

What are the barriers to accessing palliative end of life care at the right time?

Introduction

Palliative care is defined by the World Health Organisation as an approach which aims to improve the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. This is done via early identification, correct assessment and treatment of pain and other problems. The aim of palliative care is to relieve symptoms, manage pain and address the emotional, psychological and spiritual needs of the patient (1). Although curative treatments target the illness itself, palliative care centres on providing comfort and support, regardless of the stage of the disease.

In England, the term 'end of life care' refers to the last year of life(2). Most people stated they would prefer to die at home but in England in 2022, 43.4% of all deaths occurred in hospital, compared to 28.7% at home. 20.5% people died in Care homes and 4.7% people died in care hospice (3).

The NHS England Mandate (2013-15) sets an ambition for the NHS to deliver a globally recognised' standard of end-of-life care (4). This was supported by an assessment of global end of life care performance in which our end-of-life care was rated the best in the world (5). However, in 2017, Hospice UK (e-hospice 3rd July Hospice UK analysis 'One in four UK families who need end of life care miss out on crucial support')(6). It is estimated that one in four people, approximately 118,000 who require end of life care were not able to access the expert care they need at the end of life, including hospice care or other support that they need(4,6).

The palliative and end of life care needs, of babies, children and young people are distinct from adults and need to be considered separately. In the UK, an estimated, 86,625 children and young people are living with life-limiting or life threatening conditions and are in need of palliative care services(7). Around seven in 10 children and young people with life limiting conditions die in hospital and that has not differed in the past 15 years. Specialist end-of-life (palliative) care is not consistently available for children across the country, while some children hospitals do not have palliative care services (8).

This literature review aims to explore the barriers to accessing palliative end of life care at the right time.

Barriers to accessing palliative end of life care at the right time

Despite its critical importance, access to palliative end-of-life care remains uneven across various populations and settings. Numerous barriers can hinder timely access to these essential services. An overview of barriers to palliative care include fractured

communication, miseducation and misconception, unpredictable disease trajectory, lack of time and low supply of palliative specialists (9).

Breakdown in communications

Breakdown in communications is one of the greatest barriers to the delivery of palliative care (10). Communication between provider and patient and or between providers themselves is often an issue which leads to reduced access to palliative care (9). Healthcare providers may struggle to convey the goals of palliative care in a way that resonates with patients and their families. If the focus on improving quality of life and symptom management is not discussed early and clearly, patients may choose to pursue aggressive treatments, even when palliative care would be more beneficial. Many physicians are not comfortable talking to their patients and families about a change in prognosis or making a palliative care referral. In addition, some physicians believe that referring patients to palliative care could lead to alienation and loss of the patient-doctor relationship(18). A qualitative meta synthesis of patient, caregiver and clinical perceptions of palliative care found that there was a lack of trust between clinicians (19). Non-palliative care physicians feel that their palliative care counterparts assume too much of the patients care and provide inaccurate prognosis predictions. One oncologist had stated that a palliative care physician told patients they were going to die that were not even dying and it was terrible to backpedal from what the palliative care physician said(19). A study of hospice uses among individuals with Severe Persistent Mental Illness (SPMI) found that there was often inadequate communication about preferences for end-of-life care(20). The disorganised thought patterns that typify schizophrenia could lead to inadequate communications of symptoms by individuals with schizophrenia and cancer, potentially hindering palliative care referrals. The study also found that behaviours and symptoms associated with SPMI may complicate the assessment and interpretation of physical symptoms, affecting the care delivered to these individuals, including hospice care (20). A mixed methods cohort study of providing end-of-life care for people with a history of substance use , found that one practice would withdraw service provision and prescribing services if a patient with substance misuse was on palliative care. This was done to avoid double prescribing; however it may miss the opportunity for continued substance-related end-of-life care, particularly if patients become non-verbal(24). This shows that importance of communication between different healthcare providers as a miscommunication may lead to detrimental effects to patients care.

Misconception of the term palliative care

Miscommunication and misconception of the term palliative care is often a barrier to initiating palliative care. A pilot study among patients with Hepatocellular carcinoma who undertook semi-structured interview on their perception of palliative care found that there was a significant misperception of the purpose of palliative care (11). 9 out of

21 participants had no prior knowledge of palliative care and 16 perceived palliative care to mean end-of-life therapy. After a brief explanation of the term palliative care, almost all the participants accepted palliative care and some supported a name change to mitigate stigma (11). A qualitative study among onco-haematologists found that advance care planning and palliative care was not a familiar topic to them and was often confused with advanced directives (17). Their ignorance of advance care planning meant that patient discussions only focused on the medical aspects, particularly to that of disease progression, without exploring the aspects of palliative care (17). A qualitative systematic review of healthcare providers attitudes towards a palliative care referral found that oncologists and haematologists mistakenly perceived that a palliative care referral was a symbol of abandoning treatment rather than a complement towards continuing treatment (18). It is necessary to enhance doctors understanding and awareness of the term palliative care, eliminate misconceptions and negative attitudes to promote more timely and appropriate referrals (18).

Unpredictability of disease trajectory

The unpredictability of prognosis of an individual patient is one of the main obstacles for timely initiation of palliative care (12). A systematic review of prognostic scoring systems to identify end of life in patients with Chronic Obstructive Pulmonary Disease (COPD) found that current evidence does not allow clinicians to reliably predict which patients with COPD are approaching end of life, limiting ability to provide palliative care services appropriately (13). The decision to initiate palliative care should be based on the presence of refractory chronic symptoms and patients' unmet needs and preferences (12). Clinicians should set a goal of initiating longitudinal palliative care from the moment COPD is diagnosed, alongside the usual management of disease and intensified palliative care in the end-of-life stages of the disease (12). Although the implementation of palliative care in patients with COPD is challenging due to its unpredictable illness trajectory, the trajectory of many cancers follows a more predictable path and allows for earlier and more planned integration of palliative services (21).

The right timing to initiate palliative care

The wrong timing for starting palliative care discussions may also lead to a barrier to accepting palliative care. A meta-ethnography systematic review of people with cancer's reasons for declining end-of-life care found that if conversations of end-of-life care occurred too early, then patients' need for end-of-life care was sometimes not yet apparent and found the referral to be distressing (14). A focus group study on physicians' views on the usefulness of identifying and disclosing patients' last phase of

life found that most clinicians thought it was useful and feasible to start end-of-life discussions early, but they found that disclosing this information should be done gradually, preferably during multiple consultations, as it gives the patient the opportunity to process the information and to think about preferences for care(15). A series of case studies comparing early and late referrals to paediatric palliative care found that one patient who had delayed introduction to palliative care services ended up having a costly cycle of palliative chemotherapy that led to intolerable side effects and had to be discontinued. Fortunately, effective integration of palliative care services was done and the patient was able to pass away peacefully at home(23).

Lack of time and low supply of palliative specialists

Increasing workload and time pressure is another barrier to the initiation of palliative care. A qualitative study of nurses in pneumonology and renal unit found that most nurses did not have enough time to for palliative care conversations with patients and their families (16). They felt that their workload was too high to provide the palliative care needed for their patients because the time available for each patient had shortened and their nursing tasks had increased (16). A qualitative meta synthesis of patient, caregiver and clinical perceptions of palliative care found that clinicians felt that their current system did not provide enough time for for palliative care discussions (19). They also felt that it was challenging to communicate with a wide range of people in a limited amount of time. In addition to that the clinicians found that there was a lack of palliative care resources (19). For instance, a primary care physician stated that they only had one palliative care physician that worked part-time and felt that it was not fair to refer all the patients who may have needed a palliative care referral to their palliative care physician (19). A systematic review for the implementation of hospital based-palliative care found that there are administrative difficulties like securing optimum space, staff and sufficient time needed to launch the implementation of palliative programme (22). The review found that the integration of the palliative care model into a hospital-based settings, was often most successful when senior managers and heads of tumour streams provided support, funds, education and human resources into the programme (22). A focus group study on the perspectives of people with intellectual disabilities found that staff turnover was a huge barrier to receiving palliative care(25). These subgroup of patients with intellectual disabilities expressed how hard it was to make decisions when staff who knew them well could no longer support their decision making(25). Carers of these patients agreed with the statement as they it was particularly challenging to make decisions where no one had in-depth knowledge about the person(25).

Conclusion

Accessing timely palliative end-of-life care remains a complex challenge, influenced by a range of barriers that span communication, misconceptions, unpredictability of

disease trajectories, timing of discussions, and resource limitations. Effective communication between healthcare providers and patients is crucial for facilitating an understanding of palliative care's benefits, yet breakdowns often occur, leading to missed opportunities for timely referrals. Misunderstandings about the purpose of palliative care further complicate the initiation of these services, with many patients and even healthcare professionals viewing it as synonymous with abandonment of curative treatment.

The unpredictable nature of various illnesses can hinder timely palliative care integration, as providers struggle to identify the optimal moment for initiating these conversations. Moreover, the pressures of time and the scarcity of palliative care specialists exacerbate the difficulties in delivering comprehensive support.

Addressing these barriers requires a multifaceted approach: enhancing education and awareness among healthcare providers and patients, fostering open and continuous dialogues about end-of-life preferences, and ensuring adequate resources and support systems are in place. By prioritizing these areas, we can improve access to palliative care, ultimately allowing individuals facing life-threatening illnesses to receive the compassionate support they need at the right time.

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