Bereavement Support Following a ‘bad death’.
Findings from research

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Aims of Presentation

- To consider support needs of a largely hidden and overlooked group of people, i.e. those left behind after a ‘bad’ death, drawing on research into the experiences of
  - Adults bereaved after a death in which alcohol or drugs were implicated, in some cases involving suicide
    - Those working for services involved in dealing with these deaths/bereavements
- To show how these experiences have informed new practice guidelines to improve how services understand and respond to these bereaved people.
- Your thoughts
The research

- Funded by ESRC(2012-2015)
- SW England (University of Bath) and Scotland (University of Stirling).
- Research team of 9, including 1 Bereaved family member; and Advisory Group of 6 members involved with either addiction or bereavement support
- The first sizeable study of impact of substance-related deaths on families and close others:
  - substantial body of work on how families cope with living with a members’ substance use but little attention given to how they cope should the person die.
  - Policy and practice initiatives inevitably focused on treatment and prevention. However, these are not always successful, as one interviewee noted

‘There are limits to what you can do... It may be that with all your best efforts the problem will still be there and ... get worse and in the end it may result in death’

http://www.bath.ac.uk/cdas/research/understanding-those-bereaved-through-substance-misuse/
Method

- **Interviews** with 106 bereaved family members in England and Scotland – 47 alcohol deaths and 15 suicides.
- **Focus Groups** with 40 practitioners from a range of services (some also bereaved), including police and coroner services (and Procurator Fiscal in Scotland), PHE, funeral services, clergy, media, drug and alcohol treatment and bereavement support services.
- **Working group** of 12 practitioners (some also bereaved) tasked with developing a set of **guidelines** for improving the way practitioners respond to these bereaved people.
1. The Interviews

Grief compounded by

1. **The Life** - stress and strain of **living with** another’s substance use. “*A living bereavement*”

2. **The Death** – the circumstances, official procedures and how services responded to grieving individuals and families. “*the police just came in... told me my son was dead.. and then went*”

3. **The Memory** – remembering (formally/informally) a life that may be considered wasted. “*There are so many bad memories that you actually forget any good memories*”

4. **The Stigma** – pre/post death i.e. family seen as dysfunctional, even complicit and their grief unrecognised. “*A lot of people think well he caused his own death so you don’t get the sympathy you would get normally*”
Circumstances surrounding the Death

- Interviewees’ experiences mostly far removed from ideal of dying peacefully, at home, with close others, etc., (though partially achieved in a few cases).

- More often the person had died alone or away from home, in the presence of professionals, without privacy, dignity or peace: ‘...it’s not a pleasant sight when someone has died from carbon dioxide poisoning...and also he’s ravaged by his alcoholism...’ ; ‘the thought of him being there for so long and no one having found him was hard’.

- Encounters with professionals and service personnel frequently (though not always) insensitive and unhelpful.

- Negotiating official procedures could be daunting due to complex and fragmented system, which could involve official, in some cases criminal investigation.
Encounters with services

- **Key finding**
  - Responses of services in the aftermath of a death made a big difference to how people coped with their grief.
  - Depended on whether or not practitioners showed common humanity, i.e. kindness, concern, tact, etc., or were abrupt, off-hand, dismissive, etc.
  - What bereaved people said they appreciated was
    - Being treated with kindness, tact and concern.
    - Having their privacy protected.
    - Professionals being available and taking time.
    - Being kept informed about what was happening.
“And there seemed to be a lot of policemen and they said we’re searching the house. I said, have you got a search warrant? He said we don’t need a search warrant. I questioned...how they could do this, but they were very sort of - they treated us terribly” (Parents talking about son).

“But a person who helped us absolutely incredibly at the most crap time was [my son’s] doctor ...he came round and he was absolutely incredible. He was so understanding and we talked...I mean that was the best counselling that we had” (Mother talking about son).
Protecting/not protecting privacy

“The police weren’t brilliant, the way they told my mum. She has a post office....a policeman came in and said ‘do you have any relatives in (town)?’ She went ‘oh, oh yes, my son...and he just went ‘oh, well he’s been found dead’... He said this in the shop with customers there” (Sister)

“They just said that they needed to talk to me about something, so I immediately said, oh it’s [my partner] isn’t it? And they said yes, can we come and speak to you? And I said well I’m at work now...Can it wait? And they said, we do need to speak to you and it is urgent.....they were....as gentle as they could be and asked me was there somewhere where we could go to speak in private..... I took them to one of the...[rooms] where we sit and have a cup of tea and they [told me]” (Partner)
"Our GP never visited, never phoned, never came near when my son died....I came back from the undertakers and we got an ansaphone message to say, ‘Hi Doctor (X) here, yes I was supposed to phone you yesterday but I didn’t, sorry, I am phoning today, you are obviously not in, just to let you know tomorrow we are running industrial action so if you need a doctor phone on Monday’" (Mother talking about son).

“There were two policewomen who came and they stayed and made us tea and they comforted us...And [son] was known to the police... because he had been an addict, had been in trouble and that’s awful as a mother. You feel like society looks down on you. But I didn’t get that sense... They couldn’t have been more helpful” (Mother talking about son)
Being kept informed

“I said it wasn’t her for a year…I just kept telling myself, she’ll be back, she’ll be back….I mean, people were coming down, I couldn’t tell them because I didn’t know anything - the police basically just said ‘We’ve found your daughter, she’s dead, phone that number the morra’, and left” (Mother talking about daughter).

“I tried to find out what happened, so I phoned the police to find out and to query some stuff. And they in turn contacted the doctor who done the autopsy who in turn contacted me and then tried to explain. So the doctor and the procurator fiscal, they helped me no end” (Father talking about son).
2. The Focus Groups

- *Practitioners’ perspective*: confirmed what interviewees reported; and highlighted what practitioners were up against:
  - Pressures of working in a multi-agency context, with constantly changing service landscape and services not working together.
  - Role of front line services to deal with the death rather than provide bereavement support, a role that only formed part of their work.
  - Little understanding/experience of this kind of bereavement.
Confirming what interviewees reported

“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 and...the stigma that surrounds people who have died through these circumstances...”

Lack of understanding/experience

“Largely in the first instance it is going to be uniformed officers who potentially might be sort of relatively inexperienced that will be there in the first instance”.

Constantly changing service landscape

“One of the things that’s difficult for us is there’s a lot of groups that have developed over the last few years and things have changed quite significantly in the number of support groups there are. But we’re not aware ... and unfortunately we haven’t got the time to research, and if we were made aware we would be putting people in touch with support groups far more frequently...”
Addressing support issues

- Why practice guidelines?
  - Severity of the bereavement
  - Lack of existing guidance
  - Being in a position to provide guidance that was evidence-base as well as practice-based.

- How?
  - By comparing data from the interviews and focus groups in light of ideas from wider health and social care policy research, we identified
    - Five key messages any practitioner whose work brought them into contact with substance use deaths could use to improve their response to the bereaved people left behind.
      - Interlinked and inform each other.
      - Form backbone of a set of practice guidelines, developed by an interprofessional working group of twelve members.
The 5 Key Messages

1. **Show kindness and compassion** – important antidote to the stigma these bereaved people may be up against. Therefore showing care and concern for their situation will mean a lot to them. However, question raised in focus groups as to whether compassion can be taught.

2. **Language is important** – linked to above and importance of challenging stigma, i.e. language can either stigmatise/pass judgment or affirm and show respect, e.g. ‘The doctor in A&E who signed his death certificate... he said, “This gentleman had died” and that made such a difference to us.’

3. **Every bereaved person is an individual** – reminder that regardless of commonalities, people’s experiences and needs are always diverse, i.e. not just another ‘bereavement. So do not make assumptions, e.g. about what someone may need/feel etc.; or about the deceased person’s life.

4. **Everyone has a contribution to make** – encouragement to take personal responsibility for doing what you can rather than using excuse that it’s someone else’s job. Similar to ‘safeguarding’ ethos, i.e. everyone has a responsibility.

5. **Working together** – in a multi-agency system joint working between agencies is crucial to ensuring both a continuity of support and that bereaved peoples’ complex and multiple needs are comprehensively met. Many of our interviews found a lack of joined up working.
The Working Group

- 12 members: a DS with family liaison experience from Police Scotland, a funeral director, a senior coroner’s officer, a GP, a paramedic/trainer of paramedics, a senior alcohol policy and research officer, a university chaplain, four people working in either substance use or bereavement field who were also bereaved by substance use and a counsellor and trainer who chaired the group.

- Group Task: to produce practice guidelines - developed over a 5 month period, ending with their launch on 23rd June 2015.
  - Drafted by the Chair and edited by the researchers.
  - Reviewed by other practitioners, from services not represented in the WG, e.g. a freelance journalist, a social worker.

- Dissemination: circulated to all relevant national and local organisations and are available on a wide range of websites, though important to note that we know little about what impact, if any, they are having.
Guidelines – key features/style

- **Generic and accessible** to a range of relevant services – does not assume reader has specialist knowledge of either substance use or of bereavement.
- ‘**Less is more**’ approach - two pages for each key message.
- **Engages reader** by inviting them to empathise with the bereaved service user’s experience with reference to their own experience, and to reflect on their own working methods.
- **Treats reader with respect**, i.e. as a peer and equal, for example, stating in the Introduction that the Guidelines were written by the reader’s peers; using ‘you’ and ‘we’ to address the reader; ‘asking’ rather than telling or directing; and ideas being ‘suggested’ for ‘consideration’.
- **Focuses on specific practical guidance** to help reader do their job and invite them to consider what they see as relevant to their work.
- **Application to both England and Scotland**, e.g. taking account of the different legal processes.
- **Includes all basic information** for supporting the bereaved person, i.e. adopting a ‘one stop shop’ approach rather than referring the reader to other sources.
Your thoughts?

Reflect on the messages with reference to the following two questions:

1. What are the obstacles to getting these messages across? E.g. Can compassion be ‘taught’ or ‘developed’?

2. How are these messages relevant to you/your work?