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RESEARCH BRIEFING NO. 4

Experiences of families, friends and carers: End of Life Care for People with Alcohol and Drug Problems

“Families, friends and carers experience multiple stresses and strains, often over many years. These stresses and strains, which may include demanding caring responsibilities, can intensify as their relative reaches their end of life.”

Authors:

**Lorna Templeton
Gemma A. Yarwood
Sam Wright
Sarah Galvani**



Key findings

1. Families, friends and carers¹ of people with problematic substance use experience multiple stresses and strains, often over many years.
2. Support to families is generally lacking, and many families do not recognise their own support needs. These stresses and strains, which may include demanding caring responsibilities, can intensify as they reach the end of life (EOL).
3. People with problematic substance use may deny that their use is problematic. As a result, families may be unaware of their relative's² poor health. This often means that identification of, and communication about, EOL, and hence care, is absent or late.
4. People with problematic substance use often struggle to care for themselves, which may mean that care decisions are left to families. Health and Social Care Practitioners³ (HSCPs) often do not recognise this when delivering care and communicating with families; this can make the provision of good formal and informal care more difficult.
5. HSCPs need to be confident in initiating frank but compassionate conversations about substance use and EOL, addressing the immediate needs of those who are dying but also the practical and emotional support needs of families.
6. Families need empathy and encouragement from HSCPs to recognise their own needs and seek specialist support before death, when death occurs, and after death. Such support can help them to better prepare for their loved one's death, overcome feelings of stigma, and minimise the long-term trauma of substance-related bereavement.

¹ The terms 'families' and 'family' are used throughout this briefing to refer to family members, friends and carers of people with substance use and end of life (EOL) issues. Many people with substance use problems regard friends as family.

² The term 'relative' is used to refer to the person with experience of substance use problems and end of life care needs. This includes family members and friends.

³ HSCP is used to refer to health and social care practitioners.

Introduction

Despite recognition of the need to address complex multiple morbidities, the needs of people with alcohol and/or drug problems and their families rarely feature within health and social care policy. There is a lack of research about palliative and EOL care for people with substance use problems and their families, and a lack of policy and practice attention about the specific experiences and needs of these cohorts of people. However, the desire to reduce inequalities in relation to access to palliative and EOL care provides an opportunity to develop new pathways and approaches to care that could substantially improve the situation for families.

This Briefing summarises findings from the family-focussed strand of a wider research programme exploring end of life care for people with problematic substance use. The aims of the family-focussed research were to:

1. Explore how families of people with alcohol/other drug problems experience their relative's end of life care;
2. Examine the extent to which services recognised or responded to the family's needs, and
3. Record the challenges and practice (both good and poor) that families encountered in accessing formal and informal support, for themselves and for their relative.

Methodology

This research comprised two qualitative studies.

1. Study 1: secondary analysis of interview transcripts from a study with adults bereaved through a relative's substance use in England and Scotland (Valentine, 2018).
2. Study 2: primary interviews with families who were experiencing/had experienced EOL care for relatives with active or historic substance use problems. Interviewees were recruited from a range of sources, including hospices, substance use treatment services and community networks.

The interviews conducted for Study 2 were audio recorded and transcribed. Both datasets were analysed using thematic template analysis (King, 2012) supported by the computer-based NVivo 10 software package.

Findings

Study 1 comprised interviews with 102 adults bereaved as a result of substance use by a relative. Interviewees were parents, adult children, partners, siblings, nieces and friends who had been bereaved for periods of time ranging from six weeks to over 20 years. Their relatives were primarily alcohol or heroin users.

Study 2 comprised interviews with 18 individuals, two thirds of whom were female. Interviewees were children, parents, partners, friends, siblings and nephews. In the majority of cases the relative had already died, usually at hospital or at home, and as a result of alcohol-related illnesses and/or cancers.

Qualitative analysis of the two studies identified the same three broad themes.

1. Identification and communication about EOL.
2. Provision of care and support, including missed opportunities.
3. Family support needs (formal and informal).

Identification and communication about EOL

There was wide variation across the interviews in terms of the extent to which EOL was anticipated and, subsequently, whether any communication about, or delivery of EOL care occurred. In Study 1, there was no mention of palliative or EOL care (including hospices) throughout the dataset. Furthermore, in only approximately one fifth of interviews was EOL explicitly identified by a health professional, and in the majority of cases these deaths were alcohol-related and occurred in hospital. The absence of such conversations and care meant that, despite often recognising how unwell their relative was, interviewees were not prepared when they died and also felt that their relative did not die peacefully or with dignity:

There was nobody overtly saying, 'This is end of life.' (Friend, Study 2)

He went into hospital. He was fine actually. He was walking. He was quite happy, fit and healthy, and then seven days later he died...it was really,

really quick...he seemed fine and then all of a sudden he's just like taken away. I never really got to grips with that. (Niece, Study 1)

Provision of care and support

Despite frequent involvement with health services, many of the families in both studies talked about their relative's reluctance to engage with health and social care services. They also highlighted that their relative did not readily identify their substance use as being problematic or accept how unwell they were. This often resulted in their relative presenting late (if at all) to services which, combined with the unpredictable nature of many complex health conditions (including those which are alcohol-related), impeded palliative EOL care.

To varying extents, interviewees in both studies described how they felt that the professionals had missed opportunities to identify EOL. This meant missed opportunities to initiate the relevant conversations between combinations of the interviewee, their relative, professionals, and other family members. In many cases, the relative had multiple interactions with health services (including GPs and hospitals) in the months and years prior to death (associated with their substance use and/or other conditions), including pronouncements from HSCPs that the person would die if they did not change their behaviour. Yet, there seemed to be a dearth of cases where appropriate and timely palliative and EOL care was provided:

When we were in and out of [Accident & Emergency], maybe we could have done with some help or advice or somebody [speaking] to us and say[ing]: 'Look, you know, it's obvious your sister's got this problem, have you tried this? You know or have you tried contacting this organisation, or this?' (Step-sister, Study 1)

Interviewees also described poor care for their relatives and the impact this had on both themselves and their relative. Interviewees highlighted experiences or perceptions of stigma:

I'm thinking what do I have to say or do for somebody to actually listen and realise that as much as the care I gave [him] was the best I could give him, it would have been so much better had he had the help and support available. But it just wasn't there, no matter what I did...we were being treated as if we were diseased creatures.

(Female ex-partner, Study2)

Why did [the hospital nurses] always have a stern, cold exterior to everything that they said? Whenever you spoke to them, it was so abrupt and there was no feeling, there was nothing there...they didn't want to help you at all...Never showed any sympathy whatsoever, nothing just cold. (Nephew, Study 2)

Fortunately, albeit less common, some interviewees described cases where a HSCP had provided appropriate and compassionate care to the person who was dying and those supporting them:

She [social worker] coordinated the care package over the phone with me. (Friend, Study 2)

The hospital staff: I couldn't fault them at all, they did everything. There was at no point any suggestion that he was anything other than just someone in hospital who needed care...The level of care for both him and the family was - I couldn't fault it 100%...We slept around his bed, they gave us extra blankets. (Son, Study 2)

I remember when I actually got him into hospital and it was just me and [my son] there at first and the doctor, just she rubbed my arm...It was very empathetic I think and very helpful at that point. (Mother, Study 2)

Family support needs

Families had health and social care needs of their own before, at and after death of their relative. These were commonly tied up with how they had been affected by their relative's substance use, often for many years before they died. Sadly, however, despite clear evidence of the prolonged strain they were under, their attempts to seek help over the years had rarely proved successful. This lack of support, or experiences of poor support, continued after their relative's death, which could have a negative impact on grief and bereavement:

I did think about it [accessing support] seriously and I wasn't quite sure how to go about it, and I didn't really think that it would be for wives, husbands, sons and daughters of people who are alcoholics. I

rather just thought it was for, the help was there for alcoholics, I didn't realise that the family could have help. (Wife, Study 2)

If some person could have come down to the ward and said, 'Can I talk to you?...How [are] you feeling?...Are you okay?'...How can there be no acknowledgement of what's going on?

(Daughter, Study 2)

We weren't signposted to anything decent, I'm going to say it's a very niche thing but there must be so many people suffering from the same type of things in this area. (Sister, Study 2)

Again, examples of good support were rarer but when experienced they really made a difference:

The chaplain arrived actually, which was very lovely...really comforting...next to the consultant...although they were there for a very short time, they were just the most gentle and reassuring presence there. (Daughter, Study 2)

The thing that makes it work...people that genuinely care and that what they're doing doesn't come out of a professional / information / scientific statement. They genuinely commit and love you and care for you and you can sense and feel that. (Friend, Study 2)

Summary

Together, the two studies highlight the distress and complexity of being a family member (or friend or carer) of someone with problematic substance use and a life shortening illness. Multiple factors before and at death can affect what is already a difficult time. The data also illustrate how difficult it can be for families to determine when someone is approaching the EOL, meaning that intervention and care does not happen, or happens very late. This can also greatly affect the quality of death and dying and how families are involved in, and affected by, their relative's EOL.

Good EOL care requires overtly empathetic approaches from HSCPs to both family members and their relatives. This includes clear communication that explicitly addresses both prognostic uncertainty and substance use, and a

holistic approach to care that includes families, friends and carers. Health and social care services also need to address complex issues such as patient reluctance to engage with services, low levels of self-care and possible impaired mental capacity, in order to work effectively with people most in need of support. It is imperative that both people at the EOL and their families can access compassionate and skilled health and social care practitioners. For families where there are alcohol or other drug problems, practitioners need to be able to openly discuss substance use, explicitly recognise the long-term stress the family members may have been experiencing, and counteract the shame or stigma they may feel. Families also need bereavement support due to the additional stigma and shame they may feel about their relative's death.

Conclusion and implications

The two studies have given a unique, and hitherto largely unknown, insight in to the experiences of families of people with substance use problems and a life shortening illness. Families can experience multiple stresses and strains before, at, and after death, meaning that timely, appropriate and compassionate support is required at all times. There is much to do to meet the needs of a sizeable, but largely neglected group of families – these studies offer constructive suggestions for how practice, policy and research can do this. They can:

1. Recognise the needs of families caring for a relative with problematic substance use at EOL in policy, and through commissioning and service provision.
2. Develop proactive community outreach and hospital in-reach service delivery models for families and their relatives to foster engagement, and build joint working approaches with substance use, palliative and social care services.
3. Increase awareness of, and understanding of how to communicate about, the impact of substance use at the EOL with families and relatives, covering issues such as unpredictable health trajectories, complexity and denial.
4. Ensure equal access to the best possible EOL experience for families and their relatives, even where relatives are reluctant to engage with services.
5. Recognise, and act upon, the need for dedicated bereavement support for families of people with substance use problems.
6. Ensure future research works in partnership with both GP and acute hospital services in order to reach a broader demographic of families.

7. Facilitate community networks, including working with 'people with lived experience', to help develop pathways to identify and engage with potential research participants outside services.
8. Establish a programme of research and evaluation which is designed to understand how best to support families and the positive outcomes that services, interventions or practice models may have.

Further Information

- Our programme of research on *End of Life Care for People with Alcohol and Other Drug Problems* has six strands. This Briefing summarises Strand 4, which aimed to investigate the experiences of families, friends and carers.
- This Briefing was authored by Sam Wright (Manchester Metropolitan University), Gemma Anne Yarwood (Manchester Metropolitan University), Lorna Templeton (Independent Research Consultant), and Sarah Galvani (Manchester Metropolitan University).
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- Ethical approval for Strand 4 was obtained from Manchester Metropolitan University, and all interviewees gave informed consent.
- For further information please contact Professor Sarah Galvani, s.galvani@mmu.ac.uk

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