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Will a new approach to end-of-life care for people who use substances improve their access to, and experience of, palliative and end-of-life care?

Executive Summary – February 2023

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Executive Summary

This research, funded by the National Institute for Health Research (NIHR), took place from October 2019 to March 2023¹. The research was located in the City of Liverpool and the Borough of Sefton in the North-West of England. Liverpool has one of the highest rates of alcohol-related mortality and drug-related harm in the country. Inspired by earlier research that revealed the dearth of policy and practice on providing care and dignity at end of life for people using substances (Galvani, 2018), it set out to answer two primary research questions:

1. What should a new, co-produced, model of care look like for people using substances needing palliative and end-of-life care?
2. Does the new model have the potential to improve people's access to, and experience of, end-of-life care?

Participatory Action Research to co-create a new model of care

The project worked in partnership with a mixed and complex network of 10 social and health care agencies and the project's PEAT² to co-create a new model of end-of-life care for people using substances. This process revealed that little was known formally about responding to substance use at end of life, that more practice engagement was needed ahead of policy and practice change, and there was a need for widespread dissemination of knowledge.

The new model of care

An initial theory of change set out a consensus about the long-, medium- and short-term goals for improving care. Given the project's timespan, the focus was on short-term impact, with four short-term outcomes:

1. Carers equipped to have sensitive conversations about serious and advancing ill health, substance use, and advanced care planning.
2. Consistent advocacy for people using substances navigating health and social care provision to access palliative and end-of-life care.
3. Practitioners and peers feel better supported to work/live with SAIH and substance use.
4. Resources available for family/carers to access information and support.

Research design and methods

Mixed methods research measured the impact of this new model of care³ through:

- i. In-depth individual interviews and focus groups with social and health care practitioners and managers who had experience of supporting people using substances at end of life;

¹ The original completion date was March 2022. The Covid-19 pandemic took hold in March 2020 resulting in a 14-month delay. The individual and structural impact of the pandemic and its after-effects made completion of all the original aims untenable.

² A **People with Experience Advisory Team** (PEAT) was established to support and facilitate the involvement of people lived experience of both substance use and end-of-life care in the project at a place and pace that took account of their needs.

³ A more comprehensive research design was originally planned but could not be delivered due to the Covid-19 pandemic severely restricting access to key participant groups.

- ii. Bespoke questionnaires⁴ to capture practitioners' pre- and post-model of care experiences of unmet physical, psychological, emotional, spiritual, information and support needs among people using substances approaching end of life; and
- iii. Responsive engagement with a group of individuals with lived experience of substance use and palliative needs to produce a series of case studies.

Research findings

Practitioner focus groups: These revealed how the complex needs of people using substances at end of life were often unmet due to professional boundary concerns and the lack of cross-agency working. Existing end-of-life care provision placed unwanted restrictions on people using substances, meaning that their wishes were not met. The lack of both suitable training for staff and any specialist accommodation to support choices about place of death created moral challenges for service providers.

Manager interviews: With a common goal of supporting people to die with dignity, these interviews revealed that more needed to be done at an earlier stage to identify people with advancing ill-health and support sensitive conversations with them about their future care. Action is needed to develop: routine questioning; integrated care pathways between agencies; specialist roles to support people and link services; specialist supported accommodation; substance use specific family support (needed to counter stigma) and staff training (for example on: terminal health conditions, having conversations about end of life wishes, Advance Care Planning and supporting people who want to continue using substances). There was clear agreement that dying well involves respecting a person's choices, offering needs-led care, and minimising pain in the environment of their choosing - rather than hospital settings where ongoing substance use and intoxication is not tolerated.

Practitioner surveys: These revealed differences in perception of effectiveness of interdisciplinary working and access to palliative care by job role/type of service provider, revealing a degree of silo working and limited care pathways for social care agencies.

Case studies with people with experience of substance use and palliative services: These revealed people's lived experiences of being 'invisible/dismitted' in dealings with (some) practitioners/service providers, sometimes through the inadvertent activation of past experiences of discrimination. Complexities around handling pain medication require practitioners who move beyond procedural approaches to build trusting relationships grounded in 'points of connection' between practitioner and person.

Case studies with family, friends and carers: Friends in particular tend to play a much more central role in providing end-of-life health and social care for people using substances than with 'traditional' patients or clients. There is a stark need for greater understanding of the family's and friends' support needs and exploration of systemic strengths and challenges around this area.

⁴ Based on the Palliative care Outcomes Scales (POS).

Development of information and training resources

To facilitate the dissemination of the new model of care and to respond to the fieldwork limitations created by the pandemic, website resources were developed to support training for practitioners, and information for families and for people with lived experience. Pilot support forums for practitioners and families were also established.

The website (<https://endoflifecaresubstanceuse.com/>) comprises more than 40 podcasts and over 17 different publications. It provides worldwide access to the resources and information from this and previous projects for professionals, people with lived experience and family/friends/carers.

The training presentations introduced practitioners to the new model, how it had been developed and the resources in place to support it. 164 people were trained across 11 social and health care providers in Liverpool and Sefton.

Six support forums were held, three for practitioners and three for family members. The practitioner forums ran very well but the family members' forums need to be run by family focussed organisations to maximise attendance and overcome shame and stigma. Discussions are ongoing with partner agencies about co-hosting both forums.

Training evaluation

The training evaluation⁵ found that, compared to other services, addictions service staff do not expect to manage end-of-life clients. Whilst general expectations and attitudes towards supporting people with comorbid substance use and end-of-life needs were high among all practitioners surveyed, they reported experiencing difficulties in managing complex clients. There were also differences in relation to practice change beliefs between addictions/palliative care staff (3rd sector services) and social care/health staff (statutory services) - whereby the latter had less confidence or belief in being able to change practice.

Conclusion

This development of resources and training for project partner agencies showed how little was known about responding to substance use at end of life and how much more thinking and engagement was needed by practice partners ahead of significant changes to policy and practice. There is a need for better knowledge set within a clear policy framework to facilitate clear pathways to better more appropriate care and resources that avoid people facing stigma and unnecessary additional suffering at the end of their lives.

⁵ The training evaluation used a bespoke 25-item questionnaire, originally designed to be completed prior to, (T1) and within six weeks of undertaking training (T2). Once again, Covid reduced the opportunity to conduct a follow-up survey at T2, so only T1 data were analysed. There were 42 trainee responses of which 33 provided complete questionnaire responses.