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When “Good Enough” Isn’t Good Enough: Interdisciplinary Perspectives on Caring for Adults Using Substances at the End of Life

Lorna Templeton¹ · Sarah Galvani²  · Marian Peacock³

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Abstract

This paper draws on data from one strand of a six-strand, exploratory study on end of life care for adults using substances (AUS). It presents data from the key informant (KI) strand of the study that aimed to identify models of practice in the UK. Participant recruitment was purposive and used snowball sampling to recruit KIs from a range of health and social care, policy and practice backgrounds. Data were collected in 2016–2017 from 20 KIs using a semi-structured interview approach. The data were analysed using template analysis as discussed by King (2012). This paper focusses on two of seven resulting themes, namely “Definitions and perceptions of key terms” in end of life care and substance use sectors, and “Service commissioning and delivery.” The KIs demonstrated dedicated individual practice, but were critical of the systemic failure to provide adequate direction and resources to support people using substances at the end of their lives.

Keywords End of life · Palliative · Substance use · Alcohol · Drugs · Dying

While there are clear disparities between poorer and richer populations in relation to life expectancy, overall life expectancy has increased in the last 10 years (Marmot et al. 2020). One of the implications of this increased longevity is a rise in the number of years spent living with poor health, chronic illness and life-limiting conditions (Bell and Marmot 2017). This places increased demands on palliative and end of life (EoL) care services (Etkind et al. 2017). In the UK, evidence shows the specific and complex EoL needs of some population cohorts and

✉ Sarah Galvani
s.galvani@mmu.ac.uk

¹ Independent Research Consultant, Bristol, England, UK

² Manchester Metropolitan University, Geoffrey Manton Building, Rosamond Street West, Manchester, England M15 6LL, UK

³ Edge Hill University, Ormskirk, England, UK

conditions are under-recognised and unmet (Aldridge et al. 2017; Care Quality Commission (CQC) 2016; Jones et al. 2016; Marie Curie 2015).

One such cohort is people using alcohol or other drugs (hereafter, “substances”), a group about whom there is growing public health concern in relation to morbidity and mortality. For example, there were over 7600 alcohol-specific deaths (Office for National Statistics (ONS) 2018) and more than 4350 deaths involving legal and illegal drugs registered in England and Wales in 2017, with the latter being the highest number since records began (ONS 2019). Over 11,500 people died with an underlying cause of liver disease in England in 2014 (Public Health England n.d.) with mortality associated with (alcohol-related) liver disease increasing in the UK while decreasing elsewhere in Europe (Pimpin et al. 2018). There are also concerns about morbidity and mortality in both older and younger age groups of people using substances (Beynon et al. 2010; Kaplan et al. 2012; Rao and Roche 2017). However, overall, very little is known about the prevalence of life-limiting illnesses in adults using substances worldwide (Witham et al. 2019). In addition, because life-limiting conditions may be either directly or indirectly related to the substance use, it is extremely difficult to estimate the scale of need for EoL care among this people using substances (Webb et al. 2018). Nevertheless, the high rates of overall morbidity and mortality suggest that the target population is likely to be a sizeable one and is set to grow further with increasing longevity.

In the UK, there are a number of barriers that impede the development of best quality EoL care for adults using substances (AUS). First, the commissioning climate in which substance use treatment services are commissioned and delivered rarely makes reference to EoL care (Advisory Council on the Misuse of Drugs 2017; Adfam 2017; Alcohol Concern/Alcohol Research UK 2018). Second, there are inequalities in palliative and EoL care which mean that specific groups (for example, people from black and minority ethnic groups, or people in the criminal justice system) are not identified as EoL in a timely way (CQC 2016). This can mean that planning for EoL does not happen and peoples’ needs are not met (Aldridge et al. 2017; CQC 2016; Marie Curie 2015). Third, a lack of consensus around defining palliative care means that it is predominantly oriented towards cancer and the last 12 months of life, and often lacks the more nuanced understanding which is needed when considering people with non-cancer conditions as is common in the substance-using population (Mitchell et al. 2015; Van Mechelen et al. 2012). Finally, the concept of addiction recovery, widely used by treatment services in the UK (UK Drug Policy Commission 2008), does not account for those who are unable to “recover” as it emphasises “health and wellbeing” (UKDPC 2008: 6).

In order to further understand this complex and under-researched area, we completed a programme of exploratory, mixed methods, research on EoL care for adults using substances. While the key informant (KI) strand of the research presented here aimed to identify existing models of practice in the UK, the whole programme of research was designed to address the following research questions:

1. What does the existing international research and wider literature tell us about current practice responses to end of life care for people with substance problems?
2. How many people with substance-related chronic or terminal illness are receiving, or in need of, end of life care in the UK?
3. How do people with substance problems, past or present, experience end of life care?
4. How do family members, friends and carers (FMFCs) experience the care and support provided to their loved one?

5. To what extent have services been responsive to FMFCs own support needs?
6. What are the challenges and opportunities professionals face supporting people with substance problems and chronic or terminal illness?

The research consisted of six strands: a rapid evidence assessment of existing research; a scoping review of existing databases to better understand prevalence; and four strands covering the perspectives of people with lived experience (PWE); family, friends and carers (FFCs); professionals; and key informants. This paper presents findings from the latter, namely the KI interviews which aimed to investigate existing models of practice and care for adults using substances needing end of life care and their FFCs.

Methods

Sampling Strategy

The sampling strategy for the KI interviews was a purposive one (Palinkas et al. 2015). This is a form of sampling adopted when people are recruited for their particular knowledge or expertise (Marshall 1996). It comprised (i) a small group of existing contacts, and (ii) new contacts recommended by the study's practice partner group. These individuals then suggested other potential interviewees to us who were working in this field, so some snowball sampling (Naderifar et al. 2017) was used to compile a third group of interviewees. Our aim was to secure a range of different perspectives (policy, practice, research) including individuals working nationally and locally from both the substance use and EoL fields to inform the various strands of our project. Therefore, it was a highly diverse group of informants in terms of their disciplines, roles and geographical locations. In order to be inclusive and reflect a range of perspectives in our KI data, our KI interviews also sought the perspectives of a person with lived experience and a family whose relative had died through substance-related illness. KIs are often considered professionals only, but given this research was designed to explore EoL care and AUS from a range of perspectives, the team decided to include both a PWLE and family members as KIs,

The original target was for approximately 15 interviews—this number was set pragmatically rather than with an aim of data saturation or comprehensiveness and was appropriate for the exploratory nature of the project. A researcher undertook all but one of the interviews (the principal investigator (PI) conducted one interview). The majority of the interviews were conducted face-to-face with two conducted using Skype online communication software.

Data Collection

Given the exploratory nature of the research among a diverse range of KIs, the method of data collection needed to offer flexibility while retaining a focus on the combined topics of end of life care and substance use. We therefore adopted a semi-structured interview approach to data collection (DeJonckheere and Vaughn 2019). This is a form of interviewing that allows for the researcher to direct the interview focus but leaves enough space for prompts and follow-up questions where appropriate (DeJonckheere and Vaughn 2019). A semi-structured approach

meant that the interviews could focus on a priori topics set out in the topic guide while also allowing for flexibility to explore and develop the participants' responses.

Given the dearth of existing information at this point in the project, the interview guide was informed by the project's research questions, and included the KI's experience of working, or living with, both substance use and EoL needs.

Ethical approval was obtained from Manchester Metropolitan University, and all interviewees gave informed, written consent. No further governance procedures were necessary as no NHS patients or local authority service users were interviewed—just a small selection of staff (NHS Health Research Authority 2020) with others from a range of third sector organisations. All interviews were audio-recorded and transcribed by an external agency that had signed a non-disclosure agreement provided by the University.

Data Analysis

The analysis of the data used a template analysis approach (King 2012) and thematic networks to help visualise the emerging codes and themes (Attride-Stirling 2001). This was to allow similarities and differences to be identified in the data. Template analysis is a form of thematic analysis that combines structure with flexibility and is commonly used to analyse individual interviews (King 2012). It can combine “top down” with “bottom up” analysis and allows the use of both a priori themes and themes that emerge from the analysis itself.

The analysis followed a number of stages. First, approximately two-thirds of the interviews conducted with were read. Second, emerging themes were noted, and a draft coding template was prepared alongside a thematic map which organised the emerging ideas visually. A small number of broad a priori codes were considered at this stage (e.g. commissioning or uncertain illness trajectories), based on discussions with the researcher who completed the majority of the interviews, the interview topic guide, and broad knowledge of the area and some of its literature. Third, as analysis progressed, the a priori codes were integrated into major or minor themes. Fourth, the remainder of the professional interviews were then read, with some minor changes made to the coding template (e.g. collapsing or removing codes, adding a small number of codes). Fifth, the template was reviewed by the co-investigator of the strand, and the PI, before it was transferred to an online software, QSR NVivo 10. Sixth, all the interviews were coded in NVivo in a grounded, bottom up way, with a small number of final changes made, such as removing a small number of codes that had not been used.

Overall, the analysis was challenging because of the diversity of the interviewee cohort. This meant that the early stages of analysis involved reading more of the transcripts than is standard in template analysis so that the most representative template could be developed (King 2012).

Findings

Sample Profile

A total of 18 interviews were completed with 20 individuals. The majority of interviewees were from England and Wales with two from Scotland. Interviewees consisted of 16 professionals (two were interviewed together), one person with lived experience (PWE) and three family members (FFCs) who were interviewed together and talked about the same relative

who had died. This paper focusses on the professionals' interviews only, as the KI data for PWE and FFCs is being written up separately, alongside the wider PWE and FFC data. The 16 professional interviewees were from a diverse range of professional backgrounds. To ensure anonymity, they have been categorised into four broad professional groupings as follows:

1. **Group 1 (N = 8)**—Health and social care professionals (HSCP) working directly, and at a local level, with AUS at, or near, the end of their lives (hereafter, “frontline” professionals). This group included a GP (with special interest in substance use), a specialist EoL social worker, three clinical nurse specialists, a homelessness nurse specialist working in a hostel, a prison worker and a specialist in EoL care and homelessness at a homeless charity.
2. **Group 2 (N = 4)**—Senior health and social care professionals working at a local level—a CEO of a drug/alcohol treatment service, a palliative care consultant, a consultant hepatologist and a registered premises manager (bail hostel).
3. **Group 3 (N = 2)**—Those working nationally in policy or commissioning—one in substance use and one in palliative and EoL care.
4. **Group 4 (N = 2)**—Other professionals—a coroner and a researcher.

Identified Themes

As a result of the template analysis process detailed above, seven broad themes were identified (see Fig. 1). These were grouped further into two thematic clusters: “The wider policy landscape of EoL care for AUS”, and “Engaging and responding to AUS at EoL”.

This paper focusses on two themes from “The wider landscape” cluster: (i) Definitions and perceptions of key terms, and (ii) the service commissioning and delivery landscape. Together they raise important considerations for the policy agenda in responding appropriately to people using substances at, or near, the end of life. The five remaining themes will be addressed in future publications. To ensure anonymity, direct quotations from the interviewees are identified by their membership of the four groupings listed above.

Definitions and Perceptions of Key Terms

It was clear from the KI interviews that the key terms used in both substance use and EoL specialist sectors served as potential barriers to the development of joint policy or practice. The KIs reflected on the dominant terms used within their policy or practice work, namely “end of life care”, “palliative care” and substance use “recovery”. In particular, they discussed how such terms can facilitate or impede care for people using substances at, or near, end of life, in relation to (i) joint working, (ii) identifying care needs and (iii) service access.

For example, KIs from the EoL care sector thought that “palliative care” was often perceived by other people as only about dying and that this narrow perception would be an obstacle for joint working between the substance use sector—which is dominated by a “recovery” discourse—and EoL services. On the surface at least, the language and terminology of “dying” and “recovery” appear to be at opposite ends of the spectrum. Furthermore, identifying who is at the “end of life” or “dying” is complex for people using substances.

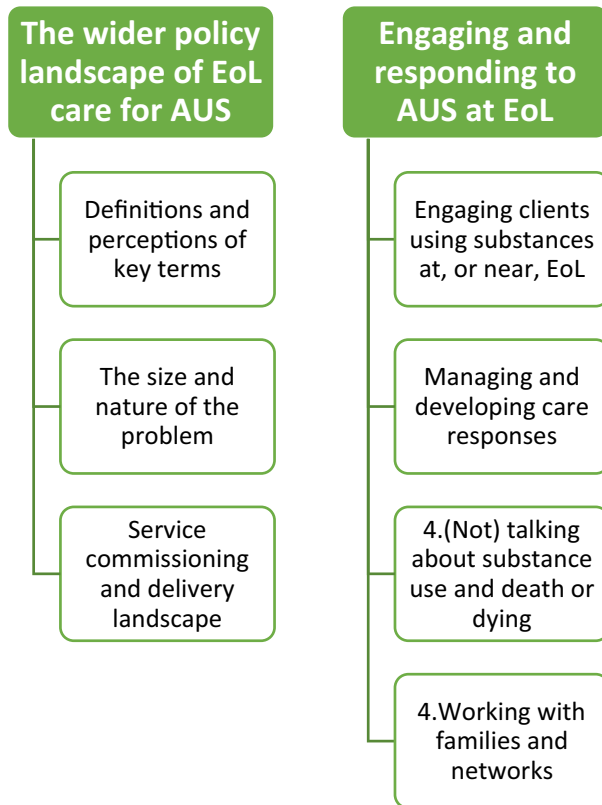


Fig. 1 Two thematic clusters and seven sub-themes

Some EoL conditions have a clear disease progression, for example, cancers. However, some terminal health conditions that are common among people with long histories of substance use do not have a clear disease progression, for example, liver disease.

“So the steady decline that you see in malignancy [cancer], which is where palliative and end of life care developed as a specialty ... is not there in liver disease, so that unpredictability of the trajectory, which can sometimes even result in survival from the disease, makes it very difficult” (Group 2—Senior HSCP)

The additional impact of the person’s ongoing substance use can make it even more difficult to distinguish between the symptoms of a fluctuating health condition or the fluctuating effects of the substance, as some substances will mask or mimic the symptoms of declining health. One interviewee stated that palliative care, when interpreted as “dying”, can potentially damage interactions with challenging and complex patients who may feel that their situation is hopeless and continue with damaging levels of substance use.

In the substance use sector, some interviewees felt that the “recovery” paradigm, which is currently dominant in UK substance use treatment settings, had limited applicability to people at, or near, the end of their lives making the delivery of substance use treatment extremely difficult. KIs discussed the relevance and appropriateness of recovery-oriented approaches for

those who cannot or do not want to “recover” (reduce or be abstinent) from their substance use. Some KIs stated that people would rather be supported to use substances at the end of their life and not engage with substance use interventions framed in a recovery discourse. Furthermore, some people who were ill would not be able to fully participate—physically or mentally—in activities that may emphasise looking to the future through employment, rebuilding relationships with family members or housing support. These are often the focus of recovery programmes, associated service targets, and performance indicators. A focus or insistence on recovery can alienate clients:

“within the drugs movement now, there is this big push around recovery, recovery.... that even more marginalises them because they think, ‘I can’t recover and what do I do?’” (Group 2—Senior HSCP)

Related to the definitional challenges for this group of people were concerns about service commissioning and delivery within that discourse and definitional framework.

Service Commissioning and Delivery Landscape

In the UK, the commissioning of substance use services has been in flux in the past decade as government departments have been restructured and responsibility for commissioning has moved from central to local government. Funding for substance use services has been reduced and contracts with service providers have been subject to repeated rounds of re-procurement (ACMD 2017). Some substance use services have ceased to exist while others struggle to survive. End of life care commissioning has not been affected in quite the same way, relying as much of it does, on charitable donations for its third sector provision. It is within this context that KIs spoke about the service commissioning and delivery landscape.

Overall, the KIs had a negative view of the current national commissioning arrangements for both substance use treatment, and palliative and EoL care in the UK. They felt that substance use policy does not sufficiently address EoL care, and vice versa. Problems included the shift from protected to localised budgets, the increased frequency of recommissioning cycles, integrated drug and alcohol services which were seen to have a particularly negative impact on alcohol services, and addiction not being prioritised as a commissioning issue or including consideration of EoL:

“...unless we get the pathways commissioned it really is going to be about trying to convince GPs to incorporate this client group into their current palliative care arrangements” (Group 1—Frontline HSCP)

With regard to commissioning for palliative and EoL care, KIs said that commissioning does not consider needs in specific areas such as substance use. Furthermore, interviewees felt that commissioning is biased towards pain management rather than broader aspects of care. One interviewee said that funding constraints means that a national programme of work to address the needs of AUS is not possible, meaning that there is a need to think creatively about how to integrate the issue with other national programmes of work, such as mental health, homelessness and prisoners:

“[we] can only champion so many things...but certainly I think substance abuse as a precursor to all kinds of conditions, all kinds of diseases, that lead to end stage and death and dying, is an obvious path” (Group 3—Policy & Commissioning Professionals)

Interviewees outlined a number of issues which they felt affected national and local commissioning and practice, service fragmentation and inflexibility, inadequate resources and shifting frameworks of service delivery (Fig. 2).

First, interviewees thought that fragmentation was rife at both national and local levels, and at sector, organisation and service levels. This was seen as particularly challenging when people were presenting with more complex needs:

“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” (Group 3—Policy & Commissioning Professionals)

The lack of continuity between services resulted in a lack of joined up care for people using substances at, or near, the end of their lives.

Second, interviewees talked about inflexibility in services, specifically around appointment times, and how services were not able to do enough to ease access for vulnerable and chaotic patients:

“A health service that is designed around schedules and appointments, [doesn’t] necessarily work for people who have more chaotic lifestyles ...” (Group 3—Policy & Commissioning Professionals)

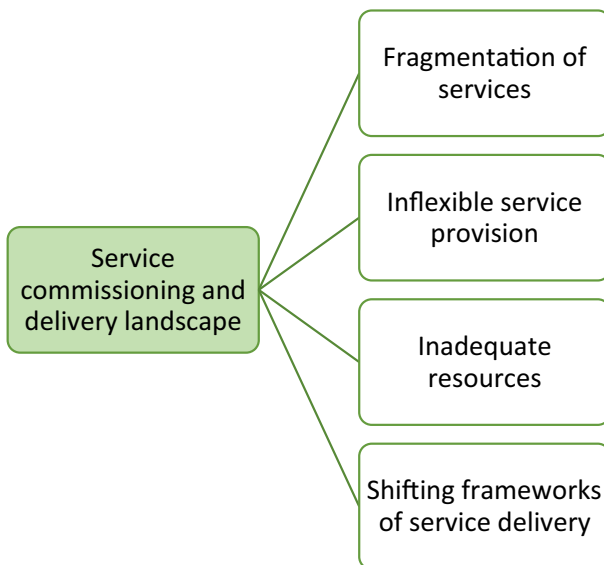


Fig. 2 Service commissioning and delivery landscape: sub-themes

This also impacted on relationships between professionals who found it hard to develop effective ways of collaborative working where systems were so inflexible, particularly when other specialist colleagues were already over stretched.

Third, many interviewees were pessimistic about services and sectors that were seen to be struggling with financial resources and capacity, frequent recommissioning and a lack of pooled budget arrangements. They also described working reactively rather than having the capacity to focus on prevention and early intervention:

“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’” (Group 1—Frontline HSCP)

Far from increasing collaboration as a way to respond to increasing demands and shrinking budgets, some KIs said competition had increased as providers were set against providers in chasing the same resources.

Fourth, interviewees raised a number of issues about how services are developed and delivered, including whether dedicated roles spanning substance use and EoL care are needed, whether there should be integrated and/or specialist commissioning across sectors, and whether care should be centralised or community-focused.

The decrease in resources and the subsequent attempts to change models of delivery to get more out of less resource resulted in a sense of constant change which KIs felt damaged service delivery and thereby damaged care.

Discussion

This research set out to explore existing practice models for adults using substances at the end of life, and their families. KIs voiced concerns about (a) the definitions and concepts of palliative and EoL care and (b) the recovery-focussed discourse in substance use. They were viewed as getting in the way of adequate care for people using substances at, or near, the end of their lives. Palliative and EoL care are perceived as services for people where there is a predictable trajectory from serious ill health to death (Dixon et al. 2015); in substance use services, the expectation is towards recovery and reintegration into the community (H.M. Government 2017). It is possible that these two dominant paradigms are impeding the development of the most appropriate response to people with co-occurring substance use and EoL care needs. For adults using substances at, or near, the end of their lives, the dominant discourse of recovery is unhelpful at best. While it continues to be a widely contested and debated concept (Radcliffe and Tompkins 2016; White 2007), there is a need for substance use services to adopt a new outcome measure that focusses on the person’s quality of life and what the person wants for their death, learning from policy and practice standards devised by the EoL sector (Bausewein et al. 2016). This shift could be easily underpinned by concepts of harm reduction and person-centred practice that have previously been at the core of substance use service delivery (McNeil et al. 2012).

Similarly, there is a need to consider how the concept of palliative and EoL care might need to be flexibly applied (Van Mechelen et al. 2012) to respond to the fluctuating needs of this people using substances at, or near, the end of their lives. One definition of palliative care may not be sufficient for the range of conditions it must apply to (Mitchell et al. 2015). For example, the “surprise question”—“Would you be surprised if the person dies within the next few months, weeks, days?”

(Gold Standards Framework (GSF) and the Royal College of General Practitioners (RCGP) 2011)—could be a useful tool for substance use professionals to use, but it could also cover the majority of people using substances in treatment with multiple, co-existing health conditions. It has also been criticised as having poor to modest accuracy as a predictive tool, particularly for non-cancer conditions (Downar et al. 2017). The definition must apply to conditions where palliative and EoL phases cannot be confidently predicted, and where substance use can complicate someone's progress on standard prognostic indicators (GSF and RCGP 2011).

While dominant discourses in both EoL and substance use services have relevance to policy and commissioning in these specialist areas, it is the wider political climate that provided the landscape for the professional practice of our interviewees. This included the impact of EoL funding cuts and disinvestment, retendering cycles, staff attrition and the loss of capacity and resources, lack of political focus and concerns about the cessation of ring-fenced public health funding (Adfam 2017; ACMD 2017; Alcohol Concern/Alcohol Research UK 2018; Marie Curie 2015). In a broader climate of austerity and concerns about funding for adult social care in the UK (Association of Directors of Adult Social Services 2019), the risk is high that people using substances will remain a group of people who will suffer health inequalities at the end of life. Indeed, they are not currently acknowledged in policy and guidance literature on addressing health inequalities in end of life care in the UK (CQC 2016) or international, English language literature (Witham et al. 2019). Other marginalised groups who have been recognised as disadvantaged at the end of life include people with dementia, people with learning disabilities and homeless people (CQC 2016). However, for AUS, research has shown it is the additional stigma, negative stereotyping and negative judgement from professionals (Hammarlund et al. 2018) that can prevent people from accessing primary or acute care or from being referred for particular end of life services (Ashby et al. 2018). With an ageing population in most countries around the world (World Health Organisation (WHO) 2018) as well as evidence showing an increase in alcohol-related morbidity among older people, there is an expectation that people who use substances are a growing population in need of palliative and end of life care. Policy and commissioning must keep pace.

There are both strengths and limitations to this KI dataset. A key strength is that it has, for the first time, brought together the experiences of a diverse cohort of individuals from a range of settings and disciplines working with the overlapping issues of problematic substance use and EoL care. However, the diversity of the interviewee cohort made analysis challenging, and there is possibly some interviewee selection bias as interviewees were generally known or suggested to us. It is not possible to generalise from these findings alone. However, many of the findings align with findings from the other strands of our project (Galvani, 2018), and with other similar research (Witham et al. 2019), indicating a consistency of experience at very least.

Implications

Future public health policy in EoL or substance use needs to move away from homogenising and dichotomous terminology to language that is more inclusive and transparent. Key terms need to be developed that foreground the inclusion of more marginalised groups, such as people using substances, and avoid misunderstanding and narrow interpretations. Harm reduction in EoL care would fit just as well as it does within substance use policy and practice. Substance use policy needs

to change its recovery-focussed language and revert to language of harm reduction in order to apply to people across the life course, including people who are using substances at, or near, the end of their lives. The argument that “recovery” is what you want it to be still does not work for people living with a terminal illness. Importantly, however, is the need for policy from both areas of specialism to include the “other” issue. Based on current evidence, the exponential increase in people presenting to substance use services with life-limiting illness, and those presenting to EoL and palliative care when still using substances, will continue, and policy must support practitioners and practice responses. Future policy should also think creatively about changing the service provision models, particularly in substance use services, to models that provide greater flexibility of service response and allow for a quality community-based care response to people at the end of their lives.

While this group of specialists were critical of policy and service commissioning roles to improve end of life care for AUS, they were committed to finding solutions and keen to share and hear about good practice. This commitment and expertise needs to be harnessed and disseminated to service providers.

Conclusion

The KI interviews have given a unique, and hitherto unknown, insight into the experiences and challenges of working with adults using substances at, or near, the end of their lives.

Interviewees highlighted numerous challenges in the area of policy and commissioning and gave indications as to the impact such challenges are having on the identification of people using substances at, or near, the end of their lives, and the delivery of timely, efficient, joined up and compassionate care. Overall, interviewees identified similar issues for policy and commissioning 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 and multiple pressures which often means that this group of patients, and their families, is unlikely to receive the right care at the right time, delivered in the right way. However, the interviews also contained optimism and hope for how the needs of a sizeable, but largely neglected, group of adults and their families, should be best met.

Declarations Research with participants in this study were in conducted in accordance with the ethical standards of Manchester Metropolitan University and the UK’s national *Research Governance Framework for Health and Social Care* (Department of Health, 2005).

Conflict of Interest The authors declare no conflict of interest.

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