

**In your opinion what are the most important ethical issues for the specialty in the next five years and how could we address them**

### **Introduction**

A multitude of challenges are likely to confront the field of palliative care in the coming years, many of these with huge ethical implications. With demographic shifts resulting in the over-65 population resting at almost 12 million, combined with an unprecedented increase in the burden of diseases of old age such as dementia; it is likely that palliative care as a specialty will need to adapt to new demands (1). As theorised by Block it may well be that many of the dilemmas emerging today have been fuelled by the ever-increasing sophistication of our medical system itself and its “unintended side effects”(2). The term palliative care is defined by the World Health Organisation (WHO) as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness”(3). In order to achieve this aim, it is concerned with not just managing a patient’s physical symptoms, but also their emotional, spiritual and psychological needs (4). Additionally, careful consideration is given to the patient’s social care and the varying needs of those close to them. The field of palliative care relies on a diverse workforce, with input coming from numerous professionals, some working in generalist roles and others working in specialist roles. Professionals integral to the field include, but are by no means restricted to: GPs, district/community nurses, palliative care physicians, nurse specialists, counsellors, physiotherapists and occupational therapists (4).

This essay will examine just some of the emerging ethical challenges faced by the specialty in the next five years and put forward potential solutions.

## **Developing an ethical framework**

Due to this essay focussing on ethical concerns, emphasis will be placed on how aspects of palliative care may be examined using established ethical frameworks. Medical ethics is a form of applied ethics and concerns the study of moral values and judgements as applicable to the field of medicine. Bioethicists have traditionally favoured the principlist approach for framing ethical dilemmas. This approach utilises the four key principles of non-maleficence, beneficence, autonomy and justice to frame ethical judgements(5). Briefly, non-maleficence refers to a professional's responsibility to do no harm , beneficence refers to an individual's duty to do all they can to benefit a patient, autonomy concerns the right of an individual to retain control over his/her body, and justice requires there to be an element of fairness in all medical decisions (6). To further complicate matters, it has been proposed that other approaches such as "virtue ethics" and "ethics of care" frameworks could provide valuable alternative perspectives. Virtue ethics is concerned with moral character in a broad sense and is less concerned with the rightness of individual actions. The "ethics of care framework" focusses more on interpersonal relationships and recognising the vulnerability of the human condition (5). Due to this aspect of vulnerability, it is becoming one of the favoured approaches in this field. Key areas for discussion will include the challenges posed by considerable demographic changes and how equity of access to services can be ensured for diverse population groups. Issues of underfunding and prioritisation will also be addressed in the context of this specialty. Although a topical and contentious issue relating to the field of palliative care, physician assisted suicide will not be discussed in this essay due to the complexity of this topic and the limits of this essay.

## **Demographic challenges**

From the beginning of the 19<sup>th</sup> century the UK has seen a dramatic decline in mortality rates coupled with a considerable increase in life expectancy (1). As a result, a child born in 2018 is expected to live for an average of 79.9 or 83.4 years if they are male or female respectively. However, the “disability free” or “healthy life expectancy”, defined as the “number of years of life expected to be without a disability or in good health” has not increased in line with overall life expectancy (1). This means that the population is now spending a greater proportion of their lifetime managing complex health conditions.

Not only this but whilst the proportion of the population with multi-morbidities aged 65-74 currently rests at 46%, this figure is even higher in the 85+ age bracket at 69% (1). The term “multimorbidity” refers to the coexistence of two or more long term medical conditions or diseases (7). The data referenced above is concerning in the context of palliative care as between 2014-2040 the number of people aged 85+ needing palliative care is expected to more than double (8). This is likely to place considerable pressure on the specialty and have significant implications for how services should be structured. The increasing prevalence of multimorbidity is also expected to result in substantial increases in the cost of care particularly in the last year of life. For example, costs in this final year are anticipated to grow by 25% by the year 2030 (8). The increasing complexity of patients’ health is also likely to make risk-benefit decisions around discontinuation of treatment even more complicated. Balancing the ethical positives and negatives of interventions is likely to become far more challenging due to the boundary between beneficence and non-maleficence becoming increasingly blurred.

## **Shifting priorities**

The relative prevalence of conditions requiring palliative care input is also expected to continue to shift. Dementia has long been underrepresented in palliative medicine despite its undeniably terminal nature. An unprecedented increase in deaths due to the condition has been forecast despite Sampson et al. already estimating that one third of people aged over 65 years in the UK will die with a dementia diagnosis (9). Due to the prolonged and unpredictable course of diseases such as dementia, it has been suggested that issues regarding access to palliative care need to be addressed (9). Whilst some conditions seen under palliative care are better suited to continuous input, patients suffering from dementia may be better suited to short term palliative care interventions at critical points within the disease course. The level of baseline function is also often lower among dementia patients due to the elderly nature of the population and their likely accumulation of comorbidities. In contrast, the trajectory of terminal cancer patients usually features an initial slow overall decline from high functionality and then a more predictable sudden decline in function(9). Complications such as pneumonia, febrile episodes and feeding difficulties are not just restricted to palliative patients with cancer but are commonly seen in their counterparts with dementia (9). Therefore, palliative patients with dementia may benefit from a needs-based access approach to palliative care as it is difficult to time when interventions will be necessary. In this way certain triggers for review could be created in order for these individuals to gain rapid access to palliative care assistance at relevant time points.

A new model of generalist-led dementia-specific palliative care has been proposed by some palliative care physicians as a more appropriate care pathway for these patients (10).

Patients with end stage dementia are likely to also benefit from input early on in their disease course with a large emphasis being placed on advanced care planning. The Gold Standards Framework advises that the following three questions are integral to these discussions: 1)

What do you want to happen (advance statement of wishes and preferences) 2) What do you not want to happen (advanced decision to refuse treatment and do not resuscitate orders) 3) who will speak for you (lasting power of attorney) (11). It is well documented that advanced care planning is carried out inconsistently across populations with a general practice study finding that only 58% of patients who died from a chronic condition had an advanced care plan; 74% with cancer and 41% with organ failure. Here it is becoming increasingly evident that patients with a non-cancer diagnosis are being missed by both generalist and specialist palliative care services (12). Whilst evidence is mixed with respect to the benefits of advanced care planning, it is generally considered to be hugely beneficial for both individuals with dementia and also their families. Less aggressive medical care, better quality of life near death and decreased rates of hospital admission have all been associated with the presence of advanced care planning in patients with dementia (11). Advanced care planning is considered important as it is seen to extend patient autonomy into a potentially more uncertain future. The conditions required for autonomy are as follows: 1) patients have the relevant internal capacities for self-government and 2) patients are free of coercion to make decisions (13). It is only when these two conditions are highlighted that the beneficial role of advanced care planning becomes unmistakable for patients with dementia.

There are also challenges associated with identifying the palliative care needs of patients with dementia and this can result in symptoms such as pain being poorly addressed in comparison to other palliative patients. This may result from impaired communication or from difficulties with recall or interpretation of sensations. Here the concept of beneficence is crucial as health professionals have an obvious responsibility to attend to patients needs even if these are not immediately obvious. These patients also constitute an extremely vulnerable population and therefore in order to promote the principle of justice, additional time and resources may need to be invested in them in order to remove barriers to their care. Non-maleficence also dictates

that these patients should not be subjected to any burdensome tests and interventions which are unlikely to yield substantial benefits. From an ethics of care perspective, these patients perhaps to an even greater extent, need to be recognised as interdependent and in need of “respect, protection and care” due to their obvious vulnerabilities (5). In addition to the aforementioned difficulties with communication there are also concerns around accurate identification of the terminal phase in this population and their suitability for existing interventions. Experts such as Sampson have expressed great concern surrounding the lack of research into palliative care for people with dementia (9). No service in isolation is sufficient to provide palliative care to those with end stage dementia due to the complexity of the condition and the variety of settings that it is seen in and therefore innovative approaches are likely to be required.

### **Equity of access:**

It has been found that both nationally and internationally there are wide variations in both the quality of palliative care services and their ease of access. In order to discuss the relevant ethical issues associated with this, it is important to first define some key terms.

Firstly, equality refers to a situation or state where “all the members of a group have the same status, rights, and opportunities” whilst equity describes “the absence of avoidable, unfair or remediable differences among groups of people” (14)(15). In this way promoting health equity also aims to reduce health disparities by considering the additional needs of underserved and vulnerable populations. As first described by Aristotle in his “formal principle of equality”, it is important to “treat equals equally and unequals unequally in proportion to the morally relevant inequalities” (16). The term “justice” is defined as “the

moral obligation to act on the basis of fair adjudication between competing claims” (17).

Therefore, it follows that justice can only be achieved when inequities and subsequent inequalities have been accurately assessed. The above concepts and disparities in healthcare are relevant to all branches of medicine but seem particularly cruel in the context of palliative care. Huge variations in the ease of access to palliative care exist between different racial groups, age groups, socioeconomic groups and between patients with different categories of illness. Furthermore, a combination of inadequate staffing and chronic underfunding in the specialty is only likely to worsen existing inequalities.

Only a minority of the public in need of specialist palliative care receive it, and investment and access is heavily weighted towards those with cancer. Data produced by Dixon indicates that whilst 90% of UK specialist palliative care is provided to patients with cancer, only 29% of deaths in 2014 resulted from malignancy (18). Furthermore, timely identification of people at the end of life is often poorly fulfilled in non-cancer patients, which can mean they do not receive the correct care at the correct time point. It has been hypothesised that this may be due to the comparatively more predictable disease course of malignancy, which palliative care services have traditionally been structured around. Despite this a Marie Curie review also revealed inequalities between cancer diagnoses. For example, individuals with blood cancers are even less likely to receive specialist palliative care input than other cancer patients and are twice as likely to die in hospital (19). Those with brain tumours were also found to have more unmet needs perhaps due to, or worsened by, an increased prevalence of additional barriers concerning their mental health or communication. Current literature also suggests that race and ethnicity have a large bearing on ease of access to services. A report released by LSE found that individuals from black and minority ethnic communities (BAME) were less likely to report their care as “excellent” or “outstanding” than the surveyed individuals of white ethnicity (18). Not only this but a range of other barriers affected the

care of these groups including insufficient translational resources, shortages of female staff for female Muslim patients and stereotypical assumptions surrounding BAME families always being able and willing to care for their relatives at home. It is clear that in many cases palliative care services are struggling to cater to the different needs of minority ethnic groups. What constitutes a “good death” is likely to vary hugely between different cultures and it is a challenge for any health system to accommodate this. Similarly, Marie Curie found that LGBT individuals with palliative care needs were also less likely to receive timely care (20). Many viewed anticipated stigma, religious complexities and varied support networks as significant barriers to receiving appropriate support. Clearly, the above issues are not confined to palliative care as a speciality however they seem particularly unjust in the context of end of life care. Older individuals and those subject to social isolation have also been found to have difficulties accessing services. It has been suggested that increasing the diversity of the palliative care workforce may help both minority and vulnerable populations to access services.

Furthermore, place of death has been found to vary hugely by geographical region, despite populations having similar preferences. Research conducted by the Institute for Public Policy Research found that whilst 42% of deaths occurred in hospital in the South West region of the UK, this figure was as high as 53% in London (21). Healthcare disparities are even more stark when they are considered in a global context. It is estimated that globally 100 million individuals that would benefit from palliative care input are being neglected (22). This has been extensively documented in the context of cancer care. The disease burden of cancer is greatest in low- and middle-income countries and it is within these countries that 70% of global cancer deaths occur (23). Whilst cancer deaths are expected to rise worldwide, they are predicted to rise by an alarmingly dissimilar rate. This inequality is compounded by the developing world only having access to 5% of the world’s resources for cancer care (24).

Analgesia is also a global concern with more than 90% the global supply of morphine being consumed by economically developed nations (24). Whilst the UK clearly has local concerns around funding and maintaining high quality care for its patients, it may also have a responsibility to address global inequalities.

### **Justice and resource allocation**

Justice is the key ethical principle to be discussed when considering priority setting and the allocation of resources within healthcare. Although justice was previously mentioned in the context of the fair treatment of individuals, its role will now be considered in the equitable allocation of resources and priority setting. Here, “distributive justice” is concerned with “what is fair when decision makers determine how to divide burdens and benefits” (25).

Place of death is often a key concern for patients, and it is also an important marker of quality of services due to its inextricable link with quality of life and bereavement outcomes. The majority of individuals prefer to die at home or in their usual place of care and important steps have been made towards achieving these preferences. Leadbeater hypothesises that hospitals are unpopular places of death due to their social shortfalls which neglect the social, psychological and spiritual aspects of dying (26). It is therefore fortunate that if current projections prove to be accurate then deaths in care homes, homes and hospices will almost double by 2040 (accounting for 76.0% of deaths) (8). However, in order to enable patients to die outside of the hospital environment, additional home support and funding will be required. Although hospices are comparably popular places of death they are hugely underfunded with only one third of their income coming from the NHS government and the rest being gathered from charitable earnings. Projections show that care homes are likely to become the “hospices of the future” however in order for these patients to receive adequate

care they will need additional input from adequately trained health professionals in the field. Specialist multidisciplinary palliative care is designed to deliver care to patients with complex needs in a range of settings. Unfortunately, as demand for specialist palliative care increases in line with the increasing complexity of patients, it is likely that resources will not be able to stretch adequately. One way that this could be addressed would be to create a shift in focus and funding from specialist palliative care services to a more general palliative care service in order to reach more patients. This approach is egalitarian in nature as it seeks to create the greatest overall benefit for the greatest number of people. Some experts have however raised concerns about diluting the quality of services by trying to spread the workforce too thinly and reducing the benefits experienced by all. Certainly, it could be argued that by cutting funding into specialist care, care may be compromised to such an extent that it can no longer be considered specialist in nature. It is therefore important that new innovative ways of integrating generalist palliative care services, for example into general practice, are considered in order to not simply dilute existing services. Furthermore, the application of an egalitarian principle to palliative care is problematic in that it requires extensive value judgements to be made on a patient's level of need. In a qualitative study carried out by Philip, palliative care professionals (mainly doctors and nurses) were asked to take part in semi-structured focus groups and interviews to identify common views towards prioritisation in palliative care (27). When asked how they would prioritise the needs of their palliative patients, many participants suggested that physical symptoms would need to take priority over psychological and spiritual concerns, and that higher priority should be assigned to those with cancer related symptoms due to their perceived greater acuity. It is clear that being forced to prioritise in this manner leads to discomfort within professionals due to the challenges posed to the holistic nature of the specialty itself.

There are also resource allocation concerns in the context of research. Spending on palliative

and end of life care research is chronically low and is consistently below 0.7% of the total spend on cancer research in the UK (28). It is of particular importance to invest more in the field given that projections show that services are likely to need considerable restructuring to meet future demands.

### **Discussion and conclusion**

Palliative care as a specialty is likely to face a multitude of challenges in the next five years and beyond. This essay has considered just some of these along with their accompanying ethical considerations. Current issues range from large demographic shifts and demands, to issues with underfunding and healthcare disparities. In order to address some of the above concerns health professionals need to be better equipped for their new more integrated roles. Whilst it is clear that there will need to be further development of generalist palliative care to match demand, it is crucial that specialist palliative care does not lose funding if complex patients are still to have their needs met. For example, GPs have disclosed that they frequently feel out of their depth when faced with palliative patients. Predicting the course of such illnesses can be challenging and GPs worry about this resulting in a “prognostic paralysis” (29). Considerable attention also needs to be paid to the education of care home staff for their potentially more involved roles. Moreover, a paper produced by NT suggested that care home staff were in fact very keen to undertake end-of life training, suggesting that care homes may prove to be valuable learning environments (30).

It is both unsafe and unfair to expect individuals to provide complex care to patients without adequate training and also adequate psychological support. In order to ensure that care homes are fit for this purpose they require clear regulation and will need to be financially secure in order to maintain standards. Better integration of services and information sharing between hospitals, hospices, care homes and GPs is also likely to improve patient care. Hospices are

widely respected due to their holistic nature and it is crucial that hospitals and care homes strive to match these values. Lastly, it is vital that healthcare inequities are addressed, particularly those that are impacting upon vulnerable people accessing services. It is important that staff act as advocates for these patients and that stereotypes and misconceptions are identified and challenged.

In conclusion, the challenges faced by the palliative care specialty are vast and the specialty will be required to change dramatically to accommodate its patients. Nevertheless, palliative care will still have a moral obligation to retain that holistic and individualistic nature that is so integral to the specialty.

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## Reference list:

1. Age UK. Later Life in the United Kingdom. Available from: [https://www.ageuk.org.uk/age-uk/documents/later\\_life\\_uk\\_factsheet](https://www.ageuk.org.uk/age-uk/documents/later_life_uk_factsheet) (accessed 16 November 2019).
2. Block S. Palliative care and ethics . New York : Oxford University Press; 2014.
3. World Health Organisation. Palliative Care . Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care> (accessed 16 November 2019).
4. Marie Curie. What are palliative care and end of life care? Available from: <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care> (accessed 16 November 2019).
5. De Panfilis L, Di Leo S, Peruselli C, Ghirotto L. “I go into crisis when ...”: ethics of care and moral dilemmas in palliative care. *BMC Palliative Care* 2019; 18(1). Available from: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0453-2> (accessed 16 November 2019).
6. Saint Joseph's University. How the four principles of health care ethics improve patient care. Available from: <https://online.sju.edu/graduate/masters-health-administration/resources/articles/four-principles-of-health-care-ethics-improve-patient-care> (accessed 16 November 2019).
7. Cassell A, Edwards D, Harshfield A, Rhodes K, Brimicombe J, Payne R et al. The epidemiology of multimorbidity in primary care: a retrospective cohort study. *Br J Gen Pract* 2018; 68:669. Available from <https://doi.org/10.3399/BJGP18X695465> (accessed 16 November 2019).
8. Etkind B, Bone A, Gomes B, Lovell N, Evans C, Higginson I et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine* 2017; 15:102. Available from: DOI 10.1186/s12916-017-0860-2 (accessed 16 November 2019).
9. Sampson E, Candy B, Davis S, Gola AB, Harrington J, King M et al. Living and dying with advanced dementia: a prospective cohort study of symptoms, service use and care at the end of life. *Palliat Med* 2017; 32(3). Available from: DOI: 10.1177/0269216317726443 (accessed 16 November 2019).
10. Ellis A, Gough N, Brewer K . Palliative care in advanced dementia: a qualitative study exploring the view's of consultants involved in dementia care. *Palliat Med* 2014; 28(6) . Available from: <https://doi.org/10.1177/0269216314532748> (accessed 16 November 2019).

11. Mullick A, Martin J, Sallnow L. An introduction to advance care planning in practice. *BMJ* 2013; 347 Available from: DOI: 10.1136/bmj.f6064 (accessed 16 November 2019).
12. Hamilton I. Advance care planning in general practice: promoting patient autonomy and shared decision making. *British Journal of General Practice* 2017; 67(656): .  
<https://doi.org/10.3399/bjgp17X689461> (accessed 16 November 2019).
13. British Medical Association. Autonomy or self-determination. Available from:  
<https://www.bma.org.uk/advice/employment/ethics/medical-students-ethics-toolkit/2-autonomy-or-self-determination> (accessed 16 November 2019).
14. Collins. Equality definition and meaning . Available from:  
<https://www.collinsdictionary.com/dictionary/english/equality> (accessed 16 November 2019).
15. World Health Organisation. Health equity . Available from;  
[https://www.who.int/topics/health\\_equity/en/](https://www.who.int/topics/health_equity/en/) (accessed 16 November 2019).
16. UK Clinical Ethics Network. Ethical Issues: Resource Allocation . Available from:  
[http://www.ukcen.net/ethical\\_issues/resource\\_allocation/ethical\\_considerations3](http://www.ukcen.net/ethical_issues/resource_allocation/ethical_considerations3) (accessed 16 November 2019).
17. Gillon R . Medical ethics: four principles plus attention to scope . *BMJ* 1994; 309(6948)  
Available from: <https://www.ht.lu.se/utbildning/dokument/kurser/FPRB01/gillon>  
(accessed 16 November 2019).
18. Dixon J, King D, Matosevic T, Clark M, Knapp M. Equity in the Provision of Palliative Care in the UK: Review of Evidence. Available from: [www.pssru.ac.uk/publication-details.php?id=4962](http://www.pssru.ac.uk/publication-details.php?id=4962) (accessed 16 November 2019).
19. Marie Curie. The hidden challenges of palliative cancer care. Available from:  
<https://www.mariecurie.org.uk/blog/palliative-cancer-care-actions/57070> (accessed 16 November 2019).
20. Marie Curie. Enough for everyone: Challenging inequities in palliative care . Available from: <https://www.mariecurie.org.uk/documents/policy/policy-publications> (accessed 16 November 2019).
21. Hunter J. End of life care in England: A briefing paper, IPPR. Available from:  
[www.ippr.org/research/publications/end-of-life-care-in-england](http://www.ippr.org/research/publications/end-of-life-care-in-england) (accessed 16 November 2019).
22. Sternsward J, Pampallona S. Palliative medicine- A Global Perspective. In Hanks G et al. *Oxford textbook of Palliative Medicine*. NY: Oxford University Press;1988.

23. World Health Organisation . Cancer- Key statistics. Available from: <https://www.who.int/cancer/resources/keyfacts/en/> (accessed 16 November 2019).
24. Kanavos P. The rising burden of cancer in the developing world. *Ann Oncol* 2006; 17(8): viii15-viii23.
25. Armstrong C. *Global Distributive Justice: An Introduction* . NY : Cambridge University Press; 2012.
26. Leadbeater C. Dying for Change. In Faull C. *Handbook of palliative care* , 3rd ed. NY : Wiley- Blackwell; 2012.
27. Philip J, Russell B, Collins A, Brand C, Le B, Hudson P et al. . The Ethics of Prioritizing Access to Palliative Care: A Qualitative Study. *American Journal of Hospice and Palliative Medicine* ; 36(7). Available from: DOI: 10.1177/1049909119833333 (accessed 16 November 2019).
28. Palliative and end of life care Priority Setting Partnership (PeolcPSP). PeolcPSP: Background . [https://www.mariecurie.org.uk › media › PeolcPSP\\_ExecSummary\\_English](https://www.mariecurie.org.uk › media › PeolcPSP_ExecSummary_English) (accessed 16 November 2019).
29. Murray S, Boyd K, Sheikh A. Palliative care in chronic illness . *BMJ* 2005; 330(7492): 611-612.
30. Percival J. End-of-life care in nursing and care homes. *Nursing Times* 2013; 109(1): . <https://www.nursingtimes.net/roles/care-home-nurses/end-of-life-care-in-nursing-and-care-homes-10-01-2013/> (accessed 16 November 2019).