Palliative care can be called the “heaven for the few”: how can we improve access to good palliative care?

Introduction

Albeit obvious, when I embarked on the beginning of my career as a palliative care healthcare assistant, it soon became apparent that nobody can escape death. Months into adulthood, and straight from school, optimistic for my future; the sudden confrontation with death was not the morbid experience that may be expected, when an only recent adolescent starts their first healthcare job in a hospice.

I remember very clearly my first patient death. But I also very clearly remember the care I was taught to provide. How we helped her with her meals – whatever she fancied, whenever she fancied them. I remember helping her with a bed bath and arranging her pillows how she liked them. Ensuring she moved every few hours to prevent her skin breaking down. I remember how she looked so relaxed and peaceful as her breathing changed, and how the syringe driver would be checked and changed to ensure she had all the medications she needed. I remember when she died, and how beautifully gentle the team were when preparing her to be taken into the care of the funeral directors.

As the seasons changed, this devoted standard of care remained the same, accentuated with personal touches from patient to patient, as we had the privilege of learning their idiosyncrasies. I saw patients who were really old. I saw patients who were scarily young. Patients burdened with a long list of morbidities, and patients burdened with one overriding deathly diagnosis. I saw people who reminded me of my loved ones, and people who appeared to have very different ideas and beliefs in life to me. Ultimately, each and every patient was different despite there being an apparent common factor – they were all dying. All whilst being looked after by a specialist palliative care team, in a hospice and in the community.

This role was and continues to be a window for me into the world of palliative care medicine, and illustrated holistic care in a way no lecture at medical school ever could. My experience in this role has allowed me to reflect on the importance of palliative care, but also consider potential barriers. This essay considers some obstructions to good palliative care and contemplates how these can be overcome, with a focus on the provision of palliative care in the community setting.

Dying where you choose

An important shift in palliative care medicine is the increase in patients being cared for and dying at home (1). In my view, having the control to decide to be cared for and die in a setting where you are comfortable, is incredibly important. Therefore, giving as many people the choice as possible is significant, and should very much be encompassed within good palliative care practice. Focussing on preference of place of death and end-of-life care, a cross-sectional survey by O’Sullivan et al., found that 52% of the participants, who had all been recently bereaved, advised their preferred place was home (2).

Despite individual’s preferences, expanding the population of patients who are given the opportunity to discuss their options and voice their thoughts and concerns is a crucial stepping stone as we expand the reach of palliative care medicine in the UK. One way to address this, could be to increase awareness of advance decision making, where patients can document their preferences. Interestingly, there has been an association made in England between patients with advance care plans and dying at home (3).

This study also found that the outcomes associated with dying at home had a range of quality of outcomes (3). Whilst empowering patients to document their preferences is undoubtedly important, this raises an important question - what is the standard of palliative care that is accessible in the community, if accessible at all? Whilst the results suggested variable success in terms of the care provided, and the choice to die at home can be absolutely invaluable for those patients and their loved ones, perhaps some of the barriers to good palliative care, including end-of-life care, are accentuated as a result of the current logistics of community care?

For example, for those patients who live rurally, is it possible to provide a good standard of palliative care for those people, in their homes? A study by Pesut et al. describe a trial of a rural palliative care support service across two rural locations, where twice weekly visits were carried out (4). The study found that their model was feasible and provided patients with continuity of care (4). From the relationships I and colleagues have built with patients and their loved ones, I appreciate the value of continuity of care. However, I also recognise the challenges and strain of caring for and being cared for by a loved one, and that this may not be suitable for all families, and also may not be comprehensive for all patients.

Furthermore, the challenge of caregiver burden is highlighted by Enguidanos et al (5). This study highlights some of the benefits of patients with advanced heart failure receiving palliative care at home, including prevention of hospitalisation and good symptom control (5). Moreover, Fernando et al. also describe the importance of integration across specialties to provide good palliative care at home for those living rurally with cardiovascular pathology – with teams including general practitioners, cardiac and palliative care teams (6).

Additionally, a common recognition from these studies is the need for further research to decode the solutions for provision of palliative care in rural locations (4-6). Whilst the research we have should be informative on the provision of care, the apparent gaps should not be a barrier to their implementation, on the understanding that we are not stagnant, and we can learn and adapt. We know that the disparity of the standard of palliative care is diverse across the UK, and it would be unrealistic to suggest a one-size-fits-all approach for organisational restructure for better palliative care provision. Not knowing how is best to provide a service, should not be preventing us from providing that service, but an opportunity to mould it to fill the hole in care that is present. This also should include active investigation into how marginalised groups in society can access good palliative care, with geographical focus on the individuals ostracised within each specific area.

Accessing Medicines

Continuing the focus on community-based palliative care, are patients able to access the medications they require? Miller et al. investigated this, with the encouraging finding that in 80% of cases the local pharmacy was able to dispense all required prescribed palliative medication in the initial visit (7). However, this still leaves 1 in 5 vulnerable – in a position where they cannot easily access the medications they need, with the maximum time to access palliative medicine approaching 80 hours (7). This difficulty was also mirrored by Campling et al. when investigating the accessibility of palliative medicines in the community (8). Although palliative medicine should be proud of its holistic approach, we should not undermine the value of medications in the provision of comfort to many patients from their brutal symptoms. Therefore, ensuring access of medication needs to be encapsulated within expanding access to good palliative care.

Promisingly, the Pharmacy Quality Scheme Guidance of 2023/2024 includes guidance regarding the stock of palliative care medication, as well as plans for when these medications need to be acquired quickly (9). Moreover, an article in the *Pharmaceutical*

Journal describes the work of a Specialist Palliative Care Pharmacist and the crucial work they carry out (10). Further training for pharmacists on palliative medicines, and an increase in specialist pharmacists will likely improve and expand the care of palliative care patients. In line with this, the conclusions of the aforementioned study by Campling et al. suggested that an increase in the amount of nurse and pharmacist prescribers could contribute to improved medicine access (8). Furthermore, the Scottish government's draft strategy of 'Palliative care matters for all' involves specialist pharmacists, as described in Nayyar's article (10, 11). These sources highlight the benefit of the MDT-wide approach necessary for an individual to receive good palliative care, as well as how expanding training opportunities for specialists will broaden their scope of practice, directly improving and expanding the reach of patient care.

Education

Increasing awareness and knowledge of palliative care is hugely important. People should know about the care that they are entitled to, and how it help them. For this to happen, we need public awareness of palliative care, as well as a workforce who can recognise a patient who may benefit from it and make the appropriate referrals. Whilst education has a huge role to play in the efforts to improve access, it will also help tackle stigma. This in itself should be a multi-tiered approach – education for healthcare professionals, including students, education for the public, and for patients who are receiving, or may benefit from palliative care input.

Firstly, for both clinicians and patients, by combating the stigma around death and dying, encompassed within palliative care, we can empower patients to feel as confident and comfortable as possible discussing their care going forward. The stigma around death and dying needs addressing to make these conversations easier for patients and their loved ones. A 2021 census wide survey commissioned by Palliative Care Charity *Sue Ryder* found that 60% of people have not discussed their end of life wishes (12). Projects such as *Hospice UK's Dying Matters Awareness Week* and *Sue Ryder's* aims to change attitudes about death and dying are great examples of this (13, 14). However, the more visible these campaigns and messages are to the public, the bigger impact they will hopefully have. Moreover, making this information accessible in as many forms as possible so it can have a wider reach. For example, leaflets, radio and television adverts, newspaper articles and adverts on buses. Local campaigns of the services unique to each area, to promote a feeling of community. This needs to reach the difficult to reach people – for example, those who are very isolated and the homeless communities.

Spreading awareness is particularly important as our nation potentially undergoes a pivot in our stance and laws regarding assisted dying. The Assisted Dying Bill is complex and beyond the scope of this essay. However, it should jolt us into action of ensuring that the public are aware of their options when they live with a terminal illness, and how palliative care could serve them, so people are able to make informed choices.

Next, for clinicians, education to promote a proactive approach to palliative care. By educating healthcare professionals of the roles of palliative care, they may be more likely to consider and go onto refer appropriate patients to the specialty. This in turn can expand the opportunities for your patient in terms of the scope of care and interventions they receive. Moreover, reminders that the referral to palliative care isn't necessarily handing over the baton, but rather can promote a collaborative approach to the care of that patient, as suggested by the aforesaid research by Fernando et al (6).

Conclusion

The NHS is undergoing many ongoing challenges, plus the pressures of those to come. As healthcare professionals we will contribute to the navigation of the NHS through these unprecedented times and must ensure palliative care is not overlooked. In a resource-stretched healthcare system, expanding any service will come with challenges. However, we have the advantages of a society where messages can spread quickly due to technology and the media, and we should tailor this to our advantage. Likewise, with the ongoing discussion regarding assisted dying may provide platforms for palliative care experts to raise awareness of this medical specialty. The multitude of barriers mean there is not a single solution for improving access to palliative care, hence the solutions are multifaceted, and require the alliance of the policymakers, specialists, and mostly importantly, the patients and their loved ones.

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