This is a repository copy of *Reappraising 'the good death' for populations in the age of ageing*.

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

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

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[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 [3][4].

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 [8][9]. 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

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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.

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