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An Exploration of the *Good Death*

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For many patients with a life-threatening illness, modern hospitals prevent a good death. When aggressive treatment is selected for a disease process with a remote cure, nurses engage in patient care that is psychologically exhausting and ethically demoralizing. Nursing is well positioned to lead a paradigm shift regarding end-of-life care. The concept of good death is explored through sociology, Christian theology, medicine, and nursing. Of the many determinants for a good death, the ones that transcend the disciplines include making adequate preparations, experiencing no unpleasant symptoms, having someone by one's side, and being spiritually whole. Empirical indicators for measuring a good death are also explored.
Key words: *good death*, *concept exploration.*

IN the year 2000, 2.4 million people died in America,[1] and about half of these deaths occurred in hospitals.[2] One would think that hospitals would have perfected the *good death* by now, that the healthcare team and their most ill patients would have found mutually meaningful, peaceful ways to cross the chasm separating life and death. However, this is often not the case. In fact, 40% of the dying patients experience severe pain most of the time in their final days, 80% suffer severe fatigue, and 25% have moderate dysphoria.[3] Sixty-three percent of dying patients have trouble enduring the physical as well as the emotional aspects of death.[3] The healthcare agenda continues to focus on life by providing technical interventions to sustain a heartbeat. Eleven percent of dying patients have a final resuscitation attempt, 25% are placed on ventilators, and 40% receive artificial nutrition through feeding tubes.[3]

For nurses in acute care settings, caring for patients approaching death with highly invasive and technical measures that often inflict pain, suffering, and emotional distress is psychologically exhausting. The dissonance generated from the disconnection of the physical being from the whole being is counterintuitive to nurses' clinical focus. When healing and cure are real possibilities, nurses can appreciate the infliction of noxious therapies. However, when cure is remote, even impossible, and aggressive treatment is unrelenting, the same "care" suddenly borders on abuse. Unfortunately for these most fragile patients, "once patients and their families enter the medical world, particularly the institutional world of the hospital, their actions are guided by the values and pervasive practices of that world, especially the technological imperative of the political, structural, and economic forces that drive it."[4(p14)]

Overcoming the aggressive medical imperatives of modern hospitals should be a highly prioritized focus for healthcare research. Knowing ***when*** a patient has reached the critical threshold indicating that the dying trajectory has actively begun is crucial knowledge for implementing next steps. According to Kaufman, "One of the essential features of the contemporary problem of death is a lack of clarity, among health professionals, patients, and families alike, about when dying begins."[4(p3)] Oncology has done a better job of discerning this transition than has

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other disciplines owing to better prognostication methods.[5,6] However, that does not mean that other specialties can ignore the issue. In fact, greater attention and focus is needed to overcome lapses in the care of the dying and answer the increasingly vocal cries of the public.[7]

The purpose of this article is to explore the concept of the good death. It is the ultimate goal of humankind to end their physical life in a way that takes them away from their earthly bodies into the next realm without strife, discomfort, or emotional turmoil. Helping patients achieve this goal is a strength inherent to nursing practice. Once the medical plan of care includes a palliative focus, nurses are free to independently intervene through compassionate interventions that bring the physical, psychological, spiritual, and social aspects of the person together for one last healing moment before death. Indeed, nurses' attention to palliation early on ensures a smooth transition from aggressive care to comfort care.

The good death has been conceptualized by various disciplines. This article focuses on the contributions from sociology, theology, medicine and nursing. As the dominant religion of the Western culture, Christian theology will be the focus of the theology section. As an additional point of clarification, when researchers have investigated those from other disciplines (ie, a sociologist interviewing a nurse), the results will be discussed as knowledge originating in the researcher's discipline. This practice acknowledges unique disciplinary perspectives that influence findings and how they are interpreted.

SOCIOLOGY

Because death is "an essentially social, communal phenomenon,"[5(p929)] sociology has focused much attention on the shared aspects of a good death.[8] Care of dying people affects the whole of society and should be understood within this context. The French historian Phillipe Ariès has studied death as far back as the Middle Ages.[9] Ariès describes the death of long ago as a public event, with the dying person surrounded by family and friends. He calls this *tamed death*. In contrast, modern death Ariès's characterizes as *wild death*, where the dying person is hidden deep inside a hospital, isolated from the outside world to protect society from the embarrassment and revulsion.

However, the 2 studies that mark the beginning of sociology's proliferation of death work are Glaser and Strauss's[10]*Awareness of Dying* and Sudnow's[11]*Passing On: The Social Organisation of Dying*. Glaser and Strauss first introduced the concept of a dying trajectory, which described the *good* or *appropriate* death as one of open awareness that allowed time for quality interactions between the dying and their family and friends. A sudden death was considered a crisis because it prevented this closure. Sudnow's ethnographic study of dying in modern hospitals reaffirmed the wild death described by Ariès. Death had become a routine event, made as efficient as possible by hospitals, often at the expense of dignity and compassion. People were dying in isolation, with power and control over their final hours stripped away.

It was not until Kübler-Ross's[12] book *On Death and Dying*, however, that healthcare providers started to take notice of the unmet needs of dying patients.[9] Kübler-Ross, a physician, interviewed over 200 dying patients and identified the 5 now well-known stages the dying person often passes through: denial, anger, bargaining, depression, and acceptance. Once this process of grief was worked through, the dying person could die a good, peaceful death. Although her work has been mentioned in the sociology section of this article, it has had a profound influence on all disciplines, apart from sociology.

During the 1990s, sociologists began conducting studies to define the good death and determine exactly what it entailed. Kellehear[13] interviewed dying people to better understand what constitutes our modern understanding of the good death, and if it did indeed exist. Using interview data from 100 oncology patients who were all aware of their terminal prognosis, Kellehear found that the good death *can* exist in hospitals, and was characterized by awareness of dying, preparations for death, giving up roles and responsibilities, and saying good-bye.

Long[14] conducted fieldwork in American hospitals during the 1990s and spent time observing rounds and patient care, as well as interviewing patients and staff. She identified 6 aspects of a good death: peaceful, pain-free, surrounded by caring family, recognition that life is a continuation through death, personalized according to values and life conditions, and not burdensome to others.

McNamara et al[15] added to the definition of a good death by asking 22 hospice nurses about their perceptions of a good death. The concept of the good death is central to hospice's philosophy of how people should die. However, the increasing institutionalization of hospice care has led many people to question whether the good death can still be achieved within this construct. The nurses interviewed in this study could relate many good death stories in which "excellent standards of care and adequate symptom control"(p1504) prevailed. They recognized, however, many challenges to hospice's good death concept. For one, bad deaths drained resources. Bad deaths included those patients who did not "internalize hospice's philosophies,"(p1504) leaving staff frustrated and overwhelmed. These were the patients who had not accepted their impending death and refused to conform to the hospice patient role. Another barrier to the good death was institutionalization, which allowed therapies to continue despite the terminal prognosis. For instance, physicians sometimes gave their hospice patients intravenous antibiotics in response to an infectious process. Finally, a good death to many families meant that everything should be medically done before, and right up until, death. This obviously compromised the ideal of a peaceful, natural death.

Tong et al[16] conducted community focus groups with various minority and nonminority groups to determine what defines a good death. They found seven domains of a good death common to all groups: physical comfort, minimal burden on the family, ideal location and environment, presence of others, a natural end to life, good communication, and a sense of completion. They also identified 3 other domains that were more important to minority groups: spiritual care, cultural concerns, and individualization.

Through a review of the death literature, Carr[17] conceptualized a good death as having the following attributes: awareness of or peace with impending death, pain-free, timeliness, positive spousal interactions, presence of family, outside a nursing home, minimal burden to family, and after a full and rewarding life. She interviewed older widowed persons 6 months after the loss of their spouse to determine the presence of these good death attributes. She found that those who died after a period of forewarning had significantly greater number of good death attributes than those who died suddenly.

Good et al[7] studied 163 hospital internists to gain their perspective on the good death. They were asked about their most recent death as well as their most emotionally powerful death. Interestingly, although the concepts of *good death* and *bad death* were prevalent in the literature, Good et al found that physicians rarely used these terms. The study revealed that physicians who cared for dying patients in the hospital had relatively brief relationships with their patients. Only 7% were with the patient at the time of their death. When asked to rate their closeness to the patient on a scale of 1 to 10, with 10 being *very close*, the mean response was 2.9 ($SD = 2.3$). Physicians described a good death as follows: expected, peaceful, timely, having rational/coherent/appropriate medical care, smooth, and including effective communication. The physicians admitted that the transition from aggressive care to end-of-life care is a very tough challenge. The authors of the study concluded by saying that the complexities of end-of-life care in today's high-tech hospitals is much different from the environment reported by Glaser and Strauss. Physicians do not have as much social power now as they did then. They cannot stop therapies when they deem appropriate, but must negotiate with patients and families.

In 2004, McNamara[5] followed up her 1994 study with a continued focus on hospice and palliative health professionals' perceptions of the good death. Pulling data from 52 interviews, she found that the good death to these participants included an open awareness of dying, gradual acceptance of death, settling of practical and interpersonal business, and being in control. However, the ideal good death was not as prevalent as desired, leading McNamara to the conclusion that the most that can be hoped for is a "good enough death."(p934) If health professionals can ensure proper symptom management, then the patient has achieved a good enough death, whether the more elusive psychological, social, or spiritual stressors were overcome or not.

Long[14] described 4 cultural scripts of dying identified by sociologist Clive Seale. These scripts frame the concept of the good death. The first script is *modern medicine*. Patients submitting to this script experience a private event with oversight by a physician. It is a secularized version of death, with access to all that medicine has to offer. The second script is *revivalism*. In this more modern, enlightened approach, death is known in advance and may even be prolonged. It is shared with family and friends and thus encourages reconciliation and deepening of relationships. The dying person is an active decision-maker and in control of the death experience. This script is often limited to those with an open awareness of pending death, such as patients diagnosed with cancer or AIDS. In opposition to the revivalist script, the *antirevivalism* script favors a closed awareness. The patient does not really want to know the prognosis and often refuses palliative services, such as hospice. Patients adhering to this script are often of lower education and socioeconomic status, and prefer to die at home. The fourth script is usually not a separate script but is woven throughout the other scripts. The *religious* or *spiritual* script places emphasis on God's sovereignty. The dying person, for example, may acknowledge God working through the hands of the physicians and nurses. By understanding which script the patient subscribes, the good death is individualized and more readily achieved.

Dignity is a concept also frequently linked with the good death. Society depicts a dignified death as one in which the dying person is respected, well cared for, and commands a degree of control. However, Radley[18] describes dignity as a give-and-take between the dying and the comforter. It is something to be given as well as something to display in social contexts.

The many characteristics of the good death as defined by the philosophies and research of sociologists are summarized in Table 1. The pro-euthanasia and right-to-die viewpoints, which are often linked to the good death, are purposely omitted from this exploration and beyond the scope of this article. Christian theology will add further dimensions to the concept of the good death.

CHRISTIAN THEOLOGY

As would be expected, the writings of Christian theologians focus deeply and passionately on the spiritual aspects of the good death. In fact, hardly any of the characteristics identified by sociologists are mentioned by theologians, and several are even dismissed as counterproductive to the work of death. Before modern hospitals, dying was a religious event, not a medical one.[19] A good death meant reconciliation with God and one's neighbors. However, the modern good death is one made completely invisible.[19] Not the wild death portrayed by Ariès, but one in which even the dying are blinded to the process. Walters[19] describes this repressed viewpoint as the *death that does not happen yet* (it will happen in the future, not now), *death that is not seen* (hidden within hospitals), and *death that*

Table 1. Determinants of the good death by discipline

	Sociology	Theology	Medicine	Nursing
Able to help others			√	
Acceptance of impending death	√			√
After having lived a full and fulfilling life	√		√	
Awareness of dying, expected	√			√
Being mentally aware			√	
Being treated as a whole person			√	
Completion and emotional health	√		√	
Conflict resolved, relationships improved		√	√	
Control of location/environment	√		√	
Control over timing			√	
Control over treatment	√		√	
Cultural concerns met	√			
Die during sleep			√	
Dignified, with integrity	√			√
Excellent standards of care	√			√
Good communication	√			√
Individuation, personalized	√			
Making preparations	√		√	√
No burden on the family/society	√		√	
No knowledge of dying			√	
Nursing presence				√
Pain and symptom control	√	√	√	√
Palliative care team involvement				√
Peaceful	√			
Presence of others	√	√	√	√
Private space				√
Quick			√	
Relinquishing roles and responsibilities	√			
Saying good bye	√			√
Spiritual needs met	√	√	√	
Timeliness	√			

happens without noticing (without warning, sudden). Walters further acknowledges that a postmodern viewpoint of death has emerged as a death that is now completely visible, and to be controlled. However, control of death seems rather anti-Christian. Indeed, Jesus' death was not something he controlled. A more realistic depiction may be that people struggle with death as best they can. Walters borrows the phrase *dying with panache* to describe dying in one's own style, perhaps without acceptance or peace, but certainly with integrity and honesty. This phrase is suggestive of McNamara's[5]*good enough death*, which implies the myth of the completely good death.

Theologians agree that the Christian experience of death is best portrayed as a struggle, not simply a willing desire to enter paradise. Vogt[20] uses Luke's version of the passion of Jesus to more accurately depict the Christian experience of the good death using the concepts of patience, hope, and compassion. Jesus first shows patience with his impending death in the Garden of Gethsemane. It is at this point that Jesus first understands that his suffering and death are very near. However, he *reluctantly* accepts this fate as he pleads with God to take this burden away, acknowledging that God's will be done not his. He relinquishes all control to the Father, an ideal frowned upon by postmodern views of death. At this point he patiently awaits his fate, deep in prayer, drawing close to God. Hope is with him during his tortuous night in Gethsemane. As he cries out to God, an angel appears, to give him strength. Feeling God's presence he prays more earnestly, indeed his sweat becomes like drops of blood. Jesus understands that he will suffer greatly, but that God is with him at all times. This provides a source of hope crucial at the most fragile point in Jesus' death trajectory. The final image underpinning Jesus' death is compassion—not only the compassion that Jesus receives from his followers but, more important, the compassion he expresses to others. When Jesus looks at Peter after he denies him 3 times, his gaze expresses a compassionate understanding and the trust that Peter will rise to be a rock of the Christian church. Jesus also compassionately forgives an unknown criminal as they are crucified side-by-side.

Jesus' death would never be considered "good" by any secular definition. However, through the Christian values of patience, hope, and compassion, Jesus' agonizing death is portrayed as a model for the present-day Christian who indeed also struggles with fear and suffering as death draws near. Peterson[21] acknowledges this Christian perspective on dying as she describes the death of her husband to AIDS. Despite the agony of his untimely death, he finally submitted to God's will by scribbling these final words in response to his wife's assertion that it was time to go, "Focusing on God's sovereignty."(p66)

Hardwig[22] also recognizes the difficult work needed to be done as death draws near. He sees this work as a purely spiritual issue, not a medical one. As such, doctors should be on the periphery as the dying focus on their spiritual needs. Because physicians are not suited to handle this last, ultimate crisis of humankind, "then we ought to 'demedicalize' death."(p30) The good death, then, can only be defined as one in which spiritual issues are resolved. Whether Christian or not, religious or not, spiritual concerns are of utmost importance at the end of life.[23]

Within the theological literature explored on the good death, all discourse focused solely on the spiritual needs of the dying, except for one study which asked churchgoers (both laity and clergy) their definition of a good death. Braun and Zir[24] held 18 focus groups attended by 121 people from Christian churches. They specifically asked for definitions of a good death. The most frequent responses included pain and symptoms are managed, inappropriate prolongation of dying is avoided, family is present and supportive, conflict is resolved, and spiritual issues are addressed. Echoing the concerns of Hardwig,[22] one clergy said, "What prevents a good death sometimes is an overly clinical atmosphere in the hospital or healthcare facility where the medical agenda supersedes the human agenda."[25](p694) Braun and Zir's findings are consistent with good death descriptions from the social sciences and reflect the secular concerns of Christians. These definitions are included in Table 1 under theology, but the argument could be made that they are better suited with sociology. If so, only *spiritual needs met* would be Christian theology's definition of the good death. Attention is now turned toward medicine to further understand the concept of the good death.

MEDICINE

In 1908, Osler studied 486 deaths at the Johns Hopkins Hospital.[3] He noted that 90 suffered pain and 11 suffered anxiety, but in the great majority, death was nothing more than falling asleep. This picture of death contrasts sharply with the *wild death* of modern hospitals 100 years later. Very little medical research on death was conducted after Osler's study until the 1990s. In 1995, the outcomes of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) were published.[26] This was a 2-year prospective observational study, followed by a 2-year randomized clinical trial. The trial measured the use of specially trained nurses to work with dying patients and families to address end-of-life issues. The observational phase found shortcomings in pain control, poor communication regarding do-not-resuscitate orders, and excessive ICU time. The clinical trial failed to show improvements in patient outcomes with the use of nurse facilitators. The disappointment of the SUPPORT project led some medical researchers to further explore the impact of physician services on end-of-life issues and to define the good death.

The same year that SUPPORT was published, Asch et al[27] published their survey of 879 intensive care physicians regarding their practices with medically futile patients. Thirty-four percent reported that they had continued life-sustaining treatment despite surrogate wishes that such treatment be discontinued, and 83% reported that they had unilaterally withheld or withdrawn life-sustaining therapy they deemed futile. While these results suggest medical paternalism, the reasons cited for such decisions indicated complex medical situations that included ethical and legal considerations layered on top of poor prognoses.

The study by Aschet al[27] and the SUPPORT study[26] were published 5 years after the passage of the Patient Self-Determination Act (PSDA), which required hospitals to document advance directive statuses for all inpatients. The purpose of this law was to ensure patient input in end-of-life decisions in an effort to realize more good deaths within hospitals. Most healthcare professionals would agree that the PSDA has been a total disappointment, with no real change in how patients die. Sullivan[28] cites several reasons for this failure. For one, no one can know entirely what their wishes will be given the very specific situation they will find themselves in. In addition, proxies usually do not fully follow patient preferences at the end of life, but interject their own wishes for the patient. Physicians often wait too late to determine that the patient is terminal and to implement advance directives. Sullivan calls for a "reasonable social consensus about 'the good death' and good care at the end of life"(p369) instead of relying on the illusion of patient self-determination.

However, the "reasonable social consensus" is also fraught with unknowns regarding specific, complex situations. For example, Saunders et al[29] described a case study involving a 19-year-old man with terminal cancer. While on the palliative care unit he began having massive gastrointestinal bleeding. He panicked when he realized he would die without an immediate transfer to another facility for emergency angiogram and embolization. Should the physicians have let him die that night, or was emergency treatment justified? He was indeed treated and peacefully died 18 days after the procedure with his mother and father at his side. The authors argue that on the surface emergency treatment seemed futile and wasteful, but it allowed for an eventual good death. There are no easy answers to such ethically complex cases, despite social, legal, and ethical debate to find such an answer.

The modern hospice movement has made some of the best attempts at achieving good deaths. In fact, Gazelle[30] reports on her astonishment after accepting a position as an outpatient hospice director that the patients "just die,"(p95S) without the *wild death* component of inpatient units. The reasons for this disparity, according to Gazelle, are many. For one, physicians rarely have a hospice rotation in their residency and rarely witness a home hospice death. They are taught that no matter how bad things get, always provide hope to the patient and family. This oversight in medical education has led to overly aggressive physicians who are not taught how to let patients die.

A provocative study published in the *New England Journal of Medicine*[31] surveyed hospice nurses to determine if they were aware of patients who purposefully refused food and fluids to hasten death. One third of the respondents indicated they had cared for such a patient, 85% of these patients had died within 15 days, and on a scale of 0 (*a very bad death*) to 9 (*a very good death*), the median score was 8. This study begs the question of physician reaction to the inpatient who refuses food and fluids. Certainly, at the very least, a feeding tube would be offered.

At best, the good death seems elusive in modern American hospitals. Like their sociology colleagues, physicians have conducted several studies to more clearly define the good death. Singer et al[32] analyzed transcripts from 3 qualitative studies that looked at end-of-life decisions in patients with end-stage renal disease, human immunodeficiency virus, and patients in long-term-care facilities. They found 5 common domains important for a quality death: adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones.

Steinhauser et al[33] sent surveys to seriously ill patients, bereaved family members, physicians, and other care providers to determine what they thought were the most important issues at the end of life. They found differences in how patients and physicians defined a quality death. All groups indicated the following items as very important: pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a whole person. Patients, but not physicians, also indicated having mental awareness, being at peace with God, felt they were not a burden to family or society, being able to help others, taking part in prayer, having their funeral arrangements planned, and feeling that one's life is complete as important.

Vig et al[34] focused their study on older people who were *not* terminally ill. They asked 16 men and women, "What would you consider a good/bad death?"(p1541) The top responses for a good death were as follows: no pain and suffering, die during sleep, die quickly, no knowledge of impending death, being prepared, and family and friends present. Some of the responses indicate contradictions in end-of-life views. For example, some participants did not want to know they were going to die, yet wanted time to prepare. Vig and Pearlman[35] followed up their 2002 research with a study posing the same question to 26 terminally ill men. The top 3 responses from the earlier study were repeated with this population: die during sleep, quick, and painless.

Clark[36] polled visitors to the *British Medical Journal* Web site on what they considered a good death. Nonhealthcare professionals' ($n = 171$) top responses were as follows: freedom from unpleasant symptoms, choice over timing of death, and choice over place of death. Healthcare providers' ($n = 521$) responses differed slightly: freedom from unpleasant symptoms, freedom from heroic interventions, and choice over place of death. The fact that healthcare providers included freedom from heroic measures speaks to their insider observations of bad deaths resulting from aggressive and futile interventions.

Beyond isolated research studies, Emanuel and Emanuel[37] addressed good death from a more theoretical perspective, providing a multidimensional framework for a good death. Their conceptualization included fixed and modifiable characteristics of patients who interact with care-system interventions to produce an overall experience of dying. Understanding the various influences on the dying process allows caregivers to influence death outcomes in an individualized way. The model includes tangible interventions that may assist in the achievement of a good death. However, since its publication in 1998, it has only been cited in one other article in the PubMed database.

Nurses also have insider perspectives on the good death. As an integral part of the healthcare team, their viewpoint will conclude the multidisciplinary portion of this article.

NURSING

Although nurses have probably witnessed more deaths than any other profession, the nursing literature is relatively sparse concerning determinants of the good death, except to confirm through experiential knowledge the accuracy of research in the field. To gain greater insight into the perception of end-of-life issues in nursing, it will be explored from an expanded view that includes not only how they define a good death but also how nurses experience patient deaths.

Hopkinson et al[38] used a phenomenological approach to determine how nurses care for the dying in hospitals. They interviewed 28 newly qualified nurses and asked them to discuss patients who had died or were near death. They found 6 essences underpinning the nurses' stories. The first essence, *the personal ideal*, was common to all nurses. It concerned what the ideal death should be like (eg, the good death). The second essence, *the actual*, concerned descriptions of what actually happened in practice with dying patients. The *unknown* essence involved all the unknowns that surround the dying, such as when death will come. The fourth essence, *the alone*, described the things that only nurses who are intimately involved with the dying know. The last 2 essences, *tension* and *antitension*, worked in opposition to each other. Tension involved obstacles to the ideal death, such as not having enough time to spend with a dying patient. Antitension concerned thoughts and activities that helped relieve the tension, such as supportive collegial relationships. Through the arrangement of these essences, a model of the experience of caring for dying people emerged. The model portrays a see-saw with *comfort* as the central balancing point. At either end of the see-saw are tension and anti-tension. The personal ideal, the actual, the unknown, and the alone all weigh heavy on the tension end of the balance. To balance the tension, nurses engage in relationships and thoughts that support and strengthen them, thereby achieving a sense of personal comfort with the dying experience. While the focus in this model is clearly on the nurse, implications for the patient's good death (*the personal ideal* essence) are recognized.

Another significant nursing contribution in the quest for the good death involved the articulation of a model describing how healthcare providers shift patient and family goals from curative to palliative.[39] Using interview data from 10 nurses, 5 physicians, and 5 family members, the authors constructed a model to address a situation where patients or family members have an unrealistic "big picture."[39(p268)] The next 3 steps of the model attempt to move the patient/family member to a more realistic understanding of their condition by laying the groundwork, shifting the picture, and determining if the patient and family accept the new picture. If these strategies are successful, the model ends in a good death.

Only one nursing study was found that attempted to define, from the nurse's perspective, the good death.[40] Seventeen registered nurses from acute care and community settings participated in open-ended interviews that explored their perceptions of death in the end-stage heart failure population. The authors did not clearly categorize their findings into succinct themes; however, several determinants of a good death were identified. For a death to be considered good by nurses, patients and families needed to be informed and involved with decisions, accepting of death, and cared for in an appropriate environment—one in which there was adequate staffing and a private space for the patient and family. In addition, a good death included planning ahead, saying goodbye, dying with integrity, open communication, and adequate symptom control. Interestingly, spiritual concerns were not specifically mentioned. Finally, consultation with a palliative care team was a crucial finding in this study. Nurses noted that patients who were managed by such a team experienced much better deaths.

In the past 5 to 10 years, many disciplines have been interested in defining the good death. Their results overlap and support one another's findings as well as enhance each discipline's perspective (see Table 1). Some of the determinants could be collapsed into common categories. However, they purposefully are listed separately to capture the nuances of the various items.

Of the 31 determinants of the good death reported from these studies, only 2 were common to all 4 disciplines—pain and symptom control and presence of others. Two others were mentioned by 3 of the 4 disciplines—making preparations and meeting spiritual needs. Those identified only by sociology include items with a psychosocial component, such as meeting cultural needs and relinquishing roles and responsibilities. Those items identified only by medicine deal more with the mechanics of dying, such as dying during sleep, without knowledge, and quickly. Nursing is uniquely concerned with a private, supportive environment that includes ample nursing presence. Theology did not have any one item exclusive to their perspective, although meeting spiritual needs is clearly their ultimate definition of the good death. The top 4 determinants might best sum up how most people in Western cultures would like to die—after making preparations, without any unpleasant symptoms, with someone at their side, and spiritually whole. How the good death can be measured is the final topic of this article.

EMPIRICAL INDICATORS

Being able to measure whether a patient experienced a good death is an important step in furthering an understanding of this concept. As evidenced by the literature presented thus far, most studies have used a qualitative approach. This research methodology is appropriate for beginning explorations in an area and continued in-depth examinations of various perspectives. However, it is very time consuming, cumbersome, and may not be suitable for generalizing to other populations. Empiric measures that allow valid and reliable data collection on a continuous scale are much needed to begin research efforts of a quantitative nature. Currently, 3 instruments have been published that attempt to measure the good death. They have been used minimally, if at all, in published research studies. Therefore, their validation as useful measures of quality death outcomes is greatly needed.

The first tool was developed specifically for dialysis patients.[41] The Dialysis Quality of Dying Apgar uses the familiar newborn measurement scheme for quickly tallying 5 dimensions of death using a 3-point (0–2) scale. The 5 dimensions include pain, nonpain symptoms, advance care planning, peace/dignity, and duration dimension. To be completed by healthcare providers in collaboration with family, the scale yields a score of 0 to 10, with higher values indicating a good death. The authors have not yet validated cutoff points for delineating very good, good, and bad deaths. While meant for the dialysis population, it could easily be used with nondialysis patients. Given the many determinants of a good death, the scale may not capture important components of a good death, although the top 4 items from Table 1 are included. In addition, the scoring for the duration dimension may not be valid. A score of 2 is given for a brief death, including suddenly and unexpected. Studies have shown that a sudden death denies a patient time to prepare and prevents saying good bye.[10,17] Moss[42] points out that the scale does not take into account the patient's and the family's perspectives. Although the tool does not directly ask how the patient or family feels about the quality of the dying experience, it does indirectly by allowing their input into the 5 dimensions. The concept behind this tool is intriguing; however it needs further modifications and testing before extensive use.

The second published instrument is the Concept of a Good Death measure.[43] It is a 17-item questionnaire that elicits the importance of various determinants of a good death using a 4-point Likert-type scale. The 17 items load onto 3 subscales—closure, personal control, and clinical. The scale performed well in reliability and validity determinations. The items appear to be a good representation of determinants of a good death. As in the Apgar tool, an item refers to the "sudden and unexpected"[43(p578)] death as a feature of a good death. This may not always be so. This tool was developed to measure what healthcare providers and lay people determine to be important for a good death. It can be used in educational sessions to measure baseline and postintervention changes. It does *not* measure if a patient experienced a good death.

The final published instrument to measure a good death is the Quality of Dying and Death (QODD) questionnaire.[44] It is a 31-item tool that lists determinants of a good death and asks the respondent to rate each item from 0 (*terrible experience*) to 10 (*almost perfect experience*), yielding a score of 0 to 100, with higher values indicating a better death experience. Wording the responses in this way allows the respondent to place his or her own value judgment on each item. For example, one item is "location of death."[44(p31)] If the family member died where he or she wanted (home, hospital, or somewhere else), the item would receive a high score without implying that dying at home is preferable for a good death. The tool is comprehensive and the authors have documented reliability and validity. Two items require further consideration. Item 12 states, "Have the means to end your life if you need to."[44(p31)] This item is not mentioned in the many studies to define a good death. At best it is controversial and may even be offensive to grieving family members. Item 20 states, "Avoid being on dialysis or mechanical ventilation."[44(p31)] This wording may be confusing for long-term dialysis patients who, at one time, functioned well with the support of dialysis. The authors have used the tool in one study with 252 bereaved family members. The tool provided continuous level data that was subjected to statistical analysis with intriguing results. For example, the QODD showed a statistically significant negative correlation with the Memorial Symptom Assessment Scale, which measures symptom burden ($r = -0.52$, $P = .001$).

CONCLUSION

The good death is a concept shared by people of most cultures as the one final conquest of life. The determinants of a good death have been explored by many disciplines and, when viewed collectively, provide a richly complex and value-laden conceptual framework. For nursing, however, *good death* is a relatively undocumented phenomenon. Without further attention to it, patients will continue to suffer institutionalized, overmedicalized deaths. Why must this be nursing's burden? For one, sociology has published the most work on this concept, yet it has not effected change because sociologists are not practitioners at the bedside of the dying. In contrast, ministers and deacons are often present at the bedside of the dying. However, they are relegated as guests of the dying and often are not a full participatory member of the healthcare team. As such, they rarely speak with physicians to recommend spiritual plans of care that include measures to ensure a good death. Finally, medicine is a curative profession. Physicians seek cure and rehabilitation for as long as medically possible. Their curative paradigm is a powerful influence on patients and families desperately seeking answers to mounting health crises. Often death is seen as defeat and not easily accepted as the most biologically natural "cure" of all.

This leaves nursing. Nurses work closely with terminally ill patients and often recognize the dying trajectory. Their vigilant contact with patients in all settings provides entrée to patients, families, and other healthcare disciplines. Nursing's holistic perspective is not encumbered by cure at all costs. In fact, a palliative perspective can be nursing's greatest rationale for providing leadership in a movement toward more good deaths. Motivated by the personal participation in the undue suffering of patients in their final days of life, nurses are ideally positioned to evolve the concept of a good death to an actualized standard of care. The discipline's challenge at this point is to identify the beginning of the dying trajectory, find measures for assessing an individualized good death, implement strategies for quality palliative care, and evaluate collectively and individually the achievement of the good death.

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