End of life care and homelessness

What do experts by experience and providers of care think?

Early findings from a collaborative qualitative study

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Research team

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End of life care and homelessness

- High numbers of young deaths
- Limited advance care planning
- Avoidance & uncertainty
- Deaths are often surprising but not unexpected
- Limited research in this area in the UK
- St Mungo's/UCL liver disease

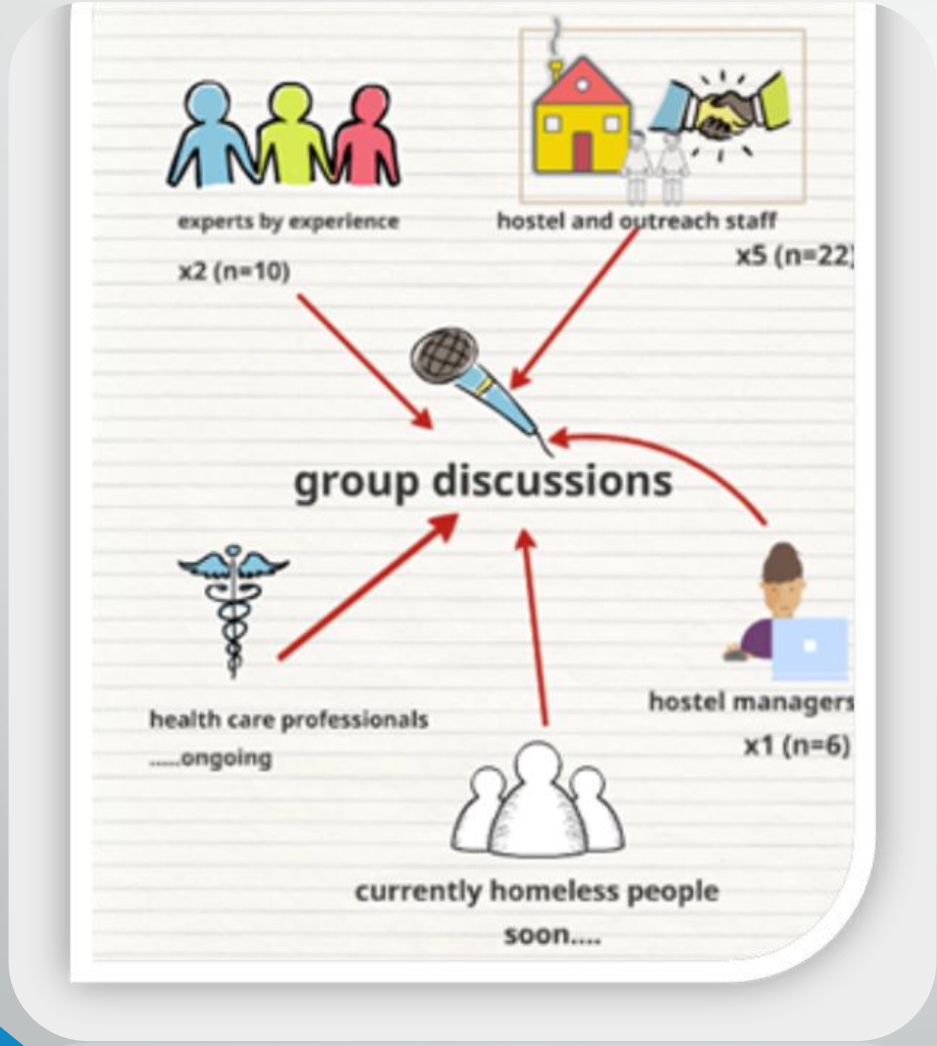
How can we help support homeless people to live and die well?

Research Aims

Develop a richer understanding of the complexities and needs of end of life care for homeless people- from all perspectives.

- Provide a platform for the voices of homeless people & those working with them
- Extend training on end of life issues for more professional groups
- Make recommendations for policy & service provision

Methods



Group discussions with

- Experts by experience
- Hostel and outreach staff
- Hostel managers
- Health care professionals
- Currently homeless people

Across Lambeth, Westminster & Hackney

Initial findings

There are huge gaps in the options available to homeless people with advanced illness & those supporting them.

Examples…

Specialised high support facilities

"….as much as we wanted to try and stretch our shifts in order to accommodate her and try to make her room not be covered in urine and faeces…. we also had up to 30 other residents in the hostel as well …"

*"It was really hard to get that [*social services support*], it was really, really, really, really hard to get that, and to begin with, I think they only wanted to give us two hours a week".*

Female in 30s

Examples….

Hospices

"In the past we have tried to put people into hospice … one person we did get in there. And he was asked to leave because of his behaviour when drunk. And in the end he died in the hostel, he had cancer."

Man in his 40s

Examples…

Early onset dementia

"We fought and fought with the social work team and threatened to go to the papers, and we got him into a nursing home…. A year later he comes up for review, has no one advocating for him and they evict him for not meeting the criteria…. a year ago he had Korsakoffs…and you're not getting better from that. He couldn't remember his own age or anything. He went missing and I found in a morgue a few months later… That's how our clients are treated currently…"

Man in 50s

A square peg in a round hole 1

- **Lack of adequate flexible services**
  - Hostels having to deal with increasing complexity, with limited resources.
- **Challenges of providing adequate support**
  - Low staff:client ratios, little night cover
  - Difficulty accessing social services.
  - Hostel staff end up providing personal care.

A square peg in a round hole 2

Mixed views on hostels as a place of care & death

- Choice? Hostel as home
- Recovery model
- Hostel environment – chaotic, safeguarding concerns
- Impact on staff & residents

What contributes to deterioration?

- **Lack of services and choices**
  - Wet **and** dry hostels
  - Rehab/detox carousel
  - Lack of relapse support

Missed window of opportunity?

Example…
Missed window of opportunity

- 42 year old man with advanced liver disease
- Hospital admission with encephalopathy and sepsis
- Dry for 4 weeks while in hospital
- Said he wanted to remain abstinent
- Assessed and deemed not appropriate for rehab due to previous lack of engagement and cognitive impairment
- Discharged to wet hostel
- Returned to drinking
- Multiple readmissions
- Died suddenly and "unexpectedly" in the hostel

Advance care planning

Planning is currently often lacking

- Complexity & uncertainty
- Who should start conversations
- When should they start

How should this information be shared?

What's needed to provide better care?

Caring for homeless people with advanced illness

- Incorporating uncertainty – mapping, key working, parallel planning?
- More training & support - EoL conversations, what to expect, support for clients & staff, bereavement support
- Increased in-hostel support services eg personal care.
- Early & sustained input from specialist palliative care (in hostels?)
- Improved relationships & communication between hostels, hospitals & hospices.

What's needed to provide better care?

Service needs

More options - wet & dry specialised high support facilities

Integrated health & social care

A pan London approach to homelessness

What's next for this research?

- Further interviews with specialist health care professionals and homeless people.
- Use this information to extend and further develop training for professional groups.
- Develop and disseminate recommendations for policy and practice.

Thank you for listening.

We would love to hear more about your experiences, concerns and comments on these issues.

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