People with alcohol and other drug (AOD) problems, and their families, deserve the same respect and dignity at the end of their lives as people without AOD problems.

They deserve care that is based on their needs, care that is delivered without judgement, and care that offers them the best possible choices in the final months, weeks and days of their lives. Our unique research project at Manchester Metropolitan University explored whether or not this was the case. It sought the views of a range of people including people with experience of AOD use and end of life care needs, their families, friends and carers, and the professionals and experts who supported them. It also examined existing evidence to find out what we know and where the gaps are in our knowledge. Our partners included two substance use agencies, ADS (Oldham and Bury) and Aquarius (Midlands); three hospices (St John’s in Lancaster, St Catherine’s in Preston and Trinity in Blackpool), and a Manchester-based community enterprise partner, VoiceBox Inc.

The project was funded by the The National Lottery Community Fund.

CASE STUDY – PEOPLE WITH EXPERIENCE

RICHARD, AGED 67
Richard used heroin for many years, but stopped eight years ago. He describes never being trusted by workers and being asked to wait outside the chemist’s when trying to pick up his methadone prescription, while they served other people before him. He has been living with cancer for three years and was recently told that there are no further treatment options. He and his wife are now thinking about his end of life care needs and planning for a funeral with little money. Having experienced poor healthcare treatment in the past, which he largely attributes to being a drug user, Richard and his wife want to remain as independent as possible, but recognise that they may soon have to accept help from the community palliative care team.

CASE STUDY – FAMILY MEMBER

DEBBIE, AGED 61
Debbie’s son had a longstanding alcohol problem and she felt he would die young. He was getting alcohol treatment but eventually died in hospital from alcohol-related liver disease after a period on life support. Debbie described her son’s death as a ‘good death’—surrounded by family and with compassionate care for both him and the family. However, there were no specific conversations about end of life care and Debbie felt that her grief was complicated by her son’s death being associated with alcohol.
ALCOHOL AND OTHER DRUG PROBLEMS: WHAT THE PROFESSIONALS TOLD US

‘Despite often coming from very different disciplinary backgrounds, there were a lot of shared common experiences and challenges.’

WE WANTED TO LEARN ABOUT the key challenges facing the professionals who worked with people with AOD problems at the end of their lives. We talked to two groups of people:

- seventeen specialists from around the UK who work in professions such as social work, hepatology, general medical practice, nursing, and senior policy roles
- more than 130 professionals who work, or volunteer, in our partner agencies (some via survey, others via individual interviews or focus groups)

Despite often coming from very different disciplinary backgrounds, there were a lot of shared common experiences and challenges. These fell into three broad categories: (i) challenges at an individual level; (ii) challenges at an organisational level; and (iii) challenges at a systems level.

INDIVIDUAL LEVEL CHALLENGES

1. Hospice professionals did not find it easy to ask, or talk, about a person’s substance use, and substance use staff did not find it easy to talk to someone about their end of life needs and wishes.
2. Not knowing how to raise the topic of substance use or end of life care was a barrier for some professionals. There was a clear lack of confidence about how to have that discussion.
3. Recognising end of life care needs was complicated at times by not knowing whether the symptoms people were experiencing related to the person’s failing health or to their substance use (or withdrawal), as both might change daily.
4. The professionals we spoke to had often advocated for someone where they felt the person was being stigmatised, treated unfairly, or their needs were being overlooked because of their substance use.
5. Professionals also found it emotionally difficult working with these overlapping issues: hospice professionals felt frustrated when working with someone whose substance use prevented them from having a better quality of death; substance use professionals felt loss and sadness when someone they worked with died, and this was not often recognised.

SYSTEM LEVEL CHALLENGES

8. The recovery focus of national policy and most treatment services was seen as unhelpful for this group of people. A harm reduction approach would be more beneficial given this group of people were never going to be able to ‘recover’.

9. There were calls for collaborative national policy to fill the policy gap underpinning work with people with substance problems at the end of their lives.

GOOD PRACTICE EXAMPLE

**DANIEL, AGED 41**

Daniel has been a heroin user since he was 15. He has been in drug treatment several times, but never managed to abstain from drugs. Daniel found out that he had hepatitis B and C almost a decade ago and is under the care of his local hospital’s liver unit. Over the past ten years he started drinking alcohol as well, but his mother’s terminal illness has motivated him to become abstinent before she dies. Daniel has been attending the substance use service for two years, receiving methadone treatment, key worker support and attending an art group. He has stopped drinking. At home, he is assisted by a carer for ten hours a week who makes sure he attends all his appointments and supports him with some social activities. Daniel understands that he is not going to recover; fortunately, his carer has received end of life training and they have both recently attended a Death Café (where people can gather to talk about death) as a first step in beginning to plan for a good death. (Ashby et al, 2018: 25/26)
Many people reported positive experiences of care from substance use and specialist end of life services… These resulted from holistic and compassionate approaches.

PEOPLE WITH AOD AT THE END OF LIFE

Many people reported positive experiences of care from substance use and specialist end of life services. These resulted from holistic and compassionate approaches to care, in contrast to less helpful short-term, single-issue treatment. Examples of good care included staff being available to answer questions, offer reassurance and adopt a non-judgmental attitude to their care. These approaches allowed for trusting relationships to be built and enabled people to begin to overcome the marginalisation and stigmatisation they had typically experienced as a person with a substance problem. Services that were not effectively ‘joined up’ did not help people to have a positive experience of end of life care.

From the experiences of people we interviewed, we identified several care needs at the end of life. These include the need for:

1. Better consideration of palliative and end of life care needs within specialist substance use services to avoid people leaving treatment when they are chronically ill (or are discharged for non-attendance).

2. Greater practitioner understanding of how people ‘carry’ a substance use identity, and how guilt and self-blame can substantially impair people’s confidence in engaging with services. Some research participants described feeling that they did not ‘deserve’ treatment, declining to seek help at a time of real need.

3. More empathic approaches from health and social care practitioners to facilitate trusting relationships. Previous experiences of stigmatisation and discrimination from service providers tended to result in people anticipating future mistreatment from health and social care professionals. This led to: (i) late presentation to services (often only when a health crisis occurred); (ii) communication barriers with health and social care practitioners; and (iii) severely limited opportunities for end of life care planning.

4. Greater clarity in communicating end of life issues, with all services providing opportunities for people to discuss fears of dying and make informed decisions so that personal wishes could be acknowledged.

FAMILY, FRIENDS AND CARERS

Families were often unaware of the extent of their relative’s illness until their health had substantially deteriorated. This was often due to their relative denying or minimising their substance-related health problem, avoiding healthcare services, or only seeking medical help at a late stage. For some families, their relative’s end of life condition was a shock and they needed clear communication from health and social care practitioners to understand how unwell their relative was. However, many families described multiple ‘missed opportunities’ for professionals to identify palliative and end of life care needs in the days, weeks, months and years before their relative’s death. Many also gave examples of poor care, more commonly from primary and acute care staff. Where professionals communicated clearly with families, and delivered compassionate care including recognition of their needs, the difficulty of their situation could be minimised.

Other families anticipated their relative’s ill health or death. They faced demanding caring responsibilities, which impacted negatively upon their own health and wellbeing. Families wanted support to help them deal with both the stigma they felt from having a relative die from a substance-related condition, and the longer-term effects of substance-related bereavement. Yet health and social care practitioners often had little recognition of families’ support needs as carers — whether before, at the time of, or after their relative’s death.

Practitioner training or new delivery approaches are needed to meet the many needs of this group of families.

RAPID EVIDENCE ASSESSMENT (REA)

We conducted an REA between 1 January 2004 and 1 August 2016 to explore the peer-reviewed evidence base in relation to end of life care and problematic substance use. There were 60 papers meeting the inclusion criteria. We found there was only a small and diverse literature that lacked depth and quality. Using recurring themes to categorise findings, the papers fell into three broad groups focusing on:

1. pain and symptom management (25 papers)
2. homeless and marginalised groups (24 papers)
3. alcohol-related papers (7 papers)

There were four ‘other’ papers that did not fall into the above categories. The headline findings of the REA included:

- Some clinicians might under-prescribe pain medication to people with problematic substance use because of an inappropriate fear of opioid misuse or a fear of overdose.
- Harm reduction appears to be a more appropriate treatment approach for this group of people than abstinence-focused treatment, and there is a need to involve local substance specialists to help people reach more realistic harm reduction goals.
- More creative support is needed for homeless and marginalised groups. This could include delivering services in settings familiar to service users (eg shelter/hostel-based care, end of life services in needle exchanges).
- Piloting supervised consumption of substitute medication with homeless people at the end of life by health and social care staff could be trialled in order to ensure safety and to avoid medication diversion and stockpiling of opioids.
- Health and social care staff need to assess and treat alcohol withdrawal at the end of life.

Most authors recommended universal screening for substance misuse in palliative and end of life care settings using a validated assessment tool. The screening and subsequent monitoring would then give clinicians the opportunity to communicate with patients effectively about their medication and treatment and generate effective supportive strategies alongside them. Assessing mental health needs and regular symptom reviews was also highlighted.
As a community partner, VoiceBox Inc’s main contribution was to extend the reach and access beyond the scope of the other practice partners – in particular, people with direct experience who may sit outside the parameters of substance use services and palliative care services. The process was a blend of initiation and opportunity, facilitation and exploration, responsiveness and reactivity to circumstances and diverse contexts. Working closely with the MMU researchers was key to the approach.

**COMMUNITY OF PRACTICE**
At the request of practitioners, we have set up a Community of Practice for people wanting to share information on policy and practice around end of life care for people with AOD problems.

Please send us your email address if you would like to be added to this group.

**FURTHER INFORMATION**
The project website gives an overview of the project as well as providing links to our project reports and digital resources. These can be found at: https://endoflifecaresubstanceuse.com/reports-and-resources-2/

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