

## Free papers 16–18 | ACP and end-of-life-care

### O-16 IATROGENIC SUFFERING AT THE END OF LIFE: AN ETHNOGRAPHIC STUDY

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A significant proportion of older people in the United Kingdom (UK) die in hospital, with variable quality of care. A palliative approach, which involves recognising and alleviating suffering, might lead to improved quality of care. Yet suffering is an intangible and contested phenomenon and little is known about people's actual experiences of suffering in this clinical setting. Further, it has been argued that an acute hospital setting is not well equipped to support dying well.

**Aim** To examine the context of end-of-life care for older people in an acute hospital setting, particularly focusing on the experience of suffering.

#### Methods

**Design** An observational study was conducted guided by the principles of sensory ethnography, within an interpretivist framework. Data analysis was inductive and iterative. Reflexive analysis included observations and inferences from a participant-observer perspective. Over a period of three months in 2016, 186 hours of observations were carried out.

**Settings/Participants** The study was carried out on a 30-bedded acute older peoples' hospital ward in the UK. Participants included 11 patients and 33 members of staff and visitors.

**Results** Patient suffering was influenced by a range of factors. Delays in recognising and acknowledging dying often led to treatments that were burdensome or futile, exacerbating patient suffering. Environmental factors in the physical clinical setting also exacerbated suffering. Finally, aspects of interpersonal interactions were observed to adversely affect patient experience.

**Conclusion** Acute care for older people in hospital was shaped by an overarching ideology of rescue which predicted and dictated the process of care. Findings demonstrated that suffering was not restricted to the direct experiences of life-limiting illness but was also associated with the experience of receiving care in an acute hospital setting. Avoiding or minimising iatrogenic suffering is an essential component of compassionate care.

### O-17 'SOMETIMES THEIR DEATH IS PROLONGED, NOT THEIR LIFE': THE EXPERIENCES AND NEEDS OF HIGH DEPENDENCY NURSES WHEN CARING FOR PATIENTS APPROACHING WITHDRAWAL OF LIFE-SUSTAINING TREATMENT: A QUALITATIVE STUDY

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**Background** Nurses in critical care are frequently required to facilitate the withdrawal of life-sustaining treatments and provide end-of-life care for deteriorating patients. Providing this care has been shown to cause nurses distress, potentially leading to stress, burnout and cumulative grief. Despite a wealth of research looking at the experiences of intensive care unit

nurses regarding end-of-life care, there remains a lack of research focusing on the period of care leading up to withdrawal of life-sustaining treatment and the experiences of high dependency unit (HDU) nurses.

**Methods** 15 qualified nurses took part in digitally recorded individual interviews, conducted within one HDU in the North West of England. Interviews were analysed using qualitative thematic analysis. University and NHS Ethical approval were obtained.

**Results** Participants reported difficulty caused by conflict in decision making, which they perceived to prolong treatment and suffering for patients who were not expected to survive. Resulting in moral distress, especially in situations where they voiced their concern that the patient was dying but the decision was made to continue life-saving treatments. Coping mechanisms were reported and the need for de-briefing or a talking therapy service was highlighted. The lack of education focused on how to provide optimal care and how to cope with this situation were highlighted.

**Conclusion** HDU nurses need time to talk about their experiences in caring for this patient group and education to support them to provide optimal end-of-life care in critical care settings is needed. The impact of this study has resulted in several local changes including debriefing sessions and development of a bespoke education programme has begun to ensure nurses are adequately prepared when caring for deteriorating patients approaching life-sustaining treatment withdrawal.

### O-18 A QUALITATIVE EXPLORATION OF ADVANCE CARE PLANNING IN PATIENTS WITH HOME NIV FOR COPD

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**Background** The HOT-HMV study in 2017 demonstrated that patients with persistent hypercapnia following an exacerbation of chronic obstructive pulmonary disease (COPD) who received home non-invasive ventilation (NIV) benefitted from prolonged time to readmission. Advance care planning (ACP) is recognised as being able to improve palliative care outcomes for patients with COPD. This study aimed to explore the benefits of and barriers to ACP in patients with COPD on home-NIV and how barriers might be addressed.

**Methods** Semi-structured qualitative interviews were conducted with health care professionals (HCP) from the North East Assisted Ventilation Service (NEAVS) (12 interviews) and with patients (11 interviews). Interviews were analysed using the principles of thematic analysis.

**Results** The findings emphasised the importance of ACP whilst also raising a number of challenges. NEAVS is a regional service therefore multiple local teams are also involved in patient care, resulting in a lack of clarity of responsibility for ACP conversations and geographical disparity with care continuity. HCP felt COPD patients were an under-served group both in medicine and society. They often have an uncertain disease trajectory resulting in difficulty in ascertaining appropriate timing for initiation of conversations. The patient group gave insights into the factors that affected their engagement in ACP

discussions including high levels of anxiety and communication factors, notably a reduction in face-to-face consultations due to Covid-19.

**Conclusions** This study allowed us to map out many of the perceived challenges facing patients with COPD on home-NIV in carrying out meaningful and timely ACP. Being conscious of the challenges allows a deeper understanding and awareness of the importance of individualised ACP discussions. The study supports a review of the structure of similar services to formally incorporate ACP and assign responsibility. Formal palliative care involvement is also suggested, to provide both education for HCP and direct patient input.

## Free papers 19–21 | equity and access

### 0-19 EXPLORATION OF METHODS USED FOR GOAL SETTING IN PALLIATIVE CARE WITHIN THE EAST ASIAN POPULATION: AN INTEGRATIVE REVIEW

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**Background** Goal setting in Palliative Care (PC) helps to tailor patients' care through their active participation. Methods used in Western Countries may not apply directly to the East Asian (EA) population due to cultural differences.

**Objective** To explore the methods used for goal setting in PC within the EA populations, involving patients' and families' perspectives.

**Method** An integrative review was conducted. A literature search was performed in five databases (e.g., AMED and Medline), limited to studies published in English and between 2000–2020. Studies evaluating methods for goal setting in Adult EA populations (>18) under PC, or not under PC but with life-limiting diseases, and their families were included. Data extraction and analysis were conducted on qualitative and quantitative data for this integrative review.

**Results** 8 studies, involving 931 patients and 346 families, were eligible. The studies took place in Hong Kong, China, Japan, Korea, and Taiwan. 6 intervention types were identified including education, treatment discussion, and documentation. Significant improvements were found in the patients' Advance Care Planning (ACP) readiness, quality of life, and in both their and their families' knowledge and decision making.

**Conclusion** This review provides information about goal setting methods in PC catering to physical, emotional, social, and spiritual needs of the EA population, ranging from very low to moderate quality evidence. Further research on breakdown of types of single interventions and on non-seriously ill patients in PC are needed in East Asia.

### 0-20 PALLIATIVE AND END OF LIFE CARE EXPERIENCES OF PEOPLE OF AFRICAN AND CARIBBEAN DESCENT (PEACE) DURING COVID-19

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**Background and Aims** People of African and Caribbean descent experienced the highest mortality rates during the pandemic, yet often have the poorest access to palliative care. This study aims to identify how palliative care services can better meet the needs of people of African and Caribbean descent, by exploring patients' (by proxy), families' and health, social care and community workers' experiences of end-of-life-care during the pandemic.

**Methods** Bereaved relatives, and professionals were recruited using social media, community networks and direct advertising to over 100 organisations. Semi-structured interviews explored experiences of end-of-life-care using a topic guide, developed with patient and public involvement partners. Participants' suggestions for care improvement were foregrounded throughout. The theoretical framework combined Critical Race Theory and Saurman's model of access. Thematic analysis was used.

**Results** Over 40 participants were recruited. Results indicate that people of African and Caribbean descent are poorly served by current services. Interviewees identified distinct differences between the culture of care, and that of the patient. Participants reported institutional racism. Processes were insensitive to diversity in family and community support structures in different cultures. Themes describing end of life care services included:

Unavailable: spiritual support, paid carers, specialist care, visitation and choice

Inadequate: advertisement of services, cultural diversity and the appreciation of the importance of extended families

Unacceptable: communication surrounding death and bereavement (upstream/proactive early discussions would improve engagement) and mental health and bereavement support.

**Conclusions** People of African and Caribbean descent are often termed a 'hard to reach' group. Yet our study suggests that current configuration mean it is services that are hard to reach. Prioritisation of person-centred, culturally competent spiritual, psychological and social interventions remains an aspiration for palliative care. A focus on cultural sensitivity and communication may be a good start to enhance palliative and end of life care for all.

### 0-21 NEW RESOURCES TO SUPPORT HEALTH PROFESSIONALS WORK WITH PEOPLE FROM DIVERSE ETHNIC COMMUNITIES

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10.1136/spcare-2022-SCPSC.21

**Background** There is inequity in the palliative and end of life outcomes for people from minority ethnic backgrounds. Some of this may relate to the practices of health care professionals. We have developed an evidence based training resource to enhance confidence and competence in providing this care. This is part of a wider NIHR funded study exploring the barriers and enablers to advance care planning.

**Methods** To share our findings we developed fictionalised narratives and stories. These were constructed from 93 interviews exploring the experiences of 18 longitudinal patient-centred case studies, as well as interviews with 19 bereaved family caregivers from diverse ethnic backgrounds. Facilitated virtual workshops, or workbooks, with 50 public and professional