A Historical Essay about Notions of a 'Good Death':

Toward Shared Decision-Making at the End of Life

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Abstract

The purpose of this essay is to explore different notions of a 'good death' in Western history, in order to better understand the clinical implications of their co-existence in the contemporary period. Different notions of a 'good death' are explored chronologically, including traditional representations, the medicalisation of death, the development of palliative care, and the right-to-die movement. The current period is characterised by competing notions of a 'good death', and the primacy of the individual to select one over another. The diversity of notions of a 'good death' that can currently be drawn upon to bestow meaning upon the end of life and guide decision-making makes clinical practice particularly challenging. Shared decision-making (SDM) is suggested as a promising approach to explore and co-create individual preferences toward the end of life. If achieving a 'good death' has become a matter of dying one's way, then end-of-life conversations should focus on the co-creation of an acceptable end of life among patients and health care providers.

Keywords: Good death, dying well, social history, individualism, patient preferences, shared decision-making.

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Introduction

 This essay examines different notions of a "good death" in Western history and suggests that shared decision-making can help health care providers manage these competing notions at the end of life. The idea of a 'good death' may come across as somewhat of an oxymoron. After all, death is definitively the last and arguably the worst thing that can happen to a human being. Yet, the inevitability of human mortality encourages societies to strive collectively for deaths that are, if not 'good', then at least 'acceptable' or 'tolerable'. The belief according to which death is never an appropriate ending may turn into a self-fulfilling prophecy, because it prevents the dying from creating the circumstances that would lead to an appropriate death. At a time of shifting demographics toward larger elderly populations in many industrialised countries, it comes as no surprise that there is a growing interest in examining the quality of dying (Emanuel & Emanuel, 1998; Smith, 2000). Notions of a 'good death' are influenced by and constitutive of the ideas circulating in modern care organisations and institutions, such as hospitals and palliative care units. They thus deserve attention to better understand the ideals that are strived for by health care professionals in delivering end-of-life care.

 The concept of a 'good death' itself is shrouded in confusion, and its meaning has evolved through time. In the 1960s and 1970s, the primary signification of a 'good death' was euthanasia, so that authors would often talk about social prescriptions surrounding the end of life rather than referring to a 'good death' (Ariès, 1975). In fact, the Greek words Eu Thanatos refer to dying well in a painless manner, whereas Kalos Thanatos, which is closer to the present day mainstream meaning of a 'good death', means dying beautifully in an exemplary manner (Kellehear, 2007). From the 1980s onward, the notion of a 'good death' became more oriented

toward what could make death better, albeit with a lingering connotation of euthanasia in the public perception (Kehl, 2006). A variety of other terms, such as 'dying well', 'dying with dignity', and 'quality of dying' are sometimes being used interchangeably in discussing current societal expectations surrounding death and dying (Hales et al., 2008). The notion of a 'good death' can also refer to either the very final moment of life, or to the social preparations during the process of dying. For the purpose of this essay, a 'good death' will be defined broadly as the social prescriptions guiding both the preparation for and the end of life itself.

Recent health research literature has demonstrated a co-existence among different notions of a 'good death' (Steinhauser, Clipp, et al., 2000). What are the competing notions of a 'good death' that guide the end of life in the contemporary period? And what are their implications for clinical practice? A historical perspective can shed light on the current lack of support for any way of dying beyond individual preferences, because notions of a 'good death' remain fundamentally social constructions, created and legitimated in particular contexts. We will explore prevailing notions of a 'good death' chronologically, starting with traditional representations of the Middle Ages, then into the early modern period when great progress in medical science was achieved to avoid death, and ending with the emergence of palliative care and the right-to-die movement as alternative sources of meaning to rehabilitate a 'good death' in the modern period. We will then address the diversity of notions of a 'good enough' death as influenced by individualism. Shared decision-making will finally be introduced as an approach that can help us reconcile the current competing notions of a 'good death'.

Historical Notions of a 'Good Death'

Ariès (1975) describes death in the early Middle Ages as a public ceremony carefully organised along shared social protocols. Death was to be awaited in bed; children were present, and the clergy would be called on to assist with an orderly death scene (Ariès, 1975; Vovelle, 1983). According to modern scholars, this 'traditional good death' was tamed, resigned, and controlled by the community. During the second part of the Middle Ages, death became more connected to the individual salvation of one's soul, and thus called for strictly regulated preparations following the Ars Moriendi. These documents contained very clear prescriptions about the moment of death which represented the passage to the another world, and how it should be publicly orchestrated in the room of the dying (Ariès, 1977). These preparations emphasised community order and moral values; it was a textbook on how to die well. Although there were important differences in notions of a 'good death' throughout the Middle Ages as religious self-perceptions and protocols evolved, the image of a 'traditional good death' to this day is one that is controlled by the community and that uses the vocabulary of religion (Walter, 1994). The romanticism expressed toward 'traditional' death as more ritualised and incorporated into agrarian ways of life (Hart et al., 1998) has lingered in the Western imagination and served as the benchmark against which modern death would be denounced.

By the late eighteenth century, the doctor had control over dying more than the dying and the clergy (Walter, 1994). As part of a process of secularisation, the master narratives of religion came to be replaced with trust in medical progress in the face of death (Howarth, 2007). Death was no longer depicted as a passage to God, but rather as a natural event that could be narrowed down to many diseases and germs, an end in itself (Bruckner, 2010). Death came to be seen as a failure of medicine, thus justifying the practice of subjecting patients to a more extreme range of medical interventions to stave off death at all cost, no matter the human suffering incurred

(Webb, 1997). Under medical control, death took on a technical quality often reached through the medical decision of stopping interventions. The process of dying gradually became longer than it once was, because its causes shifted from infections to cardiovascular diseases and cancer, thereby explaining the renewed interest of scholars in the social management of death toward the end of the 1960s. Several scholars documented the taboo around death and dying, with the absence of social norm to guide behaviours surrounding modern death (Gorer, 1955; 1965), the lack of diagnostic and prognostic disclosure (Glaser and Strauss, 1965; 1968), as well as the perceptions of death as a medically non-relevant event in the social organisation of dying (Sudnow,1967). In describing early observational studies of death in hospitals, Seale claims that "their defining characteristic has increasingly become the normative rehearsal of failings of impersonal hospital routines in providing a humane environment for dying" (1998, p. 103). Perceptions of modern death's inadequacies fuelled alternative movements to restore meaning at the end of life.

In light of the modern medical management of death, rising discontent with inhumane dying conditions in medical institutions set the stage for the development of hospice and palliative care. Hospice care was driven by a definite oppositional stance, insofar as it depicted the existing modern management of dying as inadequate (James & Field, 1992). Saunders (1983) coined the term "total pain", to refer to the different forms of physical, psychological, social, and spiritual distress that exist at the end of life. This fostered a holistic and multidisciplinary approach to dying. The influential work of Elisabeth Kübler-Ross (1969) describing the classical five-stage theory at the end of life has also been described as a modern Ars Moriendi providing a tangible script on dying well (Seale, 1998). The hospice philosophy attempted to reincorporate death and dying as normal parts of life by promoting both adequate pain relief and open

communication about terminal status so that patients could reach a stage of acceptance upon death (Byock, 1997). Lofland (1978), however, had foreseen the ironic consequences of reinventing a role for the dying, namely that those who fail to fulfil its expectations face isolation and failure. In a sociological critique of the concept of a 'good death' in palliative care, Hart and colleagues (1998) suggest that the social management of dying can also constrain the choices of dying people. Patients who fail to meet the 'good death' of palliative care are deviant and found in violation of the social norm (Hart et al., 1998; McNamara et al., 1994). These critiques of palliative care ideals have mainly drawn on individual autonomy as will be explored further below.

Another alternative that emerged as a reaction to the medicalisation and isolation of dying in modern institutions was the call for aid in dying and euthanasia, which could reassert individual control over the end of life. The birth of American bioethics can be contextualised in light of the civil rights' movements of the 1960s, when a set of secular principles heavily emphasising self-determination gained prominence (Fins, 2006). While hospice and palliative care have contributed to a definite alleviation of terminal pain, they have also paradoxically raised the public awareness about suffering beyond physical pain. There are forms of suffering that are not readily eased in hospice and palliative care, such as those generated by physical dependency. As Seale (1998) explains, euthanasia can help preserve "an intact narrative of dignified self-identity" (p. 183). Although, aid in dying is widely resisted for imposing a utilitarian value on the life of society's most vulnerable members, exerting control over the very circumstances of ones' death can restore a form of order to the end of life by providing an alternative 'good death'. Finally, both the script of aware dying in palliative care, and the control

over the time and manner of dying offered by euthanasia and advance directives represent attempts to give meaning to the end of life (Seale, 1998).

Contemporary Notions of a 'Good Death'

While none of the historical notions of a 'good death' disappeared in the current period, imposing any one of them has become unacceptable, such that choosing one over another becomes a matter of individual preferences in health research literature. Patients and family members may now draw on different notions to argue that they experienced a 'good death' (Bradbury, 1999; Green, 2008). According to McNamara (2001), we cannot overestimate the impact of the value of individualism on popular and professional notions of death and dying. The notion of a 'good death' promoted by hospice and palliative care is still very influential in assessments of quality of care at the end of life, but the individual is absolutely central to current dying scripts (Field, 1996). With an increasing emphasis on self-determination, palliative and hospice care have also recently adopted a more pragmatic notion of a 'good death', whereby it is adapted to individual circumstances. "The practice of palliative care, a holistic form of care for dying people, which follows the individualistic ethic of choice, has emerged from and replaced the original hospice movement" (McNamara, 2004, p. 929). Given the gap between the ideal of dying in acceptance and the reality of people's various reactions to their end of life, we can now only talk about a 'good enough death' (McNamara, 2001). This pragmatic philosophy of hospice care suggests that people tend to die very much the way they lived (McNamara, 2004).

The current emphasis in health science research on advance directives, informed choices, and funeral products contributes to affirming the primacy of the individual in Western societies (Green, 2008). Walter (1994) describes current notions of death as elusive, malleable,

individualistic and consumerist, lacking the collective protection and cohesion that religion and medicine used to provide. In addition, an intact physical body is now particularly important to self-identity, so that a disintegrating body entails the alarming destruction of the self and a reprehensible lack of self-control (Nuland, 1993; Kellehear, 2007). Personhood has become fundamentally linked with the appearance of the body and its performance (Lawton, 2000). The primacy of the individual to select the meaning of his or her end of life and concern for bodily containment remain the only guides to a 'good death' (Kearl, 1996). There appears to be a paradox in present day dying. On the one hand, dying individuals are depicted as more isolated than ever and rituals have become trivialized. On the other hand, the options available to create ceremonials 'à la carte' and imbue them with personalised meaning have never been greater, for example with green funerals for the environmentally conscious. The value attributed to individualism is taken to its end point: individuals appear to be the only actors having any legitimacy in interpreting their end of life (Walter, 1994).

Recent health research about notions of a 'good death' strives to provide empirical documentation of the diversity of perspectives on the topic. Death tends to be characterised as good in clinical care if it corresponds to the way the patient would have wanted to die. Whether empirical research involves nurses (Low & Payne, 1996; Kristjanson et al., 2001; Costello 2006), physicians (Good, et al., 2004), patients suffering from a variety of life-threatening conditions (Singer et al., 1999; Masson, 2002; Pierson et al., 2002; Vig et al., 2002; Vig & Pearlman, 2004; Willems et al., 2004; Goldsteen et al., 2006; Gott et al., 2008; Hughes et al., 2008), family members (Bosek et al., 2003) or a combination of those groups (Payne et al., 1996; Johnson et al., 2000; Steinhauser, Christakis et al., 2000; Steinhauser, Clipp, et al., 2000; Heyland et al., 2006; De Jong & Clarke, 2009), only two attributes appear to cross all patient, family and

professional categories: an absence of physical suffering with adequate management of symptoms and pain, and the importance of patient autonomy and control. A 'good death' is agreed to be pain free and controlled by the dying individual; other attributes, such as the need for spiritual support or for reasserting meaningful relationships, vary both within and across groups of participants, and thus leave health care providers focusing on individual preferences (Steinhauser, Clipp, et al., 2000; Heyland et al., 2006).

Shared Decision-Making and the Co-Creation of Individual Preferences

While we may now long for a pristine end of life where medicine does not interfere with the manner and timing of death, the cost of avoiding premature deaths is the social responsibility to manage a longer dying process through decision-making and medical interventions. There has been a long medical tradition of silence and resistance toward sharing the burden of uncertainty and decision-making with patients, partly based on the assumption that physicians are already committed to protecting their patients' interests (Katz, 1984). However, "altruism cannot promise that, without conversation, physicians will know what patients' needs are or that, without conversation, patients will know in what differing ways doctors can meet their needs" (Katz, 1984, p. 95). It has become less acceptable to make decisions without having a conversation with patients, especially in contexts such as preventive care among the elderly, where choosing one therapy over another will not reduce the overall risk of mortality, but rather shape their manner of dying and their quality of life (Mangin et al., 2007). Making decisions for patients while ignoring what they consider to be important at the end of life has become profoundly uncomfortable for health care providers. The diversity of meanings that can be

bestowed upon the end of life to guide decision-making makes clinical practice particularly challenging for practitioners.

Shared decision-making (SDM) is a promising approach to explore and co-create individual preferences toward the end of life (Frank, 2009). SDM involves the elucidation of patients' goals, values, and preferences to guide an appropriate treatment plan. The most common definition of SDM encompasses the involvement of the patient and the health care provider (at least two participants), information-sharing between the two parties including the values of the patient, deliberation or the expression of treatment preferences on each side, and finally deciding on an appropriate treatment plan (Charles et al., 1997). The process can help the co-construction of preferences through sharing information with patients and families who admittedly have limited pre-existing knowledge of the organisation of end-of-life care (Kaufman, 2005). Decision support tools such as video decision aids have been found to reduce uncertainty even for patients who have difficulty understanding health information when making decisions about end-of-life care (Volandes, et al., 2010). The importance of individual choice has been rightly criticised for transferring the responsibility of decision-making exclusively to unqualified patients (Mol, 2008). What is at stake at the end of life is rather the discovery and alignment of expectations across the different people involved. In the current cultural climate, no single notion of a 'good death' can be imposed unproblematically to the individual, yet the failure to anchor the end of life in any wider source of meaning creates a characteristic social malaise. If achieving a 'good death' has become a matter of dying one's way, then health care providers should focus on developing a relation with patients and co-creating an acceptable end of life with them.

Conclusion

　　With the objective of contributing to current debates about death and dying, this essay proceeded to explore the evolution of notions of a 'good death'. Representations of the 'traditional good death', which dominated from the Middle Ages to the eighteenth century, relied on social and religious prescriptions whereby death was to be quietly awaited in bed with public displays of devotion. With medical developments, notions of a 'good death' were increasingly replaced with a general desire to avoid death. Our knowledge of the medicalised modern death cannot be separated from the work of social scientists in the 1960s. As a reaction to their depictions of the unacceptable modern medical management of death, the hospice movement proposed a modern notion of a 'good death' with awareness, acceptance and growth at the end of life (Saunders, 1983; Kübler-Ross, 1969). While still very influential in shaping end-of-life care, the hospice and palliative care movement were criticised for being imposed as a norm. Technological interventions and the apparition of states 'worse than death', as well as the recognition that some types of suffering remain difficult to alleviate, have also contributed to the creation of an alternative 'good death' by the right-to-die movement based on self-determination (Seale, 1998).

　　Recent research on notions of a 'good death' has contributed to deepening our understanding of the consequences of a cultural climate of individualism on attitudes toward death and dying. Personhood now depends heavily on appearance and performance, in such a way that the breaking of the body's boundaries and physical dependency really undermines patients' self-identity and brings about a distress that is difficult to address (Lawton, 2000). There is overall a lack of consensus about current notions of a 'good death', and patients have retained exclusive legitimacy over selecting one for themselves (Walter, 1994). The existence of

competing notions of 'good death' cannot be ignored and represents a challenge for clinical practice. Using shared decision-making as an approach to end-of-life conversations could contribute to the co-creation of 'good deaths' giving specific meaning to the end of life of autonomous individuals.

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