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Exploring the idea of death cafés for people experiencing homelessness: a qualitative study

Jodie Crooks[1,2], Gareth Davis[3], Mandy Pattinson[3], Emma Casey[4], Dr Caroline Shulman,[2,3], Professor Kate Flemming[5], Dr Briony Hudson[1,2]

[1]Marie Curie, Policy and Research, UK

[2]University College London, UK

[3]Pathway, UK

[4]Groundswell, UK

[5]Department of Health Sciences, University of York, UK

Abstract

Background: People experiencing homelessness often die at a younger age than the general population. Terminal illness diagnosis often occurs late in its trajectory (if at all), leaving many people experiencing homelessness to die without adequate support from palliative care services. Despite the high rate of bereavement and exposure to death among people experiencing homelessness, there are rarely opportunities for them to reflect on their experiences, thoughts and preferences around death or receive bereavement support.

Death cafés are a global social franchise, providing a space for people to participate in an open group discussion about death, dying and bereavement. They are free to attend and unstructured but facilitated.

Objectives: To explore the idea of death cafés for people experiencing homelessness and raise awareness around the complexities and considerations for death cafés with this population.

Methods: A qualitative study comprising of: interviews with nine professionals with experience of running death cafés for, or supporting people experiencing homelessness in other ways, and two focus groups with nine people with lived experience of homelessness. The research was co-produced with a lived experience co-researcher forming a core part of the research team. Reflexive thematic analysis was utilised to develop themes.

Results: Five themes were developed to highlight the perspectives and experiences of death cafés for people experiencing homelessness: Choice; Expertise in facilitation: recognizing risk and the unstructured nature; Promoting safety against potential risk; Potential benefits; and Potential practical considerations. Themes highlight the need for a trauma informed approach. Death cafés could be impactful, where done well, but they are not without risk.

Conclusions: Death cafés for people experiencing homelessness pose risks that require comprehensive consideration and trauma-informed, expert facilitation. However, this research highlighted that a low-pressure space to explore thoughts around death, dying and bereavement is currently an unmet need within this population.

Strengths and limitations of this study

- This research was co-produced by academic researchers and people with lived experience of homelessness. The lived experience co-researcher role enabled the research to be grounded in direct experience from conceptualisation and throughout. Relationships developed through the coproduction process enabled a relaxed approach to data collection and adds nuance to the analysis.
- Though participants bought a range of experiences, including lived experience of homelessness, further research may be required with a larger sample size.

Background

Homelessness, death & bereavement

People experiencing homelessness (PEH) often die prematurely, at a younger age than the general population (1, 2). People with long histories of homelessness may also experience accelerated ageing, geriatric conditions including frailty as early as in their 40's (3). Many PEH are not recognised as living with advanced ill-health until late in its trajectory, if at all, for reasons including barriers to health service access and unpredictable illness trajectories (4, 5). In the UK in 2023, 1474 people died whilst homeless; the equivalent of one person every six hours (6). Importantly, one study looking at 3882 people experiencing homelessness in England, found that one in three deaths among PEH were due to causes amenable to being prevented or managed by timely and effective healthcare (7).

Many PEH with advanced ill-health die without adequate support from relevant health and social care services (including palliative care), leading to poor experiences and, undignified deaths (5, 8). In addition, the majority of people with multiple-exclusion homelessness have experienced significant trauma in their lives, often starting in childhood: one study reported up to 94% of people who have experienced homelessness also identified as having at least one traumatic experience (9). Furthermore, people experiencing homelessness have often experienced bereavements and loss among their peers: in the UK, the estimated number of deaths among PEH has increased by 54% since 2013 (10).

Despite the high rate of bereavement and exposure to death (11), a high palliative care need and limited access to health and social care services among this group, there are infrequent opportunities for PEH to explore their own thoughts and preferences around death and the end of their lives or receive bereavement support.

Death Cafés

Death cafés have become a social franchise, expanding quickly across Europe, North America, and Australasia; to date, over 16,000 cafés have been held (12). Death cafés aim to provide a space for people to participate in an open group discussion of death alongside refreshments (12). It is a space “where people talk about whatever is on their minds related to death, dying, and bereavement” (13). There is no agenda to the meetings, with no intention of directing people to any course of (medical) action. Importantly, death cafés are intentionally not grief support groups, educational sessions, or a source for information on end-of-life topics (13).

Very few death cafes, thus far, have been tailored towards PEH, despite the outlined increased exposure to death and bereavement. This could be for various reasons, including: low engagement with services; professionals from health and homelessness services and PEH finding death difficult to discuss; and staff fearing that raising issues related to palliative care may be detrimental to service users’ well-being and their relationships with them (14). Furthermore, hostels and other frontline services that support people experiencing homelessness are often recovery-focused in nature, aiming to support people ‘out of’ homelessness. This forms a juxtaposition between the nature of many homelessness services against talking about death and dying, which has been cited as a barrier for PEH to access palliative care services (14).

Therefore, there is a need to increase opportunities for PEH to consider their views and preferences with regards to bereavement support and their own palliative care preferences if/when necessary. When considered in combination, the emotional nature of the topic of death, and the level of complex trauma experienced by many PEH, it is crucial that we understand the views of PEH, and those that support them with regards to death cafés; whether they could be helpful for PEH, and what adaptations may be needed to traditional death café approaches to tailor them for this group.

Aim

This research aimed to explore the idea of death cafés for people experiencing homelessness and raise awareness around the complexities and considerations for death cafés with this population.

The core research question was: what are the views and experiences of people with lived experience of homelessness, health and social care professionals, inclusion health and homelessness professionals, around death cafés for people experiencing homelessness?

Methodology

Design

The perspectives of people with lived experience and professionals were studied using a qualitative approach. An exploratory stance was taken to begin to tentatively investigate an area yet to be addressed by research (15). This approach is defined by Stebbins (16) as “a broad-ranging, purposive undertaking designed to maximize the discovery of generalisations leading to description and understanding of an area of social or psychological life". Reporting of this research is guided by the Reflexive Thematic Analysis Reporting Guidelines (RTARG; (17)). Ethical approval was sought and approved by UCL (ID: 6202/011).

Population

Participants were people with lived experience of homelessness and associated professionals. Homelessness was self-defined by participants and included street homelessness, hostel or other temporary accommodation, and sofa-surfing. Some professionals had been involved in death cafés for PEH previously. However, given the extremely small number of previous death cafés for this group, professionals were eligible to participate if they had experience of working closely with PEH. Participant demographics can be seen in Table 1.

Recruitment

Existing networks were consulted using snowball and word of mouth methods to share the opportunity to participate with professionals who may be eligible and interested in the study. An experienced Peer Coordinator from Groundswell, a UK leading peer advocacy organization led the recruitment of people with lived experience of homelessness.

Data collection

Data were collected between March and May 2024. Online, semi-structured interviews were conducted with professionals via Microsoft Teams. These were co-delivered by the principal researcher (JC) and the lived-experience co-researcher (GD). A semi-structured approach was selected to "permit interviews to be focused while still giving the investigator the autonomy to explore pertinent ideas that may come up in the course of the interview" (18). Interviews lasted between 30 and 60-minutes.

People with lived experience of homelessness attended one of two online focus groups. These lasted for 90-minutes and were organized and facilitated by Groundswell. Discussions were semi-structured using a pre-defined list of prompts, and covered topics such as reviewing example advertisements for death cafés, perceived benefits and concerns surrounding death cafés for PEH, and practicalities such as venue, professionals and safety. Interviews and focus groups were audio recorded and transcribed.

Data analysis

Given the exploratory nature of the research generated from a relatively small number of participants' individual perspectives, inductive reflexive thematic analysis was chosen to emphasise the inescapable subjectivity of data interpretation (19).

The six recursive phases of reflexive thematic analysis guided the inductive interpretation of data. JC familiarised herself with all transcripts, before generating codes. GD also engaged in this process for 5/11 transcripts. Codes from each researcher were reviewed and combined where appropriate. JC, GD and BH generated key themes, before collaborating to refine, define and name themes (19).

Patient and Public Involvement

Patient and Public Involvement (PPI) was central to this research project. A lived experience co-researcher was employed on a part-time (0.1 FTE), fixed term basis. They were recruited through a partner organization, Pathway. One aspect of Pathway's work is to support people with lived experience of homelessness to be involved in research. The lived experience co-researcher was a core member of the research team, involved in conceptualising the study and its methodology. developing the interview and focus group guides, co-interviewing during the data collection phase, independently coding transcripts and supporting analysis, and inputting to this manuscript. To plan and carry out this involvement, we utilised our previously published TIFFIN recommendations, aiming to promote the safe involvement of PWLE homelessness in palliative care research (20).

Additionally, four further people with lived experience of homelessness supported the analysis. Recruited through the working partnership with Pathway. PPI contributors gave feedback on initial themes and supported refining of the themes, through an additional online focus group. All PPI contributors were reimbursed in line with the NIHR INVOLVE guidelines (21).

Results

Nine interviews and two focus groups with a total of 18 participants (9 professionals, 9 PWLE) were carried out. Professionals were from a diverse range of backgrounds including hospice staff, clinicians, mental health professionals and staff from homelessness services. Five out of the nine professionals had experience of facilitating, observing, or attending a death café for PEH. Five themes were generated from the combined data: choice, expertise in facilitation, promoting safety against potential risk, potential benefits, potential practical considerations. These themes represent the participants experiences of each stage of a death café, including preparation, delivery/attendance, and aftercare. They highlight both participants interest and concerns regarding death cafés for this population.

Table 1. Participant demographics

Demographic	Categories	Number
Professionals		
Gender	Female	9
	Male	0
Employer organisation type	Charity	3
	Hospice	2
	Housing Association / Hostel	4
Role	Palliative care professional	3
	Clinical psychologist	2
	Counsellor	1
	Social worker	1
	Hostel staff	2
	Registered nurse	1
People with lived experience homelessness		
Gender	Female	6

Male	3

Choice

Choice was seen as integral to the concept of death cafés for people experiencing homelessness. There was unanimous agreement from participants that attendance cannot be compulsory, due to the potential risks associated with forcing people to face the emotionality of this topic, particularly where they are likely to have experienced previous trauma. To ensure autonomy in decision making is upheld, clear information should be provided on what a death café is, and isn't as people cannot make an informed choice about attendance without adequate information.

As with any population, not everyone experiencing homelessness will want to attend a death café. Participants discussed how many people experiencing homelessness often face severe exclusion and barriers to accessing services, thus may not wish to engage with a death café.

"The crew that I'm working with at the minute are the severe and multiple disadvantaged. So my cohort are the people who do not engage. They don't engage with their GP. They don't engage with secondary care…they will struggle with anything like this." (Registered Nurse, hostel)

Professionals highlighted a reason for not wishing to engage was people's perceptions that it was unnecessary, because they were *'not dying yet*'. However, PWLE homelessness expressed how they were often aware of their heightened risk of death, making attending a death café *"too morbid" (PWLE)* and perceived as needless.

"I wouldn't have bothered going. It's more likely for me to die when I'm on the streets, and I knew that, so I wouldn't have wanted to go into somewhere and speak about death when I was homeless." (PWLE)

For people experiencing homelessness, their willingness to attend may depend on what is happening in their life at that time. Both professionals and PWLE suggested that death cafés "*might attract the people who are further along their recovery journey [out of homelessness and/or addiction] … who are ready for something like this" (Palliative Care professional).*

Expertise in facilitation: recognizing risk and the unstructured nature

Participants emphasised the importance of a confident, skilled facilitator to lead and manage a death café. It was recognised that more than one facilitator may be required, bringing expertise from professionals from different backgrounds together, for example professionals across the fields of palliative care, homelessness services, or mental health working in partnership. Professionals acknowledged that their experience in one area did not automatically mean they were a suitable or appropriate facilitator: *"just because a couple of us here have got good knowledge of death, or grief or palliative care doesn't necessarily mean that we're absolutely ace at facilitating groups like this." (Palliative Care Professional).*

Importantly, participants highlighted that facilitation needs to be trauma informed. It is important that professionals within a death café can recognise the potential for conversations to trigger an emotional response, or lead to behaviours that may be harmful. That is, attendees can't be expected to *"leave their* *complex trauma and chaotic lifestyles at the door" (Social Worker).* Therefore, due to the typically unstructured nature of death cafés, confident facilitation is key to "*steer conversations if they look like they're becoming too difficult or if there are things which you can hear are likely to trigger other people." (Clinician and researcher).*

This skilled facilitation was also thought to be integral to the wellbeing support provided both during and after death cafés. Traditionally, death cafés don't offer wellbeing follow-ups. However, all participants agreed that the availability of post-session support was important: due to the potential for emotional or sensitive discussions during death cafés, coupled with the limited support networks or previous negative experiences that attendees may have. There was a perceived risk that following a death cafe, people may return to the streets or temporary accommodation whilst experiencing distress. Professionals experienced in facilitating death cafés within a hostel environment described methods for providing support, such as debriefs, informal check ins, or staying behind following a session.

"If you are facilitating these sorts of conversations we always hang around for about 20 minutes after just with a cup of tea. It's just something that somebody needs to chat around in private or they've been distressed by the conversations that have taken place" (Bereavement Counsellor).

Signposting people to where they may access support was debated by participants. PWLE homelessness often felt they were 'over-signposted', leading to them feeling dismissed. However, professionals highlighted the necessity of helping people to access further support and suggested non-tokenistic signposting such as referrals made at the time, if possible, or continued support in accessing services, rather than just providing information could be beneficial.

Promoting safety against potential risk

Participants discussed the need to manage the possibility that attendees may have active addiction issues. First, they outlined the need to consider how to manage people at varying stages of recovery. People with lived experience expressed that attending a session during a period of sobriety, with a peer who was actively using substances, could be triggering. Furthermore, participants recognised the need to manage intoxication at sessions. The general consensus was that banning substance use is likely to be ineffective, as it would lead people who were dependent on alcohol to simply not attend. Instead, both professionals and PWLE homelessness participants suggested that facilitators would need to be confident making behaviour-based decisions on attendance on a case-by-case basis.

"If somebody's in addiction, there's no point saying to them, you can't be on drink, or you can't be high on drugs. Because that's their life. That's, that's how they function in, in their daily lives. So, having a limit- if you're overly intoxicated, or you're overly aggressive whilst you're that intoxicated" (PWLE)

Participants also discussed the potential risk for re-traumatisation during a death café. The potential for discussions around death to resurface emotions and trigger distress was recognised.

"The process of looking after themselves or exploring their own needs or exploring things that has the propensity to bring up really difficult emotions, then they might not have the skills or resources to be able to sit with and manage and might escalate their drug use or lead to self-harm." (Clinical Psychologist)

Participants outlined how this could be unexpected, even for people who felt able to attend. Given the unstructured nature of a death cafe, it is not possible to control the direction of the conversation, or what topics people may be exposed to: **"***they may be triggered by just being present in this room where people might be opening up, it maybe what other people might say might trigger them" (Clinical Psychologist)*

Potential benefits of death cafés for people experiencing homelessness

Despite the potential for risk, participants agreed that, if done safely, death cafés could provide a space for people experiencing homelessness to talk about death and dying. An absence of other spaces where they felt welcome and free to talk about death and dying without judgement was noted.

"Even though he was only in his 30s, he had a big fear of what was going to happen to him when he died, and there was nowhere he had ever talked about that. But he was able to do so in that group. He felt safe to raise it." (Hostel staff)

An example of a successful, hostel-based death café that had been facilitated by a psychologist working within a community palliative care team, outlined that the event allowed residents to discuss things they hadn't previously: *"Some of the discussions that came up were areas that absolutely were concerning the residents, but they never felt that they were things they could raise with their support worker." (Hostel staff)*

Both professionals and people with lived experience felt that through holding a death cafe, a supportive space was created in which existing power dynamics were reduced: *"there was no staff versus residents, everyone was able to share experiences and share on a very level playing field really." (Palliative care clinician)*. Furthermore, people experiencing homelessness expressed that they *"didn't know (hostel staff) cared that much*" (PWLE) about them, with regards to holding the event and sharing their own thoughts and feelings.

Participants highlighted how a death cafe could provide an opportunity for attendees to begin to consider their own preferences for end of life. Although attendees at a death café traditionally will not complete any formal advance care planning, it could be a catalyst for initial exploration of preferences. For some people, in time, this could be a pre-cursor to an openness to having more detailed discussions about making their preferences for care and treatment known.

"Some people might not be able to think about it, but for some people, having a space to at least talk about how they want to live and how they want to be and what they want to do in the rest of their life." (Clinical Psychologist)

Potential practical considerations

Initial considerations regarding practicalities for holding a death cafe were discussed. Given the exploratory nature of this research, these should not be considered as recommendations for developing a death café, but points for consideration.

Both professionals and PWLE homelessness expressed a preference for fewer attendees per session, allowing space for each attendee to talk without the environment feeling overwhelming: *“It shouldn’t be crowded because if it is crowded there’ll be so many questions and opinions and you wouldn’t, there’d be panic.” (PWLE).*

People with lived experience highlighted they would be put off by negative, dark imagery in advertisements for the event. Instead, they outlined a preference for colourful advertisement (such as *“a sunset, a tree of life...a bit light and bright with a bit of hope to it” (PWLE)* that importantly, contained clear information on key elements of the session.

To create a safe space, participants discussed the need for ground rules, termed as a *“group agreement” (PWLE).* Participants suggested this could cover topics such as confidentiality, substance use and being respectful, with the aim *“to try and help people understand that this is part of keeping the safe space. If we didn’t have this rule, then it could lead to the space and individuals feeling more unsafe.” (Clinical Psychologist).*

When considering venues, some participants felt it would be beneficial to hold the event somewhere known to potential attendees: *“I would always think that a Death Cafe should be undertaken where somebody is comfortable and where a locality that they are familiar with but also their needs. So, for example if it's for people living in a hostel, I would think you go to a hostel.” (Palliative care clinician).* However, some participants had concerns that this may *“force other people who don't want to necessarily participate to feel that they're being forced to participate.” (Hostel staff).*

Participants debated their preferred name for these events. Some felt that ‘death café’ was too negative, intimidating and off-putting.

“I think because we, as a society, don’t talk about death, so death’s quite taboo. So even the word ‘death’ would probably be quite off-putting to some people." (Registered nurse)

"Going into something that sort of says death café, forgive the pun, is like adding another nail to the coffin, isn’t it?" (PWLE)

However, others expressed the need for clear, transparent naming to ensure participants understood the brief of the event and were able to give informed consent to attend. *"If you’re going to call it something different, you would still need to help people to be aware that it is going to be talking about death. Otherwise, they might get a bit of a shock when they turn up" (Palliative care professional).*

Discussion

This qualitative research utilised interviews with professionals and focus groups with people with lived experience of homelessness to explore the idea of death cafés for people experiencing homelessness. Five themes were generated: Choice; Expertise in facilitation: recognizing risk and the unstructured nature; Promoting safety against potential risk; Potential benefits; and Potential practical considerations.

Trauma informed care and wellbeing support

A key finding is the need for death cafés to be trauma informed. This is supported by a plethora of existing evidence connecting trauma and homelessness (22), which consistently recommends that "service providers must consider trauma when designing and offering services to persons with a history of homelessness" (23).

Pertinent to death cafés, people experiencing homelessness have often witnessed a high number of deaths, both prior to and during periods of homelessness (11). Death experienced on the streets can be traumatic (11, 24, 25) and are often sudden or unexpected (26). Furthermore, death of loved ones is often described by people experiencing homelessness as one of the negative "turning points" in their lives, acting as a significant risk factor for their homelessness (27-30). This potential history of traumatic experiences surrounding death, dying and bereavement means that extra considerations of psychological safety are required in the planning, conduct and follow up from of a death café.

Additionally, experiences of trauma can heighten the importance of adequate emotional support in services or spaces such as death cafés. Repeated or multiple traumatic experiences can "overwhelm a person's available internal and/or external resources", leading to ineffective coping and reduced capacity for emotional regulation (31). Clinical psychologists (amongst other professionals) in our research suggested techniques for wellbeing support during sessions (including regular breaks, non-tokenistic signposting and referral at time where possible), and after sessions (such as debriefs, staying in place for one-to-one conversations, and checking in with attendees where they are known).

Facilitation

This research highlights that expert facilitation of death cafés for people experiencing homelessness is essential. This is supported by previous research from death cafés aimed at the general population. Facilitation can promote meaningful conversations and guide attendees through an event. A death café facilitator needs to be able to: "manage speaking turns and pay close attention to conversational flow, group climate, and expressions of emotion" (32).

Traditionally, death cafés propose that facilitators "leave their professional identity at the door", aiming to enable death cafés to be egalitarian spaces. However, based on the findings of this exploratory research, it may be important that facilitators for death cafés for PEH have adequate professional experience that they utilise in the events to support attendees.

Participants felt that no one group of professionals could adequately run a death café for this population and that a multi-disciplinary approach was seen as useful. Previous research has (33) partnered palliative care professionals with hostels aiming to build relationships and introduce the benefits of a palliative approach to support for people with advanced ill health. This found benefits such as better working partnerships, hostel staff feeling empowered to discuss death and dying, and integration of the ethos of each place. A death café was held as part of this work which was found to address some anxiety within hostel staff when discussing death with residents. This supports the findings of this work which suggest co-facilitation across the fields of homelessness and palliative care can be beneficial.

Recommendations

To the best of the authors' knowledge, this is the first research to qualitatively explore the idea of death cafés for people experiencing homelessness. These initial explorations have raised further points for consideration. For example, while recognizing the potential benefits of death cafés for people experiencing homelessness, it is important to fully explore the potential risks and how these can be managed. This may include an in-depth exploration of facilitation of death cafés for people experiencing homelessness, taking into account issues raised in this research such as previous experiences of attendees, risk moderation and the importance to partnership working, with the potential to develop training for facilitators in this space.

Conclusions

As death cafés continue to grow, exploration of their applicability to varying populations facing multi-faceted social exclusion is key. Death cafés for people experiencing homelessness may pose risks that require comprehensive consideration and trauma-informed, expert facilitation and support. However, this research highlighted that a low-pressure space to explore thoughts around death, dying and bereavement is currently an unmet need within this population, which warrants further exploration.

Declarations

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Competing interests

The authors declare no competing interests.

Author contributions

JC, BH and GD conceptualized the study. JC and GD carried out interview data collection. EC facilitated focus groups. JC and GD led on data analysis. BH supported data analysis. JC led on writing the manuscript. BH, GD, MP, EC, CS, KF (all authors) reviewed the final manuscript.

Data availability

Data is available upon reasonable request.

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Exploring perspectives regarding death cafés for people experiencing homelessness: a qualitative study

Jodie Crooks[1,2], Gareth Davis[3], Mandy Pattinson[3], Emma Casey[4], Dr Caroline Shulman,[2,3], Professor Kate Flemming[5], Dr Briony Hudson*[1,2]

[1]Marie Curie, Policy and Research, UK

[2]University College London, UK

[3]Pathway, UK

[4]Groundswell, UK

[5]Department of Health Sciences, University of York, UK

*Corresponding author

Abstract

Background: People experiencing homelessness often die at a younger age than the general population. Advanced ill-health often occurs late in its trajectory (if at all), leaving many people experiencing homelessness to die without adequate support from hospital-, hospice- or community-based palliative care services. Despite the high rate of bereavement and exposure to death among people experiencing homelessness, there are rarely opportunities for them to reflect on their experiences, thoughts and preferences around death or receive bereavement support.

Death cafés are a global social franchise, providing a space for people to participate in an open group discussion about death, dying and bereavement. They are free to attend and unstructured but facilitated.

Objectives: To explore the perspectives of people experiencing homelessness and the professionals that support them with regards to the potential acceptability, benefits and challenges of death cafes.

Methods: A qualitative study comprising of: interviews with nine homelessness and/or palliative care professionals with experience of running death cafés for, or supporting people experiencing homelessness in other ways, and two focus groups with nine people with lived experience of homelessness. The research was co-produced with a lived experience co-researcher forming a core part of the research team. Reflexive thematic analysis was utilised to develop themes.

Results: Five themes were developed to highlight the perspectives and experiences of death cafés for people experiencing homelessness: Choice; Expertise in facilitation: recognizing risk and the unstructured nature; Promoting safety against potential risk; Potential benefits; and Potential practical considerations.

Themes highlight the need for a trauma informed approach. Death cafés could be impactful, where done well, but they are not without risk.

Conclusions: Death cafés for people experiencing homelessness pose risks that require comprehensive consideration and trauma-informed, expert facilitation. However, this research highlighted that a low-pressure space to explore thoughts around death, dying and bereavement is currently an unmet need within this population.

Strengths and limitations of this study

- This research was co-produced by academic researchers and people with lived experience of homelessness.
- Relationships developed through the coproduction process enabled fast rapport with participants throughout data collection and adds nuance to the analysis.
- As recruitment occurred opportunistically, there is a risk of sampling bias including self-selection bias and/or bias introduced through snowball methods.
- Further research may benefit from a larger, more diverse sample of people with lived experience of homelessness, as evidence demonstrates the complexity and heterogeneity of experiences.

Background

Homelessness, death & bereavement

People experiencing homelessness (PEH) often die prematurely, at a younger age than the general population [1, 2]. People with long histories of homelessness may also experience accelerated ageing and associated life-limiting, long-term conditions (including frailty) as early as in their 40's [3]. International evidence consistently demonstrates the high prevalence of multi-morbidity among people with experience of homelessness [4-7]. For many people experiencing homelessness, health care access and outcomes are influenced by intersecting factors related to trauma, physical, mental health and exclusion [8].

Many PEH are not recognised as living with advanced ill-health until late in its trajectory, if at all, for reasons including barriers to health service access and unpredictable illness trajectories [9, 10]. In the UK in 2023, 1474 people died whilst homeless; the equivalent of one person every six hours [11]. Importantly, one study looking at 3882 people experiencing homelessness in England, found that one in three deaths among PEH were due to causes amenable to being prevented or managed by timely and effective healthcare [12].

Many PEH with advanced ill-health die without adequate support from relevant health and social care services (including palliative care), leading to poor experiences and, undignified deaths [10, 13]. In addition, the majority of people with multiple-exclusion homelessness have experienced significant trauma in their lives, often starting in childhood: one study reported up to 94% of people who have experienced homelessness also identified as having at least one traumatic experience [14]. Furthermore, people experiencing homelessness have often experienced bereavements and loss among their peers: in the UK, the estimated number of deaths among PEH has increased by 54% since records began in 2013, representing an extra 259 deaths [15].

Despite the high rate of bereavement and exposure to death [16], a high palliative care need and limited access to health and social care services among this group, there are infrequent opportunities for PEH to explore their own thoughts and preferences around death and the end of their lives or receive bereavement support.

Death Cafés

Death cafés have become a social franchise, expanding quickly across Europe, North America, and Australasia; to date, over 16,000 cafés have been held [17]. Death cafés are unstructured meetings which aim to provide a space for people to participate in an open group discussion of death alongside refreshments [17]. It is a space "where people talk about whatever is on their minds related to death, dying, and bereavement" with the aim of helping "people to make the most of their (finite) lives" [17, 18] (page 153). There is no specified agenda to the meetings, with no intention of directing people to any course of (medical) action. Importantly, death cafés are intentionally not grief support groups, educational sessions, or a source for information on end-of-life topics [18].

Very few death cafes, thus far, have been held specifically for PEH, despite the outlined increased exposure to death and bereavement. This could be for various reasons, including: low engagement with services and competing priorities day-to-day, such as sourcing food or shelter, which are likely to take priority over discussions of death and bereavement [19]. In addition professionals from health and homelessness services and PEH have reported finding death difficult to discuss with staff fearing that raising issues related to palliative care may be detrimental to service users' well-being and their relationships with them [20]. Furthermore, hostels and other frontline services that support people experiencing homelessness are often recovery-focused in nature, aiming to support people 'out of' homelessness. This forms a juxtaposition between the nature of many homelessness services against talking about death and dying, which has been cited as a barrier for PEH to access palliative care services [20].

Homelessness is associated with loss in a variety of ways [21]. Loss may be related to stable housing, loss of identity due to changed circumstances or the loss of family, friends of peers. Bereavement has been identified as a common route into homelessness [22].

Given the likely high exposure to death and dying among people experiencing homelessness, exploration and consideration needs to be given to ways in which conversations around these issues can be facilitated, for people that wish to engage with them. As formal bereavement services may be less accessible to this population, consideration needs to be given to community based initiatives, such as death cafes, that can provide space for people to discuss issues around dying and loss. However, in light of the high prevalence of ill health, trauma, exposure to loss and the challenges to accessing health and social care support, it is crucial that we understand the views of PEH, and those that support them with regards to death cafés. This paper explores whether death cafes could be helpful for PEH, and what adaptations may be needed to traditional death café approaches to tailor them for this group.

Aim

This research aimed to explore the perspectives of people experiencing homelessness and the professionals that support them with regards to the potential acceptability, benefits and challenges of death cafes. The core research question was: what are the views and experiences of people with lived experience of homelessness, health and social care professionals, inclusion health and homelessness professionals, around death cafés for people experiencing homelessness?

Methodology

Design

A co-produced, qualitative approach was taken to explore the perspectives of people with lived experience and the professionals that support them. An exploratory stance was taken to begin to tentatively investigate an area yet to be addressed by research [23]. This approach is defined by Stebbins [24] as "a broad-ranging, purposive undertaking designed to maximize the discovery of generalisations leading to description and understanding of an area of social or psychological life". Reporting of this research is guided by the Reflexive Thematic Analysis Reporting Guidelines (RTARG; [25]). Ethical approval was sought and approved by UCL (ID: 6202/011).

Population

Participants were people with lived experience of homelessness and associated professionals who worked within the sectors of homelessness and/or palliative care. Homelessness was self-defined by participants and included street homelessness (i.e., people who sleep on the streets, without shelter), hostel or other temporary accommodation, and sofa-surfing [26]. Some professionals had been involved in death cafés for PEH previously. However, given the extremely small number of previous death cafés for this group, professionals were eligible to participate if they had experience of working closely with PEH. Participant demographics can be seen in Table 1. The relatively small number of participants reflects the infancy of considering death cafés for people experiencing homelessness, while representing a diverse range of professional and lived experience perspectives. The study took place remotely, within participants located across England, UK.

Recruitment

An opportunistic approach was taken to sampling. Project details were shared within existing networks attended by professionals who may be eligible and interested in the study. These included the National Homelessness and Palliative Care Network and informal working groups.

Groundswell, a UK leading peer advocacy organization, led the recruitment of people with lived experience of homelessness. Groundswell work collaboratively over the long-term with a large group of experts by experience, supporting them to get involved in research projects. A Peer Coordinator employed by Groundswell shared project details with the group, both via email and in-person at regular meetings.

Interested and eligible participants were provided with a Participant Information Sheet and given a minimum of 24 hours to consider participation. People with lived experience of homelessness also discussed the information sheet with the Peer Coordinator at Groundswell. All participants were given the opportunity to ask questions. Informed consent was gathered and recorded via RedCap online software.

Data collection

Data were collected between March and May 2024. Online, semi-structured interviews were conducted with professionals via Microsoft Teams. Data was collected remotely to enable recruitment of professionals situated across England, UK within the budgetary scope of the research. Interviews were co-delivered by the principal researcher (JC) and the lived-experience co-researcher (GD). A semi-structured approach was selected to “permit interviews to be focused while still giving the investigator the autonomy to explore pertinent ideas that may come up in the course of the interview” [27]. The interview schedule was developed based on discussions within a previous research project by the authors [26]. Professionals were asked about their experiences of death cafés (including venue, attendees, and content), which professionals were involved in preparation and facilitation, and general reflections on the death café. Where professionals hadn’t been involved in a death café previously, they were asked about their views of death cafés, covering similar topics. Interviews lasted between 30 and 60-minutes.

People with lived experience of homelessness attended one of two online focus groups. These lasted for 90-minutes and were organized and facilitated by Groundswell. Discussions were semi-structured using a pre-defined list of prompts based on the interview schedule, and covered topics such as reviewing example advertisements for death cafés, perceived benefits and concerns surrounding death cafés for PEH, and practicalities such as venue, professionals and safety. Interviews and focus groups were audio recorded and transcribed. Interview and focus group schedules can be found in Supplementary Material 1.

Data analysis

Given the exploratory nature of the research generated from a relatively small number of participants’ individual perspectives, inductive reflexive thematic analysis was chosen to emphasise the inescapable subjectivity of data interpretation [28].

The six recursive phases of reflexive thematic analysis guided the inductive interpretation of data. Initially, immediately following each interview co-conducted by JC and GD, they reflected upon the interview content and produced short, written reflective notes on pertinent or interesting aspects. To begin analysis, JC familiarised herself with all transcripts through reading and re-reading. Then, JC manually coded transcripts in NVivo qualitative analysis software, detailing inductive descriptive codes by marking similar phrases or words from the interviews and focus groups. GD also engaged in this process for 5/11 transcripts. Reflexive thematic analysis was a useful approach for enabling GD to consider the data in relation to their own lived experiences. Codes from each researcher were reviewed and combined where appropriate. JC, GD and BH collaboratively generated key themes, before refining, defining and naming themes [28].

Patient and Public Involvement

Involvement of people with lived experience of homelessness was central to this research project. A lived experience co-researcher was employed on a part-time (0.1 FTE), fixed term basis. They were recruited through a partner organization, Pathway; a homeless and inclusion health charity who advocate for and work towards equitable health care for people experiencing homelessness. One aspect of Pathway's work is to support people with lived experience of homelessness to be involved in research through working in partnership with organisations to carry out in-depth research and increase collective understanding of the links between homelessness, exclusion and health [29]. The lived experience co-researcher was a core member of the research team, involved in conceptualising the study and its methodology, developing the interview and focus group guides, co-interviewing during the data collection phase, independently coding transcripts and supporting analysis, and inputting to this manuscript. To plan and carry out this involvement, we utilised our previously published TIFFIN recommendations, that aim to promote the safe involvement of people with lived experience of homelessness in palliative care research [26].

Additionally, four further people with lived experience of homelessness supported the analysis. Recruited through the working partnership with Pathway. PPI contributors gave feedback on initial themes and supported refining of the themes, through an additional online focus group. All PPI contributors were reimbursed in line with the National Institute for Health and Care Research guidelines for involving people in research [30].

Results

Nine interviews and two focus groups with a total of 18 participants (9 professionals, 9 PWLE) were carried out. Professionals were from a diverse range of backgrounds including hospice staff, clinicians, mental health professionals and staff from homelessness services. Five out of the nine professionals had experience of facilitating, observing, or attending a death café for PEH. Five themes were generated from the combined data: choice, expertise in facilitation, promoting safety against potential risk, potential benefits, potential practical considerations. These themes represent the participants experiences of each stage of a death café, including preparation, delivery/attendance, and aftercare. They highlight both participants interest and concerns regarding death cafés for this population.

Table 1. Participant demographics

Demographic	Categories	Number
Professionals		
Gender	Female Male	9 0

Employer organisation type	Charity	3
	Hospice	2
	Housing Association / Hostel	4
Role	Palliative care professional	3
	Clinical psychologist	2
	Counsellor	1
	Social worker	1
	Hostel staff	2
	Registered nurse	1
People with lived experience homelessness		
Gender	Female	6
	Male	3

Choice

Choice was seen as integral to the concept of death cafés for people experiencing homelessness. There was unanimous agreement from participants that attendance cannot be compulsory, due to the potential risks associated with forcing people to face the emotionality of this topic, particularly where they are likely to have experienced previous trauma. To ensure autonomy in decision making is upheld, clear information should be provided on what a death café is and isn't, as people cannot make an informed choice about attendance without adequate information.

As with any population, not everyone experiencing homelessness will want to attend a death café. Participants discussed how many people experiencing homelessness often face severe exclusion and barriers to accessing services, thus may not wish to engage with a death café. Furthermore, professionals felt that previous negative experiences of accessing services could negatively influence engagement with or expectations of a death café, if it is perceived to be another service that is delivered to them, and not for them.

"The crew that I'm working with at the minute are the severe and multiple disadvantaged. So my cohort are the people who do not engage. They don't engage with their GP. They don't engage with secondary care…they will struggle with anything like this." (Registered Nurse, hostel)

Another reason highlighted by professionals for not wishing to engage could be people's perceptions that it was unnecessary, because they were *'not dying ye*t'. However, PWLE homelessness expressed how they were often aware of their heightened risk of death, making attending a death café *"too morbid" (PWLE).*

"I wouldn't have bothered going. It's more likely for me to die when I'm on the streets, and I knew that, so I wouldn't have wanted to go into somewhere and speak about death when I was homeless." (PWLE)

For people experiencing homelessness, their willingness to attend may depend on what is happening in their life at that time. Both professionals and PWLE suggested that death cafés "*might attract the people who are further along their recovery journey [out of homelessness and/or addiction] … who are ready for something like this" (Palliative Care professional).*

Expertise in facilitation: recognizing risk and the unstructured nature

Participants emphasised the importance of a confident, skilled facilitator to lead and manage a death café. It was recognised that more than one facilitator may be required, bringing expertise from professionals from different backgrounds together, for example professionals across the fields of palliative care, homelessness services, or mental health working in partnership. Professionals acknowledged that their experience in one area did not automatically mean they were a suitable or appropriate facilitator: *“just because a couple of us here have got good knowledge of death, or grief or palliative care doesn’t necessarily mean that we’re absolutely ace at facilitating groups like this." (Palliative Care Professional).*

Importantly, participants highlighted that facilitation needs to be trauma informed. It is important that professionals within a death café can recognise the potential for conversations to trigger an emotional response, or lead to behaviours that may be harmful. That is, attendees can’t be expected to *“leave their complex trauma and chaotic lifestyles at the door” (Social Worker).* Therefore, due to the typically unstructured nature of death cafés, confident facilitation is key to “*steer conversations if they look like they're becoming too difficult or if there are things which you can hear are likely to trigger other people." (Clinician and researcher).*

This skilled facilitation was also thought to be integral to the wellbeing support provided both during and after death cafés. Traditionally, death cafés don’t offer wellbeing follow-ups. However, all participants agreed that the availability of post-session support was important: due to the potential for emotional or sensitive discussions during death cafés, coupled with the limited support networks or previous negative experiences that attendees may have. There was a perceived risk that following a death cafe, people may return to the streets or temporary accommodation whilst experiencing distress. Professionals experienced in facilitating death cafés within a hostel environment described methods for providing support, such as debriefs, informal check ins, or staying behind following a session. This also highlighted the need for building trust and rapport between facilitators and attendees, to improve support offered both during and after death cafés.

“If you are facilitating these sorts of conversations we always hang around for about 20 minutes after just with a cup of tea. It's just something that somebody needs to chat around in private or they’ve been distressed by the conversations that have taken place" (Bereavement Counsellor).

Signposting (i.e., helping people or directing them to access appropriate support if needed) people to where they may access support was debated by participants. PWLE homelessness often felt they were ‘over-signposted’, leading to them feeling dismissed. However, professionals highlighted the necessity of helping people to access further support and suggested non-tokenistic signposting such as referrals made at the time, if possible, or continued support in accessing services, rather than just providing information could be beneficial.

Promoting safety against potential risk

Participants discussed the need to manage the possibility that attendees may have active addiction issues. First, they outlined the need to consider how to manage people at varying stages of recovery. People with lived experience expressed that attending a session during a period of sobriety, with a peer who was actively using substances, could be triggering. Furthermore, participants recognised the need to manage intoxication at sessions. The general consensus was that banning substance use is likely to be ineffective, as it would lead people who were dependent on alcohol to simply not attend. Instead, both professionals and PWLE homelessness participants suggested that facilitators would need to be confident making behaviour-based decisions on attendance on a case-by-case basis.

“If somebody’s in addiction, there’s no point saying to them, you can’t be on drink, or you can’t be high on drugs. Because that’s their life. That’s, that’s how they function in, in their daily lives. So, having a limit- if you’re overly intoxicated, or you’re overly aggressive whilst you’re that intoxicated" (PWLE)

Participants also discussed the potential risk for re-traumatisation during a death café. The potential for discussions around death to resurface emotions and trigger distress was recognised.

“The process of looking after themselves or exploring their own needs or exploring things that has the propensity to bring up really difficult emotions, then they might not have the skills or resources to be able to sit with and manage and might escalate their drug use or lead to self-harm." (Clinical Psychologist)

Participants outlined how this could be unexpected, even for people who felt able to attend. Given the unstructured nature of a death cafe, it is not possible to control the direction of the conversation, or what topics people may be exposed to: **"***they may be triggered by just being present in this room where people might be opening up, it maybe what other people might say might trigger them" (Clinical Psychologist)*

Potential benefits of death cafés for people experiencing homelessness

Despite the potential for risk, participants agreed that, if done safely, death cafés could provide a space for people experiencing homelessness to talk about death and dying. An absence of other spaces where they felt welcome and free to talk about death and dying without judgement was noted.

"Even though he was only in his 30s, he had a big fear of what was going to happen to him when he died, and there was nowhere he had ever talked about that. But he was able to do so in that group. He felt safe to raise it." (Hostel staff)

An example of a successful, hostel-based death café that had been facilitated by a psychologist working within a community palliative care team, outlined that the event allowed residents to discuss things they hadn’t previously: *"Some of the discussions that came up were areas that absolutely were concerning the residents, but they never felt that they were things they could raise with their support worker." (Hostel staff)*

Both professionals and people with lived experience felt that through holding a death cafe, a supportive space was created in which existing power dynamics were reduced: *“there was no staff versus residents, everyone was able to share experiences and share on a very level playing field really." (Palliative care clinician)*. Furthermore, people experiencing homelessness expressed that they *“didn’t know (hostel staff) cared that much*” (PWLE) about them, with regards to holding the event and sharing their own thoughts and feelings.

Participants highlighted how a death cafe could provide an opportunity for attendees to begin to consider their own preferences for end of life. Although attendees at a death café traditionally will not complete any formal advance care planning, it could be a catalyst for initial exploration of preferences. For some people, in time, this could be a pre-cursor to an openness to having more detailed discussions about making their preferences for care and treatment known. Giving people space to discuss their thoughts may also support them to feel valued, seen and heard:

"Some people might not be able to think about it, but for some people, having a space to at least talk about how they want to live and how they want to be and what they want to do in the rest of their life." (Clinical Psychologist)

Potential practical considerations

Initial considerations regarding practicalities for holding a death cafe were discussed. Given the exploratory nature of this research, these should not be considered as recommendations for developing a death café, but points for consideration.

Both professionals and PWLE homelessness expressed a preference for fewer attendees per session, allowing space for each attendee to talk without the environment feeling overwhelming: *"It shouldn't be crowded because if it is crowded there'll be so many questions and opinions and you wouldn't, there'd be panic." (PWLE).*

People with lived experience highlighted they would be put off by negative, dark imagery in advertisements for the event. Instead, they outlined a preference for colourful advertisement (such as *"a sunset, a tree of life...a bit light and bright with a bit of hope to it" (PWLE)* that importantly, contained clear information on key elements of the session.

To create a safe space, participants discussed the need for ground rules, termed as a *"group agreement" (PWLE).* Participants suggested this could cover topics such as confidentiality, substance use and being respectful, with the aim *"to try and help people understand that this is part of keeping the safe space. If we didn't have this rule, then it could lead to the space and individuals feeling more unsafe." (Clinical Psychologist).*

When considering venues, some participants felt it would be beneficial to hold the event somewhere known to potential attendees: *"I would always think that a Death Cafe should be undertaken where somebody is comfortable and where a locality that they are familiar with but also their needs. So, for example if it's for people living in a hostel, I would think you go to a hostel." (Palliative care clinician).* However, some participants had concerns that this may *"force other people who don't want to necessarily participate to feel that they're being forced to participate." (Hostel staff).*

Participants debated their preferred name for these events. Some felt that 'death café' was too negative, intimidating and off-putting.

“I think because we, as a society, don’t talk about death, so death’s quite taboo. So even the word ‘death’ would probably be quite off-putting to some people." (Registered nurse)

"Going into something that sort of says death café, forgive the pun, is like adding another nail to the coffin, isn’t it?" (PWLE)

However, others expressed the need for clear, transparent naming to ensure participants understood the brief of the event and were able to give informed consent to attend. *"If you’re going to call it something different, you would still need to help people to be aware that it is going to be talking about death. Otherwise, they might get a bit of a shock when they turn up" (Palliative care professional).*

Discussion

This qualitative research utilised interviews with professionals and focus groups with people with lived experience of homelessness to explore perspectives on death cafés for people experiencing homelessness. Five themes were generated: Choice; Expertise in facilitation: recognizing risk and the unstructured nature; Promoting safety against potential risk; Potential benefits; and Potential practical considerations.

Trauma informed care and wellbeing support

A key finding is the need for death cafés to be trauma informed. This is supported by a plethora of existing evidence connecting trauma and homelessness [31], which consistently recommends that “service providers must consider trauma when designing and offering services to persons with a history of homelessness” [32].

Pertinent to death cafés, people experiencing homelessness have often witnessed a high number of deaths, both prior to and during periods of homelessness [16]. Death experienced on the streets can be traumatic [16, 33, 34] and are often sudden or unexpected [35]. Furthermore, death of loved ones is often described by people experiencing homelessness as one of the negative “turning points” in their lives, acting as a significant risk factor for their homelessness [21, 22, 36, 37]. This potential history of traumatic experiences surrounding death, dying and bereavement means that extra considerations of psychological safety are required in the planning, conduct and follow up from of a death café.

Additionally, experiences of trauma can heighten the importance of adequate emotional support in services or spaces such as death cafés. Repeated or multiple traumatic experiences can “overwhelm a person’s available internal and/or external resources”, leading to ineffective coping and reduced capacity for emotional regulation [38]. Clinical psychologists (amongst other professionals) in our research suggested techniques for wellbeing support during sessions (including regular breaks, non-tokenistic signposting and referral at time where possible), and after sessions (such as debriefs, staying in place for one-to-one conversations, and checking in with attendees where they are known).

Facilitation

This research highlights that expert facilitation of death cafés for people experiencing homelessness is essential. This is supported by previous research from death cafés aimed at the general population. Facilitation can promote meaningful conversations and guide attendees through an event. A death café facilitator needs to be able to: “manage speaking turns and pay close attention to conversational flow, group climate, and expressions of emotion” [39].

Traditionally, death cafés propose that facilitators “leave their professional identity at the door”, aiming to enable death cafés to be egalitarian spaces. However, based on the findings of this exploratory research, it may be important that facilitators for death cafés for PEH have adequate professional experience that they utilise in the events to support attendees.

Participants felt that no one group of professionals could adequately run a death café for this population and that a multi-disciplinary approach was seen as useful. Previous research has [40] partnered palliative care professionals with hostels aiming to build relationships and introduce the benefits of a palliative approach to support for people with advanced ill health. This found benefits such as better working partnerships, hostel staff feeling empowered to discuss death and dying, and integration of the ethos of each place. A death café was held as part of this work which was found to address some anxiety within hostel staff when discussing death with residents. This supports the findings of this work which suggest co-facilitation across the fields of homelessness and palliative care can be beneficial.

Limitations

As recruitment occurred opportunistically through advertising at networks and allowing people to put themselves forward, there is a risk of sampling bias including self-selection bias. Further bias may have been introduced by the snowball nature of sampling.

Furthermore, although participants bought a range of experiences, including lived experience of homelessness, further research may be required with a larger sample size. This would enable the participant sample to represent a more diverse sample of people with lived experience of homelessness, or involvement in death cafes as evidence demonstrates the complexity and heterogeneity of experiences.

Recommendations

To the best of the authors’ knowledge, this is the first research to qualitatively explore the idea of death cafés for people experiencing homelessness. These initial explorations have raised further points for consideration. For example, while recognizing the potential benefits of death cafés for people experiencing homelessness, it is important to fully explore the potential risks and how these can be managed. This may include an in-depth exploration of facilitation of death cafés for people experiencing homelessness, taking into account issues raised in this research such as previous experiences of attendees, risk moderation and the importance to partnership working, with the potential to develop training for facilitators in this space.

Conclusions

As death cafés continue to grow, exploration of their applicability to varying populations facing multi-faceted social exclusion is key. Death cafés for people experiencing homelessness may pose risks that require comprehensive consideration and trauma-informed, expert facilitation and support. However, this research highlighted that a low-pressure space to explore thoughts around death, dying and bereavement is currently an unmet need within this population, which warrants further exploration.

Declarations

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Competing interests

The authors declare no competing interests.

Author contributions

JC, BH and GD conceptualized the study. JC and GD carried out interview data collection. EC facilitated focus groups. JC and GD led on data analysis. BH supported data analysis. JC led on writing the manuscript. BH, GD, MP, EC, CS, KF (all authors) reviewed the final manuscript. JC is guarantor for the manuscript.

Data availability

Data is available upon reasonable request.

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