed to someone else
2	Mother whose son died aged 28 in 2001 (S)	Intravenous heroin overdose, found outside on the pavement and pronounced dead at accident & emergency
3	Woman whose fiancé died aged 17/18 in 1998 (S)	Methadone/tablet intoxication. Interviewee found the deceased at their home
4	Man whose (half-)brother died aged 29 in 2009 (S)	Accidental intravenous heroin/drugs overdose. Died in a house where he had been taking drugs with others
5	Father whose (step-)son died aged 24 in 2008 (S)	Accidental heroin/drug overdose. Found at home by his parents
6	Mother whose son died aged 20 in 2001 (S)	Heroin/drugs overdose. Died in a house where he had been taking drugs with others
7	Mother whose son died aged 23 in 1995 (S)	Blood clot linked to intravenous heroin/drug use. Deceased found in another person's house three weeks after last seen by his mother
8	Mother whose son died aged 29 in 1999 (S)	Heroin overdose, found by his mother at their home
9	Woman whose friend died aged 28 in 2001 (S)	Drugs (unknown) overdose, found by his mother at their home
10	Mother whose son died aged 26 in 1999 (S)	Drugs (assume heroin) overdose. Deceased died on his own in his flat
11	Mother whose son died aged 28 in 2010 (S)	Heroin/methadone overdose. Deceased found at home by his seven-year-old brother
12	Mother whose son died aged 23 in 2007 (S)	Unascertainable drugs overdose – cocaine contaminated with subutex and other substances. Deceased died at another's house
13	Mother whose son died aged 26 in 2010 (S)	Heroin overdose. Deceased found in the flat of a known local drug dealer
14	Sister whose brother died aged 43 in 2005 (S)	Heroin (probably intravenous) overdose. Deceased found at a local residence
15	Mother whose son died aged 26 in 2007 (S)	Heroin overdose. Deceased found dead in a local "midden" (bin shed)
16	Mother whose son died aged 32 in 2012 (S)	Heroin overdose. Deceased found dead on the sofa by his mother
17	Mother whose son died aged 21 in 1996	Aspiration pneumonia due to intravenous heroin use. Deceased died at his probation hostel
18	Mother whose son died aged 32 in 2006 (E)	Morphine overdose complicated by liver and pancreas problems. Deceased found collapsed in a supermarket car park and died in hospital
19	Friend whose friend (both male) died aged 24 in 2007 (E)	Interviewee injected his friend (heroin) in his (interviewee's) bathroom and was present when the friend was pronounced dead the following morning
20	Friend whose friend (both male) died aged 40 in 2006 (E)	Drugs overdose. Deceased died in another person's bathroom
21	Man whose ex-wife died aged 33 in 1994 (E)	Heroin overdose. Deceased died in her flat
22	Man whose friend (both male) died aged 27 in 1990 (E)	Suicide (methadone overdose). Deceased died in his own flat and was not found for about one week
23	Father who son died aged 20 in 2010 (E)	Intravenous heroin overdose (other substances also present). Deceased found in a pub toilet and died in hospital
24	Couple whose son died aged 27 in 2007 (E)	Accidental intravenous heroin overdose. Deceased died at another's house and was found dead the next morning
25	Mother whose son died aged 20 in 2012 (E)	Ketamine (intravenous) and codeine overdose. Deceased died at his father's house
26	Mother whose son died aged 27 in 2003 (E)	Heroin overdose. Deceased found by his mother at her house and died in hospital
27	Mother whose son died aged 20 in 2007 (E)	Cardiac arrest linked to alcohol/drugs toxicity (including intravenous and smoked heroin). Deceased found in a public toilet and died in hospital
28	Mother whose son died aged 21 in 2007 (E)	Respiratory failure/misadventure as a result of an accidental heroin overdose. Deceased died in another person's flat. Death occurred abroad
29 and 30	Couple & sister of a man who died aged 30 in 2009 (E)	Respiratory failure as a result of a heroin overdose. Deceased died in his bedroom at home and was found by his parents

All but one of the deceased were male. Their age range was 17/18–43 years (one interviewee was unsure of the deceased's age when he died), though the majority (18) were aged 21–29 when they died and five were aged 20 or under. There was variation in how long ago the death occurred: the majority of deaths (16) occurred in the 2000s, with seven deaths taking place in the 1990s and six deaths occurring between 2010 and 2012. The majority of the deaths (25) involved opioids, primarily heroin (usually intravenous use, in some cases other substances were also present). While one death was a suicide by methadone overdose the majority of deaths were accidental overdoses. However, in some cases the interviewee did not know the official cause of death other than it being an overdose.

Findings

The qualitative findings are discussed below using five themes: drug use, the death, official processes, stigma, and overdose awareness and prevention (quotes: E identifies an interview in England and S an interview in Scotland, and is followed by the ID number in Table 1).

Drug use

Many of the deceased were long-term drug users although some had been involved with drugs for much shorter periods of time, usually a matter of months. Alongside their drug use many had a history of other problems including mental health and/or behavioural problems and offending. Some of the

deceased had served prison sentences and two had very recently (a matter of days) been released from prison when they died. Some were engaged with drug treatment (including substitute medication) and a small number had relapsed shortly before their death, though in some cases the interviewees believed that their loved one was drug free when they died.

Not only did we find [our son] dead, we found out as well that he was back on heroin (FatherS5).

Approximately one third of interviewees said that there had been one or more previous overdose (and/or other suicide) attempts, and some described finding the person after a non-fatal overdose.

He overdosed about half a dozen times. ...you would find him in the bedroom unconscious and 999, ambulance and get him around (MotherS10).

I went in to his room and he's slumped over obviously really struggling to breathe. So I called my parents and they got [the] paramedics out and they actually saved his life that night (SisterE30).

Such experiences, coupled with the other common challenges of having a relative or friend with a drug problem, impacted significantly on the interviewees. Some talked about grieving for a person who they felt they had already lost, which at least one described as a 'living bereavement', and of facing the possibility that the drug use would ultimately lead to the person's death. This was summed up by one mother.

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. Addicted families have been bereaved. ...they have actually lost that person a long time ago when the addiction kicked in and so they have been grieving for a very long time (MotherS16).

Overall, many interviewees reported having struggled with their loved one's drug use for some time and faced the prospect of their dying as a result, while for others the death was much more unexpected.

The death

There were a range of difficult circumstances surrounding the death and its aftermath, including the association with (intravenous) heroin use, how the deceased was found, the involvement of others, and the complex emotions experienced by interviewees. First, some interviewees believed that their loved one had died from taking drugs after a period of abstinence and did not have the tolerance or resistance to the drugs that they took.

This is what killed him, because there's no resistance there (FatherE23).

I don't believe he was a daily user of drugs and I think that perhaps the thing that killed him was that he didn't have the tolerance (ParentsE24).

Furthermore, three interviewees highlighted that the deceased had not been previously known to use heroin although they had a history of drug use. All made links between the first time use of heroin and the death. In two further cases, interviewees believed that the death resulted from the first time that their loved one had specifically *injected* heroin or methadone.

They were used to it [taking heroin intravenously], he wasn't and he fell asleep and never woke up. ...I don't know for sure but I think that was the one and only time he injected (ParentsE24).

Second, the discovery of the deceased could be distressing; for example, the person's body was found at home by the interviewee or a significant other, the person died alone and, in some cases was not found for some time, the person overdosed/died in a public place, or the person died at another local residence where the drug use had taken place. Many interviewees talked about the impact on themselves or others who had found the deceased. For example, a mother described how her seven year old son suffered sleeping problems and panic attacks as a result of finding his older brother. A friend and drug user, who was with the deceased when he died and who had administered the drugs to him a few hours earlier, described the continued impact of this on him several years later.

Six interviewees, five of whom were parents, said that they had found the deceased either unconscious or dead (usually at home).

I found him on the Sunday morning...he was in his bed...as soon as I walked into his bedroom I knew straightaway there was something wrong with him...I felt his foot and it was cold [and] he was blue from the chest up (FatherS5).

In a large proportion of these cases the interviewee described attempts to resuscitate the relative/friend.

I phoned 999...and the woman told me how to do mouth to mouth resuscitation...and I kept doing that until the ambulance came (MotherE26).

And when she [deceased's mother] went up [to my friend's room] he was lying on the bed with a needle hanging out of his arm. And she had that horrific experience of trying to revive him and dialling 999 (FriendS9).

Third, in approximately half of the interviews there was, or there was believed to be, someone else was involved in the death. Several interviewees discussed particular circumstances surrounding the death which led them to believe that someone else was present at or involved with the death. This included cases where the interviewee believed that someone else had injected the deceased. A sister said that a coroner's officer asked whether the deceased was right or left handed, and drew attention to the location of the single needle mark on the body.

I don't really know the circumstances but we all feel, and I believe, that she did inject him because it was in his right arm and he was right handed (BrotherS4).

There was only one mark on his arm, now [my son] was right handed [so] as true as God is above I know without any doubt she injected [him] (MotherS7).

Other interviewees believed that others were present but did nothing, did not do enough, or delayed intervention, to assist the person when they overdosed. A mother said that her son was found on the pavement by others who had not attempted CPR (cardiopulmonary resuscitation) or called for an ambulance.

I got there and he was on the ground, on the pavement. . . I said 'has anybody done CPR?', they just went no. . . So I immediately did CPR. But I knew he was dead (MotherS2).

Another mother said that her son was found in a public toilet by someone else who did call an ambulance but did not stay on the scene. A father recalled that his son appeared to have taken drugs with a friend in his bedroom, with the friend leaving in the morning saying that the son was awake, yet the time of death indicated otherwise. The majority of these interviewees indicated that the deaths were potentially preventable had there been intervention by others.

I think that somebody knew and they left him. And if they hadn't left him there would have been a chance (MotherS12).

In most cases there were no charges brought against the person, or people, believed to be involved in the death. This was usually due to a lack of evidence, or an investigation concluding that there were no suspicious circumstances.

I don't know if she was prosecuted for dealing drugs. . . [but] there was no charges brought against [her] in terms of culpable homicide or nothing like that. She wasn't charged for injecting him or anything like that (BrotherS4).

Many interviewees were therefore left not knowing the full story of the death and how others might have been involved. A small number talked about the impact of seeing those they believed to be involved in, or responsible for, the death around the local area. A few interviewees talked about the resultant anger, hatred and bitterness which they and others held towards those they believed were involved in or responsible for their loved one's death.

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 (FatherS5).

This bitterness and hatred and that, I had to get rid of that because I couldn't have moved on (MotherS7).

There's still some resentment, still some anger, but I feel I can understand it a little bit more now, than I did at the time (BrotherS4).

I will never forgive the person who's gave it him (MotherS13).

Additionally, a few interviewees invested considerable time and energy (and in one case money) in wanting answers

about the death, something which took its toll on them and which impeded their grief but which they felt they had to do.

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 (MotherS1).

It was very difficult to grieve my brother because I had to spend my time fighting (SisterS14).

Finally, as illustrated above, interviewees could experience difficult and complex emotions associated with the death and its aftermath. A further emotion which was expressed by almost half of the mothers in this sub-group, and by a small number of other interviewees, was guilt. Descriptions of guilt after death were often extensions of guilt experienced while the deceased was alive, and usually focused on feeling that they had somehow failed them.

If I had to lose him I wish it hadn't been through drug addiction because it makes you sometimes feel that you failed your child (MotherE18).

That's the thing about losing somebody through drugs. . . that. . . you could have done something (MotherE30).

What did I do wrong? I must have been a horrible mum (MotherS2).

For some, guilt manifested as not being able to prevent the death itself.

Part of the process of coming to terms with it is that the person who's lost somebody blames themselves. . . at first I used to say if only I'd done this, I should have done that (MotherE17).

I moved out again and then it happened shortly after that and then I blamed myself that I wasn't there. . . that I'd caused it (SisterE29).

Overall, interviewees talked about the emotional impact on both themselves and others of how the deceased died, including when it was they who had discovered the deceased, and of how this could complicate grief. This was particularly the case when the death was accompanied by the shock of (intravenous) heroin having been involved, and the belief that others were somehow involved in, or could have acted to prevent, the death.

Official processes

The majority of this group of deaths required a police investigation and post mortem, thus requiring the involvement of the police and coroner (England) or the procurator fiscal (Scotland). Interviewees described very mixed experiences with these processes and the officials involved, including the time that such processes take (between several months to over one year in some cases). This had a knock-on effect on, for example, releasing the body and holding the funeral. There were some positive experiences – for example, a supportive coroner's officer, coroner or doctor, a journalist willing to work with the bereaved to prepare newspaper articles about the death, a funeral director who explained to a father why he might not be able to take his son's body if the post-mortem

showed any indication of drug use/disease, and police and mortuary staff who accompanied a family so they could see and touch their loved one rather than viewing him through a glass screen. However, such examples were relatively rare and there were more poor experiences reported.

[I said] ‘I am not wanting to speak to the papers. . .it’s a private matter and all the rest of it’ . . .they said well you’ve got two choices, you either talk to us or you don’t talk to us, we are writing something about it whether you like it or not. So my wife and I made a decision there and then to speak to the newspapers or at least try and control it somehow (FatherS5).

I thought there is no emotion or anything with you [the procurator fiscal], it was just a job. . .I felt her mannerism wasn’t somebody with compassion and empathy. . .The police. . .were more interested in getting the drug dealer and the names of who [my son] had been with. . .He was just another drug death (MotherS12).

Other examples include a mother who was not told there had been a post-mortem, a mother who was not called to be with her son who was fighting for his life in hospital, a father who was told by the coroner’s office that he could not see his son on a Sunday or bank holiday, and a father who said that he called the procurator fiscal repeatedly in the first three months after the death because they had not contacted him. Interviewees summarised how involvement with such processes rarely accounted for their feelings and needs.

We were just part of the process. We weren’t a bereaved family or anything (FatherS5).

One issue raised by a small number of interviewees was the viewing and preparation of the deceased’s body when it was believed that they were an injecting user or where there was a risk of infection. A family was told by the funeral director that the deceased could not be embalmed or dressed because he was an intravenous drug user. A mother was told that she could not touch her son’s body because of concerns around infection.

Because it was Subutex they thought he was a heroin user but he wasn’t, he hadn’t used heroin, so it took longer to prepare his body. I think they were thinking obviously infection and things like that, HIV and all that (MotherS12).

Another family talked about the dilemma that they faced in limiting the involvement of a young child in investigations by the police and the procurator fiscal. Overall, interviewees’ experiences of official processes included numerous examples of delays, often without explanation, and of responses from officials which were found wanting because they lacked compassion and consideration of their situation. These experiences in part reflect the complex, multi-agency system within which practitioners work and a lack of understanding of this kind of bereavement, particularly by those working for services where dealing with overdose deaths only forms part of their work. Walter, Ford, Templeton, & Valentine (2015) have further explored interviewees’ experiences of compassion, highlighting how an unkind and uncompassionate response can

exacerbate grief, how a lack of compassion is often intertwined with stigma, and how professionals can be supported to deliver a more compassionate response.

Stigma

Many of the interviewees talked about stigma, both direct and perceived, associated with the death and how this could also attach itself to those close to the deceased. Two mothers described how they felt like “second class citizens”. Experiences of stigma included the response of others, particularly officials, and the approach taken by the media in their reporting. Two parents repeated newspaper headlines they read about their sons – “Drug Addict Dies in Supermarket Car Park” and “Unemployed Man Dies of Drug Overdose”. In the former case the family complained to the local newspaper and received an apology. In the latter case, the father wrote to the editor but received no response.

Some interviewees believed there to be a direct link between the nature of the death and the stigma which they experienced or perceived.

I think when it’s a drug death they don’t matter. . .You don’t matter, it’s endemic throughout the whole process when they die (MotherS12).

I always say I had a son and I always add that he died of a drug overdose. And some folk, well they don’t say anything but there is stigma out there or you will get, well it’s only a junkie that died. Well they don’t say that to your face but you don’t get the same support I think you would get if he had died in an accident or he had died of something else. You certainly get stigma because it was drugs, because they will say oh it was self inflicted (MotherS10).

A small number of mothers believed that others would question their parenting in having a child die because of illegal drugs.

You do have a lot of guilt. . .you do feel I was a bad parent. . .People must think you are a bad parent. . .They must think well what made him turn to that (MotherS11).

Another mother felt that an administrative task related to her son’s affairs was made easier because she had an interim death certificate which did not specify that drugs were involved in the death.

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 (MotherS1).

In responding to stigma interviewees explained their decisions to be open about, or keep private about, how their loved one died, and some described how that decision changed over time.

I’ve always talked about [my son’s] drug problem, I have never shoved it under the carpet. . .it’s part of who we are now (FatherS5).

I think it took five years before I could tell anybody. I could not say. I did not tell people how he had died (MotherE26).

Moreover, many did not want the deceased to be defined solely by their “addiction” and the associated stigma.

[He] was a wonderful son, brother, uncle, grandson, a very special human being, not just a drug addict, I hated that stigmatised thing of it (MotherE18).

Given the stigma which is attached to, particularly, illegal/intravenous drug use, it is unsurprising that many interviewees talked about their experiences of direct or perceived stigma. As one of the most prevalent themes in interviewee narratives, experiences of stigma affected practical tasks, grief, and how the truth about the death was or was not acknowledged.

Overdose awareness and prevention

A few of the deaths occurred at a time when there was less knowledge and awareness about overdose prevention, and about naloxone (the opiate antagonist which is central to many opiate overdose prevention programmes). No interviewee had ever used naloxone to reverse an overdose, and only four mentioned naloxone (one in relation to a previous overdose), although two did not name it specifically and one said that it had not been available when her partner died. One mother in Scotland said that, through her role in setting up a local bereavement support group, they had received naloxone and first aid training, while a father in England demonstrated substantial awareness of naloxone.

There’s a wonder drug called naloxone...it’s mainly for heroin...if you’ve got this syringe, as long as you can catch them and there’s still some breath in them...You inject it in and within five seconds they’ll spring up. It completely dissolves the drug in the system and...at the same time it stimulates the respiratory system and the heart (FatherE23).

Some interviewees, in talking about previous overdose attempts and/or the death itself, mentioned commonly known signs of an opiate overdose although few were sufficiently aware to be able to take action.

I heard in my brother’s room this heavy sort of breathing, this sort of laboured breathing...like gurgling (SisterE30).

They said...he was making a funny noise but they thought he was sleeping and that he was snoring (MotherS6).

And when he came home he was wheezing but none of us knew that was symptoms because it was symptoms we had never encountered (MotherS11).

Two parents questioned why naloxone (although it was not always named specifically) was not used to save their sons.

I can’t understand, with all his files, they could see he was a heroin user, why didn’t they administer him that stuff like

an antidote, whatever they do, I don’t know how it works but (MotherE18).

If they’d caught him at the right time the doctor said, they wouldn’t have given him the naloxone in the ambulance, they wouldn’t have done it until they got him to accident & emergency. So, it just goes to show how the doctors are completely and utterly wrong...I found out that all ambulances in the UK carry a phial of naloxone...But if they’d just gone up to him and given him an injection of naloxone...if they’d got to him on time then that would have been fine (FatherE23).

However, two mothers, who had experienced one or more non fatal overdoses before the death of their sons, admitted that they had questioned whether they would respond to future overdoses. For some, the trauma of living with their child’s drug use, coupled with responding to earlier overdoses, resulted in a degree of ambivalence, and a desire for a reprieve from the suffering which both they and their loved one endured

Sometimes you would look at him and wonder will I phone the ambulance this time (MotherS10).

I had had to do CPR three times in the past...and part of me wondered if I could leave him the next time. Because that thing about, he is your child, you brought him in to the world and maybe you have a right to see them out of it (MotherS16).

This indicates just one of the complexities in involving significant others in overdose prevention programmes (which will be discussed further below). In summary, while some interviewees had responded, in some cases on more than one occasion, to an overdose, there was an overall lack of awareness of the common signs of an opiate overdose, and of naloxone, and of how to respond.

Discussion

Collected as part of a larger study (Templeton et al., submitted for publication, www.bath.ac.uk/cdas) the findings presented here describe the experiences of adults bereaved following a fatal drugs overdose. Analysis of the full dataset highlighted the diversity of interviewee experiences, and the aim of this paper was to further explore such diversity within one of the largest subgroups in our sample, those bereaved following an overdose. An important finding from this further analysis is that the experiences of this group of interviewees are equally diverse. Though they comprise mainly parents, also represented are siblings, partners and friends; there is also variation with the time since the death and the circumstances of the overdose. In some ways the profile of the deceased is as might be expected, particularly the prominence of heroin/intravenous drug use and the presence of factors which are associated with a greater risk of overdose, such as relapse and prison release. However, in other ways the deceased’s characteristics are more unexpected: the number of males is striking, the sample is younger than official statistics would predict, and there are several deaths where the deceased was early in their heroin or injecting career or where the death occurred on the first occasion that the deceased had

taken/injected heroin (personal communication: Professor John Strang, 13 April 2015).

Our data illustrate why this type of bereavement should be classed as a “special death” (Guy & Holloway, 2007). There are a number of ways in which the experiences of this group appear to differ from those bereaved following other deaths associated with alcohol and drugs, or where themes are more dominant in this sub-group than our whole sample. Hence, these findings offer new insights in to the key features of this type of bereavement. These include the direct involvement of some interviewees in responding to both non-fatal and fatal overdoses; the difficult circumstances surrounding the death; the knowledge or belief that someone else was involved in, or somehow responsible for, the death; having a sense that the death could have been prevented if others had intervened; how the deceased’s body was handled and prepared; interactions with officials such as the police, coroners and the procurator fiscal; the stigma associated with such deaths; and complex emotions such as guilt, self-blame and an unworthiness to grieve. The presence of one or more of these factors could significantly amplify and/or impede grief because of the knock-on effect on how those who are bereaved in this way manage their emotions, cope, seek support, and remember the deceased. For example, Riches and Dawson, in their study of those bereaved by murder, found that involvement with official processes and the criminal justice system can result in grief being “subordinate to justice” (1998, p. 153). Also, particularly for parents (the majority of the sample considered here), there was an additional question hanging over them of whether they could have done anything differently when the deceased was alive and if they had in some way failed their child, something which has been seen with those who are bereaved through suicide (Wertheimer, 2001).

Several interviewees had directly responded to a non-fatal and/or fatal overdose, or highlighted that others had been present when their loved one overdosed. However, while some described common symptoms of such an overdose they lacked awareness to respond appropriately, and few interviewees mentioned naloxone. This suggests a need for more training and awareness raising in recognising and responding to overdose, and supports arguments for comprehensive overdose prevention programmes (Bird, Hutchinson, Hay, & King, 2010; McAuley, Best, Taylor, Hunter, & Robertson, 2012; Strang et al., 2014), including naloxone administration and availability, across the UK (although there may be differences within UK administrations). Such initiatives should include families and friends (including drug using peers) as well as lay and non-medical professional groups, as indicated in new guidance on this area (PHE, 2015). Several studies have reported the positive impact of overdose training, including how to administer naloxone, on knowledge, attitudes and confidence of relatives/carers and drug using peers in how to respond to an overdose (Bennett & Holloway, 2012; EMCDDA, 2015; McAuley et al., 2012; NTA, 2011; Strang et al., 2008a, b; Williams, Marsden, & Strang, 2013). There is also evidence that such programmes can reduce mortality although the numbers are small (Bennett & Holloway, 2012; Bird, Parmar, & Strang, 2015; EMCDDA, 2015; Williams et al., 2013). However, as our data indicate, thought processes around how to respond in an overdose

situation are complex, and are often tied up with their experiences of living with their loved one’s drug use, including where there have been previous overdoses. It should not be assumed that having access to naloxone means that family members will automatically seek to administer it. Issues such as whether the family are comfortable carrying out such a procedure, and the impact of placing responsibility on them, are themes requiring further exploration.

Those who are bereaved by special deaths often face struggles in accessing support from both formal and informal circles; there can be further barriers when such deaths are stigmatised or when official or criminal investigations are ongoing. To improve both the quantity and quality of support for all of those who have been bereaved in this way, including following a fatal overdose, our study has produced a set of practice guidelines which are based around five key messages. These are to show kindness and compassion, consider language, treat each bereaved person as an individual, understand the contribution each person can make to supporting the bereaved, and work together (Cartwright, 2015). There are several areas where specific support for those who have been bereaved following an overdose might be helpful in addition to these generic guidelines, including understanding and negotiating official processes, and dealing with the raw emotions associated with the belief that others were involved with or responsible for the death.

Given the lack of previous research with this population, it is unclear whether these findings can be applied globally. However, given that there appears to be a core experience of how families in different international locations are affected by a relative’s substance misuse (Arcidiacono et al., 2010; Orford et al., 2005; Orford, Velleman, Natera, Templeton, & Copello, 2013), and given that there also appear to be great similarities in the ways that such affected family members can be helped and empowered (Natera, Mora, Tiburcio, & Medina, 2010; Velleman et al., 2006, 2011), it is likely that there are considerable overlaps in the experiences and needs of those who are bereaved following an overdose specifically, and by substance use generally. Therefore, we hope that this work can inform future research, practice and policy, both in the UK and elsewhere, to meet the needs of a hitherto largely marginalised, ignored and isolated population.

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Declaration of interest

The authors report no conflicts of interest.

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