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

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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 health-care 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

can lead to poor coping strategies and the ability to process and come to terms with death and dying. The Samaritans service at the prison reported that previously bereavement was consistently among the top three presenting issues of inmates, since the service began this is no longer cited as a reason for contacting their service.

Conclusions The need was identified to support a group of people who rarely engage with talking therapies or hospice care. By creating the bereavement service, we have made a measurable difference to the lives of inmates. We intend to use the learning from this project to develop services for other hard to reach groups.

0-4 REACHING THOSE WHO WOULD NOT ACCESS HOSPICE CARE IN THE COMMUNITY – UNIVERSITY

Tracy Tuffs. *St Barnabas Hospice, Lincoln, UK*

10.1136/bmjspcare-2019-HUKNC.4

Background Having developed the service in the prison we decided to look at other services in Lincolnshire and who they are supporting to be able to identify any other groups of people who do not engage with hospice care or bereavement support.

Aim To develop a service supporting teenagers who have been affected by bereavement. We know that this is a group where there is little support available due to scoping the availability of services in the county and the stigma of talking about bereavement and feelings which still remains which we identified through our scoping conversations.

Methods We had conversations with local University and colleges about how they support students through bereavement and the impact this can have on their education. This identified a lack of support other than some pastoral care with mentors in the school setting.

Results We now have a bereavement counsellor based in the local University, and two colleges around the county. We have had very positive feedback about the impact the service has had on the wellbeing of the students. The services now have a waiting list for students requesting support.

Conclusion The evidence in the growth of the service highlights the need to be supporting people more in the community rather than expecting them to reach out to us for support. This raises the profile of hospice care and the services which can be offered.

Parallel Session 2: Informing Service Development

0-5 FINDINGS FROM THE FIRST ROUND OF THE NATIONAL AUDIT OF CARE AT THE END OF LIFE (NACEL)

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NACEL is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death

in acute, community hospitals and mental health inpatient providers in England and Wales.

The audit, first undertaken during 2018/19, comprised:

- an **Organisational Level Audit** covering trusts (in England) and Health Boards (in Wales);
- a **Case Note Review** completed by acute and community providers only, reviewing all deaths in April 2018 (acute providers) or deaths in April – June 2018 (community providers); and
- a **Quality Survey** completed online, or by telephone, by the bereaved person.

Data was collected between June and October 2018. 206 trusts in England and eight Welsh organisations took part in at least one element of the audit (97% of eligible organisations). A total of 11,034 case note reviews were included.

Key findings included the following Documentation that a person may die imminently was high. For half of patients, imminent death was recognised less than one and a half days before they died, leaving a limited amount of time to discuss and implement an individual plan of care.

People's experience of care was good, excellent or outstanding in most cases (80%) as reported by the Quality Survey. However, 20% felt that there was scope to improve the quality of care and sensitive communication with both the patient and the family/others.

Governance of end of life care was strong.

Improvement is required in the documentation of an individual plan of care (documented evidence of a plan for 62% of people who died). Similarly, for one third of people who died, a discussion about the plan of care, and discussions about medication, hydration and nutrition had not been recorded.

The second round of NACEL is running in 2018/19.

0-6 CREATING A COMMUNITY OF OUTSTANDING PRACTICE: WE'RE STILL STANDING BETTER THAN WE'VE EVER BEEN

Linda Prendergast, Louise Pickford. *Mountbatten, Isle of Wight*

10.1136/bmjspcare-2019-HUKNC.6

18 months on: background The Island Better Care Programme commenced in January 2018 to support the local care sector to improve Care Quality Commission (CQC) inspection ratings against a background of ratings of 'inadequate' or 'requires improvement'. Delivered by this hospice following an Outstanding CQC inspection with funds from the Local Authority cascaded down from Central Government Better Care Fund.

Aim To provide and share support and tools to evidence good and outstanding care against the CQC key lines of enquiry inspection document. To streamline systems and form networks amongst the groups which may ultimately lead to consistency and ongoing support in the sector where there would have previously been competition for business.

Method A five-day classroom programme and support visits are available to the Proprietors, Managers and Deputies from local Care Providers. A programme of support to approx. 120 care providers: four cohorts per year over a three-year project length.