Drug and alcohol-related bereavement and the role of peer support

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Abstract: Many people experience acute isolation, lack of support and social stigma following a drug or alcohol related bereavement. This article highlights trends within drug and alcohol-related bereavement and the common themes which surface when someone dies in this way. It goes on to explore the work of the *BEAD – bereaved through drugs and alcohol* project between Cruse Bereavement Care and Adfam in supporting this overlooked and under-supported group of bereaved people. It gives a particular emphasis on how BEAD's team of dedicated, trained, peer support volunteers – all themselves bereaved through alcohol and drugs – are playing a significant role.

Keywords: Drugs, alcohol, traumatic bereavement, stigma, peer support

Introduction

The degree of isolation and lack of support experienced by many people bereaved through the drug or alcohol use of someone close to them can be particularly acute, driven by a powerful social stigma around the misuse of illegal drugs and alcohol which often appears to be magnified when a person dies as a result of their substance use. As a consequence, the deep pain of the bereaved person's loss can become intensified still further by a fear of speaking out about their grief and about the person who has died. This can have far-reaching and serious consequences in terms of their physical and mental health, relationships and general wellbeing.

Despite affecting tens of thousands of people each year, targeted support for drug and alcohol-related bereavement has been limited to a handful of trailblazing organisations and groups, such as DrugFAM, Bereavement through Addiction in Bristol, Rebound in Portsmouth and Carers Support West Sussex, chiefly founded by bereaved parents, offering one-to-one and/or group support. In response to overwhelming evidence of significant unmet need, Cruse Bereavement Care and Adfam, the leading charity in the UK advocating for families affected by drugs and alcohol, established a ground-breaking partnership and set up the Bereaved through Alcohol and Drugs (or BEAD) project in England[1], following the award of a four-year Big Lottery Fund grant in 2013.

This article highlights trends within drug and alcohol-related bereavement whilst emphasising the very wide range of experiences encompassed within this umbrella term and the uniqueness of each individual experience: this is essential if we are to avoid stereotyping and falling into stigmatising assumptions about those who died and those who are bereaved. Nonetheless, common themes do run through this diversity of experience, in particular the intense and complex emotional impact, the legacy of having lived with a loved one's drug or alcohol use and profound experiences of stigma leading to disenfranchised grief.

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The article goes on to explore the groundbreaking work of the BEAD project in supporting this overlooked and under-supported group of bereaved people, with a particular emphasis on how BEAD's team of dedicated, trained, *peer support* volunteers – all themselves bereaved through alcohol and drugs – are playing a significant role in breaking down isolation and overcoming stigma, by enabling people bereaved through alcohol or drugs to talk openly and without fear of judgement, both one-to-one and in a group setting.

Scale of drug and alcohol-related bereavement and recent trends

There are no definitive statistics for how many people are bereaved through a loved one's alcohol or drug use each year. However, we do know, according to official figures, that drug and alcohol-related deaths accounted for approximately 1 in 50 of all the deaths registered in 2014 (ONS 2015a, 2015b, 2015c). Nearly 8,700 deaths were registered in the UK in 2014 in which alcohol was the direct cause of death[2], the vast majority of these a result of chronic conditions associated with long-term misuse of alcohol such as cirrhosis of the liver or alcohol-induced pancreatitis (ONS, 2015a). Alcohol Concern estimates that this number rises to over 21,500 if all deaths where alcohol is a *contributing factor*, such as certain cancers, falls and other accidents, are counted (Alcohol Concern, 2016). In the same year, over 3,300 drug-related deaths[3] were registered in England and Wales[4], the highest level since comparable records began in 1993. Of these, more than 2,200 were drug misuse deaths[5], that is, those relating to long-term drug dependence and/or involving classified drugs (ONS, 2015c): this represents a 17% increase on the previous year's figures (ONS, 2015c).

Demographic trends within drug and alcohol-related deaths

- Two-thirds of those who die from alcohol-related causes are men (ONS, 2015a).
- The mortality rate for alcohol-related deaths is highest between 55 and 64 for both women and men (ONS, 2015a).
- Alcohol-related deaths are highest in the North West and North East of England and lowest in the South East and East of England (ONS, 2015a).
- Two-thirds of those who died of drug-related causes were men (ONS, 2015c).
- The mortality rate for drug-related deaths is highest among the 40 to 49-year-old age group (ONS, 2015c).
- Around one in seven deaths of people in their 20s and 30s were drug-related (ONS, 2015c).
- Drug-related deaths are highest in the North East and North West and lowest in London (ONS, 2015c).

Which substances are involved?

- Opiates such as heroin, morphine and methadone (a medicine prescribed to replace the use of heroin which is sometimes diverted to be sold illegally on the street) are the most common cause of death among those using illegal drugs, accounting for nearly 1,800 deaths in 2014 (ONS, 2015c).
- Stimulants including cocaine, amphetamines and MDMA (ecstasy) were implicated in a rising number of deaths.
- Novel psychoactive substances (NPS) is a term used to describe the many new drugs which have emerged in recent years, many of which were and are known as 'legal highs', though they are now controlled under a new Act. NPSs such as mephedrone were involved in 82 deaths in 2014 (ONS, 2015c).
- Prescription medicines and solvents are also involved in a number of drug-related deaths.
- Many deaths follow poly-drug use, with the person who died using a mixture of drugs, including alcohol. Around a third of drug-related deaths also name alcohol on the death certificate (ONS, 2015c).

No typical bereavement: a broad range of experiences

This demographic information is useful in identifying trends and gauging the approximate scale of drug and alcohol-related bereavement. Yet, just as there is no 'typical' drug or alcohol user, so too there is no typical drug or alcohol-related death (Feigelman, 2011) or bereavement (Templeton *et al*, 2016) and acknowledging this is essential if we are to

2 The National Statistic definition of alcohol-related deaths includes 'underlying causes of death regarded as those being most directly due to alcohol consumption.' This is primarily chronic conditions and includes to a lesser extent acute conditions and alcohol poisoning. It excludes other external causes of death, such as road traffic and other accidents, and diseases that are partially attributable to alcohol.

3 This total covers accidents and suicides involving drug poisonings as well as deaths from drug misuse and drug dependence (both overdose and long-term health complications) (ONS, 2015c).

4 Drug-related deaths are referred to the coroner and an inquest is held. This means deaths registered in 2014 may have taken place in previous years. The average delay between a drug-related death and registering the death is 161 days (ONS, 2015c).

5 The ONS defines drug misuse deaths as '(a) deaths where the underlying cause is drug abuse or drug dependence and (b) deaths where the underlying cause is drug poisoning and where any of the substances controlled under the Misuse of Drugs Act 1971 are involved, (ONS, 2015c).

avoid viewing the person who died and bereaved family and friends as stereotypes.

Many variables can impact on the experience of drug or alcohol-related bereavement.

The **relationship** with the person who died – whether parent, partner, adult child, younger child, friend, or peer who used drugs or alcohol alongside the person who died, amongst others – can have a bearing on how the bereaved person grieves, as can the nature of the substance use and which substance they were using, as described in Box 2 above.

Whilst the **circumstances of death** are almost invariably traumatic, for example if the bereaved person found the person who died, (Templeton *et al*, 2016), death can occur in many different ways, whether through a sudden event such as an accidental overdose, rapid deterioration in health, suicide or accident *or* through a gradually worsening chronic health condition over a longer period of time. Death often occurs within the context of addiction though a sizeable minority of people are bereaved after a loved one's occasional or more casual use, for example through stimulants while clubbing or through an accident whilst intoxicated.

As such, the bereaved person may or may not have been **aware** that the person who died was using drugs or alcohol at all or may not have known the full extent of their use. Shock is common in all bereavement (Worden, 2001) and can be made even more intense and disorientating when it includes discovery of drug or alcohol use or unfamiliar aspects of the person's life (Adfam and Cruse Bereavement Care, 2014).

The person who died may or may not have been receiving **treatment** for their drug or alcohol use, or may have done so in the past. One-third of people who died as a result of drug use were in treatment at the time of their death or had been during the previous 12 months (Public Health England, 2016). Death can also occur during relapse after a period of abstinence, for instance following release from prison. Families and friends often support the drug or alcohol user practically, financially and emotionally through their problems and in some cases into recovery and through treatment. The loss of hope of recovery is a particularly poignant aspect of this kind of bereavement (Lawton, Gilbert & Turnbull, 2016).

All of these variables interweave to make up the tapestry of each individual's personal experience of being bereaved through alcohol or drugs.

Common themes

At the same time as acknowledging this diversity of experience, it is also possible to identify some common themes experienced by many, though perhaps not all, of those affected by drug and alcohol-related bereavement.

Firstly, the **emotional impact and complexity** of a drug or alcohol-related bereavement is immense. Guilt, self-blame and profound regret are common: bereaved people often feel they should have been able to do more to stop the person from using drugs or alcohol, for example, or, in the case of hidden use, that they should have known. Feelings such as these are often very intense for bereaved parents. Unanswered questions, for example about why their loved one was unable to stop using or about what exactly happened when they died, can be deeply troubling and impact on the bereaved person's ability to make meaning following their death.

Bereaved people often identify a complex mix of emotions, describing love intermingled with, for example, anger, disappointment, relief or shame. Relations may well have been strained with the person who died or indeed they may have been estranged at the time of their death. These can be extremely difficult emotions to accept, leading to a further layer of guilt. People can struggle to remember the person as they were before they began using drugs or alcohol and this can also be acutely painful (Adfam and Cruse Bereavement Care, 2014). Indeed, it can make the continuing bond (Klass, Silverman and Nickman, 1996) with the person who died problematic, though many do report that this can change for the better over time.

Secondly, the **legacy** of having lived with drug or alcohol use for those families and friends impacted by known, problematic use can continue to have a profound impact after the death. Families may find themselves in financial difficulty, for example if they have paid off drug debts or for rehab. The strain of coping with a loved one's drug or alcohol use can have serious physical and mental health implications (Adfam, 2012) which can continue (Feigelman, 2011) or even worsen after their death. Those bereaved after living with a known drug or alcohol problem often describe the impact of living with the fear of their loved one's death for a long period of time as well as the sense of having undergone a double bereavement, having already lost the person they loved to drugs or alcohol *before* they died as well as after their death (Templeton *et al*, 2016).

Thirdly, one of the most consistently present themes for this group is **stigma,** both actual and perceived, (Adfam and Cruse Bereavement Care, 2015; Templeton *et al*, 2016), and the experience of disenfranchised grief whereby bereaved people feel their grief is not legitimate or socially sanctioned (Doka, 2002). The illegality of drug use and popular perceptions around the associated lifestyle as well as social censure around some forms of alcohol misuse can lead to powerful stigma which families and friends often feel is also attached to them as well as the person who was using drugs or alcohol. In fact, family and friends can sometimes even be described as having been part of the problem, for example seen as being 'co-

dependent' (Walter *et al*, 2015), or 'enabling' the drug or alcohol user, and many families report feeling judged, for example for their parenting, both while their loved one was alive and after their death (Adfam and Cruse Bereavement Care, 2015). This means they are often not only experiencing the loss itself but also a sense of 'secondary victimisation' through the response of others (Doka, 2002; see also Feigelman, 2011).

We know that bereavement of any kind is, if not always directly stigmatised as such, then certainly still something of a taboo in contemporary society, with three-quarters of those surveyed for the Dying Matters coalition agreeing that people in Britain are uncomfortable discussing death, dying and bereavement (NCPC, 2016). Therefore it could be said that a drug or alcohol-related bereavement carries the double stigma of both bereavement *and* drugs or alcohol.

On top of this, additional stigmatising factors can further intensify the shame felt by bereaved families and friends, particularly lifestyle judgements, for example around those who die using chemsex drugs, or people with entrenched heroin and/or crack cocaine use and associated issues such as mental health, homelessness and imprisonment. Doka hypothesises that deaths that can be perceived as self-destructive are experienced as much more threatening to wider society than those that are not (Doka, 2002). Widespread misunderstanding about the nature of dependence, particularly the notion that the person who died 'chose' alcohol or drugs, contributes to this stigma.

Since all drug-related and some alcohol-related deaths are referred to the coroner, people who are bereaved through alcohol and drugs are much more likely to experience the involvement – or intrusion – of professionals, such as the police, paramedics and coroners, and their potential judgements. The kindness of individual professionals is valued deeply by bereaved families (Walter *et al*, 2015). By contrast, stigmatising language or behaviour, sometimes subtly conveyed in tone of voice or body language, can add an additional burden to the grieving process. A useful publication from the Universities of Bath and Stirling sets out guidelines for professionals on how best to support people bereaved through alcohol and drugs (Cartwright, 2015) in order to address precisely this issue.

People bereaved through drugs or alcohol are also more likely to be subject to public scrutiny through sensationalist or judgemental media coverage. On occasion, the media can handle drug or alcohol-related deaths sensitively and respectfully. However, more commonly, reporting adds to families' distress and can make it even harder for bereaved people to make meaning for themselves when their narrative about their loved one's life and death and their own grief is disrupted and undermined by a competing public 'story' (Valentine, Bauld & Walter, 2016).

BEAD project

Support needs

It is little wonder, against this backdrop, that people bereaved through alcohol and drugs often feel judged, isolated and lacking support for their bereavement (Adfam and Cruse Bereavement Care, 2015). It is for precisely these reasons that Cruse Bereavement Care and Adfam established a unique partnership – the first at a national level to create such close joint working between the bereavement and drug and alcohol sectors where to date there has been limited overlap – and set up the Bereaved through Alcohol and Drugs (BEAD) project to offer targeted peer support, following a Big Lottery Fund grant in 2013. The involvement of the support groups DrugFAM and Bereavement through Addiction in supporting both the partnership and the BEAD project was also valuable.

Consultation for the project (Adfam and Cruse Bereavement Care, 2015) consisted of an online survey completed by 100 bereaved people, 10 in-depth telephone interviews and one consultation event. It identified three important dimensions to the support needs articulated by this group (Adfam and Cruse Bereavement Care, 2015; for more on support, see Templeton *et al*, 2016):

- Targeted support: People bereaved through drug and alcohol use were clear that this is a unique and special kind of bereavement and that they would benefit from targeted support in addition to generic bereavement support;
- Information: Bereaved people found themselves caught up in official procedures and processes, such as police investigations and inquests, of which they had no prior experience or understanding and for which the available information was either patchy or non-existent;
- Peer support: Bereaved people wanted to be connected with someone else 'who has been through it' (Adfam and Cruse Bereavement Care, 2015) and there was strong demand for peer support and a desire to feel connected to a wider community.

It is worth stressing that some consultees did report receiving good support, particularly from friends and family. However, the majority did not feel adequately supported overall, both in the immediate aftermath of the death and in the longer-term.

Based on these findings, then, the BEAD project has developed four pathways of support, namely: informal befriending either in person or over the telephone; structured one-to-one telephone support; peer support groups, with the first group having launched in London in April 2016; and a dedicated website as a source of relevant information and indirect support which is due to be launched soon.

Peer support volunteers

At the core of the BEAD project's ethos is an emphasis on **peer support.** Peer support within the wider bereavement context is not new, occurring either informally through networks of friends and family or facilitated by organisations such as Widowed and Young (WAY) or Cruse Bereavement Care's youth project, Hope Again, explicitly bringing together people with similar experiences of bereavement. Likewise, peer support is an established part of the drug and alcohol sector, for example within recovery and also support for families affected by substance use.

A crucial part of the application and screening process for prospective BEAD peer support volunteers was to explore not only their ability to engage and listen to others but also to establish whether they were at a stage in their own journey of grief to be able to take part in the training and offer support. Utilising the strength of both organisations' networks, recruitment of volunteers was straightforward with 48 having taken part in training and more than half of those now actively volunteering. The project team attributed the ease of recruitment to a strong desire amongst those affected by this bereavement to reach out and support one another and build a greater sense of community (see also Valentine & Walter, 2015) as well as the fact that no other comparable nationwide projects exist. A handful of volunteers had had involvement with either Cruse or Adfam previously but the majority were new to this work.

All BEAD volunteers then took part in a two-day core training, *Supporting people bereaved through alcohol and drugs*, and went on to opt for further skills-based training in either befriending, structured telephone bereavement support or facilitating peer support groups. (There was no training requirement for involvement in the BEAD website.) The foundation of the core two-day BEAD training was for volunteers to reflect on their own experiences of being bereaved through drug or alcohol use. For many, this was an intense and powerful experience, with several commenting that it had been their first opportunity to be in a group of people bereaved in a similar way and be able to talk so readily about the issues they had faced. One said during a session: 'It's like we're all talking a common language.' Indeed, some of the training sessions amply demonstrated the power of peer-to-peer contact and it was profoundly moving to facilitate and witness this.

From this basis, volunteers were encouraged to extend their awareness beyond their own experience to the wide range of variables encompassed within drug and alcohol-related bereavement, by exploring similarities and differences with others, using their own experiences as a point of comparison and a springboard for discussion with clients rather than as a template, and developing skills to enable clients to articulate their personal experiences and to find the most pertinent and effective coping strategies for *them*.

Benefits of peer support in this context

Many volunteers report that becoming involved in the BEAD project has become a significant part of their own journey of grief. Indeed, supporting others living with substance misuse or coping with a related bereavement can be an act of commemoration and a highly creative response to the volunteers' own bereavement (Valentine & Walter, 2015): this kind of activity can be part of building further resilience and post-traumatic growth (Joseph, 2012) among those volunteers offering support.

Certainly, many BEAD volunteers attest to this, describing how the project presents the opportunity for something good to come out of their own painful experience of bereavement through drug or alcohol use. For some, this has included a deeper level of healing and acceptance as part of the continuing bond (Klass, Silverman & Nickman, 1996) with the person who died. Others have expressed how much they themselves would have benefited from support such as this when they were first bereaved and that this is a motivation for their involvement.

'... the peer support volunteer can embody hope and even optimism, simply by knowing that another person who has been in your situation is now in a position to offer support to others.'

The sense of reciprocity and shared mutual understanding underpins the three fundamental benefits to clients of the peer support approach that we have identified in this context. Firstly, the fear of judgement that inhibits many people from seeking support appears to be overcome when they know that peer support volunteers have themselves been through a similar experience. Clients have expressed relief at being able to talk openly with their BEAD volunteer or in the support group about their experiences both before and after the death as well as their relationship with the person who died, particularly when that relationship was complex.

Secondly, in the face of the bleakness, despair and hopelessness experienced by virtually all people when their world has been turned upside down by a bereavement of this kind, the peer support volunteer can embody hope and even optimism, simply by knowing that another person

who has been in your situation is now in a position to offer support to others.

Thirdly, there is a normalising aspect to the peer support relationship. Since many people bereaved through alcohol and drugs may not have contact with others bereaved in this way, the peer support volunteer allows them to know that they are not alone and that others do share this experience. This, too, can have restorative benefits as they begin to feel part of a community again after the rupture and disconnection of their bereavement. For example, feedback from the first peer support group facilitated by two skilled and dedicated BEAD volunteers in London in spring 2016 was extremely positive. One participant said: '...the more I attended, the more I wanted to participate as I realised the people in the group were also suffering just like me, and I wanted to be there', whilst another fed back: 'I felt they [the facilitators] had a special empathic understanding and acceptance.' A second support group is already underway in London, with others to follow.

Of course, the benefits of peer support for clients will be as unique as each relationship between peer support volunteer and client or within each peer support group. More detailed evaluation of volunteers' and clients' experience of the BEAD project is currently underway and it will be useful in this evaluation to tease out more specifically what it is in the peer support offer that is different from support from, say, a qualified professional such as a counsellor or a more generic bereavement volunteer.

BEAD project: peer support risks

Nonetheless, peer support such as this is not without its risks and challenges.

Volunteers need to maintain clear boundaries with the people they are supporting: this can be more challenging in a more informal peer support role in contrast to a professional relationship.

Then, striking a balance between making BEAD support widely accessible to as many bereaved people as possible without asking volunteers to take on clients with complex needs that are beyond the scope of their skills and training is crucial. Hence there is a detailed telephone assessment with an experienced counsellor working on behalf of the BEAD project to ensure that it is the right source of support and to identify alternatives where appropriate, though this is not always straightforward, particularly in a period of cuts in statutory services. A not insignificant number of potential clients face a range of inter-related issues which straddle bereavement and, for example, mental health, their own problematic drug or alcohol use or complex family issues. Closer integration of BEAD peer support work with professionals such as community mental health teams has scope to offer a powerful twin-track approach to the issues these clients face and this is something that requires further exploration.

And lastly, peer support, by its very nature, brings volunteers into contact with others whose experiences may be very close to their own and may therefore trigger their own grief. For any project offering peer support around such sensitive bereavement, support for volunteers needs to be as much a part of the DNA of the project as the support they give to clients. Experienced Cruse supervisors have been recruited to offer support, though the geographical spread of the BEAD volunteers across England has made it harder to make support for volunteers as comprehensive as the project team would like.

Future directions for BEAD

Interim results from qualitative evaluation are resounding in showing that the BEAD project is succeeding in achieving its outcomes of reducing isolation, increasing a sense of community and reducing the negative effects of drug and alcohol-related bereavement on physical and mental health. Since October 2015, when the first volunteers began work with clients, 82 bereaved people have received support in groups or one-to-one and their feedback has been extremely positive. Looking ahead, three clear future priorities are emerging: 1) how to sustain and scale up the project to meet the needs of a greater number of the thousands affected by this kind of bereavement; 2) how to embed the learning and emerging good practice from the project to ensure it reaches professionals, for example in health and social care, or other volunteers, such as in Cruse branches, who may also be offering support; and 3) bringing together relevant local partners and building grassroots capacity so that BEAD can expand the number of groups offering support to people bereaved through drug or alcohol use across England.

Conclusion

There is no doubt that the experience of losing a loved one to drugs or alcohol is very often complex, traumatic and deeply painful. Many people bereaved through alcohol or drugs experience a profound stigma which can entrench feelings of isolation and lack of support still further, though this is not the case for *all* bereaved people. It is encouraging that early indications from the BEAD project are showing that isolation can be overcome to a significant degree through the support of well-trained, dedicated peer support volunteers offering targeted one-to-one or group support. In addition, raising awareness of drug and alcohol-related bereavement in both areas (the bereavement sector and the drug and alcohol field), equipping professionals who come into contact with this group of bereaved people to be supportive and non-stigmatising (Cartwright, 2015) as well as challenging wider societal attitudes are all essential in order to enable *all* those affected by this devastating experience of bereavement to be supported and feel accepted in their grief. ■

Resources

- For more information about the BEAD project, go to www.adfam.org.uk/bereavement or www.cruse.org.uk/drugs-and-alcohol, including information on how to make a referral and to be alerted when the BEAD website launches.
- The University of Bath's guidelines for those whose work brings them into contact with adults bereaved after a drug or alcohol-related death: http://www.bath.ac.uk/cdas/documents/bereaved-through-substance-use.pdf
- DrugFAM – support and information about bereavement, including the DrugFAM annual Bereaved by Addiction conference: http://www.drugfam.co.uk/how-we-help/bereavment/
- Bereavement through Addiction group in Bristol: http://www.bereavementthroughaddiction.com

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