Service failures and challenges in responding to people bereaved through drugs and alcohol: An interprofessional analysis

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Abstract

This paper reports findings from the first two stages of three-stage qualitative study which considered the role of services, including public, private and charitable organisations, in responding to the needs of adults bereaved following the drug and/or alcohol related death of someone close. The study, the first of its kind to explore the landscape and role of services in substance use deaths, was conducted over two sites: south west England and Scotland. In stage one of the research, adopting both convenience and purposive sampling, data were collected via semi-structured interviews on experiences and support needs of bereaved individuals (n=106). In stage two, six focus groups were conducted with a purposive sample of practitioners (n=40), including those working for the police, coroner's service, procurator fiscal depute (Scotland), health service, funeral service, press, clergy, Public Health England, Drugs Policy Unit, bereavement counselling/support and alcohol and drug treatment services, to investigate how services may better respond to this bereavement. Thematic analysis from both data-sets identified two overarching themes. The first, focusing on practitioner responses, captures how these bereaved people may meet with inadequate, unkind, and discriminatory responses from services. Having to navigate unfamiliar, fragmented, and time-consuming procedures compounds the bereaved's distress at an already difficult time, illustrated by a 'mapping' of relevant services. The second relates to challenges and

opportunities for those responding. Service failures reflect practitioners' poor understanding of both substance use bereavement and the range of other practitioners and services involved. Those bereaved are a poorly understood, neglected and stigmatised group of service users. There is a need for services to respond without judgement or insensitive language, and provide information about, communicate and work closely with, other services despite differences in working practices and cultures. These recommendations could positively affect bereaved peoples' experiences, alleviating stress and overwhelm at a particularly vulnerable time.

Keywords: Drug and alcohol- related bereavement; stigma; interprofessional working; qualitative interviews; focus groups.

Introduction

Literature, from the United Kingdom (UK) and elsewhere, on interprofessional working in health and social care, reports both benefits and challenges of this approach to service provision (e.g. Atkinson, Jones, & Lamont, 2007). However, the impact on service users has been little researched. In some studies, researchers have identified aspects that are key to effective interprofessional working, for example, role-understanding and appreciation, listening and authenticity (Holmesland, Seikkula, & Hopfenbach, 2014; Suter et al., 2009). While highlighting the potential of inter-professional working (Hudson, 2007), this literature has also identified pitfalls. For example, tensions between maintaining professional identities and working together, including communicating and sharing information and objectives, may pose barriers to effective service delivery (Khalili et al., 2013; Hall, 2005; Jones, 2006; Kvarnström, 2008; Milne, Greenfield, & Braithwaite, 2015; Thompson, et al, 2015). Other barriers include pressures of time, limited resources, competing priorities, lack of

understanding of others' roles and responsibilities, and insufficient access to other practitioners (Bailey, Jones & Way, 2006; Braithwaite, et al., 2012; Larkin & Callaghan, 2005)

Scholars have also explored the impact of structural healthcare reform, that is, widespread changes to the systems and structures within which health professionals operate to deliver services (Ballatt & Campling, 2011; Cole-King & Gilbert, 2011). Such changes are designed to increase efficiency and productivity, and improve quality of care and patient experience through staff-patient interactions. However, it has been argued that in health and social care services the recent focus on structural reform has compromised fostering compassion in public services, both in the UK and elsewhere (see e.g. Ballatt & Campling, 2011; Cole-King & Gilbert, 2011; Lown, Rosen, & Marttila, 2011; Youngson, 2010). Focusing on the UK National Health Service (NHS), Ballatt and Campling (2011) have argued that compassion engenders trust in patients and a sense that one's suffering is recognised and understood, while failures of compassion evoke stress and anxiety in patients and consequent feelings of rejection and alienation.

Within the interprofessional care and other services literature, however, there is a dearth of research exploring how services respond to death and bereavement (The National Council for Palliative Care (NCPC) 2014). Kastenbaum's (2007) death studies textbook, originating in the United States of America (USA) but with global examples, discusses what he terms a country's 'death system' and its functions for society. However, his broad-brush approach does not delve into how its various components are, together, experienced by individuals. Examples of breakdown in the system come from mass death through, for example, natural disasters, rather than everyday deaths, implying that in general 'the system' works. There is evidence from the UK, however, that bereaved people as a whole are poorly served by 'the system' and often face gaps and inconsistencies in service delivery (NCPC,

2014). For those bereaved through substance use, there are additional difficulties concerning both the system for processing such deaths and how the bereaved are treated (Walter, Ford, Templeton, Valentine, & Velleman, 2015; Valentine & Bauld, 2016). Indeed, service users have reported very mixed, including insensitive responses from a range of practitioners, possibly reflecting the hidden and largely overlooked status of these bereaved people use (Valentine & Bauld, 2016; Valentine, Bauld, & Walter, 2016).

The few previous studies into bereavement through substance use[i] (Da Silva, Noto, & Formigioni, 2007; Feigelman, Jordan, & Gorman,2011; Grace, 2012; Guy 2004) have highlighted the stigma these deaths attract due to being perceived as self-inflicted and therefore preventable, as well as associated with illicit activity, deviant life-styles and wilful behaviour. Stigma also affects bereaved families who may be viewed with suspicion for being in some way complicit. Some of these families will already have experienced stigma prior to the death, evidenced by studies of families living with a member's substance use (Arcidiacono, Velleman, Procentese, Albanesi, & Sommantico, 2009; Orford et. al., 2005). To experience further stigma from services when bereaved is therefore likely to be particularly distressing.

The study on which this paper reports is the first to consider the landscape and role of services that may be involved in this largely neglected, yet often devastating bereavement. The study aimed to: 1. understand the experiences and needs of people bereaved by substance use; and 2. develop guidelines to improve how services respond[ii]. By considering the perspectives of both bereaved people and services we were able to develop a picture of the challenges for bereaved people in negotiating a range of disparate services and the pressures and constraints under which practitioners work in a context requiring inter-professional working (see Valentine & Bauld, 2016).

Methods

In this article we present findings from a three year (2012-2015) UK Economic and Social Research Council (ESRC) funded qualitative study[iii] involving collaboration between two bereavement academics, six substance use academics and a bereaved mother and founder of a support organisation for people bereaved by substance use. The project design involved three stages, conducted across two sites: Scotland and south west England (Valentine & Bauld, 2016). First, we conducted 100 in depth interviews with adults bereaved by substance use, the largest and most diverse known sample of its kind, were conducted to understand the support needs of this group. An open-ended, conversational approach to interviewing encouraged biographical reconstructions from interviewees, enabling us to capture and explore the lived experiences of adults who have experienced substance use bereavement and how they made sense of the death (Mason, 2002; Riches and Dawson, 1996). The second stage involved conducting six focus groups with practitioners to investigate how services might better respond to substance use bereavement. The final stage involved establishing a working group, which developed practitioner guidelines for support delivery, subsequently launched at a special event in London in June 2015 and now available online (see Cartwright, 2015). This paper draws on findings from the first two stages of the project. Ethical approval for the study was obtained from each of the two collaborating universities, Bath and Stirling, in October 2012, one month into the study. All participants gave informed consent before participating in an interview or focus group.

Sample

One hundred and six adults (including six couples who participated in a joint interview) bereaved through substance use participated in Stage 1. Substance use was broadly defined to capture any death where drugs or alcohol were believed to be involved, including

suicide and accident. Interviewees were recruited via bereavement support organisations and groups, and drug/alcohol services. Due to the sensitive nature of the topic, initial recruitment relied upon participant self-selection and convenience sampling: participants were not approached directly to ensure there was no feeling of being pressured. Once interviewing was underway purposive sampling was used to increase diversity. The resulting sample was diverse in age, relationship to the deceased, time since death and personal experience of substance use, though black and minority ethnic groups and those under 18 were not represented (see Templeton et al, 2016 and Table 1)[iv]. Sixty-six semi-structured interviews were conducted in south west England and 34 in Scotland. Interviewees were predominantly female (n=79), (typical of bereavement research) and parents of the deceased (n= 56). Approximately one third of deaths were attributed to opiate use.

INSERT TABLES 1 AND 2 ABOUT HERE

Forty practitioners from a broad range of services that encounter this type of bereavement participated in the stage 2 focus groups. Participants were purposively identified and selected from a growing network of practitioners showing interest in the research area. Four focus groups were conducted in south west England (n=28) and two in Scotland (n=12). Each group included between five and eight representatives of different services, including the NHS, police, coroner or procurator fiscal (Scotland), government, media, mortuaries, funeral and pastoral care, and bereavement and/or addiction support (see Table 2).

Data collection

Stage 1 Interviews took place in a neutral location such as a community venue or the participant's home. Seven interviews were conducted by telephone. A semi-structured discussion guide was used to capture key aspects of how interviewees experienced this kind of bereavement. These included family relationships before death, living with the deceased's

substance use, the nature of that use, how the person died and surrounding circumstances, the involvement of services, how the interviewee had coped since the death, including their experience of the funeral and remembering the person, family relationships after death, coping and support needs. The involvement of services and the support they had received emerged through interviewees' responses. Two interviewers in England and one in Scotland took account of interviewees' possible distress in recalling painful experiences and concerns about being stigmatised. All three interviewers were female and were experienced in interviewing on sensitive topics; two being substance use researchers and the other a bereavement researcher. An open-ended, conversational approach allowed interviewees to disclose only as much as they could manage and they were advised that they could take a break at any time. Interviews lasted between 40 minutes and two hours and were digitally recorded.

From the interviewees' experiences of services we developed a topic guide for the Stage 2 focus groups. Areas for discussion were illustrated by interviewee quotes, which were sent out in advance to participants, giving them time to reflect and prepare responses to the questions in light of their own perspectives and experiences. A method used in social work practice (Broadhurst, 2015), the quotes brought bereaved people's experiences into closer view for practitioners and helped humanise discussion of practices and procedures. The discussions focused on the barriers and facilitators to providing support, including stigma. They were conducted in a local venue, lasted approximately 90 minutes and digitally recorded.

Data analysis

Stage 1 interviews were transcribed verbatim and checked for accuracy. Data were imported into qualitative data management software QSR NVivo (version 10) to facilitate

analysis. Using thematic analysis (Braun & Clarke 2006), a coding framework was developed using an iterative approach. Initially four members of the research team independently read a sample of transcripts to identify themes. Themes were discussed among the team and an initial coding framework was developed and tested with a subset of 10 interviews. Further discussions around the suitability of the framework led to modifications and additions, which were tested again until the final framework was agreed. Analysis of the data identified themes relating to service responses to bereaved people, which were then used to inform the topic guide for the six focus groups. Analysis of the subsequent focus group data followed the same approach as the stage 1 interviews. They were transcribed, the transcriptions studied and emerging themes were identified by four researchers and further clarified through discussions among the whole research team. Reflection on themes identified from both the interview and focus group data pointed to two broad, overarching themes illustrating the experiences and perspectives of the bereaved and the practitioners they may come in contact with after a death. The first theme involved 'practitioner responses to those bereaved by substance use' and included sub-themes of 'information and support' and 'compassion, language and sensitive judgement'. This theme has been represented by a map of services the bereaved may encounter after a death (a key study outcome). The second theme included the 'challenges and opportunities for practitioners in responding to substance use bereavement' in relation to 'knowledge of and links to relevant practitioners and services' and 'workplace priorities, culture and personal competence'. These themes and sub-themes structure the following presentation of results.

Results[v]

Many of our interviewees perceived themselves on the receiving end of insensitive, judgmental and abrupt responses from practitioners they encountered in the aftermath of a

substance related death. Such encounters often occurred against a backdrop of official processes related to the death, for example, investigation by the police and coroner – or procurator fiscal in Scotland - to establish the cause (see over). As a result, interviewees reported having to negotiate unfamiliar, confusing, frustrating and protracted procedures involving a range of separate organisations.   Inconsiderate responses, however, were also experienced in interviewees' contacts with practitioners from whom they might have expected to receive care and support. Responsibilities for dealing with substance related deaths and with the bereaved people left behind are split across a range of services that can be broadly categorised as:

1. *Services focusing on the deceased*. These involved statutory procedures, such as establishing the cause of death and ensuring proper disposal of the body. These may involve paramedics, the general medical practitioner (GP), the police and the coroner (in England) or procurator fiscal (in Scotland), and the pathologist. In addition, newspaper reporters are tasked to produce a story about the deceased and the death, while undertakers look after the body and arrange its disposal. Where drug use is implicated, as with cot death and suicide, establishing the cause of death may require official investigation by the police and the coroner in England or the procurator fiscal in Scotland. The family home may be treated as a crime scene, the deceased's body and possessions taken into custody and the funeral delayed until after an inquest or ongoing police investigation. Such delays can create considerable uncertainty for the bereaved, who may feel under suspicion as well as deprived of their family member's remains.

2. *Services for those left behind*. These include clergy or other religious officials providing funeral care, bereavement counsellors and support groups, family support groups, and drug and alcohol services where the bereaved person is in treatment for their own substance use.

For some interviewees, failures in the response of practitioners in these circumstances appeared to be an extension of the stigma of substance use. However, discussion with practitioners in focus groups highlighted a range of possible challenges faced by practitioners in responding to the needs of people bereaved in this way. More rarely, some interviewees spoke favourably of professional responses, which they felt relieved some of the stress accompanying the death, offering pointers to how to improve wider responses. The following sections present our study's major themes and sub-themes relating to interviewees' mixed experiences of practitioners' ability to respond to them on both a personal and practical level and the obstacles to and possible opportunities for practitioners responding appropriately.

Practitioner Responses to those Bereaved by Substance Use

Information and support. Interviewees often did not receive adequate, timely information and support regarding the processes that followed substance related deaths. This was particularly, though not solely, the case where the death was sudden and unexpected and drugs (rather than alcohol alone) were implicated – perhaps reflecting that these deaths were likely to involve official investigation by legal authorities (see above).

A key finding of our study - the daunting and complex array of services and related processes and procedures these bereaved people may need to negotiate at a time when they are least able to cope - has been represented by the following map. See Figure 1 – online supplementary file.

The map conveys the sheer complexity as well as the confusing number and range of potential services, which people bereaved in this way need to work around. The 'system' is complex enough after any death, but for substance-related deaths there are added complexities related to establishing the cause of death. Thus, the bereaved person may be faced with a daunting array of different and separate services and procedures, often with little

or no guidance, and no coherent national or local strategy for the way services respond to this group of bereaved people. As one focus group participant conveyed:

> I come from a very narrow focus in terms of supporting people when they attend the inquest process, but…when I talk to people the one thing that they say is that they have absolutely no idea about what to expect, what's going to happen, what the process will be and that's on top of trying to grieve... (PractitionerE)

Interviewees particularly appreciated being kept updated and provided with explanations about what was happening and having their concerns listened to and taken seriously. However, for this to happen, individual practitioners would need to be 'available' and 'take time', for example, one person being available as a single point of contact. Such was the case for one mother who described the continuity of support she received from a police officer following her daughter's death.

> Well the DCI [Detective Chief Inspector] who'd been on the case right from the beginning, he was the one who'd gone in and …sorted out the room and everything, he was there and he was amazing, he was so good and he said 'phone me any time'… if he wasn't on shift and I phoned up, they'd know straight away who I was, and they'd say, 'yes we will take a message' and he'd be back straight on the phone to me. (MotherE)

In contrast, encounters with practitioners who were not prepared to go beyond the immediate call of duty could undermine and alienate. One father recalled the limited and unhelpful response given by the police to his request to see his dead son.

> There was a policeman and a police lady there … he looked at me and he said, 'Yes, I'm afraid it is bad news. [Your son] has died.' And that was it... And they just left a telephone number for the coroners and I immediately said, 'Can I go and see [him]?' and they said, 'No, you can't. He's at the coroner's court.' He'd been transferred from the hospital to the coroner's court. And I said, 'Why can't I see him?' and he said, 'Well, it's Sunday. It closes on a Sunday.' And I said, 'Well, can I go tomorrow?' And they said, 'No, you can't go tomorrow because it's Bank Holiday Monday and there's no one there on a Bank Holiday Monday'. (FatherE)

Compassion, language and sensitive judgment. Interviewees' sense of being at the mercy of a system was apparent, yet their recollections inevitably tended to focus on personal encounters

with practitioners. Thus, they emphasised the importance of compassion, language and sensitive judgment in those encounters in alleviating their sense of overwhelm.

Some interviewees reported practitioners responding with compassion to their situation though many more reported being treated unkindly. Interviewees did not necessarily accuse practitioners of incompetence or inefficiency but rather of a simple lack of regard, often causing additional distress at an already difficult time. A mother reported the response of a paramedic to attending her son who had overdosed and was already dead.

> …… he [paramedic] says 'I don't know what you called us for…, there is nothing we can do, he's been dead a long time, rigor has set in' … I just thought what a horrible thing to say, it is just your first instinct to phone and get somebody to come and help you. (MotherS)

Interviewees sometimes felt that insensitive professional responses were due to the stigma of substance use extended to those left behind.

> It was just routine to them [two policemen] ... you are going into tell a mother that her son just 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 was an ordinary run of the mill thing. (MotherS)

The experience of stigma could be exacerbated by newspaper reporting, which some interviewees experienced as particularly lacking in compassion. In Scotland, a focus group participant drew attention to the lack of control that family members may have over press coverage.

> They will ignore the immediate family and go around some of the pals…to try and get a more sensational story...and the family won't be contacted but will read about it in the press…and they might phone up and complain… and the editor will say…'we have sources', and again that feeling of powerlessness … that somebody's name is being dragged through the mud. [PractitionerS]
> Yet, insensitive reporting was not inevitable, a father recalled a more positive

experience of a journalist consulting him in advance and giving him the opportunity to change wording[vi].

> She [newspaper reporter] said, '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…emailed it to me and… said, 'Have a look. Is this okay? Is there anything you want to change?' So I changed a few things. (FatherE)

Compassion from practitioners ameliorated some of the stresses interviewees felt from these deaths and helped to counteract some of the stigma many had already experienced prior to death. Moreover, some accounts showed that what one daughter termed "small acts of kindness" could make an important difference.

> They [police] were really nice actually… very sympathetic and you know... any dealing with them they were very good. And … they sat in with her when they were waiting on the undertakers coming. (NieceS)

Interviews demonstrated that the language used by practitioners can depersonalise the deceased, effectively undervaluing their worth as an individual particularly to those closest to them.

> ....the police, going back to when [my son] died, never called him [son's name]; they called him 'the body'. And that was horrible. It was depersonalised. (MotherE)

In contrast, a more thoughtful, sympathetic and personalised use of language affirmed both herself and her son.

> When we did get to see him, the mortician brought him down, and when we were ready to go he said, 'shall we go back, then, [son's name]?' And he said 'nice looking boy'. I said, 'oh, thank you.' (MotherE)

Interviewee accounts also indicated that practitioners could struggle to understand and respond to the diversity of bereaved people's experiences of substance related deaths. Bereavement experiences were wide ranging and determined by factors such as the relationship prior to death; the type of substance use; the circumstances of the death and subsequent procedures. Moreover, these characteristics combined in different ways to produce a very specific experience. Instead of approaching circumstances with an open mind, interviewees found that practitioners often tended to rely on pre-conceived attitudes and stereotypes.

> They [police] forget that they come out of decent houses do you know what I mean? They don't get dragged up you know? They are human beings. (MotherS)

Unhelpful and upsetting assumptions were even found amongst practitioners providing a more personal service to the bereaved. A daughter described how a funeral director made assumptions about what she required for the funeral of her mother whose alcohol use had alienated family and friends.

> I rang three [funeral directors] and I had to explain to them that my mum... well she didn't have any friends left…I was the only person family-wise who was still either alive or talking to her. And I fully expected it to be just me sitting in the crematorium... And so I had to explain that to them over the phone so that they knew… what to expect. And I had one funeral director went, 'Well, you basically just want a budget coffin then,' … purely because I had said it will be a very small funeral, it may only be me, he then automatically assumed, well she wants budget, cheap, whatever. (DaughterE)

In contrast, interviewees spoke of feeling comforted when practitioners rejected stereotypes and acknowledged the individuality of the deceased. A mother described a conversation with a police officer who took great care to acknowledge the person that her son was and reassure her that he did not judge her son negatively.

> He [police officer] says, 'all the books in his room are all the books I like and I know he was …intelligent by looking at all the things around about and all his interests … I never think bad of anybody that I find in a situation like that because I know…, once they do something like that it's very hard for them to overcome it … and any wee set back can drive them right back, … so don't ever think that I would think bad of him'… which I thought was really good of him. (MotherS)

Challenges and Opportunities for Practitioners in Responding to Substance Use Bereavement

Knowledge of and links to relevant practitioners and services. Despite examples of individual practitioners providing the support required by bereaved people, the complex and fragmented system outlined previously could also be challenging for practitioners to negotiate, with consequences for their ability to provide such support. As one focus group participant articulated,

> …it's challenging in terms of knowing what services there are in your area and it's quite labour intensive because services are always changing and sometimes it's coincidental that you know about a service – it can be very hit and miss and possibly there's duplication. So I don't think it feels very joined up. (PractitionerE)

Another focus group participant felt that part of the challenge was related to the different types of services involved

> And I think with the two types of services, statutory and voluntary, the onus is on voluntary services to let the statutory services know what they do. You could say that the statutory services should keep a list of voluntary but they don't do they? (PractitionerE)

Some interviewees reported frustration at a lack of communication between services.

One family received an autopsy report and realised that the pathologist had not been fully informed of the circumstances surrounding the death.

> And then we received the script [autopsy report].The doctor who done the autopsy didn't realise that [son] had been eating and he had choked on food. (FatherS)

Communication between separate organisations was found to relieve some of the pressure on the bereaved person. Practitioners who went the extra mile were noted and appreciated. Interviewees who reflected on positive experiences of organisations working together valued how helpful this was.

> I tried to find out exactly the extent and what happened so the actual doctor who done the autopsy, he phoned me, I phoned the police to find out and query some stuff. And they in turn contacted the doctor who in turn contacted me and then tried to explain. So the doctor who done the autopsy and the procurator fiscal, they helped me no end. (FatherS)

Good communication between the police and procurator fiscal, alongside understanding of one mother's concerns, helped alleviate her worry about the repercussions of a police investigation for her younger son who had found his older brother after a heroin overdose in the home.

> So then [investigating police officer] asked about [youngest son] and I says, 'you canny speak to him, you canny let him know what he's seen... 'He's only seven... to tell him that he went in that room and found his brother dead, it would affect the whole of his life'. So he said '… I whole heartedly agree with you that's not a good situation, so I will put it to the procurator fiscal that he is too young and he's not to be asked about it'. (MotherS)

Focus group participants were similarly aware that the current system made it difficult for people to access appropriate help and support. They also drew attention to gaps in knowledge of the availability and types of existing support, suggesting that practitioners would be able to signpost more appropriately and frequently if those gaps were addressed.

For example, good professional networks, with good communication and consistency of contact, would make referrals for support smoother and quicker. However, the large volume of national and local services, described by one focus group participant as "bewildering", and a constantly changing service landscape, presented a considerable challenge.

> That's a problem because there are so many services out there, statutory and voluntary. But it would be nice if there was just one specific point of contact. But what is out there is constantly changing so how do you get your head around that? (PractitionerE)

While focus group participants suggested that a central body was needed to deliver continuity and information to other practitioners, there was no consensus about who was best placed to deliver this. However, participants themselves started to highlight opportunities for practitioners to work together more closely to deliver a more combined approach.

> *I* think there could be some good inter-agency working here. If you [coroner's office] had been hooked up with an organisation like Adfam or DrugFAM[vii], if you knew that you could liaise with them so that we could get a call the next day to say 'can you have someone pop round and see [bereaved person]' (PractitionerE)

Focus group participants also gave examples of individual organisations' attempts to respond better to these types of deaths. One family support service had worked closely with police and procurator fiscal staff to try and address gaps in responding to drug-related deaths and encourage a more standard procedure[viii]. In another example, a team within one local authority had systems in place to try and ensure all organisations involved in a person's treatment were informed of their death.

Working together poses challenges for organisations, particularly where different types of services and disparate working cultures are involved (see p. 8). Yet, focus group discussions conveyed these practitioners' desire to respond better to those bereaved by substance use and their recognition of the benefits of working together.

> I would like to see services joined up in their approach and continuity across the board. And if there is ways that we can embrace that and help it grow then I'd like that to be nurtured. (PractitionerS)

Interviewees highlighted how relatively simple acts of communication between organisations had alleviated some of the stress and worry they encountered. However, rather than *"leaving it to chance",* as one focus group member put it, the situation called for *"all services getting together to look at what each other does"*, if they were to work together more consistently, effectively and compassionately to support this group of bereaved people. Another suggestion was to foster a culture of "it's everyone's responsibility" to challenge fragmentation and using the excuse of it being someone else's job. More practically speaking, suggestions were made about providing easily accessible information, for example, via an online information point.

Workplace priorities, culture and personal competence. In focus groups, practitioners suggested that insensitive responses from practitioners may reflect requirements to prioritise standard procedures and organisational policies. The main focus of police officers, coroners (England) and procurators fiscal (Scotland) is the deceased and the cause of death, rather than the bereaved. Indeed a legal representative questioned whether police officers in particular could be expected to change focus.

> And the officers at the time, it's fine to say sitting around a table that it would be great if we could show more empathy to the family … But in fairness to these [police officers] they know that they are investigating what is a suspicious death and quite frankly you don't know whether the person who has provided the drugs is standing in the room or in the room next door. So you have to be very, very careful about what you are saying. (PractitionerS)

However, as one mother conveyed, such circumstances do not preclude a compassionate response.

> …I didn't want to see him [son] going away and again that's where the police were really good. The police girl came in, she shut the door and she was there for us when they were taking him out the house. (MotherS)

Focus group findings suggested that workplace culture and practices also contribute to the prevalence of unfeeling professional responses. The use of negative labels by police and newspaper reporters may in part reflect particular cultures designed to deal with the

challenges of interacting with a wide range of people and situations and, in the case of the press, selling newspapers. Moreover, inconsiderate media reporting was thought to be a possible consequence of the practice of using a working formula to enable reporters, within the constraints of time and column space, to come up with an attention grabbing story. As one journalist explained during a focus group, *'you've got three minutes to do that story before you go on to another 'suspicious' death'*

Recognising and responding to the often diverse experiences and needs typically associated with substance related deaths could also be very challenging for practitioners whose knowledge and skills vary substantially. A focus group member from an advocacy organisation noted from their own research in this area:

> ….there's just massive disparities in the levels of skills, experiences, approaches, attitudes, personal experience but also professional experience, of the practitioners throughout the country, for all the realms GPs, police. (PractitionerE)

However, it is clear from both interviews and focus groups that some practitioners were able to negotiate the complexities of substance use bereavement. For example, a religious minister attending a Scottish focus group highlighted his appreciation and understanding of the social dynamics that substance related deaths could entail.

> One of the real sadnesses about funeral services of an addicted person is that there will often be a whole range of the people that were closest with them which is their addicted pals and it's almost like a big dividing line right down that says don't even acknowledge these people, and one of the challenges I have is to overturn that and say tell me about the friends, let me speak to the friends… (PractitionerS)

Discussion

As a qualitative study we have been able to obtain rich data representing participants' experiences and meanings in a poorly understood area. As a result we have captured a range of experiences that reflect important concerns that have relevance beyond our samples. Thus, the findings show how interviewees valued and took support and reassurance from

practitioners who were available and took time to provide support and guidance in navigating a confusing and bewildering system (see map). In an inter-agency context this involved taking the time to provide information about, communicate and work closely with, other organisations, despite differences in working practices and culture. In contrast, practitioners who were not prepared to go beyond their immediate remit, instead responding in limited and unhelpful ways left many interviewees feeling frustrated, confused, abandoned and overwhelmed at a particularly vulnerable time. In addition to taking time, interviewees conveyed the importance of compassion, language and sensitive judgment in practitioners' responses to their situation. Being subject to stereotypical assumptions, for example, that these deaths were self-inflicted and those left behind less deserving of consideration, could devalue both bereaved and deceased. At worst, such failure to recognise and respond to the bereaved person as an individual could be experienced as stigmatising, particularly for those who had already suffered stigma while the person was alive.

The complexity of the 'system' was a key finding (see Figure 1) and, as suggested by focus group members, may be a factor in compassion failures, particularly those practitioners (the police and coroner or procurator fiscal) whose work involves the statutory procedures for establishing the cause of death. Thus procedural demands requiring a more 'business-like' approach could predominate at the expense of showing sensitivity to the bereaved. Being so close to the point of death, insensitive responses of 'front-line' services to bereaved people could be particularly distressing. Yet, our data show that, despite the pressures and limitations of the system, some practitioners were still able to prioritise the human element of their work both in responding to the bereaved person and engaging with other services.

Consistent with findings from the inter-professional literature (e.g. Atkinson, Jones & Lamont, 2007; Braithwaite et al., 2012; Khalili et al., 2013; Kvarnström, 2008, Thompson et al., 2015), interviewees' experiences highlight the benefits and challenges of inter-

professional working, though in a previously unresearched context. In so doing they also contribute the service user perspective and the impact of how different organisations are able/prepared to work together on a poorly understood and particularly vulnerable, at risk group. Interviewees' emphasis on compassion extends existing findings on the compassion deficit in public services (Ballatt & Campling, 2011; Cole-King & Gilbert, 2011; Jones, 2013; Lown et al., 2011, Youngson, 2010), by providing the service user perspective and focusing on services dealing with substance-related death and bereavement. In addition, the involvement of substance use in the deaths enables compassion, or 'feeling with' to be contrasted with stigma, or 'feeling against'. Thus, for these bereaved people, failures of compassion are arguably more likely (Walter et al., 2015; Valentine & Bauld, 2016) and potentially devastating in light of the stigma and consequent shame and self-blame they may already have been coping with while the deceased person was alive. Indeed, this group is particularly vulnerable to attracting responses that confirm that this kind of bereavement is less worthy of consideration than other bereavements (Doka, 1989).

Yet, Jones (2013) writing for paramedics, argues that responding with compassion to grieving family members and close others should be integral to being professional, no matter how the deceased lived or died or how one regards their actions. In addition, compassion may counter stigma, placing those working for front-line services in a key position to make a difference at a particularly vulnerable time for the bereaved person. Yet, as reported in focus group discussions, workplace culture and practices can contribute to responding insensitively. For example, habitual use of stereotypical language may serve as a means of distancing and coping with the pressures and challenges of a wide range of potentially distressing encounters and situations. However, responding compassionately to another may create a virtuous circle by increasing well-being and reducing stress on both sides, and may also lead to greater job satisfaction for practitioners (Ballatt and Campling, 2011; Youngson, 2010).

Focus group findings both confirmed the above picture as well as illuminated the pressures and constraints under which practitioners may be working in an inter-agency context. In particular they conveyed the relationship between poor responses and an unwieldy and fragmented system, dependent on different and separate services. This situation was exacerbated by the sheer volume of national and local services and organisations, and a constantly changing service landscape. Thus fostering qualities and working methods that have been linked to effective inter-agency working, such as understanding and appreciation of roles, information sharing and communication (Suter et al., 2007; Holmesland, et al., 2014), presented a considerable challenge. While some practitioners were nonetheless prepared to go the extra mile and, for example, take time to explain things and point the bereaved person in the right direction, more often responses were unhelpful to the extent of being experienced by the bereaved as undermining and alienating. To foster mutuality and tackle the 'compassion deficit', focus group findings suggested that increasing practitioners' awareness and understanding of substance use bereavement, of the wider landscape of services and of each other's roles was needed.

The study has a number of limitations. The sample is non-representative, though the findings do have relevance beyond the sample. Although the stage 1 sample included a range of ages, relationships to the decreased, type of substance use death and time since death, as indicated, those under 18 and people from black and minority ethnic groups were not represented (see endnote v). The sample was also predominantly female and gender comparisons were not explored. Furthermore, without an objective measure of socio-economic characteristics within our data collection we have not considered the impact of affluence on this type of bereavement. Finally, the difficulty of recruiting men in bereavement research generally is widely known (Field, Hockey & Small, 1997) and greater attention to how men interpret and react to practitioner responses is warranted.

Concluding Comments

Drawing on the reported experiences of both people bereaved by substance use and practitioners dealing with substance use deaths, this paper has illuminated a previously un-researched area of service provision for a poorly understood, neglected and stigmatised group of service users. By identifying and mapping the various processes and procedures involved in dealing with death and its impact on those left behind, particularly where substance use is involved, the paper contributes service user perspectives (Atkinson et al., 2007). These have powerfully conveyed how poor communication and collaboration between organisations and services, exacerbated by failures of compassion and sensitive judgment in their dealings with bereaved service users may seriously compromise their well-being. In contrast, taking the time to communicate and work together and responding compassionately could positively affect bereaved peoples' experiences of services and alleviate their stress and sense of overwhelm at a particularly vulnerable time. Furthermore, the research demonstrates the value of engaging both practitioners and service users in understanding and addressing both sides of the situation.

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Notes

[i] For a fuller review of the literature see Valentine et al. (2016)

[ii] Discussion of the study's second aim, to develop practice guidelines, is beyond the remit of this paper.

[iii] Further details of the research team and where the research was based to be added on acceptance for publication.

[iv] Due to the sensitive nature of the topic we decided not to include those under 18. While we were hoping to include those from black and minority ethnic groups, we learned from a focus group member from a black and Asian led community-based charity that the families concerned tend not to accept the involvement of drugs in a death and therefore would be unlikely to consent to being interviewed.

v Any names used in quotes are pseudonyms; 'E' and 'S' refer to interview/focus group participants in England and Scotland respectively.

vii National organisations supporting families affected by drugs or alcohol

viii Family Addiction and Support Services (FASS) in Glasgow works closely with Police Scotland.