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# The ‘good death’ and reduced capacity: A literature review

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## Abstract

Research effort into what a ‘good death’ entails has generally concentrated on six themes initially established by Steinhauser et al. (2000): pain and symptom management; clear decision-making; preparation for death; completion; contributing to others; and affirmation of the whole person. This review explores these themes, specifically examining their applicability to those who lack mental capacity to make their own decisions. Some of Steinhauser et al.’s themes appear more relevant than others, with clear decision-making and affirmation of personhood predicating issues related to reduced capacity. Largely, however, the literature on a ‘good death’ builds on an underlying assumption that the dying patient is cognisant and capable of rationalising their death. Those instances where Steinhauser et al. do acknowledge mental capacity within their model have been met by criticism from numerous authors. Factors such as the subjectivity of substitute decision-makers (Kaufman, 2000) and the complexity associated with medico-legal interpretations of current legislation (Michalowski, 2005) help to highlight deficiencies in the application of principles of a ‘good death’ in practice. Further specific consideration is required on how to achieve a ‘good death’ for those with reduced capacity.

## Keywords

Good death; bad death; mental capacity; dying well; dignity; healthcare

## **Introduction**

Over the last thirty years, the notion of a ‘good’ or ‘bad’ death has come under increasing academic scrutiny. While a philosophy on dying has a history traceable back to Socrates, research effort to conceptualise quality of death is a relatively recent trend. Literature from the 1960s appeared as ‘opinion articles, essays and letters’ that generally saw ‘good death’ being used as a ‘synonym for euthanasia’ (Kehl, 2006, p.278). During the 1980s discussion broadened to what makes any death good (McCorkle, 1981; O’Neil, 1983). More recently, academic inquiry broadened end-of-life constructs to incorporate ‘dying well’, ‘dying with dignity’, ‘quality of dying’ and the ‘good or bad death’ among others (Hales et al., 2008). This has coincided with research examining a ‘good death’ from a range of sample populations including patients (e.g. in the period leading up to death) (Payne et al., 1996; Singer et al., 1999; Pierson et al., 2002; Vig and Pearlman, 2006), family members of the terminally ill or recently deceased (Hirai et al., 2006; Masson, 2002), professional or medical staff (Low and Payne, 1996; Kristjanson et al., 2001; Hopkinson and Hallett, 2002) and members of the general public (Rietjens et al., 2006; Leichtentritt, 2004, Tong et al., 2003). A paper by Steinhäuser and colleagues (2000) has become one of the most widely cited articles in the field. Collating the views of patients, family members, medical professionals, chaplains, social workers and hospice volunteers, it identified six themes of a ‘good death’:

- Pain and symptom management
- Clear decision-making
- Preparation for death
- Completion
- Contributing to others
- Affirmation of the whole person

This literature review will offer a critique of these themes in the context of death with reduced capacity. This review does not distinguish how reduced capacity is reached but only that it needs to be considered when thinking more broadly of what a good death can and should be. Within much of the work on a ‘good death’ there is a tendency to assume that the mental capacity to make one’s own decisions is in place so that these themes can be addressed before dying. However, recent statistics on dying with

dementia show a marked increase between 2001 (6.6%) and 2014 (15.8%) (Prince et al., 2014) which when coupled with the demographics of an ageing population, as well as other forms of acute loss of capacity, suggest it is becoming an ever more prevalent issue.

### **Search Strategy**

Several search term groupings were used prior to finalising the keywords for the review. These groupings were developed to align with the key avenues of inquiry: general ‘good death’ search terms; reduced capacity search terms; and search terms relating to each of Steinhauser et al.’s (2000) six themes. This resulted in the breakdown shown in Table 1:

(“Table 1: Search Categories and Terms” - near here)

Each category was developed over several iterations based on the articles returned. This meant, for instance, that search #1 relating to a ‘good death’ eventually incorporated phrases such as ‘quality of dying’, ‘life-sustaining support’ and ‘active treatment withdrawal’ alongside those initially considered for inclusion. Likewise, the search terms relating to capacity were broadened to incorporate ‘minimally conscious state’, ‘vegetative state’, and ‘disordered consciousness’. Searches interrogated the Web of Science database incorporating Medline, Web of Science Core Collection, BIOSIS Citation Index and SciELO Citation Index, as well as the Sociological Abstracts database. The publication date range was set between the years of 1995 and 2015 to align with the emergence of literature relating to dignity in healthcare. Only peer-reviewed, journal articles (in English) were included.

#### **Search #1 – General ‘Good Death’ Terminology**

The search relating to ‘good death’ terminology (#1) returned 1,421 records once duplicates were removed. Subsets of these articles were grouped by research setting, and type of illness. The overriding focus was upon terminal illness and palliative care (793 articles). Cancer was widely studied (253 articles), relative to dementia or Alzheimer’s (43 articles), heart problems (39 articles), HIV/AIDS (31 articles) and cerebrovascular related deaths (5 articles). In terms of the research setting, the hospice saw the largest number of articles returned (258 articles) while the hospital or acute setting also featured regularly (248 articles). The intensive care unit (ICU) (101

articles), care homes (107 articles) and private family homes (56 articles) were also common sites in which the possibilities of ‘good death’ were explored.

#### **Searches #1 and #2 – ‘Good Death’ vs. Reduced Capacity**

Search #2, relating to reduced capacity, produced over 70,000 results when combined with the terms ‘death’ or ‘dying’. When interrogated against the ‘good death’ terms from search #1 this dropped to only 66 articles. Mostly, these studied dementia or Alzheimer’s disease; leaving just 12 articles when terms related to this were absent. While this suggests a gap in the literature, it is also potentially attributable to the dominant understanding of what a ‘good death’ entails. This review will argue that aspects of ‘good death’ suggested by the likes of Steinhauer et al. (2000), rooted in the palliative care model, operate with assumptions that the dying patient has mental capacity. To illustrate, the following sections explore Steinhauer et al.’s model in relation to issues of reduced capacity, identifying the prevalence of articles on each theme and the manner in which capacity is overlooked.

#### **Pain and Symptom Management**

The issue of pain and symptom management during the dying process is well established in palliative care literature (Field and Cassel, 1997; Byock, 1997; Singer et al., 1999). Steinhauer et al. cited it as a primary aspect of ‘good death’ based on their own empirical data, and desktop research (2000, p.829). Their study involved focus groups and interviews with physicians, nurses, social workers, chaplains, hospice volunteers, patients, and recently bereaved family members to identify common ground in how a ‘good death’ was understood (Steinhauer et al., 2000, p.825). They found that discussions of a ‘bad death’ commonly focused on pain control or ‘inadequate analgesia’ (Steinhauer et al., 2000, p.827). The authors noted the uniformity of this theme, and its importance to patients, family members and medical staff alike (Steinhauer et al., 2000, p.829). The prevalence of articles that associate pain or suffering with a ‘bad death’ demonstrates how embedded this particular theme is within the literature. When combined with search terms for a ‘good death’ (#1), the terms for pain and symptom management (#3) returned 377 records, with an emphasis on cancer and hospices. The number decreased to 34 with the majority (19) relating to dementia or Alzheimer’s patients when the terms for reduced capacity were added. When pain and symptom management was included in accounts of end-of-life care, attention was given to communication or family involvement (Singer and MacDonald, 1998;

Lawrence et al., 2011; De Roo et al., 2015) as well as nonphysical sources of suffering (Caprio et al., 2011); patients' physical pain was not often examined in depth. An exception to this was Monroe et al.'s (2013) investigation into patients suffering from both dementia and terminal cancer in hospices and nursing homes. This showed severely cognitively impaired nursing home residents were at great risk of suffering unmitigated and advanced pain:

One reason for low opioid administration could be that clinicians who are using the World Health Organisation's guidelines for cancer pain treatment might believe that they are appropriately following the guidelines because people with severe dementia may appear to not be in pain (2013, p.1023)

When considering pain in the context of reduced capacity, communication is significant. Kaufman's (2000) study of a community hospital unit housing patients with long-term or permanent comatose conditions conceded that patients were often deemed as having lost 'all higher brain functions, including awareness, feelings, and the capacity to suffer' (Angell, 1994, p.1524). Kaufman notes, when the ability to express pain becomes diminished, this creates a 'juxtaposition of traditional ideas against new practices' in which 'grey areas' of disagreement between practitioners comes to exist (2000, p.77). Thus, while pain management can initially seem a relatively straightforward construct in most 'good death' scenarios, for reduced capacity this is not the case.

### **Clear Decision-Making**

Like pain control, the need for clear decision-making has been widely documented in studies examining a 'good death' (Patrick et al., 2001; Hopkinson and Hallett, 2002; Bosek et al., 2003). Literature searches conflating terms associated with a 'good death' (#1) and those on decision-making (#4) returned 385 records. Again, there was a high presence of cancer-related articles (85), a large volume based in hospital (89) or hospice (70) research settings, with dementia (18), renal (13), heart-related problems (7) and intensive care (34) settings also evident. Kehl (2006) has noted that literature on decision-making often operates in tandem with the notion of 'being in control of' one's death (2006, p.281). This was apparent in numerous articles that integrated decision making alongside issues such as communication and honouring of end-of-life preferences and, therefore, control over the death event (Mak and Clinton, 1999; Cohen

et al., 2001; Jones and Willis, 2003). For Steinhauser et al. (2000) clear decision-making was an integral part of a 'good death', being uniformly discussed by doctors, nurses, other healthcare providers, patients and the family of dying patients (2000, p.829); it was closely associated with pain management, and the capacity to manage suffering and physical distress through communication between physician and patient and the provision of appropriate pain relief (Steinhauser et al., 2000, p.827). Additionally, patients were said to feel more positive and empowered when participating in their own treatment decisions, with the potential for them to prepare for death. However, when treatment preferences were unclear, the authors argued that patients felt disregarded and practitioners feared that they would provide inadequate care. To Steinhauser et al. (2000) then, clear decision-making is a prerequisite to a 'good death'; lack of clarity is associated with a bad death.

Notably, Steinhauser et al. (2000) allude to issues of decision-making with reduced capacity in the following interview extract from a social worker discussing the death of her mother:

I had never talked to her about end-of-life issues. I'm trying to communicate with my family over the phone. "What do we do? She's intubated, her labs are worse." The doctor said, "We really don't think that she's going to make it, and we have to consider withdrawing life support." I said, "I'm sorry, but that's not a decision I can make. (p.827)

Here the bad death stems from the patient's inability at that time to express their end-of-life preferences. Where no discussions are held in advance, the decision to withdraw or sustain treatment often comes 'during a crisis, when emotional reserves were already low' (Steinhauser et al., 2000). The literature search combining terms associated with a 'good death' (#1), clear decision-making (#4) and reduced capacity (#2) further reaffirmed this point. The search returned 31 articles; the majority (18) related to dementia and a lower proportion addressed cancer (2). Notably, the palliative care model reflects the loss of capacity after a gradual decline, allowing end-of-life decisions to be discussed in advance (Ahn et al., 2013; Best et al., 2014). In research on dementia, advance decisions and care planning were commonly emphasised (Bosek et al., 2003; Vandervoort, 2012; Monroe et al., 2013). In the UK, legally binding advance decisions can be put in place to 'refuse a specific type of treatment at some time in the future'

should an individual be unable to communicate this at the time of intervention (NHS Choices, 2014a). These act in parallel with advance statements which provide guidance on matters of religious or spiritual belief, how and where a person would like to be cared for, as well as issues such as pet or child care (NHS Choices, 2014b). Substitute decision-makers are required to take advance statements into account but retain ultimate responsibility. As Jordens et al. (2005) state, advance statements allow more scope for professional and caregiver judgement than advance decisions.

While advance decisions offer future treatment instructions in the case of reduced capacity, critics have highlighted potential pitfalls (Robinson et al., 2013; McMahan et al., 2013) reflecting the theoretical, ethical and philosophical discussions on the concept of precedent autonomy (see Dworkin, 1993; MacLean, 2006). Critics argue that advance decisions are an incomplete form of self-determination taken prior to the 'crucial point when treatment decisions are activated', they are made before full understanding of the situation is achieved (Dresser, 1989, p.157). Furthermore, advance decisions arguably assume the individual remains the same moral entity once capacity is lost (Parfait, 1986). This view aligns with Kaufman (2000) and Holland et al. (2014) who highlight the blurring of ontological status at the point of an advance decision being applied. Kaufman (2000), in particular, demonstrates the complexity and subjectivity associated with advance decisions for patients lacking mental capacity by comparing two distinct case studies. In one case, substitute decision-makers decided to allow their proxy's life to end despite contrary wishes expressed prior to loss of capacity (2000, p.75). Kaufman (2000) argues this was due to the patient's autonomy and personhood being perceived as compromised. The second case described another woman whose husband was insistent on keeping her alive despite her vegetative state, bestowing on her a sense of personhood and hope that ran contrary to the physicians' perspective (Kaufman, 2000, p.76).

Additionally, the legal framework surrounding advance decisions is criticised on the basis that common law and moral arguments tend to disregard the 'validity or applicability' of advance decisions (Michalowski, 2005, p.960; also Heywood, 2015). Numerous accounts cite how proving capacity at the point of making an advance decision is a struggle for patients and carers, in spite of the Mental Capacity Act clearly stating that capacity must be assumed (Coetzee et al., 2003; Collins et al., 2006; Peel and Harding, 2015; Heywood, 2015). This may be because autonomy is only one of



several ethico-legal considerations, with the ‘medical team’s duty to act in [a patient’s] best interests’ and not bring harm also pivotal (Jordens et al., 2005, p.564). Thus for Steinhauer et al.’s (2000) theme of clear decision-making, even when issues of capacity are factored into the model of care, their efficacy remains dependent on a multitude of legal, moral and ethical variables. This problem is arguably accentuated when diminished capacity is arrived at suddenly, demanding that advance decisions are made before awareness of any health-related problems. Considering less than four percent of people in the United Kingdom have made advance decisions (YouGov, 2013), the implication is that the majority of decision-making is carried out by proxies rather than patients themselves.

### **Preparation for Death**

Literature searches conflating terms for a ‘good death’ (#1) and preparation for death (#5) saw a total of 103 records returned, markedly lower than those identified for pain management. An emphasis on cancer (40) and the hospice (32) or hospital (18) setting remained evident. For Steinhauer et al. (2000) the theme of preparation for death encompassed two major dimensions: clear expectation setting for patients and families on the dying process and death event; and preparations for what follows death, like obituaries, wills and funeral invitations (2000, p.827). However, since Steinhauer and colleagues published their paper, the conceptual boundaries associated with death preparedness have expanded to include acceptance, awareness and attitudes towards death, as well as end-of-life decision-making and care planning discussed previously (McLeod-Sordjan, 2013, p.1013). Despite this broadening of the concept, the importance of open communication between healthcare providers, dying patients and family members remained a commonly reported aspect. For instance, Boyd et al. (2011) explored nurses’ views on end-of-life communication, highlighting the perception that it was often a prerequisite to a patient or family being prepared for death. Further to this, Fawole et al.’s (2013) systematic review of interventions for patients with serious illnesses demonstrated the efficacy of a variety of communicative approaches such as ethics consultations, family meetings and physician-patient communication. Likewise, Piers et al. (2013) interviewed elderly patients with limited prognosis, finding that clear communication from healthcare staff fostered a sense of trust where acceptance of death could develop. Lokker et al.’s (2012) study also explored the correlation between awareness of the imminence of death and acceptance or peacefulness once death occurs.

Within this, the communication of prognosis is antecedent to a family or patient being aware of their condition. In turn, this is a precursor to acceptance and a state of death preparedness (see also Seale et al., 1997; Field and Copp, 1999; Francke and Willems, 2005).

The other aspect of preparation outlined by Steinhauser et al. (2000) concerned the more practical considerations for the events that follow death, such as funeral planning, wills and obituaries. Numerous writers identified the completion of 'unfinished business' as key to a 'good death', often entwining with the patient's desire to remove potential burdens for family members (see Emanuel and Emanuel, 1998; Leichtentritt and Rettig, 2000; Tong et al., 2003). This notion of burden and contribution shall be returned to more directly in subsequent sections. It is worth reiterating that the practical and attitudinal dimensions of death preparation come through an awareness and acceptance of the dying process.

When considering the theme from the perspective of reduced capacity, especially if it is arrived at suddenly, many of these ideas about preparedness become problematic. Bosek et al.'s (2003) study of Alzheimer's patients in nursing homes highlighted that their deaths were rarely regarded as good due to the patient lacking the ability to communicate preferences in changes to their treatment. Wakunami et al.'s (2009) study of severe brain damage victims highlighted the difficulties faced by families in accepting the patient is near death. These studies of death with reduced capacity indicate transference of preparatory activity to the family and away from the patient. As with decision-making, those substituting for the patient are pressed into making difficult choices (Kaufman, 2000). Their ability to fulfil this role can be variable, resulting in a poor, or undignified, death experience.

## **Completion**

Steinhauser et al.'s themes of preparation for death and completion show considerable overlap. Later overviews, group them together (see Kehl, 2006; Hales et al., 2008) due to a shared emphasis on acceptance, awareness and the resolution of outstanding conflicts in their description of the theme. The authors state:

Participants confirmed the deep importance of spirituality or meaningfulness at the end of life. Completion includes not only faith issues but also life review,

resolving conflicts, spending time with family and friends, and saying goodbye (Steinhauser et al., 2000, p.828)

The literature searches for this theme (#6) encompassed variations on the terms used in the account above, resulting in 116 records when interrogated against the ‘good death’ search terms (#1). Cancer remained the dominant illness type (39 records), while the hospice (26) and hospital (18) were the most common research setting. Exploring each aspect of Steinhauser et al.’s completion in turn showed that religion and spirituality were the most widely discussed highlighting the role of clergy or chaplains in faith-based or spiritual wellbeing (Braun and Zir, 2001; Carlson et al., 2005). The importance of recognising the subjective religious requirements of patients has also been highlighted; Phelps et al. (2012) found most patients with advanced cancer valued the spiritual dimension of their care. Likewise, the notion of religion was found to be more emphatic in studies from Saudi Arabia (Tayeb et al., 2010), Asia (Leung et al., 2009; Haishan et al., 2015) and India (Sharma et al., 2013).

The role of spiritual as well as non-religious ‘life review’ identified by Steinhauser et al. (2000) was shown to improve wellbeing for terminally ill cancer patients (Ando et al., 2010), via an ‘inner life at the end of life’ (McSherry, 2011, p.112). Such mechanisms helped develop patient acceptance, alleviating psychosocial distress at end-of-life (McSherry, 2011). Non-religious life review was broadly associated with the deeper notion of conflict resolution, with researchers suggesting that it ‘entailed dying without unresolved issues or unanswered questions’, ‘having said goodbyes’ and ‘feeling at peace both with self and others’ (Pierson et al., 2002, p.592). This peacefulness is normally desired close to death:

Patients primarily desire not to fully experience their own deaths. They would like to be asleep and pain-free, and perhaps having already resolved previous family or religious concerns they are more concerned with the peacefulness and speed of their own death (Hughes et al., 2008, p.43)

This sense of completion precludes the desire to be unaware of one’s own death; although the desire of some patients to be unaware at the stage of death was often predicated on several important steps of life resolution having already taken place (Heyland et al., 2006; Mak, 2002).

When examined from the perspective of reduced capacity, the possibility of this process being fulfilled becomes much less likely, particularly if capacity is lost suddenly. In such cases, the incomplete steps of life review, saying goodbye and conflict resolution, among other factors, often contribute to family members' perception of a 'bad death'. Cook and Rucker's (2014) study of death within the intensive care setting noted that familiar tenets of a 'good death', which were reported such as communication, decision-making and spiritual sensitivity, were often not possible. As discussed previously, this situation requires surrogate representatives such as family members to become more central. However for Bosek et al. (2003) the impediment to family experiences of a good death was more significantly linked to undesired symptoms, suggesting the severe challenges in achieving a good death.

### **Contributing to Others**

Whereas each of the four previous themes drawn from Steinhauser et al.'s work had a well-established history within palliative care literature, the final two themes of contributing to others and affirmation of the whole person were introduced as novel concepts by the authors (2000, p.829). Numerous authors have since cited these as crucial dimensions to experiencing a 'good death'. In defining the notion of contributing to others, Steinhauser et al. state the following:

Contributions can take the form of gifts, time, or knowledge. As death approaches, many patients reflect on their successes and failures and discover that personal relationships outweigh professional or monetary gains. They are anxious to share that understanding with others (2000, p.828)

Searches relating to a 'good death' (#1) and contributing to others (#7) returned 98 articles demonstrating considerable overlaps to previous themes with cancer (39), hospital (22) and hospice (19) as the dominant illness type and research settings. In unpicking Steinhauser et al.'s definition, similar notions of acceptance and awareness are prerequisites to a patient's capability of contributing to others. Also, the previously discussed feeling of resolution is partly reached through 'contributory acts' outlined by Steinhauser et al.. This idea is framed as 'leaving a legacy' (Kehl, 2006, p.282) and was shown to be of particular relevance to elderly patients (Vig et al., 2002; Leichtentritt and Rettig, 2000). In the process of their ongoing life review, older people were shown

to value being remembered beyond death, with their contributions to others enabling this.

While the thought of being remembered positively helped to enable feelings of resolution, researchers indicated that fears of negative remembrance had the opposite effect (Mitchell, 1997; Ayers et al., 1997; Gazelle, 2001; Tong et al., 2003). This was commonly raised in conjunction with a patient's self-perceived burden to family or caregivers; defined as their 'empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility and diminished sense of self' (McPherson, 2007b, p.425). This construct was referenced across a range of different studies. Cohen-Mansfield et al. (1992) and Mead et al. (1995) highlighted that older people felt particularly strongly about not becoming burdensome; a point corroborated in studies of individuals living with HIV/AIDS (Martin et al., 1999), renal disease (Ashby et al., 2005) and within younger, healthy members of the population (Resnick et al., 1998).

When considered from the perspective of reduced capacity, the notion of burden has greater significance, often informing discussions of advance decisions and planning choices. For instance, relieving the burden upon loved ones had a 'profound influence' on patient engagement with advance decisions for haemodialysis patients (Singer et al.'s, 1998). Decisions to refuse treatment are commonly informed by fears of the emotional burden of witnessing the patient's death, and the potential burden of substitute decision-making (McPherson et al., 2007a, p.120). Likewise, the perception of burden during incapacity was found to be a reason for decision-making for older people and surrogates (Tomlinson et al., 1990). Too, the importance of burden as a factor in decision-making varied between patients and surrogates, implying it was guided by the subjectivity of the decision-maker. While patients attributed considerable value to the removal of burden for others, their surrogates regarded elements like pain as more central (Libbus et al., 1995; Hare et al., 1992). The inconsistencies between surrogate and patient beliefs have the potential to result in decisions being made on criteria that the patient may not have wished. While the mechanisms for advance statements or decisions are in place to alleviate this issue, even when they are available, studies show physicians or surrogates contradicting them (see Michalowski, 2005; Heywood, 2015). For those who have had no opportunity to express future treatment

decisions, Steinhauser et al.'s theme of contribution to others by relieving the burden on them, offers no means by which such a death can become 'good'.

### **Affirmation of the Whole Person**

The final theme from Steinhauser et al. (2000) model was concerned with 'affirming the patient as a unique and whole person' not characterised by their disease but understood in 'the context of their lives, values and preferences' (2000, p.828). Writers such as Kehl (2006) have expanded this definition, and it is now associated with wholeness - as physical, emotional, social and spiritual needs - as well as quality of life and individuality (2006, p.281). The key terms from this definition (#8) resulted in only 36 records when applied to those associated with a 'good death' (#1). More common illness types were cancer (7) and dementia (4), with the hospice (8) and nursing home (3) being the most commonly identified research settings. Beyond this, the theme has been linked to broader constructs of dignity and dignified care (Bosek et al., 2003; Kehl, 2006; van Brussel, 2014; Campbell and Black, 2014).

Efforts to address issues of dignity in healthcare have followed a similar path to that of the 'good death' literature, with a recent surge in articles particularly relating to the care of older people (Hoy et al., 2007; Tadd et al., 2011; Calnan et al., 2013). The general emphasis has been on highlighting the importance of quality interactions within the caring process, such as respectful communication, understanding and addressing an individual's needs and seeing the person behind the patient up until the end-of-life (Tadd et al., 2011). Underlying much of this has been the philosophical and ethical debate around what dignity entails and which aspects are compromised in healthcare. This notion of seeing the person is particularly associated with the 'dignity of identity', defined as what 'we attach to ourselves as integrated and autonomous persons, persons with a history and persons with a future' (Nordenfelt, 2004, p.75). Whereas universal human dignity is morally intractable, the dignity of identity is argued to be malleable and can be influenced and improved through the action of others. Milton (2008) states:

Certain actions may affirm a sense of dignity, while other chosen actions may cause a lack of self-esteem or shatter self-respect. These notions place importance on the healthcare practitioner's expert thought and actions as paramount to ensure that human dignity remains intact (2008, p.208)

In its capacity to be influenced by external action, the concept of dignity of identity places emphasis on healthcare providers to act with dignity, taking into account the person beyond the disease. Moreover, it highlights the importance of communication so that personal identity is made visible to healthcare providers; only when the specifics of an individual's life, values and preferences are communicated can they be acted upon.

In the context of end-of-life care, there are clear links between advance decision-making and the ability to understand what treatments, situations and actions would compromise an individual's dignity. From the perspective of reduced capacity, decisions on ontological status, as well as those on maintaining or withdrawing treatment, often fall on surrogate representatives, physicians or family members, particularly when achieved suddenly. Kaufman (2000) in the US context highlighted how subjectivity on the part of substitute decision-makers can mean different outcomes for patients in a vegetative state, regardless of their historical preferences; this was largely down to the level of personhood ascribed to the patients from their family members at the point of capacity being lost, including understanding how a patient might respond to that loss. Thus, subjective interpretation of what a dying patient may or may not want, has the potential to enhance or detract from the dignity of their death. Furthermore, the activities involving significant others and caregivers included passive and tacit processes such as the sharing of memories and imparting recognition of the dying person's worth (Bosek et al., 2003, p.38). Striving to engage the whole person where the capacity is reduced is often dependent on subjective aspects and an external consensus on what dignity for individuals or those dying with reduced capacity looks like.

## **Conclusion**

This article has attempted to unpick some of the most common ideas associated with a 'good death', following on from the widely cited work of Steinhauser et al. (2000). By doing this from the perspective of a patient with reduced capacity, it has highlighted the inherent assumptions underpinning much of the literature in this field. The six commonly recurring themes summarised here place considerable importance on the ability of a patient to rationalise and understand their condition, as well as their ability to express it. Generally this is based on a palliative care model in which gradual decline towards death allows for patients to accept and prepare before passing away or losing

mental capacity. For those reaching reduced capacity suddenly, many aspects of a ‘good death’ appear difficult, or impossible, to obtain. Expression of pain becomes muted – making good symptom management more challenging, reduced awareness or understanding of one’s own condition decreases the ability to ‘prepare’ for death, and a sense of life’s ‘completion’ or contributing to others, though possible with support, may be more difficult to develop. The only of Steinhauser et al.’s themes offering direct guidance on death with reduced capacity demonstrate a requirement for advance decisions to have been put in place before such a condition is reached. With only four percent of the UK population having done this, even this aspect of the model appears problematic for the majority (YouGov, 2013). In addition, there are numerous studies which highlight how the advance decisions of patients have been difficult to enact even if they are in place (e.g. Kitzinger and Kitzinger, 2013; Kaufman, 2000). Beyond this, Michalowski (2005) and Heywood (2015) have also identified medico-legal barriers to end-of-life decisions that suggest a need for proof of what the patient wanted. Thus, the prospect of a ‘good death’ with reduced capacity appears elusive, even when considering the mechanisms in place to enable it. One area where notable advances have been made is with regard to end of life care for dementia patients, particularly with respect to symptom control. Sampson et al. (2005), Bayer (2006), Kupeli et al. (2016) and Downs et al. (2016) have each highlighted that the principles of a ‘good death’ outlined by Steinhauser and colleagues can be reframed in light of reduced capacity. Incorporating dementia into the palliative and hospice settings offers further potential to die well in this context. However, with national charities such as Alzheimer’s Society still investing primarily on living well and identifying cures, rather than dying well, in spite of these forward strides in learning the enactment of dying well in practice remains variable. This means that further effort on understanding a ‘good death’ with reduced capacity is very much still required.



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Search No.	Search Category	Search Terms / Keywords
#1	General good death	"good death" OR "bad death" OR "dying with dignity" OR "death with dignity" OR "dying well" OR "quality of dying" OR "quality of death" OR "quality end-of-life" OR "life-sustaining support" OR "active treatment withdrawal"
#2	General reduced capacity	"dementia" OR "Alzheimer*" OR "coma" OR "brain injury" OR "reduced capacity" OR "reduced agency" OR "diminished capacity" OR "impaired consciousness" OR "disorders of consciousness" OR "disordered consciousness" OR "minimally conscious state" OR "vegetative state" OR "impaired capacity" OR "impaired autonomy" OR "reduced autonomy"
#3	Pain management	"symptom management" OR "symptom control" OR "pain" OR "suffering"
#4	Clear decision making	"clear decisionmaking" OR "clear decision making" OR "decisionmaking" OR "decision making" OR "care planning" OR "communication" OR "decision maker" OR

Search No.	Search Category	Search Terms / Keywords
		"decisionmaker" OR "treatment decision"
#5	Preparation for death	"preparation" OR "preparedness" OR "peacefulness" OR "acceptance" OR "awareness"
#6	Completion	"spirituality" OR "meaningfulness" OR "life review" OR "conflict resolution" OR "achieving peace" OR "faith" OR "completion" OR "resolve conflict*" OR "resolves conflict*"
#7	Contributing to others	"contribution" OR "life lesson*" OR "knowledge transfer" OR "wisdom" OR "contributing to others" OR "burden"
#8	Affirmation of whole person	"identity" OR "affirmation" OR "personal relationships" OR "whole person" OR "seeing the person" OR "person-centred" OR "person centred"

**Table 1: Search categories and terms**