

Reappraising 'the good death' for populations in the age of ageing

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This is the second in an occasional series of paired commentaries in *Age and Ageing*, the Journal of the British Geriatrics Society, and the Journal of the American Geriatrics Society (JAGS). The aim is to address issues of current significance and to foster dialogue and increased understanding between academics and clinicians working in comparative international settings. Both commentaries address the urgent need to improve palliative care for older people, with a critique of some stereotypes surrounding palliative care and the 'good death'. The companion commentary, published in JAGS, was written by Alexander Smith and Vyjeyanthi Periyakoil, and is grounded in their experience as academic clinicians ¹. In the present paper, we offer a perspective on the outcome and wider consequences of misalignment between current UK policy and aspirations for end of life care in relation to epidemiological trends and patient experience of death and dying.

It is an irony that while the UK has been rated the as best place in the world to die ^{2 1} the most rapidly growing group in need - older people with multiple morbidity, end stage dementia and/ or frailty - remain largely invisible within the current paradigms of palliative care deriving from a historical focus on clearly identifiable and relatively short terminal disease trajectories ^{3 4}. Robust projections of future needs in England and Wales show that between 25% and 47% more people may need palliative care by 2040. Overall, deaths will increase due to a rise in mortality from chronic diseases, and more deaths occurring at older ages will drive a much greater growth in palliative care need than previously expected ⁵. Individuals within an ageing population tend to die following a prolonged period of

¹ The US is ranked 9th

increasing frailty and co-morbidity including cancer, but also other long- term conditions such as heart failure, COPD, diabetes or renal failure ³⁴.

The instigation in England of the hospice movement from the 1960s, and the development of palliative care which grew from it, transformed the philosophy of care and experience of dying for patients and families affected by cancer. The goal is to provide holistic care, excellent control of symptoms and enhancement of quality of life until the end. In addition, open awareness and acceptance of death is seen as enabling a process of personal development and spiritual growth ⁶. In 2008, England was one of the first countries to publish a National Strategy for End of Life Care, spearheading a stream of policy initiatives to try and improve quality, equity and access to palliative care across all settings of care and for all those who could benefit. The Strategy was organised around an end of life care pathway to be initiated once it was probable that the person was entering their last year of life. It emphasised choice about place of care and advance care planning (ACP) as the keys to a better experience of death and dying. The importance of choice and place of death is exemplified in a recent government commissioned report which calls for the offer of choice in place of death to be mandated as a *right* by 2020 ⁷. Palliative care has been promoted as a cost- effective measure for relieving pressure on over-stretched and under-resourced hospital services ⁸⁹. However, the promise to honour patients' choice to die at home will be empty in the absence of a massive financial input to resourcing specialist palliative care services in the community. In the current climate of financial austerity, this looks unlikely ⁷.

Part of the reason that the Strategy has not fulfilled its promise in transforming the quality of palliative care for older people is that such principles are challenging to apply in uncertain illness trajectories where there is often no clear- cut point at which the end of life phase begins ¹⁰. A lack of funding for both palliative and geriatric care, confusion about the relationship between specialist

and generalist providers of palliative care, and the continuing push to shift responsibility for older people's health and social care from the NHS to the care home sector and family carers, means that palliative care eludes the majority of frail, older patients with the greatest need. In addition, access to palliative care is spread unevenly in relation to geography, ethnicity, illness condition, local and personal resources ^{4 10}. More positively, recent initiatives such as acute frailty units are adopting a palliative/ geriatric care approach in their emphasis on patient centeredness, comprehensive assessment and care planning ¹¹. Work is also underway to design models of intermittent specialist palliative and supportive care that address the complex needs of older people in partnership with other stakeholders ¹². These innovations show that it is possible to 'think out of the box' to do things differently, although the evidence base for their feasibility and effectiveness is yet to be established.

The ideology of palliative care, alongside core cultural values of autonomy and choice, have shaped prevailing policy and professional constructs of 'the good death' ^{13 14}. A person facing death is ideally positioned as an informed and knowledgeable consumer, and end of life care presents a menu of choices or 'wishes' to be selected according to one's preferences. However, current notions of the good death are premised on predictable trajectories of decline which do not correspond with the experience of patients affected by multiple morbidity and frailty. Dying itself has become, in many cases, a long- term condition. Research evidence concerning patient and public experience and expectations of death and dying is not extensive. However, available findings challenge many dominant policy and professional assumptions ^{6 13 15 16}. Lack of capacity alongside prolonged and uncertain illness trajectories reduce the appeal, or even the possibility, of open awareness or active prediction of impending death. The 'good death' also places considerable responsibility for the quality of dying on the individual and, by extension, creates the morally loaded categories of 'good' and 'bad' patients. It is evident that many older people do not prioritise 'choice' or personal autonomy. Rather, they seek to make choices as relational selves, embedded in

a network of mutual obligation and often desperate to avoid dependency and being a burden to those about whom they care most ¹⁵. Despite the rhetoric of ‘empowerment’, older people towards the end of life are intensely vulnerable and profoundly dependent on those around them ¹⁷.

Real choices are always constrained and some are valued more than others: euthanasia and assisted suicide are not included within the options available to patients in the UK. The ‘good death’ is a largely professional and ethnocentric construct, which takes no account of cultural diversity and the different values which may be espoused by different groups or individuals, for example regarding continuation of ‘futile’ treatment, or the use of pain relief ⁶. The prevailing model of the ‘good death’ writes out alternative possibilities and preferences from the cultural script: e.g. for sudden, postponed and ‘unaware’ death ¹⁷. It is hard to construct a model of how to die well from chronic degenerative incapacity, frailty and mental incapacity alongside a prolonged and uncertain illness trajectory. Lowrie, et al. ¹⁴ refer to ‘a dying underclass’: patients affected by multi-morbidity and chronic disease who are not recognised to be dying and cannot occupy a culturally scripted role for a dying person. Periyakoil ⁴ comments on how the system of organisational care neglects patients whose status is not socially sanctioned through recognition by health care professionals. Most notably, acknowledgement of the corporeal reality of suffering and struggle is conspicuously absent from the normative and idealised model of how to die ¹⁷.

The development of hospice and the professional specialism of palliative care from the 1960s onwards have vastly improved the control of pain and end of life care, particularly for patients dying from cancer. However, the changing needs, experience and expectations of frail older patients dying slowly from complex multiple-morbidity have moved increasingly out of alignment with the organisation and ideology of palliative care. The prolongation of dying creates enormous new challenges throughout all levels of society: economic, social, personal and existential. In specifying the desirable, appropriate and ‘successful’ way to die, the revivalist construct of ‘the good death’ works as a mechanism of social control. It constrains, rather than enables, choice and disadvantages

those who cannot or do not wish to conform. The promise of a 'good death' for all is hollow in the absence of a massive restructuring and resourcing of health care to accommodate changing population needs. Trends in causes of mortality in an ageing population will reduce the possibility of dying at home, especially for the increasing number of people who live alone and even for those for whom death at home is a positive preference. A public health approach to palliative care requires a shift in focus from diagnosis/prognosis to need, and greater integration of specialist and generalist services in community care settings. New, and socially relevant, models of care need to incorporate awareness and tolerance of the diversity of patient and public aspirations for, and responses to, the intrinsically difficult and distressing experience of death and dying.

References

1. Smith AK, Periyakoil V. Should we bury "The Good Death"? *Age and Ageing* 2018; in press
2. Economist Intelligence Unit. 2015 Quality of Death Index, Ranking Palliative Care Across the World. London: The Economist Intelligence Unit, 2015.
3. Seymour J, Cassell B. Palliative care in the USA and England: a critical analysis of meaning and implementation towards a public health approach. *Mortality* 2016;22(4):275-90. doi: 10.1080/13576275.2016.1270262
4. Periyakoil V. Square pegs; round holes: Our healthcare is failing seriously ill older Americans in their last years. *Journal of the American Geriatrics Society* 2017; epub doi: <https://doi.org/10.1111/jgs.15161>
5. Etkind S, Bone A, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future predictions and implications for services *BMC Medicine* 2017;15(102) doi: 10.1186/s12916-017-0860-2
6. Tullis JA, Roscoe L, Dillon PJ. Resisting the hospice narrative in pursuit of quality of life. *Qualitative Research in Medicine and Health Care* 2017;1:63-72.
7. The Choice in End of Life Care Programme Board. What's important to me. A review of choice in end of life care London: Choice in End of Life Care Programme Board, 2015.
8. Smith S, Brick A, Sinead OH, et al. Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine* 2014;28(2):130-50. doi: 0.1177/0269216313493466
9. Chitnis X, Georghiou T, Steventon A, et al. The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life. London: Nuffield Trust, 2012.
10. Dixon J, King D, Matosevic T, et al. Equity in the Provision of Palliative Care in the UK: Review of Evidence. Personal Social Services Research Unit. London: London School of Economics and Political Science, 2015.
11. Conroy S, Turpin S. New horizons: urgent care for older people with frailty. *Age and Ageing* 2016;45:579 - 86. doi: 10.1093/ageing/afw135
12. Bone A, Morgan M, Maddocks M, et al. Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: perspectives of older people, carers and other key stakeholders. *Age & Ageing* 2016;45:863–73. doi: 10.1093/ageing/afw124
13. Cottrell L, Duggleby W. The "good death": An integrative literature review. *Palliative and Supportive Care* 2016;14:686–712. doi: 10.1017/S1478951515001285

14. Lowrie D, Ray R, Plummer D, et al. Exploring the Contemporary Stage and Scripts for the Enactment of Dying Roles: A Narrative Review of the Literature. *Omega: Journal of Death and Dying* 2017;online(March):1-23. doi: 10.1177/0030222817696541
15. Borgstrom E, Walter T. Choice and compassion at the end of life: A critical analysis of recent English policy discourse. *Social Science and Medicine* 2015;136
16. Gott M, Small N, Barnes S, et al. Older people's views of a good death in heart failure: Implications for palliative care provision *Social Science and Medicine* 2008;67:1113-21.
17. Walters G. Is there such a thing as a good death? *Palliative Medicine* 2004;18:404-08. doi: 10.1191/0269216304pm908oa