

Future directions of hospice care: IPU or ITU?

The Annual Marie Curie Palliative Care Research Conference, jointly with the Palliative Care Section of the Royal Society of Medicine

Oral Presentations

1 A HOSPICE'S APPROACH TO EQUIPPING A COMMUNITY TO LIVE WITH DYING, DEATH AND GRIEF

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Traditional hospice care frequently focuses on expensive inpatient care. However, a different strategy is required to meet more people's needs and ensure financial sustainability, relevant as more hospices face financial difficulty. A UK hospice has embarked on a strategy to deliver a service which encompasses a public health approach and was developed using feedback received from more than 40 interviews with people and professionals about their experiences of dying, death, caring and grief.

Alongside redesigning the provision of direct care this hospice has piloted a method, using an Asset Based Community Development approach, to equip a community to understand and enhance their capacity, skills and knowledge and return the ownership of dying back into the community, closer to the family network of care.

The results of this approach have shown a care home strengthening their connections to local GP surgery GSF meetings, other professionals, and their Parish Nurse. Strong connections between people themselves have been realised, even reconnecting people who went to school together. The results demonstrate how conversations with the community have improved people's death literacy. As a result, the hospice has developed new tools and procedures for working with care homes.

This method of working with a community has enabled the hospice to strengthen connections between statutory services, community groups and hospice provision and develop new ways of working with care homes. This pilot has demonstrated the impact a hospice can have by taking a public health approach to palliative care and provides a model for future practice.

2 BEFORE WE CHANGE, LET US UNDERSTAND: A PROSPECTIVE CHARACTERISATION OF HOSPICE INPATIENTS

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Hospice service redesign aims to achieve the greatest impact for the greatest number of people within limited resources.

The strategic direction within the NHS is towards care as close to home as possible, reducing avoidable admissions and improving patient experience of end of life care. However there is little published evidence describing patient use of hospice inpatient services, despite this significant resource. Our aim was to enhance understanding of why patients are admitted to two hospice inpatient units within one Health Board area, to describe the characteristics of patients admitted and explore their needs and wishes in this process.

We are conducting a prospective mixed methods evaluation. Using case note review, we are collecting data on approximately 250 hospice inpatient admissions. In addition, we are conducting up to 40 interviews with patients and carers to explore expectations and feelings around the admission; and seek feedback from the referrer and the receiving staff about appropriateness of admission and alternatives to admission.

We will present preliminary data on the reasons for referral to the hospice inpatient services, describe characteristics of patients referred including Adapted Karnofsky Performance Score, Phase of Illness and iPOS on admission; along with preliminary qualitative findings regarding patient and carer perspectives about hospice admission.

Our findings will inform our understanding of the use of hospice inpatient services and how resources can be most effectively allocated to meet patient and family needs and preferences within a locality. This will allow meaningful service redesign, ensuring the patient experience informs change.

3 LET IT ALL OUT: A SCOPING REVIEW OF EMOTIONAL DISCLOSURE-BASED PSYCHOLOGICAL INTERVENTIONS IN PALLIATIVE CARE

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Introduction Emotional disclosure (ED) is a term used to describe the therapeutic expression of emotion. There is some evidence to suggest physical and psychological benefits of ED-based interventions in palliative care settings. However, heterogeneity in intervention format, terminology and outcome measures has made it difficult to understand and thereby, explore how to develop a simple ED-based intervention more tailored for palliative care.

Aims To scope existing literature to develop a taxonomy of ED-based interventions for people with palliative-stage disease and their family carers.

Methods The review is guided by Arksey and O'Malley's (2005) five-stage scoping review framework. Six databases (including CINAHL and MEDLINE), grey literature, trial registers and conference proceedings were searched for relevant studies up to March 2019. Titles and abstracts were screened by 2 independent reviewers. Following full text review, data will be extracted. A taxonomy will be developed to categorise ED-based interventions. Categories will be mapped to mechanisms, intervention objectives, outcome measures and efficacy.

Results The search identified 6,611 unique citations. Further references may be identified by hand-searching references of included articles and contacting authors. Title and abstract screening has identified 278 potentially relevant papers so far.

Conclusions Full text review of relevant citations is underway. The review will be completed by autumn 2019. The results will document how ED has been evaluated in this setting and pinpoint what elements may prove most effective and in what context. This will inform future research in the development and assessment of ED-based psychotherapeutic interventions in the palliative care setting.

4 THE PLACE OR THE ENVIRONMENT: WHAT IS A MORE PREFERRED OPTION AT THE END OF LIFE FOR PEOPLE IN WALES?

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Introduction Public preference to die at home has been well documented in the literature (Schou-Andersen et al., 2016). An indicator of measuring success of End of Life Care Delivery Plan of Welsh Government is the proportion of patients who are cared for in their preferred places (Welsh Government, 2017). Uncertainties around accessing facilities to meet clinical and psycho-social need may have influence on changing public preference.

Aim To identify public preferences at end of life.

Method Online public survey using JISC tool. Data were analysed using descriptive statistics and thematic approach for this mixed method study.

Results 2210 people (Age: Mean+SD; 55+14 yrs) participated in the survey (29% were patients/cares, 23% academic/health professionals and 48% with no caregiving/bereavement experience) Only 31% of total surveyed believed that EoLC facilities were accessible and 49% thought these facilities were insufficient to meet the need. More people preferred to be surrounded by loved ones (62%); having access to trained professionals (84%), die in dignity (55%); be peaceful (40%); be symptom-free (30%), take part in care decision (26%) than those who preferred to be at home (24%). Preferred services and environment were expressed with free text by 189 and 87 respondents. Most people preferred their choices being respected; a large portion advocated for euthanasia. Pain management and having access to trained professionals came as preferred options by many but very few people preferred being at home.

Conclusions Access to trained support and having loved ones around them in a peaceful dignified environment outweigh the importance of a physical place of care.

5 UNDERSTANDING THE NEEDS OF DIVERSE COMMUNITIES IN PALLIATIVE CARE

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Current estimates suggest 1 in 4 people miss out on palliative care.¹ Older people, people with non-cancer conditions,

from BAME backgrounds, or with learning disabilities are some groups that face barriers to good end of life care.² With more people living and dying from complex chronic illnesses³ and estimates that by 2051 20–30% of the UK population will be ethnic minorities⁴, these groups' needs will significantly influence the growth in future palliative care demand.

2 projects in South Wales explored these barriers for people:

- from BAME backgrounds;
- with dementia;
- with learning disabilities; and
- from religious and non-religious backgrounds

We consulted 499 people through focus groups and interviews.

Findings

- People's understanding of palliative care is limited. Accessible and tailored communication would reduce fear and increase trust in services.
- People with non-cancer conditions and from BAME backgrounds feel they are less likely to be referred to palliative care. Some reported experiencing discrimination. Less restrictive referral processes would reduce barriers.
- People decline services for fear that their spiritual, cultural, or diagnosis-related needs will not be met. Staff need increased understanding of diverse needs and skills to meet them, and this inclusion should be promoted within communities.

As palliative care need increases and demographics shift, services will support an increasingly diverse patient population. It is vital that we work in partnership across the health and social care system to reduce systemic barriers to access services. We must also recognise the value of communities, and the experience and knowledge they have, to help us improve.

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6 BREAKING BAD NEWS TRAINING: LESSONS FROM OUTSIDE HEALTHCARE

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Healthcare workers frequently break bad news, but often lack formal training. Other job sectors (e.g. military and human resources) also break bad news on a regular basis. Lessons from these sectors may be valuable when developing training resources within healthcare.