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RESEARCH BRIEFING NO. 6

Key Informant Interviews:

End of Life Care for People with Alcohol and Drug Problems

“We need to be developing services [that] provide the same level of care around end of life for people with drug and alcohol problems [as they] would if they were dying from anything else.... everybody deserves as good a death as we can help them to have.”

(Frontline Health and Social Care Practitioner)

Authors:

Lorna Templeton

Sarah Galvani

Marian Peacock

Gary Witham



Key findings

1. Current definitions and ways of understanding palliative care, and addiction recovery, do not easily apply to people with current or previous problematic substance use and end of life conditions.
2. The client group is not a straightforward one – there are often complex and multiple physical, psychological and social morbidities which impact upon their identification, engagement with services and the delivery of care.
3. There are significant issues with the fragmentation and inflexibility of service providers which affect the care they receive. However, it is possible to identify the characteristics of a good joined-up and compassionate approach to care.
4. Substance use receives little attention in national or local policy around palliative and end of life care; and palliative and end of life care receives little attention in national or local policy around substance use.
5. Prescribing for pain and/or symptom management for people with substance use and end of life conditions is a complex area but good practice is achievable.
6. Family members of people with substance problems at the end of their lives can be viewed negatively and receive little support both at the end of their relative's life and after their death.

Background

There are growing public health concerns about the morbidity and mortality of people with alcohol and/or drug problems. Among these are concerns about the care they receive, the current climate in which substance use treatment services are commissioned and delivered, and inequalities in substance use treatment, palliative care (PC) and end of life (EOL) care. The experiences and needs of families of people with substance use problems, including those who have been bereaved by substance use, have also been highlighted. Overall, however, there is a paucity of research about 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 patients and families and of the professionals who have contact with them. There has also been a lack of research which has investigated professional views on caring for this group of patients and their families.

The aim of the Key Informant (KI) interviews was to inform the rest of the project by investigating existing models of practice or care pathways for supporting adults with substance problems needing EOL care and the families/carers of these people.

Methodology

Semi-structured interviews were conducted with a purposive sample of interviewees identified in a variety of ways. These included people identified through the literature, people known to the research team, or suggestions made by the interviewees. The interview topic guide covered five broad areas:

- i. key challenges and opportunities people faced when someone had both substance use and end of life care needs;
- ii. identifying, where possible, current models of practice at individual and organisational levels;
- iii. the relevance of the policy context at regional and national levels;
- iv. the organisations people work with or access;
- v. and awareness of projects already working in this area.

Interviews were audio recorded and transcribed. They were analysed using template analysis and thematic networks supported by the Nvivo software package.

Findings

A total of 17 interviews were completed with 20 people – 16 professionals, one person with experience and three family members (the family members talked about the same relative who had died). The professionals were a diverse group with expertise in palliative and EOL care, and substance use. They included frontline health and social care professionals (HSCPs) working at a local level, senior health and social care professionals working at a local level, those working nationally in policy or commissioning, and a small number of others.

Qualitative analysis identified seven broad themes in two overarching areas: 'the wider landscape', and 'engaging and responding'.

The Wider Landscape

Definitions and perceptions

Interviewees debated the application of the common definitions of palliative care, EOL care, and recovery from substance use, with many viewing them as not applicable to those with substance use problems at the end of life. Interviewees also recognised that it remains difficult to talk about death and dying, and that the stigma often associated with substance use can add to such challenges. Further, interviewees thought that views of what constitutes a 'good death' may also need to be reconsidered, and that societal attitudes to substance use can affect access to care.

"... palliative care with people with substance use issues needs a bit of a re-brand...it's a huge bombshell to drop on somebody with no plan of action going forward." (Frontline HSCP)

"...the majority of [substance use treatment] services really are focused on recovery – so if you've got somebody with liver disease that realistically isn't looking very likely to recover, all of the services are directed at detox and at rehab, whereas there's certain people that's not going to happen or it's unlikely to happen." (Other Professional)

Size and nature of the problem

Interviewees recognised the increasing prevalence of mortality in people with substance use problems, and of the particular problems seen in recent years with the growing use of drugs like novel psychoactive substances. Interviewees highlighted a number of common characteristics of this group, including their younger age, increasing problems in older people often because of co-existing health conditions, and of the multiple physical health, mental health, and social issues which many patients present with. Overall, this is a group of people who present many challenges for health and social care professionals.

"I think probably a bigger issue is knowing that the need is a great deal more out there than we ever see and how we reach that is an issue." (Policy & Commissioning Professionals)

"[they] end up living in dire circumstances with no support to actually look after them at their end of life.... they don't even have anybody to go to the shop to buy a pint of milk...it's very dirty, they haven't got anything, they haven't even got the basics, some people haven't got a bed." (Frontline HSCP)

Commissioning and delivery

Interviewees had a generally negative view of the current commissioning arrangements for both substance use treatment services, and palliative and EOL care services, and of the impact this has on delivering the highest quality care to people with substance use and EOL concerns. Interviewees further suggested that substance use policy does not sufficiently address EOL care, and vice versa, and that this population needs to be addressed in both areas of policy. Interviewees outlined a number of key, overlapping, challenges that they think are greatly affecting national and local commissioning and practice. Namely: fragmentation; inflexibility; being stretched in terms of both capacity and financial resources; agendas that are too mainstream and cancer focused; the need for dedicated roles, services and champions; the need for integrated

and/or specialist commissioning; debates as to whether care should be centralised or community focused; a lack of local direction and guidance; and workforce development.

"...multi morbidities seem to be becoming more common so it's not only physical health but mental health and the need to be able to treat all of those as people approach the end of life and the difficulties doing that, when services do seem to be increasingly fragmented." (Policy & Commissioning Professionals)

"It's sad because you're under-resourced for what you do and the end of life should be the best and we now have to go with good enough." (Frontline HSCP)

Engaging and Responding

Engaging clients

Interviewees talked about numerous challenges in the timely identification of EOL in people with substance use problems, and the barriers which many people can experience in accessing services. A common challenge was the unpredictable nature of some conditions like alcohol liver disease and how this affects identification at the right time that someone is coming towards the end of life. Related to this, interviewees, particularly those working in the substance use sector, discussed how hard it can be to ask questions that might lead to improved identification. Engagement is greatly influenced by stigma, which can have many forms, practical access to services, and whether services support people who want to continue to use substances while they are receiving EOL care. Interviewees made suggestions about what can facilitate engagement of a group who are largely invisible or forgotten, including building trusted relationships with people, in order to make asking difficult questions and having conversations possible.

"[the] fluctuating nature of the symptoms and the illness [of liver disease] ...it's identifying at what point should palliative care get involved." (Other Professional)

"I think they are hugely disserved...they present frequently, they're not listened to, they're diagnosed late." (Senior HSCP)

"I think drugs and alcohol users are an easy target to blame, they don't get much sympathy and no-one seems to look at why people are taking drugs and alcohol....and it's just hard to shift that out of anyone." (Frontline HSCP)

Managing and developing care responses

Interviewees talked about some of the key issues which influenced the delivery of care, particularly a person-centred approach, joined-up working, and pain and symptom management. The key components of a person-centred approach identified by interviewees were relationships, holistic care, accessible and flexible care, communication, and the provision of personal care. In relation to joined up working interviewees highlighted the importance of treatment and palliation in parallel; tackling fragmentation; reciprocal expertise and knowledge; communication; and clarifying who is responsible for care. Pain and symptom management was one of the more prevalent themes in the data and interviewees discussed the challenges of managing pain and symptoms alongside substance use; differing approaches to the problem between professionals; talking about pain and symptom management; education and training; issues related to families and peers; and working together. Interviewees also talked about their experiences of care in key settings including primary care, drug and alcohol treatment, hospitals, hostels and hospices.

“it’s a person-centred approach that palliative care, end of life care, needs to take, it’s so where are they now and what can we, how can we improve where you are or your end of life experience, how can we make that what you want it to be?
(Frontline HSCP)

“if just one of us of each can come together and keep talking...we’re going to make an improvement...it’s got to be collaborative, no doubt in my mind” (Frontline HSCP)

“people that traditionally are taking drugs, have got a higher tolerance and they’re terrified when they come to end of life and being in pain and not being given enough drugs, I just reassure them that the team will take it into account and there won’t be a limit on your pain relief and I think that stops people stockpiling as well, if you give guarantees that your pain relief will be the main focus, if you need higher amounts of drugs, you’ll get them. A lot of people just want reassurance that their end of life will be as comfortable as it can be” (Frontline HSCP)

(Not) talking about substance use or death and dying

Interviewees described three areas where conversations could be difficult to have with people with EOL and substance use issues. Namely, talking about substance use itself; giving and receiving an EOL diagnosis; and talking about death and dying, including palliative and EOL care. Interviewees discussed the

importance of choice around substance use, rather than professionals demanding abstinence. They often felt that 'wake up calls' often do not work, and highlighted the importance of a proactive and person-centred approach to discussing end of life with someone.

"I've found an interesting approach that worked for me...you don't ask them to stop drinking, you sort of take alcohol away and say '...so now because this addiction is part of your illness, we need to start thinking about how we're going to plan the end of your life'...you take away the, 'If you don't stop drinking, you'll die'...and change the focus to 'drinking is part of your pathology, we need to deal with that in the same way as we need to deal with your liver chemistry' ." (Senior HSCP)

Families and networks

Interviewees talked about the experiences of families, the perceptions of families and professionals towards each other, issues regarding death certificates and the official cause of death, and support for families both before and after death. Overall, families were more likely to be viewed negatively, and there was limited recognition and discussion of the needs of families both before and after the death of their loved one.

"I just think families is going to be...a big issue for our client group as they approach the end of life." (Policy & Commissioning Professionals)

"Why did they 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...I know sympathy and empathy are two very different things but they should at least empathise with the family." (Family)

Summary

Overall, the interviews identified similar issues at both national and local levels, and across substance use and palliative and EOL care. At times it makes for bleak reading, with interviewees talking about professions and systems under enormous multiple pressures and which, along with stigma and prejudice, mean that this group of patients (and often also their families) is unlikely to receive the right, and best quality, care at the right time and delivered in the right way. However, the interviews also contain optimism and hope for how the needs of this group of people should be best met. Characteristics of good care, and pockets of good practice, were highlighted, all of which could be harnessed to raise awareness, improve identification, encourage more good practice

(including around supporting continued substance use, and pain/symptom management) and tackle stigma. The developing care response cannot be 'one size fits all', but must cater for a client group that has a very wide-ranging demographic profile and that will most likely present with multiple, and often chronic and longstanding, physical, psychological and social problems. The response must also be holistic and include addressing the needs of families and close others.

Overall, interviewees were critical of policy and commissioning and identified a number of challenges and barriers which impede the provision of timely, holistic and adequate care. These reflect wider dilemmas and challenges which are facing both substance misuse treatment and palliative and EOL care. Given the multiple and complex needs of many people with substance use and EOL concerns, there is a greater need for multi-disciplinary and joined up care and care pathways and for national and local policy and commissioning practice to reflect this. There is also a need for resources and guidance to help professionals in a range of settings which identify, and engage with, the dual issues. Also needed is a programme of workforce development that can support people to feel comfortable and confident to talk about these issues with patients, families and colleagues.

Conclusion

The KI interviews have given a unique, and hitherto unknown, insight in to the experiences and challenges of working with adults with substance use problems and a life limiting condition. Interviewees identified numerous individual, organisational, and strategic challenges to identifying this group and delivering timely, efficient, joined up and compassionate care. There is much to do to better meet the needs of a sizeable, but largely neglected group of adults and their families – these interviews offered constructive suggestions for how care can be improved.

Implications

Implications for Practice and Policy

1. There is a need for greater reciprocity in national and local policy, where palliative and EOL policy considers the needs of those with substance use concerns, and substance use policy considers the needs of those with palliative and EOL care needs.
2. Practice and policy, at both national and local levels, needs to be fully holistic to better meet the needs of families, either alongside their loved one and/or in their own right.

3. There is a need for guidance, and improved inter-service collaboration, to support the earlier identification of, and engagement with, a complex patient/client group who are often reluctant to engage with services.
4. There is a need for guidance on issues surrounding prescribing, and how they can be addressed while not compromising the care of those who wish to continue drinking or taking drugs.
5. How can policy cater for the differing needs of sub-groups of people with substance use and EOL concerns.

Implications for Research

1. How can current definitions and ways of understanding palliative care, and addiction recovery, be better applied to people with substance use and EOL concerns?
2. What might the core components be of an improved national and local policy response to this patient/client group?
3. How can we better understand the complexities of prescribing for pain and/or symptom management, including for those who wish to continue drinking or using drugs? What are the components and facilitators of good practice and in this area?
4. Given the diversity of the KI sample, there is potentially a need for similar research to further explore the key issues which have arisen and how they might apply to different professional groups across England/the UK.
5. How does care need to differ to meet the needs of sub-groups of people with substance use and EOL concerns – for example, by gender, age, ethnicity, nature of substance use.

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 6, which aimed to investigate existing models of practice and care for supporting people with substance problems needing end of life care and their families/carers.
- ❖ This Briefing was authored by Lorna Templeton and Sarah Galvani.
- ❖ We thank the Big Lottery Fund for funding the wider project of which this Briefing is a part. We also thank all the interviewees who gave their time so generously to speak with us.
- ❖ Ethical approval for the KI interview study was obtained from Manchester Metropolitan University, and all interviewees gave informed consent.
- ❖ For further information please see/contact Professor Sarah Galvani, s.galvani@mmu.ac.uk.

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