Dying for Change: Evolution and Revolution in Palliative Care

Oral Presentations

Parallel Session 1: Delivering Care to Community Groups

0-1 LIFE’S HARD AND THEN YOU DIE: PHD EXPLORING END OF LIFE PRIORITIES WITHIN THE UK HOMELESS POPULATION


10.1136/bmjspcare-2019-HUKNC.1

Background People experiencing homelessness often die young, of treatable diseases. They are dying on the streets and in hostels without adequate support. While there is ample literature surrounding the barriers to appropriate end of life care (Klop et al., 2018), the end of life priorities of people experiencing homelessness in the United Kingdom (UK) remain poorly understood (Care Quality Commission, 2017). This study aims to bridge the gap in knowledge.

The research question The central question of this study is: ‘What matters most to people experiencing homelessness in the UK as they consider their own end of life?’

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

Methodology This qualitative PhD project is a phenomenological study underpinned by the philosophy of French phenomenologist, Maurice Merleau-Ponty. Data have been collected through semi-structured, audio-recorded, face-to-face interviews with 21 participants (people experiencing homelessness) across several UK counties. Data have been analysed iteratively using thematic analysis.

Findings Findings are reported as eight themes: Spiritual concerns; Practical concerns; Fear of needing care; Fear of being forgotten; Preference for dying suddenly; Preference for being somewhere comfortable where people know me; Prioritising autonomy and self-determination; Prioritising authenticity. Findings are interpreted using Merleau-Ponty’s philosophy.

Discussion ‘What matters most to people experiencing homelessness in the UK as they consider end of life?’ When the answers to this important question are understood, the problem of people experiencing homelessness in the UK dying without adequate support and with very little dignity or choice can begin to be addressed.

0-2 DYING AS A HOMELESS PERSON – HOW CAN WE HELP?

Barbara Sheehy-Skeffington. Royal Trinity Hospice, London, UK

10.1136/bmjspcare-2019-HUKNC.2

It is well known that homeless people do not access healthcare in the same way as the general population and the same goes for their access to palliative care. At Royal Trinity Hospice we set up the Homelessness Working Party to try and explore ways that we could reach out to those who are homeless and have palliative care needs.

Since then, we have:

- Organised a stakeholder gathering, which was well attended and started to link us in with some of the key individuals and organisations in homelessness;
- Supported the homeless with palliative care needs, at first on an ad hoc basis but now we are trying to do this in a more systematic way, through links with hostels, as well as those who support the street homeless;
- Promoted our work through visits to hostels and specialist GP surgeries, speaking at events, teaching sessions and networking at external meetings – to improve the help that we can provide and hopefully help improve access for this underserved population;
- Organised ‘Homelessness Awareness Week’ to help teach our own staff about the issues faced by the homeless population and how best we can support them.

In the future we plan to:

- Continue to visit hostels to provide both support and teaching, as well as seeing new referrals;
- Provide training on end of life care for those who work with the homeless;
- Create a leaflet, accessible to the homeless population, to explain palliative care and how the hospice can help;
- Organise a coffee morning at one of the local homeless hostels, using the Death Café model, to encourage residents to think about death and dying in a non-threatening way;
- Promote our work to the rest of the palliative care profession in order to inspire other providers to improve their outreach to the homeless.

0-3 REACHING THOSE WHO WOULD NOT ACCESS HOSPICE CARE IN THE COMMUNITY – PRISON

Tracy Tuffs. St Barnabas Hospice, Lincoln, UK

10.1136/bmjspcare-2019-HUKNC.3

Background Prison Offenders are among the often hard to reach groups of society who do not engage in bereavement care. A culture of ‘not talking’ and fear of vulnerability in a prison environment can create difficult behaviours which hide the true cause of distress. In 2018 we were invited to attend a mental health event in a local Open Prison where it became apparent that many of the inmates had suffered significant bereavements in their lives for which they had never received support. We felt immediately that this was an area we could have an impact.

Aim To support inmates/residents through current or historic bereavements and improve their life chances on release.

Methods We created a counselling service to help inmates explore bereavement, the emotions, feelings and behaviours associated with loss and grief, and effective and positive coping strategies. We also trained peer mentors and staff to support bereaved inmates and established a bereavement group.

Results Feedback from service users and prison staff has been overwhelmingly positive. Inmates report significant improvements in their ability to cope with the strong emotions that accompany grief and loss, a better understanding of how this