Life's hard and then you die: the end-of-life priorities of people experiencing homelessness in the UK

Wendy Ann Webb, Theresa Mitchell, Paul Snelling and Brian Nyatanga

Abstract

Background: People experiencing homelessness often die young and without adequate support. In the UK, they fail to access palliative care services and their end-of-life priorities remain poorly understood. **Aims:** To explore the end-of-life concerns, fears, preferences and priorities of a sample of people experiencing homelessness in the UK. **Methods:** This is an interpretive phenomenology. Data collected through semi-structured, audio-recorded, face-to-face interviews with 21 homeless participants in the UK were analysed iteratively using thematic analysis. Findings have been interpreted through the lens of Merleau-Ponty's philosophy. **Results:** Eight themes are reported: spiritual concerns; practical concerns; fear of needing care; fear of being forgotten; preference for dying suddenly; preference for being somewhere comfortable where people know me; prioritising autonomy and self-determination; and prioritising authenticity. **Conclusion:** A strengths-based, trauma-informed, person-centred, collaborative 'compassionate community' approach to care is recommended for people experiencing homelessness at end of life.

Key words: ● Homelessness ● end of life ● priorities ● compassionate community ● Merleau-Ponty

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Homelessness is a global health issue. It continues to be a growing problem both in the UK and internationally (MacWilliams et al, 2014; Foundation Abbé Pierre, 2017; Fitzpatrick et al, 2019). The eighth annual report of the Homeless Monitor in England reports a year-on-year rise in homelessness since 2010, with currently in excess of 150 000 people experiencing homelessness in the UK (Fitzpatrick et al, 2019). This number includes those who are rough sleeping or in temporary hostels, refuges and shelters, or are in unsuitable or overcrowded conditions. However, it can be difficult to estimate global statistics due to differences between countries in the way that statistics are recorded. There are also many definitions of homelessness and this adds to the complexity of reporting statistics. The media, for example, tend to equate homelessness with rooflessness or literally sleeping rough on the streets. However this does not include the 'hidden homeless', such as those who are sleeping rough, squatting illegally, sofa surfing, living in hostels, bed and breakfast accommodation, temporary accommodation, such as women's refuges, or those who are considered to be unsuitably housed (Fitzpatrick et al, 2019).

End-of-life care and homelessness

In the UK, people experiencing homelessness die, on average, 30 years younger than the general population. The average age of death for a homeless person is 47 years for a male and 43 years for a female, compared with general population statistics of 74 years for a male and 80 years for a female (Thomas, 2012). When homeless people die, it is often not as a direct result of homelessness, such as exposure in cold weather. It is most often because of advanced liver disease, respiratory and cardiac disease, blood-borne infections, such as HIV and hepatitis, and alcohol and drug-related complications (Thomas, 2012). They often die in hostels, on the streets or in shop doorways, with no support from palliative care services. There are many documented challenges and complexities around the provision of palliative and end-of-life (EoL) care for people experiencing homelessness (Klop et al, 2018; Shulman et al, 2018), yet further exploration of these challenges is beyond the scope of this article.

In the UK, the Department of Health (DH) clearly states that both palliative and EoL care should be universally accessible and inclusive (DH, 2008) and readily available at the point of

need 'wherever the person may be' and 'irrespective of socioeconomic deprivation'(DH, 2008). Numerous DH palliative care guidelines (DH, 2008; 2009; 2010; Choice in End of Life Care Programme Board, 2015) have also been developed, which focus on improving quality of care and choice, enhancing service provision and achieving positive outcomes in terms of a 'good death' for all palliative patients, wherever they choose to die. Nevertheless, some of the more vulnerable, marginalised people in our communities, including people experiencing homelessness, are still unable to access the palliative and EoL care services they need (Gunaratnam, 2006; Nyatanga, 2012; Care Quality Commission (CQC), 2017) and their particular EoL needs and preferences remain unclear and relatively unexplored, particularly here in the UK (CQC, 2016).

End-of-life priorities and preferences within the general (housed) population

The evidence that most people would prefer to die at home is extensive and consistent (Heyland et al, 2006; Volker and Wu, 2011; Higginson et al, 2012; 2013; Khan et al, 2013; Choice in End of Life Care Programme Board, 2015; Macmillan Cancer Support, 2017). However, there are many diverse factors affecting EoL decision-making, such as culture and ethnicity (Duffy et al, 2006; Barnato et al, 2009; Wicher and Meeker, 2012), spiritual beliefs (Shah et al, 2008; Wicher and Meeker, 2012; Delgado-Guay et al, 2016), sexual orientation (Harding et al, 2012; Elk, 2015) and personality (Lattie et al, 2016) and sometimes there is discordance between an individual's values and their stated preferences for EoL care (Heyland et al, 2016). Nevertheless, despite these variances, research into EoL priorities of the general population reveals a number of common priorities, such as: physical comfort and freedom from pain; the presence of family and strengthening of family relationships; peaceful acceptance of EoL and spiritual concerns being met; relieving stress or burden on the family; avoiding a prolonged period of dying; and achieving a sense of control at a time of great uncertainty (Singer et al, 1999; Heyland et al, 2006; Bausewein et al, 2013; Khan et al, 2013; Van Scoy et al, 2016).

End-of-life priorities and preferences within the homeless population

While much is known about EoL preferences within the general population, the same cannot be said about the homeless population.

Worldwide, there is a dearth of literature relating specifically to academic studies exploring advance care planning issues and the EoL preferences, concerns and priorities of people experiencing homelessness. What is known about these topics is based on research conducted in Canada and the USA, and the findings of such studies are not necessarily transferable to the homeless population in the UK, or indeed elsewhere. There are currently no such studies reported in the UK. Despite a reduced life expectancy, the homeless population is ageing and, without a clear evidence base around advance care planning and preferences and priorities, 'it is impossible for homeless advocates, clinicians and policy-makers to understand how best to meet the population's needs' (Sumalinog et al, 2016). This is a clear need for further research into the specific preferences of homeless people around EoL care. Hudson et al (2016) called for further research, 'in particular, research outside North America, that provides a platform for the voices of homeless people around the complexities of palliative care for this population'. Furthermore, Ko and Nelson-Becker (2014) suggested that future research should aim to recruit older homeless adults from multiple sites and settings in order to yield diverse perspectives on advance care planning issues. This multi-site project, exploring the EoL priorities of a sample of older homeless adults in the UK, responds directly to this call.

Aim

The aim of this interpretive phenomenological study is to explore the EoL concerns, fears, preferences and priorities of a sample of people experiencing homelessness in the UK.

Methods
Recruitment of participants

This is a multi-site study focusing on a purposive sample of homeless participants from several different services for people experiencing homelessness. In total, 21 participants were recruited to the study via gatekeepers, who were the managers of the homeless services they were accessing, rather than by direct invitation from the researcher. The concept of 'information power' helped to guide sample size by facilitating a shift of attention from numerical input of participants to the expected contribution of new knowledge that will result from the analysis (Malterud et al, 2016). The principle of 'meaning saturation' (Hennink et al, 2016) was also used

'I wrote my biography … and I got two copies'

Table 1. Demographic summary	
Attribute	**Number of participants (*n*=21)**
Male	17
Female	4
Age	
40–45 years	3
45–50 years	5
50-55 years	2
55–60 years	8
65+ years	3
Interviewed at hostels (across two counties)	9
Interviewed at day centres/soup kitchens (across four counties)	12

to guide sample size. Meaning saturation refers to the point at which the meaning of a set of identified themes is clearly understood, rather than the point at which every possible theme has been identified. Data collection continued until both sufficient 'information power' (Malterud et al, 2016) and a high level of 'meaning saturation' (Hennink et al, 2016) was achieved. This point was reached when 21 interviews had been conducted and transcribed. *Table 1* offers a demographic summary of the research sample.

Data collection

Data were collected using in-depth interviews with participants. Semi-structured, 1:1,
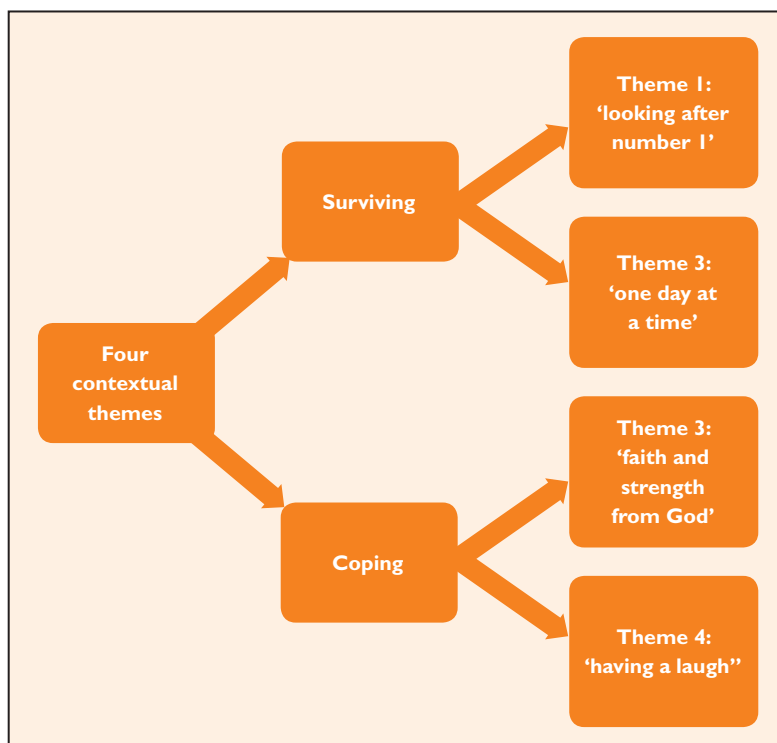

Figure 1. Contextual data themes

audio-recorded interviews took place with all 21 participants. This number of in-depth interviews generated a vast amount of complex data. For this reason, the Computer Assisted Qualitative Data Analysis Software (CAQDAS) package, NVivo, was chosen to facilitate data management (Braun and Clarke, 2006; Creswell, 2013). In total, five research sites were visited and all were staffed centres providing services specifically for people experiencing homelessness. These five sites were spread over four counties and included three hostels providing temporary accommodation, a drop-in day centre and an evening 'soup kitchen'. An interview schedule was prepared in advance and used to guide the conversation. With four sections of open-ended questions, the interview schedule was used to explore matters of life in general and then priorities, preferences and concerns around illness, death and dying and finally, preferences regarding care after death and funeral arrangements. The audio recordings were transcribed verbatim and uploaded to NVivo (Version 12Pro) to facilitate data management.

Data analysis

Data were analysed using the qualitative method of thematic analysis (TA) (Braun and Clarke, 2006; 2013), which involved searching across the qualitative data set (the 21 interview transcripts) to identify significant recurring patterns of meaning. This research is underpinned by the philosophy of Merleau-Ponty, so the uniquely situated, embodied, sociocultural perspective of each participant was sought without attending to previously identified themes in the literature. As such, a data-driven, inductive approach to the TA was adopted, searching the whole data set and initially coding all themes. Working through all 21 transcripts on NVivo, a total of 71 initial codes was initially generated.

All 71 initial codes were then scrutinised. Some codes became themes. Some codes were amalgamated. Some were re-named. A list of candidate themes was generated and then reviewed. Every extract was reviewed to verify that it belonged to that theme. Initial candidate themes were then reconsidered in relation to the whole data set. All data were re-read to check whether the themes worked in relation to the whole data set and whether the themes constituted findings of the research, in that they answered the research question. This process enabled the research findings to be separated from the rest of the data. Some data, which did not constitute research findings, were still deemed important and were coded as 'contextual data'.

The lens of Merleau-Ponty's philosophy

The philosophy of Maurice Merleau-Ponty underpins this interpretive phenomenological research, As such, some of Merleau-Ponty's key concepts (*Table 2*), or dimensions of being human, have been used as a framework to organise, understand and interpret the data, serving as lenses through which the findings have been interpreted and discussed, However, detailed discussion around his philosophy is beyond the scope of this paper.

Ethical considerations

In addition to the ethical issues that are common to all research projects involving human participants, this project, exploring a potentially sensitive topic with a marginalised group, raised numerous additional ethical concerns. These concerns were carefully and individually addressed, and the project received full ethics approval from the University of Worcester Health and Sciences Research Ethics Committee (HSREC CODE: SH16170026-R).

Results

Contextual data: four themes

The design of the interview schedule encouraged participants to talk freely. As a result, participants often chose to share candid accounts of past trauma and abuse. These outpourings of unsolicited disclosure demonstrated that participants wanted the context of their lives to be understood. Ultimately, four contextual themes were reported that do not constitute findings of this research, as they do not answer the research question, but which do offer important background information that underpins the findings. These contextual themes are shown in *Figure 1*.

These contextual themes outline the context in which the research participants live out their daily lives and are discussed later to facilitate a deeper understanding of the findings of the study, interpreted using Merleau-Ponty's philosophy of embodied perception.

Research findings: eight themes

Figure 2 presents the findings of the research within eight themes. These themes have been arranged under four headings to tell the story of participants' concerns, fears, preferences and priorities regarding EoL. In the interests of participant anonymity, all names used in this section are pseudonyms.

Theme 1: Spiritual concerns/'Why me?'

In this article, spiritual concerns are understood in
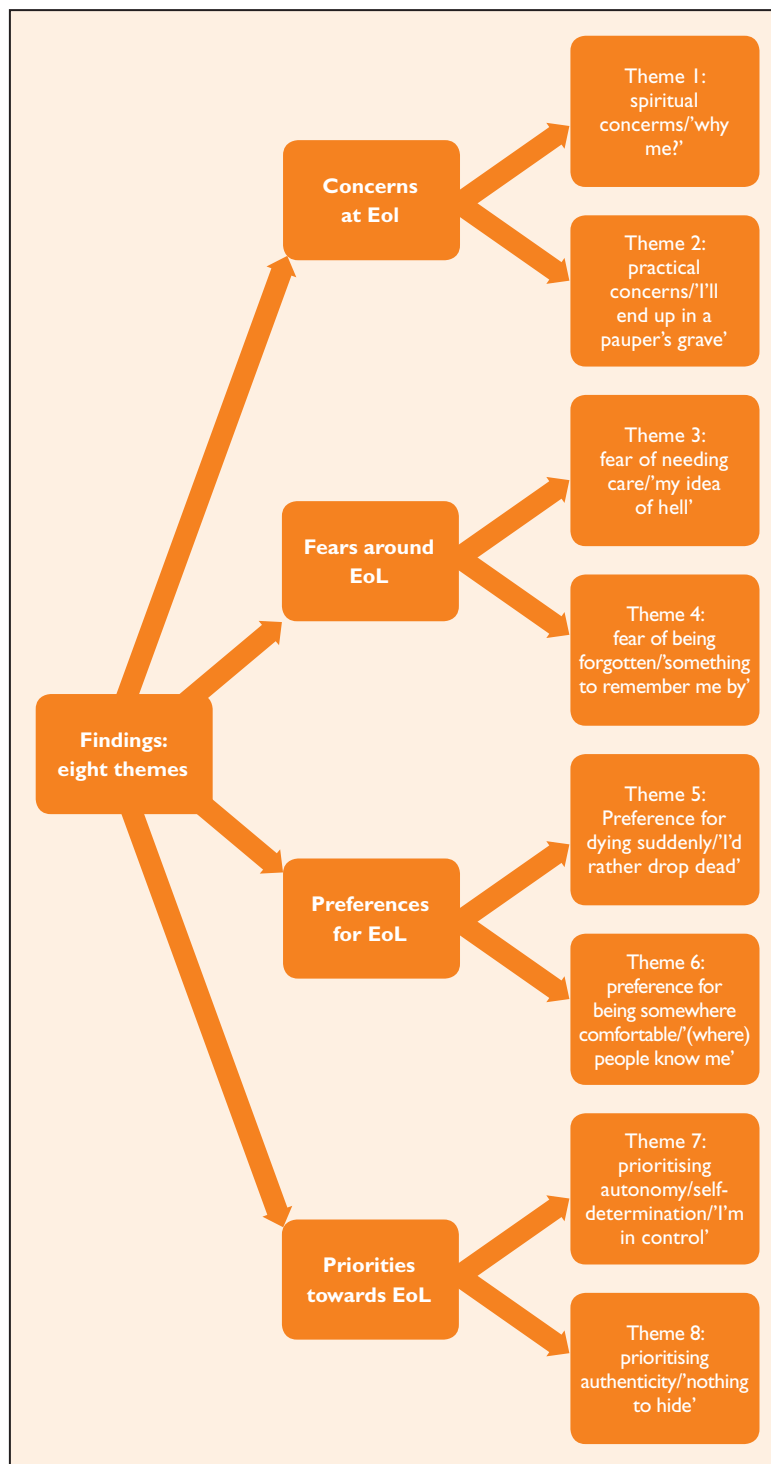

Figure 2. Findings presented within eight themess

the broadest context to include faith issues and other highly subjective, existential issues such as suffering, meaning, purpose, regret, forgiveness and reconciliation. Spiritual concerns were important for the participants when they thought about their own EoL. Participants discussed a wide range of spiritual issues, including unanswered questions, regrets, forgiveness and reconciliation. However, the most prominent

spiritual concern they wanted to discuss was the issue of suffering. Participants repeatedly voiced 'Why me?'. For example, Ray pondered:

> **'Why do we all have to go through that suffering?'**

Ghaz raised similar questions about past trauma and abuse:

> **'Why did it happen that I went through that twice in my life?'**

While Sean voiced his confusion, directing his question directly towards God:

> **'Why? why did ya let this happen [God]?'**

Within palliative care literature, 'why me?' questions are recognised as a potential indicator of spiritual distress (Bhatnagar et al, 2017; Velosa et al, 2017). In this study, these questions reveal the spiritual distress that people experiencing homelessness feel when they think about EoL.

Theme 2: Practical concerns/'I shall end up in a pauper's grave'

Participants were also concerned about practical matters, such as dying outside, funeral costs and body disposal. A recurrent theme was that of the so-called and still feared 'pauper's funeral'; a term used in the UK to denote a public health funded funeral, which carries the same stigma as the 19th century workhouses where the poorest of the poor were sent to work until they died. Jack told me that he was afraid of the thought of dying outside or alone. He explained:

> **'... because I've seen quite a few people die [outdoors] and erm ... that makes me nervous'**

The cost of funerals is also a worry. Alex's solution was:

> **'just make a fire and chuck me on it'.**

Justin's was similar:

> **'just put me on a fire ... and put the ashes on a council waste tip'.**

Whereas Sean offered this alternative suggestion:

> **'Just throw me on the scrap heap'.**

Participants wanted more information to be made available to them about the practical help they may receive as their health declines towards EoL.

Theme 3: Fear of needing care/'My idea of hell'

Participants placed a high value on physical independence and self-sufficiency. As such, the need for nursing care towards EoL was sometimes feared more than death itself. For George, independence is everything. He explained how he would hate to need 24-hour care, saying:

> **'ending up in social care? That's my idea of hell'**

Derek articulated a similar sentiment in a powerful way:

> **'send me to the vet, the way I feel'**

Needing nursing care was feared. However, in the event of a medical emergency (e.g. cardiac arrest), participants did seem to want to receive life-saving treatment. In this small study, more participants wanted to be resuscitated than not. Faced with a life or death situation, survival was the ultimate priority. Most participants were clear that they would want doctors to try and resuscitate them in the event of cardiac arrest. Leonard seemed genuinely amazed at the question and answered in this way:

> **'of course I'd want to be resuscitated! Yeah course I do! I've had two heart attacks as it is'**

Only Derek, Justin and Ray expressed a clear desire not to be resuscitated. Contextual data illustrated participants' survival mentality. Having survived much trauma, neglect and abuse, participants tend to live in survival mode. As such, they welcome life-saving treatments.

Theme 4: Being forgotten/'Something to remember me by'

Although many participants were estranged from their relatives and had no one they could identify as 'next of kin' or 'significant other', there remained a strong need to be counted as significant. Participants wanted to be remembered by others and not forgotten after death. Sentiments expressed ranged from wanting people to tell stories of their life after they had died, to wanting their presence to be almost tangibly felt after death. Derek, at 67 years of age, was the third oldest participant in the study. He told me he has no belongings because:

> **'everything's gone ... being homeless for ... for that time'.**

Derek knows that he will have 'a pauper's funeral' with no mourners. Yet Derek told me this:

>   'I wrote my biography … and I got two copies'

Such was his desire to be remembered, and not forgotten, after death.

Theme 5: Preference for dying suddenly/ '[I'd] rather drop dead'

Participants did not generally think about dying and had no real desire to make advance plans for EoL; they were too busy focusing on survival. In fact, participants would prefer to die suddenly and without any warning, rather than being given a palliative diagnosis. In one interview question, participants were asked to imagine how they would prefer to spend their final moments of life: What would those moments look like, if they could choose? Ray was the only participant who said he would prefer to know in advance if he was dying, so that he could prepare and write letters to his estranged children:

>   'yeah I could write those letters …'

Other participants hoped for a quick, painless death. Justin articulated his wishes in the following way:

>   '[I'd] rather drop dead on the floor really'

Theme 6: Preference for being somewhere comfortable/'[where] people know me'

Generally, participants did not worry about death. Neither did they fret about symptoms at EoL. Furthermore, no single, preferred place for EoL care was articulated. What appeared to matter most to participants was the attitudes of those providing the care, rather than where they would be cared for. They indicated that they appreciated being treated with genuine kindness and respect and that they wanted to be known, understood and accepted in the place where they are living or dying. Finding it difficult to trust people, they expressed the need to feel comfortable with caregivers or helpers. They wanted to be somewhere they do not feel judged or misunderstood. Barry said:

>   'it has to be somewhere you felt comfortable',

while Tina told me hesitantly about her preferred place of care for EoL and the reason behind this:

>   'I know it's a bit odd … but [I'd rather be here] at the [name of] hostel. Because you feel safe and secure here.'

Theme 7: Prioritising autonomy/ self-determination/ 'I'm in control'

Participants articulated the importance of feeling in control. For example, when asked about medication to treat agitation at EoL, Cliff explained why he would decline such medication:

>   'I'd rather … I'd rather know what I'm doing'

Most participants said that they would refuse such medication. Wherever possible, participants would rather feel in control. Trusting no one, participants strove to stay alert and in control. Some participants had also had restrictions placed on their personal freedom and the choices available to them. Jack, Alex, Sean, Owen, Dan, Tina, Peter and Saul have had experience of being detained against their wishes (either in prison or in a psychiatric unit). After such an experience, being in control and maintaining independence and self-determination can assume greater importance. Physical independence, self-sufficiency and freedom of choice can be cherished even more. As such, hospital admissions were often avoided, and participants said they sometimes chose to self-discharge against medical advice.

Theme 8: Prioritising authenticity/ 'nothing to hide'

Participants shared deeply and candidly during the interviews, providing raw details of some of the most traumatic experiences they had lived through. They wanted me to understand the context of their everyday lives, before answering any of my questions. There was no pretence. No masks were worn. Criminal history, drug and alcohol addictions and known 'character defects' (Owen's words) were shared openly. As individuals, they were refreshingly authentic. Leonard and Alex even used the exact same phrase repeatedly:

>   'I got nothing to hide'.

Box 1. Merleau-Ponty's key concepts

- Temporality and perspective
- The influence of childhood experiences
- Perception and embodiment
- Situated freedom
- Intentionality and relationality
- Ambiguity and mystery

Overall, when considering their own EoL care, participants appeared to prioritise authenticity. Despising hypocrisy and pretence, they indicated their preference for being around others they considered to be equally genuine and authentic; people who wear no masks.

Discussion

Through the lens of Merleau-Ponty's dimensions of being human

According to Merleau-Ponty's philosophy, each participant is an embodied perceiver and, therefore, sees things in a unique way that is influenced by individual life experiences and circumstances. Detailed exploration of Merleau-Ponty's philosophy is beyond the scope of this article. However, the findings of this research have been viewed through the lens of Merleau-Ponty's philosophy, with reference to some of his key concepts, described as dimensions of being human (*Box 1*)

Temporality and perspective: the context of time and space

Contextual data are crucial to understanding the findings of this research. In fact, Merleau-Ponty would argue that without the contextual data, we would be unable to adequately understand or interpret the perspectives shared by participants. For example, in understanding that participants have survived much trauma and abuse, we can appreciate that they 'look after number one' (contextual theme 1) because they have learned that no one else necessarily will. In survival mode, they live 'one day at a time' (contextual theme 2) focusing on essential, basic, daily needs. Furthermore, the abuse participants experienced at the hands of people who should have provided care and protection explains why participants had difficulty trusting people and are inherently suspicious of others' motives. Such experiences, while traumatic, had also taught participants to be resilient. They had learned to cope in high-risk environments. 'Faith and strength from God' (contextual theme 3) pulled some participants through tough times, while 'having a laugh' (contextual theme 4) represented a powerful and effective coping mechanism adopted by almost all participants. It is against this backdrop, and within this context, that all other perspectives unfold. Merleau-Ponty's philosophy requires that these contextual themes are borne in mind when analysing data and interpreting the research findings.

The influence of childhood experiences

Merleau-Ponty's philosophy acknowledged that adverse childhood experiences (ACEs) shape the way the individual learns to make sense of the world and impact on attitudes and behaviours in life, as well as health outcomes. Participants in this study had experienced significant levels of trauma and abuse in early life, which is likely to have impacted upon EoL decision-making. The contextual data help to explain why participants in this research tended not to think about EoL issues, and when specifically asked to do so, they expressed some concerns, fears, preferences and priorities for EoL that differ from those expressed by the general (housed) population.

Perception and embodiment: the impact of homelessness on end-of-life priorities

Embodiment is central to the philosophy of Merleau-Ponty. He asserted that perception is a multi-sensory, bodily experience and that the mind and body are intertwined (Merleau-Ponty, 2004); co-dependent and inseparable. Through this lens of embodied perception, it is possible to understand how the experience of being homeless (lacking the basic physical resources of a safe, stable shelter, regular meals and adequate clothing) can impact on every other aspect of life, including EoL concerns, preferences and priorities.

It is also possible to appreciate why, living in survival mode, advance care planning discussions around EoL are often avoided and why the alternative 'parallel planning' approach is promoted for use with people experiencing homelessness with advanced ill health (Hudson et al, 2017; Shulman et al, 2018). Parallel planning is simply hoping and planning for the best, alongside planning for the worst. It is a particularly helpful tool because it is not dependent upon the person being willing to talk about EoL and can also be used effectively where issues of addiction sit alongside homelessness.

Furthermore, through the lens of embodied perception, we can also understand why participants would prefer to simply 'drop dead' one day (theme 5: preference for dying suddenly), rather than receive a palliative diagnosis and live with the added concern that they are approaching EoL. For some, life is so hard that death is perceived as a welcome release from the daily struggle to survive.

Situated freedom: feeling in control

According to Merleau-Ponty, we all have 'situated freedom'. In other words, we are all constrained to some extent by the circumstances in which we find ourselves and

these circumstances impact upon perspective, attitude and decision-making. People experiencing homelessness, with a history of multiple ACEs, can feel doubly constrained by past experiences and current circumstances. Some participants in this research, having been detained in custody or psychiatric units, had experienced further restrictions on their personal freedom. As a result, being in control and maintaining independence and self-determination had assumed greater importance. They wanted to have the freedom to exercise choice regarding how to live and how to die, even if those choices appear unwise or unconventional to others. For this population it is important for limited, 'situated freedom' to be maximised toward EoL, rather than reduced further. Noting these priorities of autonomy or self-determination and authenticity, services and clinicians supporting people experiencing homelessness towards EoL in the UK are advised to incorporate the principles of person-centred care into their practice.

Intentionality and relationality

Merleau-Ponty described humanity as a complex web of intertwined relations. He emphasised the importance of relationality. Findings from this study revealed that participants wanted to be real and authentic in relationship with others. They loathed hypocrisy and preferred to be around others with similar values, wanting people who are involved in their lives, especially support workers and caregivers, to be equally authentic. This priority clearly underpinned the preferences they expressed for place of care at EoL. They wanedt to be in a place where they are known, understood and accepted; somewhere they felt comfortable (theme 6). They also loathed pretence and found it difficult to trust people. As such, they needed to feel at ease with their caregivers or helpers. In short, they wanted to be somewhere they did not feel judged or misunderstood; somewhere they could be authentic.

Therefore, services to support people experiencing homelessness at EoL may need to be developed within the familiar hostel setting. Such services are advised to take account of past trauma, adverse childhood experiences and the psycho-socio-spiritual experience of homelessness. As such, a trauma-informed approach to care is recommended (Hales et al, 2018), which embodies the following five guiding values of trauma-informed care: safety, trustworthiness, choice, collaboration and empowerment. Such an approach to care would respond to the concerns and priorities around EoL, expressed by participants in this study.

Another aspect of relationality deemed important for participants in this study was that of being remembered by others after death. In response to this finding, it is recommended that hostel staff and drop-in centre staff hold regular memorial services to enable staff and residents to remember, and to say farewell to friends within the community who have died; respecting and dignifying the deceased and comforting the living (Klop et al, 2018).

Ambiguity and mystery

Merleau-Ponty's philosophy focused frequently on ambiguity, mystery, meaning and unanswered questions. Contextual data revealed that faith and spiritual belief are important issues for participants (contextual theme 3), helping them to cope with life's daily challenges. Findings (theme 1, 'why me?') confirm that spiritual matters are important for participants when they think about their own end of life. As such, the presence of chaplains and spiritual support workers in hostels, or attached to homelessness services, could result in enhanced opportunities for people to reflect upon difficult life experiences and explore important psycho-spiritual issues, thereby enhancing the provision of holistic, person-centred care for people experiencing homelessness towards EoL.

Summary of new knowledge and implications for practice

The pauper's funeral: a previously unreported concern

Concerns around funeral costs and the so-called pauper's funeral represents a previously unreported concern in the international literature on EoL issues within the homeless population. This concern appears to be unique to the UK homeless participants in this study. However, just like homeless people in the USA, people experiencing homelessness in the UK can also worry about being forgotten after death and not having their lives counted as significant; this theme has been reported in other international studies (Song et al, 2007; Håkanson et al, 2015; Tobey et al, 2017) with one Swedish study mentioning a memorial service being held to ensure that 'the person's life and death were acknowledged in a dignified and respectful way' (Håkanson et al, 2015). In order to address the funeral and remembrance concerns expressed, accessible information about dignified funeral options, for people with no funds and no next of kin to pay for a funeral, should be readily available in hostel settings and day centres.

The 'face of care': more important than 'place of care'

People experiencing homelessness appear to be much more concerned with the personal attributes of the people who would provide care for them (the 'face of care'), rather than the actual 'place of care'. Carer authenticity was certainly a priority for participants, and this appears to represent a previously unreported finding, unique to this UK study. However, in the UK, as elsewhere, being understood and not judged is a priority for people in care situations who are experiencing homelessness, and this supports the findings of international research (Klop et al, 2018). These findings strengthen the argument for palliative care to be provided by familiar hostel staff, in a familiar hostel setting, and for peer-support workers to be trained in palliative care.

Traditional palliative care services: an unattractive resource?

Within the general, housed population, hospices and palliative care units are generally highly regarded and viewed as an attractive option for EoL care (Hospice UK, 2017), particularly if home is not a suitable option. However, people experiencing homelessness may not share the same perspective and they may not be interested in accessing traditional palliative care services. A new approach to care is required.

From hostels to hubs: the hostel as the hub of a compassionate palliative care community within a local neighbourhood

The necessary new approach will require fresh vision and a culture shift, for it represents a movement. The first steps in establishing hostels as hubs of compassionate palliative care communities include: developing and deepening existing networks and community connections; strengthening and developing an assets-based community development and compassionate communities approach to EoL care; training hospice and palliative care staff in issues around homeless health; training hostel staff in palliative and EoL care issues; bridging gaps and joining the dots in existing services; and establishing multi-disciplinary team working across both generalist and specialist services (including substance misuse and mental health services).

Working to improve access to traditional hospice and palliative care services will not necessarily improve the provision of EoL care for people experiencing homelessness in the UK because people experiencing homelessness seem to have some priorities that differ to those of the general housed population. As such, it is necessary to move away from traditional models of advance care planning and palliative care provision towards developing new pathways for supporting this population. A strengths-based, trauma-informed, person-centred, collaborative, 'compassionate community' approach to care is recommended; one which utilises the principles of parallel planning (Hudson et al, 2016) and supports people experiencing homelessness to remain in familiar, supportive environments as health deteriorates; one which also supports a harm-reduction, strengths-based approach to care.

If such an approach is facilitated, the hostel could be established as the hub of a compassionate palliative care community within a local neighbourhood. Such hubs could support the development of peer support workers from within the homeless community, while drawing on wider community of volunteer assets and resources, supplemented by professional health care services, including mental health, substance misuses, specialist palliative care, chaplaincy and spiritual/pastoral support workers.

This model of 'compassionate community', operating from a hostel hub sits comfortably within the current public health approach to EoL care (National Palliative and End of Life Care Partnership, 2015; Abel, 2018; Mills and Rosenberg, 2019) and offers the possibility of completely transforming EoL care for people experiencing homelessness. It will require vision, passion, commitment, collaboration, motivation and a can-do approach. However, the benefits would extend far beyond the reach of the people experiencing homelessness at EoL that it primarily sought to nurture. Resilient community networks would be developed, spanning across workplaces, colleges, universities, community centres, churches, temples and health and social care organisations; networks that nurture and recognise the value of connectedness; networks that facilitate genuine relationality; one-to-one, person-centred encounters that affirm personhood and worth. These compassionate communities would have the best opportunity of nurturing, 're-humanising' and even re-integrating into community life, people who have been dehumanised through marginalisation, abuse, trauma and impoverished relations.

Community life would be strengthened. People across every demographic of society would have the opportunity to participate as active citizens, contributing their gifts locally to society and building new relationships within the hostel hub 'compassionate community'. This powerful, grassroots movement has immense potential to change not only the EoL experience of people

experiencing homelessness, but also to change lives. After all, social relationships are possibly the most powerful interventions that we have (Russell and Abel, 2019).

Strengths and limitations

The strength of this research lies predominantly in awareness of issues of rigour. Every effort has been made to ensure that congruence exists between methodology and philosophical framework, so that each stage, from proposal through to the discussion and interpretation of findings, is grounded in the philosophy of Merleau-Ponty. These processes add strength to this study, enhancing credibility. Nevertheless, there are several limitations to this study. Despite attempts to capture the largest, most heterogeneous sample possible by recruiting participants from five different organisations and sites, including an evening soup kitchen, a day service centre, and three hostels, across a wide geographical area spanning four counties, some homeless people were excluded from this study. First, inclusion criteria for participants required them to be able to speak English. This means that the perspectives of the growing non-English-speaking community of people experiencing homelessness in the UK was not captured. Ethical and safety considerations also required that participants were interviewed in staffed premises serving the homeless population, rather than out on the streets. For this reason, the perspectives of people sleeping rough who do not engage with homelessness services have also not been captured in this study. Furthermore, the requirement that participants were 'sober enough to take part' may have excluded some participants with serious addictions.

Future research

The discussion section closed with the suggestion that social relationships are perhaps one of the most powerful interventions we have. This statement correlates strongly with Merleau-Ponty's closing statement in *Phenomenology of*

Perception (Merleau-Ponty, 2012) that human relationships are ultimately what matter most. Therefore, suggestions for future research focus on peer-support relationships within compassionate communities. The 'compassionate community' approach to EoL care within a hostel setting would be strengthened if suitable peer-support workers could be identified and offered training in navigating the local healthcare system and in supporting hostel residents with advanced ill health or palliative care needs. Currently there is no evidence base around palliative/EoL training specifically for peer-support workers in the hostel setting. Research in this area could bring extremely valuable insights, strengthening the evidence base for the suggestions made.

Conclusion

People experiencing homelessness consistently fail to access palliative care services. They are dying young, with very little dignity and without adequate support. This study, an interpretive phenomenology underpinned by the philosophy of Maurice Merleau-Ponty, represents the first attempt to explore the EoL concerns, fears,

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Key points

- Spiritual concerns are important for people experiencing homelessness when they consider their own end of life

- The pauper's funeral is a real, but previously unreported, concern for homeless people in the UK. Information around choice in public health funerals would be helpful

- Traditional palliative care services are possibly an unattractive resource for this population, so new approaches to care are required

- A strengths-based, trauma-informed, person-centred, collaborative, 'compassionate community' approach to care is recommended

- The development of peer-support workers, trained in the principles of palliative care, should be actively encouraged and supported within the hostel as the hub of a compassionate palliative care community

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Continuing professional development: reflective questions

- Which of the findings were most surprising to you, and why?

- Think about the challenges of providing quality EoL care for people experiencing homelessness in your locality. How you could work to overcome these challenges?

- How could you (or your team) support a local hostel to become the hub of a compassionate community for people experiencing homelessness with advanced ill health?

preferences and priorities of people experiencing homelessness in the UK. As such, it reveals the previously unreported UK perspective: the EoL concerns, fears, preferences and priorities of people experiencing homelessness within the UK, which could not be assumed to mirror those of people experiencing homelessness within other cultures.

Findings were presented within the following eight themes to tell the stories of participants' concerns, fears, preferences and priorities regarding end of life: spiritual concerns; practical concerns; fear of needing care; fear of being forgotten; preference for dying suddenly; preference for being somewhere comfortable where people know me; prioritising autonomy and self-determination; and prioritising authenticity.

Findings were then viewed and interpreted through the lens of Merleau-Ponty's philosophy using the following six dimensions of his philosophy: temporality and perspective; the influence of childhood experiences; perception and embodiment; situated freedom; intentionality and relationality; and ambiguity and mystery.

Discussion of the findings exposed four key messages: the pauper's funeral is a real but previously unreported concern for homeless people in the UK; the 'face of care' is more important than the 'place of care'; traditional palliative care services are possibly an unattractive resource for this population so new approaches to care are required; and a strengths-based, trauma-informed, person-centred, collaborative, 'compassionate community' approach to care is recommended. This is where the hostel is established as the hub of a compassionate palliative care community within a local neighbourhood and where the development of peer support workers, with lived experience of homelessness, is actively encouraged and supported.

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