

Conclusions As a healthcare community we are faced with the challenges of illness, uncertainty and death every day. However we are poor at considering our future EOL care. Despite having an awareness of the importance of sharing our thoughts with our loved ones we only do this half the time. By openly talking about death and dying we encourage our community to do the same. The hope is this will allow us to do better when talking to our patients.

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ETHICAL CHALLENGES OF ARTIFICIAL INTELLIGENCE TECHNOLOGY IN PALLIATIVE CARE

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Background Artificial Intelligence (AI) is an area of computer science which involves the development of intelligent machines that work and react like humans. AI has potential to improve healthcare delivery through purposeful analysis of clinical record data. Examples of AI use in palliative care includes the analysis of electronic patient record data to predict survival, classify pain severity and to identify important clinical discussions. Despite the opportunities of AI, there are a number of ethical challenges of using this technology in palliative care. Consequently, this study aimed to identify the ethical challenges of AI in palliative care.

Methods A narrative scoping review of literature was undertaken to identify the evidence of AI use in palliative care. Three real-world case studies using AI in palliative care were critiqued in depth, using the four ethical principle framework (Autonomy, Justice, Beneficence, Non-maleficence). Ethical challenges were identified and summarised into themes.

Results Very few studies have examined the use of AI in palliative care; no studies discuss the ethical challenges as the primary focus. Ethical challenges for AI in palliative care were summarised into four themes: (1) Data privacy and security; (2) Artificial stupidity; (3) Prognostication; (4) Unexpected results and bias.

Conclusions AI has potential to support delivery in palliative care; however, a number of important ethical challenges need to be considered. AI healthcare data analysis should be built around an ethical framework. This is important in palliative care as individuals may be more vulnerable compared to other specialities. Research to determine the views and opinions of a patients, caregivers and healthcare professionals is urgently needed. Our work has led to the development of recommendations for ethical AI research in palliative care, which will hopefully guide meaningful use of this technology.

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IN YOUR OPINION WHAT ARE THE MOST IMPORTANT ETHICAL ISSUES FOR THE SPECIALTY IN THE NEXT FIVE YEARS AND HOW COULD WE ADDRESS THEM

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Introduction Just access to palliative care for people from Black, Asian and Minority Ethnic (BAME) populations has long been recognised as a prominent ethical issue in the specialty. However, changing social, political and demographic factors mean that this issue is especially significant now.

Methods This essay reviews literature and population data to explore the barriers faced by people from these groups in the UK. They are grouped into patient-level, society-level and structural barriers, with provider-level mediators.

Findings There are numerous patient-level, personal barriers in palliative care. Frequently denoted examples include cultural, religious and linguistic differences between patient and caregiver. Although the exact nature of these barriers varies between ethnic groups, their existence remains relatively unchanged over time. However, recent society-level factors – the demographic changes of an ageing, diversifying, mobile population – is magnifying their impact currently. Structural changes also lend the issue contemporary significance. Namely, the so-called ‘hostile environment’ policies of recent governments have produced new barriers to palliative care. Although palliative care is exempt from patient charging, and the policies do not specifically target BAME populations, both are still affected. Poor implementation has led to inappropriate identity challenges, hospital fees and denial of care, which has in turn worsened health-seeking behaviour and healthcare experience amongst people from BAME groups.

Suggested solutions The solutions suggested are rooted in medical education: the provider-level factors that mediate barriers to care. These include ‘structural competencies’ to encourage engagement of clinicians in political discourse, and ‘cultural competencies’ to facilitate greater understanding between clinicians and patients. Inclusion of these extra-clinical competencies into training would create a healthcare workforce that is able to commission equitably, engage with policy and care effectively.

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ENABLING DYING PATIENTS TO TAKE PART IN RESEARCH USING ADVANCED CONSENT METHODOLOGY

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Background Palliative care research is essential to establish evidence based models of care that are required to improve outcomes for people with terminal illness. Obtaining informed consent for participation in hospice and palliative care clinical trials is an ongoing challenge faced by researchers.

Aim By consenting patients in advance, we aimed to improve research opportunities in the last week of life.

Methods Since 2017, an advanced consent methodology was used to recruit participants to two end of life care studies (UK National Institute for Health Research Portfolio study) from a specialist palliative care inpatient unit. Potential participants with capacity were given information by a researcher, which outlined the study aims and the advanced consent process. This included explanation of the end of life assessments. A ‘Personal consultee’ was

identified to act as a point of contact should the participant lose capacity to consent to further assessments. Once recruited to the study the researcher ensured regular contact with both participant and consultee throughout their inpatient stay.

Results A total of 101 people have participated in these studies over a 2-year period. The high recruitment rate (83%, n=101/121) demonstrates a willingness of the hospice to take part in end of life research; this is consistent with previous work about palliative care research participation. Feedback has been positive with patients, caregivers and staff through the entire research process.

Conclusions The advance consent process is an effective way to facilitate research participation at the end of life. People with palliative care needs want to participate in studies which include assessments in the dying phase of their illness. Caregivers have shown great desire to support research. Researchers should consider the potential to use the advance consent process to improve research participation for people who are dying.

95 **HOME PARENTAL NUTRITION FOR PALLIATIVE PATIENTS. A REVIEW OF FIVE YEARS OF EXPERIENCE AT MILTON KEYNES UNIVERSITY HOSPITAL**

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Background Parenteral Nutrition (PN) is the intravenous administration of nutrition and can be used in patients whose gastrointestinal tract is unable to function. It is a treatment that is relatively easy to initiate, but it is a difficult treatment to continue outside of hospital and can also be, ethically and morally, a difficult treatment to stop. Recent ESPEN guidelines (2016) state that 'the bioethical aspects of feeding patients with advanced disease should be considered.... There are data showing benefits of home artificial nutrition in cancer patients even in advanced cancer patients. Home parenteral nutrition is a complex therapy and selecting patients for this treatment a demanding task'.

Method Patients for whom home parenteral nutrition had been a goal were identified. A retrospective review of these patients' clinical records was undertaken.

Results Between 2014 and 2019 six palliative patients had PN commenced at Milton Keynes University Hospital, a medium sized District General Hospital. One further patient had PN started at a tertiary centre. All patients had ongoing bowel obstruction secondary to peritoneal metastases. The mean age of patients was 49 years (range 35–81 years). The average time from starting PN to hospital discharge was 47 days for the MKUH patients compared to 14 days for the patient who was started on PN at a tertiary centre. The average time from starting PN to death was 435 days (range 28 – 1825 days). One patient remains alive, 2 died in the hospital, 2 in the hospice, 2 at home.

Conclusion Carefully selected palliative patients can benefit from home PN, but in a district general hospital this requires a lengthy hospital admission to achieve. The decision to start PN should be multidisciplinary and the goals of treatment should be clearly defined and reviewed regularly.

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96 **UNDERSTANDING THE MEANING ATTRIBUTED BY JORDANIAN PARENTS OF CHILDREN WITH CANCER TO THEIR ILLNESS: A PHENOMENOLOGICAL STUDY**

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Background Jordanian culture is a variant of Arab-Islamic culture that comprises two intertwined strands: the interpretation of Islamic religion and vernacular Arab culture. Few studies have been conducted in the Middle East to explain the way culture shapes and reflects parents' lived experiences and interactions with their children, particularly concerning the meaning and philosophy of disease.

Methods The aim of this study was to explore the lived experiences of Jordanian parents of children with cancer. The study investigated the cultural meaning of illness and how it affected parents' lived experiences of their children's illness. The study adopted a hermeneutic phenomenological approach informed by the philosophy of Martin Heidegger and used semi-structured interviews. The study was conducted in one paediatric oncology unit in one Jordanian hospital.

Results Twenty-five interviews were collected from 24 mothers and one father. During the interviews, the parents expressed that their spiritual beliefs helped them accept their child's disease. Showing patience towards the suffering of their children was perceived as an important value the parents tried to stick to despite the deep suffering the children were experiencing. All the parents demonstrated a thankful approach as they perceived that everything that happens to their child is according to destiny. The beliefs the parents held about their child's illness were perceived to positively affect the way they interacted with them. This was especially so in sensitive situations, such as their reactions to initial diagnoses and receiving bad news.

Conclusion The findings of this study will inform the education of health professionals and increase their understanding of the beliefs and practices demonstrated by the study's participants and their integration into supportive patient plans.

97 **HOW DO PHYSICIANS IN SOUTH INDIA RECOGNISE, ASSESS AND MANAGE CHRONIC BREATHLESSNESS AND IS CHRONIC BREATHLESSNESS CONSIDERED A SYNDROME OR DIAGNOSIS?**

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Background Chronic breathlessness syndrome has been recently defined to help clinicians actively seek and patients legitimately present with persistent breathlessness, and to drive service development and research. There are many evidence-based interventions emerging. However, the naming and defining process did not include views from low to middle-income countries, where chronic breathlessness is a significant issue.