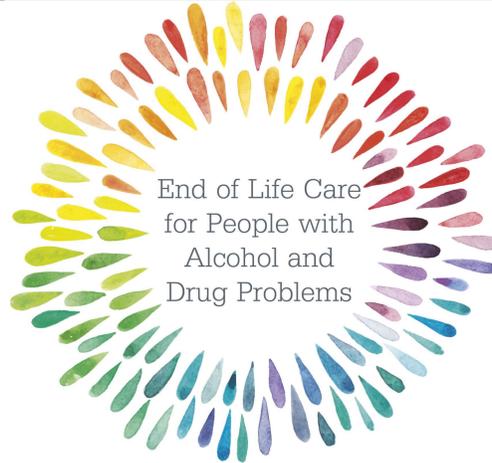


PROJECT BACKGROUND

Five strands of work:

1. Rapid evidence assessment and Key Informant interviews;
2. Scoping review of existing databases;
3. Interviews with individuals with palliative care needs who use/have used alcohol and other drugs;
4. **Family, Carer and Friends' experiences;**
5. Practitioners' perspectives.



This poster focuses on one strand of a two year Big Lottery Fund project examining end of life care needs for people with alcohol and drug use problems.

Initial examination of the experiences and support needs of families, friends and carer entailed secondary analysis of qualitative data drawn from a previous ESRC project on bereavement through substance use (BTSM project: <http://www.bath.ac.uk/cdas/documents/bereaved-through-substance-use.pdf> See also: Templeton et al. 2016¹)

STRAND AIMS

- To explore how families of individuals with alcohol/drug use problems experience their loved one's end of life.
- To examine the extent to which services recognise or respond to the whole family's needs.
- To inform design and delivery of primary qualitative data collection.

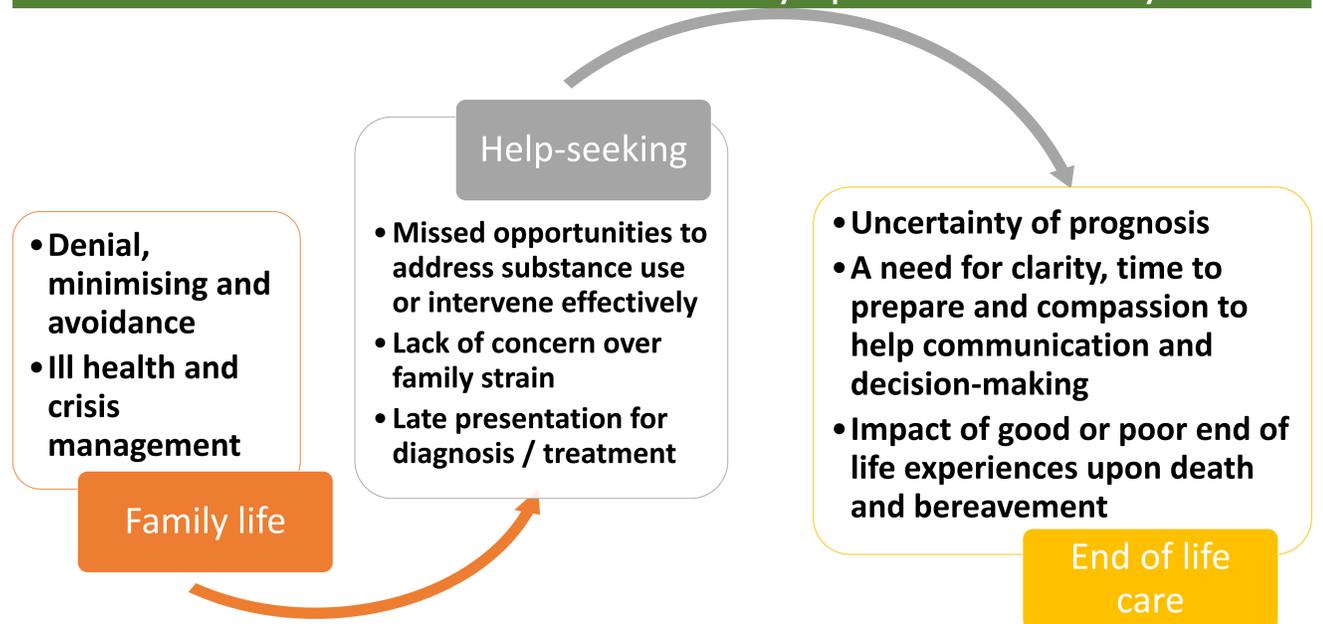
METHODS

Secondary analysis of 102 qualitative interviews with adults bereaved through substance use; originally conducted in England and Scotland. Recruited from a range of sources, participants included parents, children, spouses, siblings, nieces and friends whose bereavement ranged from a few weeks to over 30 years prior to interview.

Using NVIVO 10, thematic analysis examined:

- (1) instances where end of life was anticipated, experiences of, and need for support; and
- (2) any opportunities for support interventions among cases where end of life was not formally recognised.

FINDINGS PHASE 1 – Secondary qualitative analysis

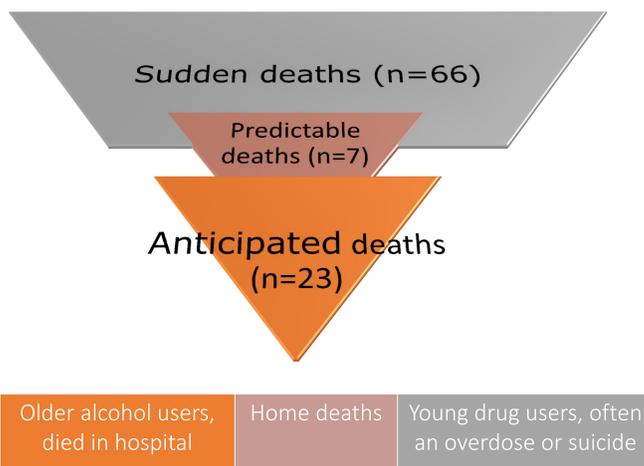


Negative experience of end of life care:

She ended up in [name] hospital and she was on a ward, full of people, confused. Didn't want to be there, kept trying to get out of bed, was driving the nurses crazy because she kept trying to get out of bed and she had a catheter in ... And every time we were there everybody just stared at us. It was horrendous and I kept saying: 'This is just not dignified, this is awful.' ... So I would hide in the corner because I just couldn't hack it.
Daughter

Positive experience of end of life care:

I just sort of sat beside him on the bed and stroked him and we talked and we talked about how we were and how things had been. He told me that he'd never loved anyone like he loved me. And we said our sorrys to each other. And I remember taking him into the shower room and showering him down and washing him and drying him off. And I think I cut his toenails and, you know, did his fingernails and put on new, clean pyjamas on him and just rubbed some oil on his skin. It just seemed right and fitting at the time. It was innate, almost ... and I was cuddling him. We were lying at the bed and he went into a deep sleep because he'd had quite a bit of morphine for the pain.
Ex-wife



NEXT STEPS

Using our learning from the BTSM interviews to design, implement and analyse in-depth, face-to-face interviews with 15 family members, carers or friends of people with substance use difficulties and palliative care needs.

Do you have personal or professional experience that you are willing to share?

We'd like to hear your experiences – good and bad - of asking about, responding to or listening to people affected by substance-related terminal illness.

Please email: BLFproject@mmu.ac.uk

¹ Templeton L., Ford A., McKell J., Valentine C., Walter T., Velleman R., Bauld L., Hay G. and Hollywood J. (2016): Bereavement through substance use: findings from an interview study with adults in England and Scotland, *Addiction Research & Theory*, DOI: 10.3109/16066359.2016.1153632

End of life care for people with alcohol and other drug problems: an exploratory study

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Practice and community partners: Aquarius (alcohol, drug, gambling charity), West Midlands; Phoenix Futures (substance misuse and housing charity), England; ADS, Greater Manchester and Staffs. St John's Hospice, Lancaster; St Catherine's Hospice, Preston; Trinity Hospice, Blackpool. Voicebox Inc, (Community group) Manchester.