"There's quite a lot of breakdown between services": Palliative Care and Supporting People Experiencing Long-Term Homelessness With Life-Limiting Illnesses in Dublin. A Qualitative Interview Study

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> **Abstract_** *People experiencing long-term homelessness have a younger age of death than the housed population. Deaths within homelessness include, but are not limited to, deaths from life-limiting illnesses. People experiencing homelessness encounter multiple barriers accessing health services which include barriers accessing palliative care services. The aim of this Research Note is to describe the experience of staff working with people experiencing long-term homelessness who are living with, or have died from, life-limiting illnesses, utilising semi-structured 1: 1 interviews. Eleven participants were recruited from four organisations in Dublin. Five overarching themes were generated: (1) challenges identifying palliative care need, (2) negative and positive experience of death of a service user, (3) identified need for external health and social care support, (4) need for service user focused care to*

enable a positive death experience, and (5) concerns regarding supporting the increasing number of ageing people living within homelessness requiring palliative care.

Introduction

People experiencing long-term and episodic forms of homelessness have substantially worse health status and a higher risk of death than the housed population (Aldridge et al., 2018; 2019; Lewer et al., 2019). Definitions of homelessness vary. O'Sullivan et al., (2020) caution researchers and policy makers to be cognisant that there are a variety of experiences of homelessness, particularly when considering the health needs of those experiencing homelessness. The European typology of homelessness and housing exclusion definition is frequently used for ease of comparison; this includes rooflessness, houselessness, insecure, and inadequate housing (Edgar et al., 2004). A typology of homelessness situations and duration was proposed by Kuhn and Culhane (1998) which describes homelessness within three distinct clusters; transitional, episodic, and chronic (long-term). Waldron et al., (2019) applied Kuhn and Culhane's (1998) methodology to the homeless service usage in Dublin between 2012 and 2016 and demonstrated that 78% of service users were considered transitional, 10% were considered episodic, and 12% were considered long-term homeless service users.

In Dublin, the standardised mortality rates for people experiencing homelessness are 3-10 times higher in men and 6-10 times higher in women experiencing homelessness compared with the housed population (Ivers et al., 2019). Homelessness is increasing in Ireland; the total number of people (adults and children) who have sought access to homeless accommodation nationally in January 2024 was 13 531, an increase by 237% since January 2016 (Department of Housing, 2024). These figures refer to the number of adults and children in emergency accommodation at a point in time and are not a measure of the numbers accessing emergency accommodation over a period of time.

A bimodal pattern of death is described among people experiencing homelessness; younger people experiencing homelessness die disproportionately from external causes and infectious diseases, and older people experiencing homelessness die from similar causes to the older housed population but at a younger age (Baggett

et al., 2013; Fazel et al., 2014). Further, while people experiencing homelessness frequently die of preventable or treatable illnesses (Aldridge et al., 2019), some die from life-limiting illnesses and could benefit from palliative care (Conneely et al., 2021). The reported causes of death for people experiencing homelessness in Dublin are drugs and/or alcohol (38.4%), circulatory (20%), respiratory (13%) and gastrointestinal causes (7%), and cancer (5.1%) (Ivers et al., 2019). O'Carroll (2020) demonstrated a link between duration of homelessness and rising death rate, with a steep increase in mortality rates after 18 months of homelessness.

Palliative care is an interdisciplinary approach focused on preventing and relieving suffering, and improving the quality-of-life for patients facing life-limiting illness(es) and their families (World Health Organisation, 2020). A life-limiting illness is an illness which is defined as progressive, or the progress of which cannot be reversed by treatment (Scotish Parliament, 2010); examples include incurable cancer, end stage liver disease, and chronic kidney disease. For the context of this paper, in Ireland, end-of-life care is defined as care which is provided during the period when death is imminent, and life expectancy is limited to short numbers of hours or days (Ryan et al., 2014). In one study, at least 64% of people dying within homelessness in Dublin over the age of 60 died from an illness that could have benefitted from palliative care input (Conneely et al., 2021).

There are a growing number of studies exploring the role and experience of staff in accommodation supporting people experiencing homelessness living with and dying from life-limiting illness(es), and these are summarised in recent systematic reviews (Hudson et al., 2016; Sumalinog et al., 2017; Klop et al., 2018; James et al., 2023). Delivery of palliative and end-of-life care to people experiencing homelessness is complex; factors contributing to complexity include high rates of physical and mental health needs, substance use, lack of stable accommodation, barriers to accessing healthcare, and frequently a lack of biological family to provide informal care and psychosocial support (Hudson et al., 2016; Shulman et al., 2018; Klop et al., 2018). International research provides recommendations for some essential elements to be considered in the provision of palliative care for vulnerable populations, including people experiencing homelessness. Key concepts include a collaborative approach to care across services, trauma-informed care, person-centred approaches, additional training for staff, and harm reduction approaches (McNeil et al., 2012; Hudson et al., 2016; Stajduhar et al., 2019). Recently in a novel project, Armstrong et al. (2021a) demonstrated that integrating palliative care provision into services for people experiencing homelessness has both benefits and challenges.

The informal caregiver role of family is recognised in facilitating a person with a life-limiting illness to live and die in their preferred location (Addington-Hall and McCarthy, 1995; Morris et al., 2015). People experiencing homelessness frequently

do not have family to provide to support with physical care needs such as washing, toileting and basic activities of daily living. In general, staff in accommodation for people experiencing homelessness cannot provide and are not trained to provide this caregiver role. Staff in homeless services come from a variety of professional backgrounds. There are frequently limited or no healthcare workers in homeless accommodation. This is an important factor when considering palliative and end-of-life care needs. To this end, the aim of this study is to describe the experience of staff working with people experiencing long-term homelessness who are living with or died from life-limiting illnesses.

Methods

Study design and setting

A contextual in depth qualitative interview study was conducted with staff employed within the homeless accommodation services in Dublin in 2017, at which time there were reportedly 3 527 adults in Dublin accessing temporary, emergency, or short-term accommodation facilities (Department of Housing, 2024). Of note, those in long-term supported accommodation (> 6 months) are considered 'tenants' and therefore not included in the 3 527 adults counted above.

Recruitment

Typical case purposive sampling (Etikan et al., 2016) was employed. Organisational approval was requested via an invitation letter and a participant information leaflet was provided. Following organisational approval, recruitment was performed via a contact individual within each organisation. The researchers did not approach individuals directly. It is unknown how many individuals within each organisation were approached. There was no specification on job role, gender, or duration of experience of the participants.

Inclusion Criteria: ≥ 18 years; currently employed within homeless accommodation services.

Exclusion Criteria: <18 years; volunteers.

The target sample size was estimated as 10-15 interviews based on recruitment from a single relatively homogenous sample (Guest et al., 2006).

Data collection

One interviewer (AC) conducted single 1: 1 semi-structured interviews. The topic guide for the interviews was informed by clinical experience of two of the researchers (AC/RMcQ) and a review of the literature. Field notes were made. Interviews were digitally audio recorded and transcribed verbatim.

Analysis

Interviews were analysed using contextual thematic analysis (Braun and Clarke, 2006). Themes were analysed with a view to both capturing the experience of participants and also to identify practical areas for collaboration and education. Line-by-line manual coding of the data was initially conducted by a single researcher (AC). To provide analytical rigour, sections of interviews were reviewed by the research supervisors (SM/KB) and consensus on coding achieved. AC generated initial themes. The themes were discussed and refined with SM, KB, and RMcQ. Themes and subthemes were reviewed, defined, and named. Analysis was informed by knowledge of palliative care and health services and structures, palliative care theories, and AC's clinical experience as a doctor. The analysis was also informed by the secondary aim of this study which was to identify areas for education and collaboration between palliative care and other services to improve access to palliative care and end-of-life care for people experiencing homelessness.

Results

Recruitment, participants, and interviews

Eleven organisations were approached to participate. Seven organisations did not take part (table 1). Eleven participants were recruited though four organisations (Table 2). Interviews were conducted between June and August 2017. All participants chose to complete the interview at their workplace during working hours. Median interview duration was 32 minutes (range 25 – 41). Median age of the 10 participants who provided their age was 32.5 years (range 26 – 38).

Table 1. Reason for organisation non-participation in the study

Reason for non-participation in study	n=7 organisations
Volunteer staff only (exclusion criteria)	2
Age range of service users 18-25 years – organisational decision to decline participation based on this	1
Expressed wish to participate but liaison individual within organisation did not coordinate interviews	1
No response to email or phone-call invitation	3

Table 2 Participant and Organisation Characteristics

Participant job specification	N=11
Social Care worker	3
Care Assistant	1
Project worker	2
Nurse	1
Service manager	1
Team leader	2
Deputy Manager	1
Participant gender	
Female	9
Male	2
Accommodation Type	
Supported Temporary Accommodation [i]	5
Long term supported housing [ii]	3
Multiple sites for one organisation	1
High support long term accommodation unit	1
Homeless accommodation services and projects	1
Drug and Alcohol Policy of accommodation	
Harm reduction model [iii]	8
Alcohol permitted. Illicit drugs prohibited	3
Gender of service-users	
Males only	1
Female only	0
Mixed	10

[i] Supported temporary accommodation is any accommodation for people experiencing homelessness where the duration of stay is maximum for <6 months.

[ii] Long-term supported accommodation is accommodation for people experiencing homelessness where placement can be >6months.

[iii] A harm reduction model when applied to substance misuse accepts that a continuing level of illicit drug and alcohol use is inevitable and aims to reduce adverse consequences of drug and alcohol use.

Findings

Overview

The term service user is used throughout to describe a person experiencing homelessness with whom the study participant (i.e., homeless accommodation staff member), has engaged with professionally. Five overarching themes were generated: (1.) challenges identifying palliative care need, (2.) negative and positive experience of death of a service user, (3.) identified need for external health and social care support, (4.) need for service user focused care to enable a positive death experience, and (5) concerns regarding supporting the increasing number of people experiencing homelessness requiring palliative care. Themes and subthemes are summarised in table 3.

Table 3. Summary of over-arching themes and sub-themes

Overarching theme	Sub-theme
Challenges identifying palliative care need	Difficulty recognising a life-limiting illness
	Unmet symptoms and care needs
	Uncertainty of disease trajectory and prognosis
	Malignant diagnosis being more recognised than non-malignant conditions as life-limiting
	Barrier to future care planning
	Perceived ability of medical staff to prognosticate
Negative and positive experience of death of a service user	Staff have experience of unexpected / sudden deaths
	Difficulty defining an anticipated death
	Service-users expressed wish not to die in hospital
	Negative and positive experiences of supporting the 'anticipated' death of a service-user
	Medication management as contentious issues
	Limited future care planning
Identified need for external health and social care support	misunderstanding of roles of staff in homeless accommodation by hospital staff
	poor communication and information sharing from health and social care staff, particularly with local hospital(s) e.g. discharge letters, medication updates
	positive experience of inclusion health service
	difficulty accessing to community health and social-care services
	both positive and negative interactions with specialist palliative care services
Need for service user focused care to enable a positive death experience	flexibility from organisation
	Individual flexibility from professionals
	Person-centred approach
	Recognition of service-user autonomy
	Duty of care towards other service users
	Conflict between wish to support service users wishes and limited ability to provide adequate care
Concerns regarding supporting the increasing number of people experiencing homelessness requiring palliative care	Rising numbers of people living in homelessness
	Aging homeless population
	Staff would welcome education and training opportunities in palliative care and end of life issues

1.) Challenges identifying palliative care need

Staff described struggles identifying that a service user has a life-limiting illness and in addressing their specific needs. This is compounded by uncertainty of disease trajectory and prognosis, particularly in non-malignant conditions. Having a cancer diagnosis was considered advantageous in accessing community services, the initiation of future care planning, and accessing specialist palliative care services.

> I mean 90% of our clients are terminally ill but we're focused on this woman because she has the diagnosis[cancer], she is one of the lucky ones that got a label (P8).

Participants identified that service users with life-limiting conditions have unmet symptom and care needs. Unpredictable disease trajectory and prognostic uncertainty was perceived as a barrier to future care planning. Unpredictable disease trajectory and prognostic uncertainty contributed to distress following death of a service-user when the death was not anticipated.

> …when I was on relief here we had a guy [service-user with chronic alcohol misuse] that passed away, he was on hourly checks but we checked him every half hour anyway. And he couldn't drink anything and he asked me for some ice-cream, and I went to get him some ice-cream, and when I brought it up he had died. So we got CPR going, got the defibrillator going, called the emergency services because he was still warm. (P4)

A common perception was that medical staff can and should provide an accurate prediction of impending death.

2.) Both negative and positive experience of death of a service-user

All participants had experienced the deaths of service users; the majority were related to drug(s) and/or alcohol overdose, or were sudden unexpected deaths. Many participants were not surprised by death. A few, but not all, participants had worked with service users who had an anticipated death in the context of a life-limiting illness. Many struggled identifying what an anticipated death is:

> It wasn't to our knowledge that he was dying. We knew he was really sick, like I had actually did a referral for respite for him and that because he was struggling to get to his [methadone] clinic every day. (P1)

It was the view that most service users who died of a cause other than overdose or suicide died in hospital. Hospitalisation was viewed as both positive and negative and sometimes simply necessary as no other support in the community was available. Hospitalisation was viewed as positive when the health of the service user improved. Frequently service users expressed a wish not to die in hospital:

> I do remember one particular girl who was chronic, chronic addiction both alcohol and heroin, and like by looking at her you know she was dying… her main thing was like "I do not want to die in A&E" and I remember the last time I put her in an ambulance and I looked at the member of staff I was on with and I go "she is not coming home this time"… she died in A&E… there were no services linked in at that point and I don't know who is to blame here, like maybe we should have been stronger advocates. But I also think because she was a drinker and because she was homeless I don't think the hospice saw her as what she was which was she was terminally ill. She was never going to recover from the disease that she had. (P8)

While participants report service users are reluctant to attend hospitals when they become unwell, in the majority of cases, this was not considered future care planning or an expression of wishes and preferences in the context of end-of-life decision making, rather participants interpreted it as the service user's aversion to hospitalisation. Only a small number of participants reported future care planning for end-of-life with their service users.

> One of them who passed away who signed a waiver saying he didn't want any medical intervention, he wanted to die in his home. So we had staff sit up with him for his last final days (P4).

All participants discussed their views on the provision of end-of-life care in homeless accommodation, but only those who worked in long-term homeless accommodation had first-hand experience. Participants acknowledged that some service users viewed their supported long-term accommodation within homeless services as their home, which influenced any decision to remain there for the end of their life.

Management and handling of medications was identified as a contentious issue. Organisations had different medication management policies. Some participants felt uncomfortable handling medications. Conversely others perceived that if staff had a more active role in medication-management, it could improve medication compliance. Identified solutions were the use of blister-packed medication; prompting by staff; lockers; and liaising with prescribers to avoid multiple medications throughout the day. The presence of medications with potential street value caused concern.

> For the people [service users] on a lot of medication like different ones have to be taken maybe three or four times a day, they [staff in the organisation] just don't have the capacity to deal with it and I would feel they'd have better health outcomes if we took that on, but we've been kind of told outright we're just not going there. (P6)

3.) Identified need for external health and social care support

Participants felt that hospital staff do not understand the limited nature of support available to service users within homeless accommodation, for example that assumptions are made that there are staff to provide assistance with personal care in homeless accommodation. Frustration was repeatedly expressed at the poor communication between hospitals and homeless accommodation staff. Participants report a concerted effort made to attend hospital appointments and emergency departments to advocate on behalf of service users, but that frequently there is

limited communication directly from the hospital to staff in homeless accommodation services. Poor communication was considered a major contributor to over-reliance on emergency services.

> There's quite a large breakdown from hospital care to the hostel, you know? We don't have the resources to provide care, even if it's like simple wound dressing and things like that (P11).

Some participants had experience interacting with an inclusion health service. This service was considered to improve guidance for staff in medication-management, the monitoring of health status of a service user, and gaining access to health services. Difficultly accessing community health and social care services was highlighted as an ongoing barrier in providing care in the community, in particular lack of access to personal care needs assistance in temporary accommodation. Others highlighted that there are individual health and social care professionals who are known locally for their pragmatic approach to providing care in the community.

Some participants had experience of local specialist palliative care team involvement in the care of a service user. They reported that the palliative care team supported the staff around end of life issues which contributed to perceived good deaths:

> The hospice were brilliant because she wanted to die in the home and she felt this was her home, in [name of organisation] and they were incredible because she was a real fighter like she you know really lived to the end and the nurses from the hospice and the doctors would come out and see her here and they were always at the end of the phone. (P7)

However, this contrasted with concern about lack of hospice bed availability, lack of access to specialist palliative care services without a formal diagnosis, and a belief that a person had to be imminently dying prior to referral to specialist palliative care services.

> When the hospice and doctors coming out and they're saying, 'no they're not there yet' you're taking that but when you look at the man and he's in the bed well you're saying, 'well how bad does he have to get?' and there's no care at night so where does this man fall like because he's totally falling between the gaps then you know. (P7)

4.) Need for service-user focused care to enable a positive death experience
Participants identified flexibility and individualised approach to care from staff in homeless accommodation, general practitioners, public health nurses, hospital teams, and organisational support as key factors when providing end-of-life care within homeless accommodation services. This was contrasted by a concern by participants about working outside of their remit.

> And definitely it caused huge upset and people [homeless accommodation staff] felt like they just weren't supported enough, it was one of the huge learning pieces for me actually but the staff felt like they just weren't clear enough on what they were supposed to do [in facilitating end-of-life care for a service user in homeless accommodation]. (P11)

While it was recognised that end-of-life care within homeless accommodation is challenging, there was a strong desire to respect the autonomy and wishes of the service users. However, participants expressed conflict between their desire to respect a service user's autonomy with concern for their health. Participants advocated for hospitalisation if they feel the service user's health care needs cannot be met within the accommodation services.

> He [service user with head and neck cancer undergoing radiotherapy] was given ((pause)) he had the option to maintain his independence and dignity and he took it. People say in hindsight that, look, he should have been in [local hospital], he shouldn't have had a choice to come back here. But at the end of the day he was given the choice to be independent and he took that. (P4)

An identified area of conflict was the ability of an organisation to balance facilitating the death of a service user with duty of care to other service users within the confines of limited resources. Furthermore, participants expressed concern that while a service user may wish to die within homeless services, that available care may not address their individual care needs.

> Like, you have got 22 other people that you're looking after behavioural issues, addiction issues, even simple things like trying to keep the house quiet so someone who is possible dying isn't disturbed and is getting a full night's sleep if they can. There are certain things we just can't control and yeah I think as a team we decided we have done as much as we could and that definitely someone could just be better at caring for her at that stage. (P8)

5.) Concerns regarding supporting the increasing number of people experiencing homelessness requiring palliative care

Participants all expressed significant concern relating to the rising numbers of people living in homelessness in Ireland, particularly the increasing number of older people with increasing health care needs.

> I can see a huge population of them [older homeless people], they're all, I've worked here for nearly 10 years, I've aged with them, you know what I mean but I'm looking at people who are my age and they're not doing as well as I'm doing because obviously there's huge things that have impacted on their health in their

lives but I can see that gap coming… it's just not going to be suitable for them because you know the body has worn down, they're going to have huge health problems and they need that extra little bit of care and attention. (P9)

Participants welcomed education opportunities and discussion about the end-of-life care needs of people experiencing homelessness who are living with or dying from life-limiting illness(es).

Discussion

This is the first Irish study to explore in depth the experience of staff in homeless accommodation working with people experiencing homelessness who have life-limiting illness(es). Walsh (2013) previously reported on attitudes to dying in an elderly Irish homeless or previously homeless cohort. This study demonstrates that challenges persist in identifying palliative and end-of-life care needs of people experiencing homelessness. Deaths occur within homeless accommodation services, and while a common experience is unanticipated death, some, particularly older people living in homelessness, die from life-limiting illnesses (Conneely et al., 2021). An anticipated death can be supported with clear communication between health and social care providers, collaborative work, and a person centred approach. The findings of our study mirror many of the findings from a small but growing body of international research (Shulman et al., 2018; Sumalinog et al., 2017; Klop et al., 2018; Stajduhar et al., 2019; Armstrong et al., 2021b) and in doing so, demonstrates commonalities across health and social care systems. This supports the need for the development of an inclusion health approach to palliative care.

While this paper aimed to explore experiences and issues relating to life-limiting illnesses and palliative care, many of the experiences reported by participants relate to barriers accessing general health and social care services which echoes recent findings by Armstrong et al. (2021a; 2021b). It is accepted internationally that palliative care and general health care are not separate entities, and there is no defined point where general health care stops and palliative care begins (Hawley, 2014). Countries such as Ireland have adopted an integrated model of palliative care provision where palliative care is not dependent on prognosis and can be delivered at the same time as curative treatment (Ryan et al., 2019).

This study highlights some examples of where end-of-life care has been accommodated within homeless services with success through future care planning, collaborative work, and organisational support. This demonstrates the importance of a person-centred approach to care which is a recognised pillar of the palliative care approach internationally (Ryan et al., 2019). People experiencing homelessness with life-limiting illnesses fulfil the conceptual framework of complexity in

palliative care as proposed by Pask et al. (2018). This conceptual framework extends beyond the familiar physical, psychological social, and spiritual domains of palliative care and includes how patients interact with family/professionals and how services respond to needs and societal perspectives on care. This concept of complexity is heavily reflected in our findings.

Considerations for Future Research

One finding of this study, which reflects findings in other studies (Hwang et al., 2001; Hakanson et al., 2016), was that some people experiencing homelessness report a fear of dying in a hospital, which may or may not be associated with an expressed wish to die in their accommodation. This requires further exploration. It is unclear if the expressed desire of some people who are homeless to die in their accommodation is because they had a strong wish to die there, or if they felt that they had nowhere else to go, bad experiences in acute hospitals, and the presence of fatalistic cognitions (O'Carroll and Wainright, 2019). It is an important consideration that refusal of place of care does not equate to refusal of care. Studies have demonstrated that frequently people who are homeless have erratic health-care utilisation (O'Carroll and Wainright, 2019), but despite this, when faced with life-threatening events, some have demonstrated a wish to pursue more aggressive medical interventions than the housed population (Norris et al., 2005). It should not be assumed that refusal of hospitalisation is an expression of wish to die in the community. This is further supported by a recent study where nearly one in three deaths of people who are homeless were due to causes amenable to timely effective health-care (Aldridge et al., 2019)

Strenghts and Limitations

A limitation of this study is the presence of recruitment bias as organisations staffed by volunteers were not included. In addition, it is not known how many people within each organisation were approached, or how they were approached to participate by their organisation. Another limitation of this study is its small size and limitation to one urban city; there were 11 participants, and while most homelessness in Ireland is experienced in Dublin, other cities and rural parts of Ireland were not included. A limitation of this study is that this is the first qualitative study conducted by the primary researcher; however, this was mitigated by the supervision of two experienced qualitative researchers who were involved in the analysis. An additional limitation of this study is that it does not contain the voice of people

experiencing homelessness; however, this was beyond the scope of this study. A strength of this study is that the research question included practical aspects of service delivery.

Conclusion

Providing quality palliative and end-of-life care for people experiencing homelessness is complex. Staff within homeless accommodation services play key roles in supporting and advocating on behalf of people experiencing homeless who are living with or dying from life-limiting illness(es). Specialist teams, such as palliative care teams, can offer expertise and knowledge about end-of-life issues, and can contribute to improving care through collaborative work, communication, and/or through educational opportunities alongside other health and social care services. A flexible person-centred approach to care is necessary.

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