

A scoping research literature review to assess the state of existing evidence on the “bad” death

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ABSTRACT

Objective: A scoping research literature review on “bad death” was undertaken to assess the overall state of the science on this topic and to determine what evidence exists on how often bad deaths occur, what contributes to or causes a bad death, and what the outcomes and consequences of bad deaths are.

Method: A search for English-language research articles was conducted in late 2016, with 25 articles identified and all retained for examination, as is expected with scoping reviews.

Results: Only 3 of the 25 articles provided incidence information, specifying that 7.8 to 23% of deaths were bad and that bad deaths were more likely to occur in hospitals than in community-care settings. Many different factors were associated with bad deaths, with unrelieved pain being the most commonly identified. Half of the studies provided information on the possible consequences or outcomes of bad deaths, such as palliative care not being initiated, interpersonal and team conflict, and long-lasting negative community effects.

Significance of results: This review identified a relatively small number of research articles that focused in whole or in part on bad deaths. Although the reasons why people consider a death to be bad may be highly individualized and yet also socioculturally based, unrelieved pain is a commonly held reason for bad deaths. Although bad and good deaths may have some opposing causative factors, this literature review revealed some salient bad death attributes, ones that could be avoided to prevent bad deaths from occurring. A routine assessment to allow planning so as to avoid bad deaths and enhance the probability of good deaths is suggested.

KEYWORDS: Bad death, Good death, Terminal care, Death, Literature review

INTRODUCTION

Around 56 million people die worldwide each year (World Health Organization, 2015). Some of these deaths could be categorized as “bad”—where a painful or otherwise problematic dying process takes place. It is of great concern that bad deaths could be occurring today, as “good” deaths have been a common global objective since the palliative care movement was initiated in the 1960s (Good et al., 2004). Moreover, good deaths are widely considered possible now as a result of advances in medications, health-

care delivery, and other areas (Hales et al., 2010). Although avoiding bad deaths may be as much or more important than trying to ensure that good deaths occur, care efforts and research attention to date have mainly focused on the good death. Many good death studies have been performed, and at least four literature reviews have been conducted to establish what is known about good deaths (Cottrell & Dugleby, 2016; Evans & Walsh, 2002; Meier et al., 2016; Proulx & Jacelon, 2004). These reviews have identified a wide range of factors for good deaths, although it is widely acknowledged that good deaths are highly individualized in relation to the person, family, context, and culture/society (Brazil et al., 2004). One would assume, though, that when good death factors are present those factors would not only enhance the

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possibility of good deaths occurring but also reduce the occurrence of bad deaths. It is also possible that different factors cause or potentiate bad deaths.

As no published literature reviews on the topic of a bad death could be located, a review of the research literature related to “bad death” was undertaken to determine the state of the science on the bad death. Moreover, our review sought to identify the factors that have been associated with bad deaths, so as to learn what contributes to or causes a bad death. In addition, evidentiary information was sought on the incidence of bad deaths to determine how important it is to design and implement plans to prevent them. Moreover, research evidence on the outcomes or consequences of bad deaths was also sought. Outcomes information is particularly relevant, as bad deaths can have serious consequences for the dying person as well as for their family, their caregivers, their community, and society as a whole.

METHODS

A scoping literature review was performed. Like other literature reviews, scoping reviews collect and organize information to gain an understanding of the existing evidence base (Arksey & O'Malley, 2005; Armstrong et al., 2011). However, scoping reviews are specifically designed to consolidate research evidence and thus create knowledge on new or undeveloped topics (Whittemore & Knafl, 2005). Scoping reviews differ from systematic literature reviews in two ways: (1) systematic reviews focus on narrow and well-defined questions as compared to scoping reviews which seek to gain an overall understanding of a topic; and (2) systematic reviews aim to provide answers to specific questions through the use of quality-confirmed studies as compared to scoping reviews where the entire research literature base is employed (Arksey & O'Malley, 2005).

Before conducting our literature search, a university librarian was consulted to determine which library databases, medical subject headings (MESH), and keywords would identify published qualitative, quantitative, and mixed-methods research reports that focused in whole or in part on the “bad death.” The goal was to find all English-language research reports published in peer-reviewed journals over the past two decades (1995–2016). The library databases Embase, PubMed, CINAHL, SocINDEX, and Medline were identified as the most relevant. The MESH/keyword terms were “bad death” OR “good death” OR “death quality” combined with “research.” The inclusion criteria were: in the English language, had an abstract, published in a peer-reviewed journal during the years 1995–2016, was a research study with information provided on the methods used to

gather and analyze data, and focused in whole or in part on the concept of a “bad death.” The search criteria excluded all non-research reports, although four “good death” literature reviews were identified and used to find research articles for review. The reference lists of all the selected articles were also read to identify articles for review.

Our search of the five library databases revealed nearly 1,000 articles for possible review. Each was assessed by way of its title and a reading of its abstract for relevance. Most were not research articles, and most studies focused solely on good deaths, which reduced the number to 212 possible articles for review. A reading of each full paper was then undertaken for relevancy, with this reducing the number to 20. Another 5 articles were found through searching the reference lists of these 20 articles and the 4 good death literature reviews (Cottrell & Duggleby, 2016; Evans & Walsh, 2002; Meier et al., 2016; Proulx & Jacelon, 2004).

Each of the 25 retained articles was read by two readers independently, both seeking to determine the state of the science on bad deaths and to identify information to answer three questions:

1. What causes or contributes to a bad death?
2. How often do bad deaths occur?
3. What is the impact or outcomes and consequences of bad deaths?

Table 1 contains the identified information from each article divided into five columns: (1) author(s), year published, and where the study was conducted; (2) the purpose of the study and type of study; (3) research methods; (4) findings in relation to the three questions; and (5) other information relevant to this scoping review. The collected and confirmed information was then assessed through team discussions. A consensus was reached on the findings, with a report then drafted and completed by the team.

RESULTS

Most investigations were qualitative ($n = 20$), with 2 others being anthropological studies, 2 mixed-methods studies, and 1 a quantitative study. The 25 studies were conducted in 10 developed or developing countries. Nearly half were conducted in the United States (US, $n = 12$), followed by England ($n = 5$), and 1 each in Bangladesh, Ghana, South Africa, New Guinea, Korea, Australia, Argentina and Spain combined, and Canada.

Five were published in 2004, 4 in 2002; 3 in 2014; 2 each in 2003, 2005, 2010, and 2015; and 1 each in 1996, 2007, 2008, 2009, and 2013. Most often, the perspectives or views of registered nurses about bad

deaths were sought ($n = 7$), followed by terminally ill or dying people ($n = 5$), family members ($n = 3$), older people ($n = 4$), physicians ($n = 3$), nursing students ($n = 2$), the community as a whole ($n = 2$), clergy ($n = 1$), younger and middle-aged adults ($n = 1$), and broad-based social insights through an analysis of print newspaper media ($n = 1$).

The Incidence of Bad Deaths

No studies were conducted to establish the incidence of bad deaths, although three identified some relevant information. One study of hospice nurses in the US found that they considered 8 of 102 deaths (7.8%) as bad as a result of food and fluid refusal (Ganzini et al., 2003). Another US study of registered nurses working in hospitals and community settings reported that they thought bad deaths were more common in hospitals than in community settings (Borbasi et al., 2005). A third US study found that 23% of family members believed that their family member had died a bad death in a hospital (Wiegand & Petri, 2010). That study focused on eight decedents, with five family members reporting that the death was bad, four reporting that the death had both bad and good elements, and one unsure about the quality of the death.

Factors or Reasons for Bad Deaths

All of the reviewed studies identified one or more factors related to bad deaths, with some factors common across two or more studies. Despite considerable variability, the identified factors could be grouped into six categories: (1) physical pain, (2) suffering, (3) sudden and unexpected deaths, (4) prolonged dying processes or terminal illnesses, (5) disrespect of the dying person, and (6) dying while experiencing a lack of dignity. Among these, the most commonly identified factor was unresolved physical pain (Adesina et al., 2014; De Jong & Clarke, 2009; Good et al., 2004; Kim & Lee, 2003; Ko et al., 2013; Shea et al., 2010; Vig et al., 2002; Vig & Pearlman, 2004). A bad death was also thought to occur in cases where the dying person in pain could not ask for pain medications, such as those with dementia dying in a nursing home who could not indicate that they were in pain (Seymour et al., 2002).

Other forms of suffering were also of concern for their potential to cause bad deaths, such as unrelieved physical symptoms other than pain (Good et al., 2004; Hanson et al., 2002; LeBaron et al., 2015; Luxardo et al., 2014; Payne et al., 1996; Pierson et al., 2002; Shea et al., 2010; van der Geest, 2004; Vig et al., 2002; Vig & Pearlman, 2004; Wiegand & Petri, 2010). Suffering could also result from non-physical factors, such as when the dying person was lonely (Hanson et al., 2002) or not at peace (van der Geest, 2004). Dying alone or when isolated

from people who care for them was similarly identified as a factor for bad deaths (Kim & Lee, 2003; Ko et al., 2015; LeBaron et al., 2015; Luxardo et al., 2014; Pierson et al., 2002; Seale, 2004; Shea et al., 2010; van der Geest, 2004; Vig et al., 2002). Existential pain and spiritual pain also identified as factors that cause bad deaths (Luxardo et al., 2014). In addition, fear during the dying process was associated with bad deaths (Shea et al., 2010).

Another category of commonly identified factors for bad deaths was sudden and unexpected death, which was considered bad by a number of sociocultural and other groups (Borbasi et al., 2005; Costello, 2006; Good et al., 2004; Hanson et al., 2002; Joarder et al., 2014; Kim & Lee, 2003; Ko et al., 2013; 2015; Garnett et al., 2008; Pierson et al., 2002). Sudden and unexpected deaths were considered bad because there was little or no opportunity to prepare for the death and ensure that a good death occurs (Adesina et al., 2014; Borbasi et al., 2005; Costello, 2006; Good et al., 2004; Luxardo et al., 2014; van der Geest, 2004; Vig et al., 2002). In some cases, signs of impending death were ignored, resulting in a sudden and unexpected death (Payne et al., 1996). When deaths occurred suddenly, the dying people, their families, and their formal caregivers (including hospital nurses if hospitalized or nursing home staff if residing in a nursing home) were unprepared (Adesina et al., 2014; Borbasi et al., 2005; Costello, 2006). Sudden and unexpected deaths were considered premature or abhorrent, as in the case of homicide, a fatal accident, or the suicide of younger persons. Early deaths were considered neither timely nor appropriate (Adesina et al., 2014; Counts & Counts, 2004; Joarder et al., 2014; Garnett et al., 2008; Ko et al., 2013; 2015; Payne et al., 1996; Posel et al., 2007; van der Geest, 2004; Vig et al., 2002; Wiegand & Petri, 2010).

In addition, prolonged dying processes and long terminal illnesses were also identified as factors causing bad deaths (Garnett et al., 2008; Good et al., 2004; Hanson et al., 2002; Ko et al., 2013; Shea et al., 2010; Vig et al., 2002; Vig & Pearlman, 2004). Vig and Pearlman's (2004) study found that dying in one's sleep was preferable to a long drawn-out dying process. Wiegand and Petri (2010) found that prolonged hospital stays with fluctuations in health that fostered and then dashed hope constituted bad deaths. Persistent vegetative states or prolonged comas were also identified with bad deaths (Kim & Lee, 2003). Moreover, long dying processes and dependency on other people contributed to bad deaths, because the family was often overburdened with end-of-life care (Kim & Lee, 2003; Ko et al., 2015; Luxardo et al., 2014; Vig et al., 2002). However, bad deaths could also occur when the person's end-of-life wishes were not known, such as when

Table 1. Literature review findings

| Author(s), year published, and where study conducted | Purpose of study and type of study (i.e., mixed-methods, qualitative, or quantitative) | Research methods, including data analysis methods and where data were collected, when, and from whom | Findings relevant to three questions: What causes or contributes to a bad death? How often do bad deaths occur? What is the impact, outcomes, or consequences of bad deaths? | Other points relevant to this literature review |
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| Adesina et al. (2014), Australia | Explore third-year undergraduate Australian nursing student attitudes, experiences, knowledge, and education on end-of-life care, including what they believe is a bad death. Qualitative | Data collected from 87 students in an Australia university, using a questionnaire with open-ended questions. Manual thematic analysis of data. | The circumstances and contexts in which death occurs affect whether the death is good or bad. Deaths where people suffer pain, are unprepared, or lacked dignity are bad deaths. The mechanism of death and age at death are also instrumental for good or bad deaths. A bad death is the opposite of a good death. | 59% had experience with a dying person either professionally or personally. Most emphasized the importance of achieving a good death experience for the patients and their families. |
| Borbasi et al. (2005), US | Explore nurse perceptions of the care provided to people with end-stage heart failure in community and hospital settings, including their opinion on what should occur to realize a good death and, by comparison, what they perceive is a bad death. Qualitative | Interviews with open-ended questions; 12 registered nurses (RNs) from 3 hospital units and 5 community care RNs. NVivo used to analyze data. | Unexpected deaths were principally viewed as bad deaths as there was no recognition of the disease advancement and so no preparation for death; with a conspiracy of denial, lack of consultation with the palliative care team, fear of discussing death, failing to manage symptoms, lack of resources, imposition of healthcare professional values, nurses not prepared for the death, and little communication among the care team. A bad death is thought more likely to occur in hospital over community settings. Medical doctor reluctance to diagnose end-stage failure and their use of curative treatments even when death is imminent impeded palliative care and contributed to a bad death. Contradictory approaches to end-of-life care by palliative and cardiac teams impacted on the end-of-life phase experienced by the patient and | This study was part of a larger study. Some participants felt it important that healthcare professionals distinguish between good and bad deaths. |

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| Counts & Counts (2004), New Guinea | Study the good, the bad, and the unresolved death in Kaliai, Papua New Guinea. Anthropological study | Observation mainly during long-term field work; no details provided of when or how data were collected—likely in the 1970s and 1980s. | family, with lower quality care as a result. In Kaliai, most deaths are considered bad, all but those occurring as expected in advanced old age. The unresolved death is the worst kind; this is one occurring with no explanation nor any agreed-upon understanding of the cause of it or why it happened. One unresolved death (a young woman committed suicide) destroyed a family and community, and one person was murdered. Suicide is a bad death, as it is beyond the control of that person. A bad death is premature and the result of violence, sorcery, carelessness, or human incompetence. Bad deaths have serious consequences for years, and they frequently result in ongoing conflict, the fission of society, and more death. | When a good death occurs, such as the expected death of an old person, it does not break down social relations or disrupt community life. Dying old people acquiesce to their death, and it is under their control as they realize they are dying and plan for it. |
| Costello (2006), England | Investigate hospital nurses; experiences of death and dying for their views about good and bad deaths. Qualitative | Interviewed 29 RNs in three hospital units caring for older people at two English hospitals. Semiotic analysis of findings | Two typologies of death emerged—good or bad. Bad deaths were sudden, with limited control over events leading to and during the death event, a lack of preparation for it, and no time to get to know the family or assess the patient's needs so that these could be met. The patient and family were also not aware of the imminent death. Family conflict and lack of time to talk with the physician also made deaths bad. Bad/sudden deaths prevented religious rites and cultural rituals. Bad deaths were those that happened when in transit and not in their hospital bed. Circumstances such as inappropriate cardiopulmonary | There were 71 deaths in 20 months on the 3 units. Most were expected; 12 were not. Most felt that bad deaths could be prevented by more monitoring of the patient (so sudden and unexpected deaths would not occur) and by more effective communication with the physician and family. Deaths were stressful for nurses, and they were working shorthanded and many care providers on the unit were not RNs. |

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| De Jong & Clark (2009), Canada | Explore, using a narrative approach, the experiences of those who are dying and those who attend them to learn about the good and bad deaths that they witnessed and to gain a description of what a good death and a bad death was for them personally. Qualitative study | 15 people in Halifax, Nova Scotia, were interviewed; 3 were palliative care patients, 3 were family members, 3 were hospital palliative care nurses, 3 were palliative home care nurses, and 3 were palliative care physicians. Thematic analysis of data | resuscitation made deaths bad. Bad deaths occurred when there was no diagnosis or when the person died in pain or with unrelieved symptoms. Bad deaths happened when there were few nurses to provide care, such as on night shifts. Bad deaths were traumatic for the nurses, as they felt guilty about them. Bad deaths had a traumatizing effect on the nurses because of a negative impact on their morale and as they caused conflict between nurses and physicians. Common bad death themes included a painful death and those with a loss of control and independence. Bad deaths were when there was conflict between healthcare team members about the patient's care management, when patients refused comfort measures, when patients had uncontrolled symptoms, when a patient's wishes were not followed by the healthcare team. Some regretted that they had not been able to do more to ensure a good death. | Despite growing interest in good deaths, the components of good and bad deaths have not been well-elucidated in the literature. The value of using narratives in palliative care research has not been extensively explored. The interview gave them an opportunity to create meaning and heal themselves. The nurses and physicians reported different factors for bad deaths. |
| Garnett et al. (2008), England | Examine the surrogate family members' view on life prolongation and their involvement in being a decision maker for a relative who is incompetent or incapable of making healthcare decisions. Qualitative study, in part, to identify bad death components | Twelve family members were interviewed in southeast England, with data analyzed using interpretative phenomenological analysis. | Good and bad deaths were based on past experiences and on perceptions of quality of life. Bad deaths were when there was a lingering dying process and a lack of control, such as when technology was used to attempt to prevent death so that the person did not die with dignity; the person did not have a peaceful death but one during a fight for life. Some thought a bad death was when a baby died or an unexpected and unprepared-for death occurred. | Identified some strategies for more family discussions, so surrogates would be better prepared for decisions, as only 1/12 had talked with their relatives about end-of-life care. Some surrogates would accept a lower quality of life for their loved one if death were prevented. |
| Ganzini et al. (2003), US | Determine differences in reasons for deaths among hospice patients who choose assisted suicide versus those who choose to stop eating and drinking to | Mailed questionnaire to all nurses employed in 52 Oregon hospice programs, with statistical analysis of data from 307 hospice nurses. These | Eight patients out of 102 (7.8%) died a bad death; these had more suffering, more pain, and were younger. One of the 8 resumed eating because of family pressure. | Older hospice patients were more likely to choose to stop eating and drinking; younger hospice patients were more likely to choose assisted suicide. |

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| Author(s), year published, and where study conducted | Purpose of study and type of study (i.e., mixed-methods, qualitative, or quantitative) | Research methods, including data analysis methods and where data were collected, when, and from whom | Findings relevant to three questions: What causes or contributes to a bad death? How often do bad deaths occur? What is the impact, outcomes, or consequences of bad deaths? | Other points relevant to this literature review |
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| Good et al. (2004), US | <p>die earlier than if nature took its course. Quantitative study</p> <p>Examine medical discourse from high-technology academic medical centers through an analysis of how physicians who are specialists in internal medicine tell stories about the deaths of patients in their care. Qualitative data among others in a mixed-methods study</p> | <p>nurses provided information about the most recent hospice death, occurring after November of 1997, where the patient chose to stop eating and drinking or chose assisted suicide.</p> <p>Internal medicine physicians from two academic medical centers in the United States completed open interviews on a recent death and the most emotionally powerful death they experienced in the course of their careers; with 75 the source for qualitative data. Analysis done using the Atlas-ti program.</p> | <p>However, most death processes were peaceful and with little suffering after the fluid and food refusal until death occurred.</p> <p>“Good death” and “bad death” are common terms, but these terms were rarely used by physicians. Their narratives were professional judgments about what constitutes quality end-of-life care. Three themes emerged: (1) time and process: whether the death was expected or unexpected, and if peaceful, chaotic or prolonged; (2) medical care and treatment decisions: whether end-of-life care was rational and appropriate or not, and if it facilitated to a peaceful/gentle death or not, and if futile and overly aggressive care fraught with irrational decisions or not, and if adverse events occurred or not; (3) communication and negotiation: if communication with patients, family, and care teams was effective, leading to satisfying management of end-of-life care, or characterized by misunderstandings and conflict.</p> | <p>Hastened deaths need to be studied more to determine how these can be made good and for the avoidance of bad deaths, such as by using sedation during the hastened death process.</p> <p>Public and professional discourses in American society about what constitutes a good death have flourished in recent decades, as illustrated by the pivotal SUPPORT study and the growing palliative care movement. When the narratives about patient deaths are compared with the sociological observations made by Glaser and Strauss in their study <i>A Time for Dying</i> (1968), historical continuities are evident, as are striking differences associated with rapid innovation in medical technologies and a new language of medical futility. This project is part of a broader effort in American medicine to understand and improve end-of-life care. It shows that dying is difficult in a modern hospital, where there are so many treatment options and where relationships with patients are short, and without the physician having any perspective of the patient as a person.</p> |
| Hanson et al. (2002), US | <p>Examine good and bad deaths in a nursing home according to experienced nursing home staff</p> | <p>11 focus groups were held with 77 participants. Discussions were structured around three questions: How does someone</p> | <p>Bad deaths could be either prolonged and expected or sudden, and they involved suffering, such as from loneliness, indignity of</p> | <p>One in four Americans aged 65+ will die in a nursing home, yet little research exists to define their end-of-life care needs.</p> |

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| | and physicians. Qualitative study | die in the nursing home? What makes the difference between a good death and a bad death? and What can aides, nurses, or physicians do to help ensure that when someone dies it is a good death? | dependency, and with unwanted changes in physical appearance. Some had no meaningful interaction with anyone when dying. | They affirmed the value of their experience and their personal relationships with residents as the basis for good care. Lack of training, regulatory emphasis on rehabilitation, and a resource-poor setting were seen as barriers to high-quality care of the dying in nursing homes. |
| Joarder et al. (2014), Bangladesh | Explore the perceptions of meaning of death (including good and bad deaths) among older people in a Bangladeshi community, to understand how the meaning of death affects one's overall well-being. Qualitative study | In February of 2008, seven interviews, daily routine mapping, and informal discussions were used to gather data. Manual qualitative data analysis. | Most respondents thought of death in a spiritual way, but some thought of it in a physiological perspective. Bad deaths were described as hanging, poisoning, homicide and accidents as these were not determined by God, but instead due to one's bad actions or deeds. Bad karma is attached to the deaths, while good deaths are ones without suffering, surrounded by family, and with death taking place peacefully. | Prior lives may determine if the person dies a good death or a bad death (with this Hindu/Buddhist cultural or spiritual perspective). |
| Kim & Lee (2003), Korea | Investigate which distinctive elements would best describe good and bad death, preferences for life-sustaining treatment, and advance directives. Quantitative study | 185 acute-care nurses working in 3 urban hospitals were surveyed using a questionnaire. Statistical analysis of data | Elements of a bad death were: persistent vegetative state, sudden death, pain or agony, dying alone, and being a burden to the family. The elements of a bad death differed significantly among these nurses. | 90.8% answered that they did not intend to receive life-sustaining treatment if they suffered from a terminal illness without any chance of recovery; 77.8% revealed positive attitudes toward advance directives; 76% stated that they were willing to discuss their own death and dying; the perception of such discussions differed according to their medical condition. |
| Ko et al. (2013), US | Identify and describe the domains that define a good death from the perspectives of older Mexican-American adults. Qualitative study | Face-to-face interviews with 18 participants residing in Southern California, with data analyzed using the methods of grounded theory. | Five categories differentiated good and bad deaths: no suffering vs. suffering and pain, sudden death versus long dying process, having time for closure with family versus family uninvolved in care decisions, dying at home versus dying elsewhere, and a natural death versus one with technology. A bad death was also due to sudden trauma, as this death interrupts a person's life. | Understanding the meaning of good and bad death within specific cultural contexts is integral to promoting cultural sensitivity when working with older adults, especially in end-of-life care. This study was part of a larger one on end-of-life care with 122 older Mexican-American adults in San Diego, California. |

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| Ko et al. (2015), US | Explore perspectives toward a good or bad death among older homeless adults residing in transitional housing. Qualitative study | Face-to-face interviews of 21 older homeless adults residing in transitional housing. Data analyzed using a grounded-theory approach. | Themes for a bad death were: (1) experiencing death by accident or violence; (2) prolonging life with life supports so their life lacks quality; (3) becoming dependent so that they are a burden on others; and (4) dying alone, as this is physical isolation from others as well as abandonment and separation from their social network. | The factors for a bad death were not the same as those for a good death. Healthcare professionals need to develop approaches for end-of-life care grounded in understanding the unique needs of older homeless adults. |
| LeBaron et al. (2015), US | Explore and describe clergy perspectives regarding good versus poor deaths within the participant's spiritual tradition. Qualitative study | 35 community clergy from various spiritual backgrounds, geographical locations, and races/ethnicities were recruited in 2013 and 2014 for one-on-one interviews ($n = 14$) and two focus groups ($n = 21$). Grounded theory was used to identify themes and subthemes. | A poor death was characterized by separation, doubt, and isolation. Four primary determinants of good versus poor deaths: dignity, preparedness, physical suffering, and community. Participants expressed appreciation for contextual factors that affect the death experience. | Some described a middle death, or one that integrates both positive and negative elements. Location of death was not viewed as a significant contributing factor. Religion influences end-of-life care in the United States, as 2/3 of patients report religion as important and half are visited by community clergy. |
| Luxardo et al. (2014), Argentina and Spain | Describe the attitudes and experiences of staff on end-of-life care treatment of dying persons to examine how they view patients and how their experiences with these patients shape their daily lives. Qualitative study | Data collected in 2012 from 30 palliative care staff using a questionnaire with open-ended questions. Grounded theory analysis of data employed. | Bad deaths were those where the patient was physically uncomfortable or suffering from spiritual/existential pain, or when death occurred within a conspiracy of silence. The role of relatives was highlighted, as bad deaths occurred with a lack of family, when families interfered in care plans, or when families were suffering during the dying process. All participants felt that their lives were impacted by work; some were emotionally overloaded and frustrated, such as when they could not reduce pain. | Professional palliative care was important for good deaths. |
| Payne et al. (1996), England | Compare perceptions of death by patients and staff in a palliative care unit. Qualitative study | Semistructured interviews designed to elicit perceptions of "good" and "bad" deaths, conducted with 20 healthcare | The staff described a bad death as involving five factors: (1) uncontrolled symptoms, (2) hemorrhage, (3) lack of acceptance | Research was recommended to illuminate the process of how good and bad deaths are |

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| Pierson et al. (2002), US | Identify and describe the domains that define a good versus bad death from the perspective of patients with advanced AIDS. Qualitative study | Face-to-face interviews with 35 patients with C3 AIDS asking them to describe a good and bad death. Grounded-theory data analysis used to identify the major domains defining a good versus a bad death. | professionals working on a palliative care unit in southern England; 18 palliative care patients were also asked about a good death. The transcribed interviews were content-analyzed. | of dying by the patient and/or their family and care team, (4) the dying person was young, and (5) not dying in their location of choice. Staff gave vivid descriptions of bad deaths, often those with blood loss and overt patient distress. There were major differences between patients and staff over what a good death was. | negotiated between patients, families, and care providers. |
| Posel et al. (2007), South Africa | Examine how a rural South African (in Agincourt subdistrict, Limpopo Province) community that is profoundly affected by escalating rates of largely AIDS-related deaths of young and middle-aged people makes sense of this phenomenon and its impact on their everyday lives. Qualitative study | Data were collected using 12 focus groups, constituted according to age and gender, that each met 3 times to explore sequentially their expectations of their lives in the new South Africa, their interpretations of the acceleration of death among the young and middle-aged, and their understandings of HIV/AIDS. These discussions were recorded, transcribed, and thematically analyzed. | | Respondents acknowledged escalating death rates in their community; yet few referred to HIV/AIDS as the cause. They focused on the social and cultural causes of death, including the erosion of cultural norms and traditions, such as cultural taboos on sex. These were bad deaths, as there were many deaths, and deaths of mainly young people, with death due to an unknown cause and having a major impact on their lives, families, and their society or community. A bad death was a symptom of a cultural and moral condition. These deaths were leading to distrust and fear, including distrust of public health efforts. | Findings highlight the relationship between AIDS and other traditional diseases. with some respondents suggesting that AIDS is a new form of other longstanding illnesses. This study points to the centrality of cultural explanations in understanding bad death (AIDS death) in the Agincourt area. Physical illness is understood to be a symptom of cultural damage. The implications of this for public health practice and research are outlined. |
| Seale (2004), England | Examine media stories about people dying alone to determine if they were bad or good deaths. Qualitative study | Assessed newspaper accounts of people who die alone, using a sample of 90 articles in the Anglophone press that appeared in October of 1999. | | Dying alone is represented as a fearful fate and a moral affair, often the outcome of an undesirable personal character, either the deceased or onlookers, | However bad dying alone was, it is possible that some people prefer to die alone at home, and these would not be bad deaths. |

Table 1. *Continued*

| Author(s), year published, and where study conducted | Purpose of study and type of study (i.e., mixed-methods, qualitative, or quantitative) | Research methods, including data analysis methods and where data were collected, when, and from whom | Findings relevant to three questions: What causes or contributes to a bad death? How often do bad deaths occur? What is the impact, outcomes, or consequences of bad deaths? | Other points relevant to this literature review |
|--|--|--|--|--|
| Seymour et al. (2002), England | Analyze data from focus group discussions with older people to illuminate how interpersonal and bodily aspects of the dying process are associated with shifting evaluations of two core techniques of palliative care: morphine administration and terminal sedation. Qualitative study | Eight focus group discussions with a total of 32 older people were held, with select people purposefully chosen from community groups representing older people, with data analyzed using the QRS NUD*IST software package for main findings. | Findings relevant to three questions: What causes or contributes to a bad death? How often do bad deaths occur? What is the impact, outcomes, or consequences of bad deaths? or involving the failings of society. It is frequently portrayed as occurring to people who are geographically or socially distant from “home.” Also evident was a degree of stigmatization, sometimes of those who die alone, sometimes of those perceived to have caused this event. A bad death is where an older person would not be able to ask for pain medication and when healthcare professionals do not listen to older people. An idealized death is when morphine administration and terminal sedation provide dying people with an easy, comfortable and quiet death. Bodily symptoms of distress are discreetly controlled, and death occurs at an appropriate time and place. The role of medicine in procuring an idealized death is linked to concerns about new risks that flow from the intermarriage of medical science with the obligation of providing compassionate care to those who are dying. | Little is known about end-of-life preferences or how risks are assessed surrounding doctor–patient or doctor–family relationships during end-of-life decision making. Older people are often excluded from end-of-life care research, although there is some evidence that most would express preferences for “comfort care” rather than life-sustaining interventions if facing terminal illness. |
| Shea et al. (2010), US | Conduct a mixed-method formative assessment of 36 graduate nursing students’ knowledge about and attitudes toward palliative care preliminary to curricular integration of the End-of-Life Nursing Education Consortium (ELNEC) graduate core modules. Qualitative study | 36 advanced practice registered nursing students had knowledge about palliative care assessed using the 106-item ELNEC examination, with qualitative data gathered using a questionnaire for definitions of palliative care, their role in palliative care, and their definitions of good and bad deaths. Thematic summary of responses. | Most indicated a bad death was one in which there was pain, with the patient suffering and in distress and fear. Isolation or being alone was also considered a major factor for bad deaths. Prolonged dying was also considered to be a bad death. | Advanced practice nurses have key roles in the care of patients who are nearing death and those living with a disabling chronic disease. Students had limited knowledge of palliative care. Most students exclusively linked palliative care with end-of-life care and believed that the treatment they provide should have the goal of prolonging life over quality of life. |
| van der Geest | Examine good and bad deaths among the people in Kwahu- | This article is based on anthropological fieldwork | Bad deaths are the opposite of good or peaceful deaths. “Peaceful” | The quality of one’s death is liable to social and political |

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|---------------------------|---|---|---|--|
| (2004), Ghana | Tafo, a rural town in Southern Ghana. Anthropological study | carried out intermittently from 1971 to 2004. | refers to the dying person having finished all business and made peace with others before death and is at peace with his/her own death, and the manner of dying: not by violence, an accident or a fearsome disease, not by foul means and without much pain. A good and peaceful death comes “naturally” after a long and well-spent life. Such a death takes place at home, surrounded by children and grandchildren. A good death is a death accepted by the relatives. | maneuvering and, therefore, inherently ambiguous. For example, the good death of a very old and successful person can be decried by the younger generation as the death of a witch who managed to live long at the expense of young people who died prematurely. |
| Vig et al. (2002), US | Explore the attitudes of older adults diagnosed with medical illness about the end of life and investigate whether current values could be extended to end-of-life preferences. Mixed-methods research | Interviews of 16 patients attending 2 geriatric clinics, for nonterminal heart disease or cancer, including “What would you consider a good/bad death?” and questions about symptoms, quality of life, and health. Additional questions elicited preferences for the end of life, such as location of death and the presence of others. Quantitative data were summarized and content analysis of qualitative data. | Bad deaths were those with pain, prolonged, accidental, being dependent, cancer, suffering, Alzheimer’s disease, family and friends present, family suffering, being unprepared, anger with others, using up savings, disfigurement, being messy, and knowledge of impending death. Each voiced a unique combination of themes in describing good and bad deaths. No theme was mentioned by even half of the participants. Participants provided differing explanations for their views. Patients with heart disease and cancer provided similar responses. However, views about good deaths, bad deaths, and end-of-life scenarios were heterogeneous. | Older adults should be asked not only questions about general values, but also specific questions about their end-of-life choices and the reasons for these choices. A thorough understanding of an individual’s end-of-life preferences may help health professionals working with older adults develop patient-centered care plans for the end of life. |
| Vig & Pearlman (2004), US | Learn how terminally ill men conceptualize good and bad deaths. Qualitative study | Semistructured interviews with 26 men identified as having terminal heart disease or cancer, with grounded theory analysis of data. | Bad deaths involve pain, are prolonged, the person is dependent, suffering occurs, others are burdened, drowning or shortness of breath, and not right with God. Many reasons voiced for why dying in one’s sleep was a good death and why prolonged dying or suffering was a bad death. Participants did not hold uniform views about the presence of others at the very end of life or a preferred location of dying. Heterogeneity in responses were found. | It is important to identify not only patient views of good and bad deaths but also how the identified attributes contribute to a good or bad death. The discussion can then focus on what might interfere with patients’ attainment of their preferred dying experience and what may be available to help them achieve a death consistent with their wishes. |
| Wiegand & | Understand if families perceive that their family members had | 22 family members participated in a hermeneutic phenomeno- | 23% thought a bad death had occurred. Bad deaths were when | Four family members felt the death has both good and bad. |

Continued

Table 1.
Continued

| Author(s), year published, and where study conducted | Purpose of study and type of study (i.e., mixed-methods, qualitative, or quantitative) | Research methods, including data analysis methods and where data were collected, when, and from whom | Findings relevant to three questions: What causes or contributes to a bad death? How often do bad deaths occur? What is the impact, outcomes, or consequences of bad deaths? | Other points relevant to this literature review |
|--|---|---|---|---|
| Petri (2010), US | a good or a bad death when a family member had life-sustaining treatment withdrawn after an unexpected, life-threatening illness or injury. Qualitative study | logical study. They were interviewed 1–2 years after a family member died after withdrawal of life-sustaining treatment. Units of meaning inductively determined. | the ill family member had a long hospitalization with up and down periods, when death was premature, and if signs of discomfort were present. Most perceived that their loved ones died a good death. Although the timing and circumstances of the death may be bad in many ways, the actual dying and death can be good. | Life-sustaining therapy is commonly withdrawn in critical care units; it is the responsibility of healthcare professionals to promote peaceful deaths, provide high-quality end-of-life care, support families, and be directed by the wishes of the dying. |

Alzheimer's disease was present and no relevant conversations between the dying person and their family or caregivers could take place (Hanson et al., 2002; Pierson et al., 2002; Vig et al., 2002). When no direction from the dying person was available, the health-care team's values and beliefs were often paramount in end-of-life care (Borbasi et al., 2005).

Disrespect of the dying person was another commonly identified bad death factor. For instance, bad deaths were thought to occur when the wishes and preferences of the dying person were not followed by the care team or their family (De Jong & Clarke, 2009). Similarly, a bad death was deemed to have occurred when older dying people were not listened to (Seymour et al., 2002). Bad deaths also occurred when the end-of-life or other decisions made by the dying person were not respected (Seymour et al., 2002). Yet, bad deaths were also considered to occur when the family had no involvement or opportunity for involvement in end-of-life care decisions (Borbasi et al., 2005; Ko et al., 2013). In one developing country, bad deaths were thought to be a consequence of the person's bad actions in this or a past life (Joarder et al., 2014).

Undignified deaths were also bad deaths (Adesina et al., 2014; LeBaron et al., 2015; Pierson et al., 2002; van der Geest, 2004). For instance, the use of life-support technology so that the dying process was prolonged preventing a natural death from occurring, and life lacking quality was often identified as bad deaths (Garnett et al., 2008; Good et al., 2004; Ko et al., 2013; 2015; Payne et al., 1996; Pierson et al., 2002). Not dying in the place of one's choice was also considered a bad death (Payne et al., 1996; Pierson et al., 2002), as well as not dying at home (Ko et al., 2013; van der Geest, 2004). Negative changes in the dying person's physical appearance (e.g., disfigurement) were also identified as a factor contributing to an undignified death (Hanson et al., 2002; Vig et al., 2002). The physical incapacity of the dying person (such as being bedridden and dependent on others) was similarly considered a factor leading to an undignified and therefore bad death (De Jong & Clarke, 2009; Hanson et al., 2002). Bad deaths also occurred when the dying person had no control over their own life (Garnett et al., 2008; Pierson et al., 2002). A negative emotional or mental state of the dying person constituted additional factors leading to an undignified or bad death (e.g., if the dying person was angry or frustrated) (LeBaron et al., 2015; Pierson et al., 2002; Vig et al., 2002).

Outcomes or Consequences of Bad Deaths

No study focused on determining the outcomes or consequences of bad deaths, but half reported on at

least one potential impact of a bad death. These impacts differed considerably because the dying individual, their family, the involved healthcare providers or healthcare team, and the community or society as a whole could be variably impacted. These impacts were often identified as immediate, but they could also occur over the long term.

Bad deaths were of chief concern for their impact on the dying people, who would die a less than optimal or perhaps even horrific death (Borbasi et al., 2005; Costello, 2006). Bad deaths were also of concern as they could impact caregivers, including nurses, who get distressed over not being able to reduce or eliminate symptoms (Borbasi et al., 2005; Costello, 2006; De Jong & Clarke, 2009). Nurses were said to feel guilty when unable to prevent a bad death or ensure a good death (Costello, 2006). Caring for dying people who were experiencing bad deaths was said to cause emotional overload and frustration among formal caregivers (Luxardo et al., 2014). Reduced morale among caregivers was also reported among hospital nurses both during and after a bad death (Borbasi et al., 2005; Costello, 2006). Caregiver distress and stress among all caregivers occurred when important conversations did not take place, such as those needed to plan good end-of-life care or to promote “closure” (Costello, 2006; Ko et al., 2013).

Bad deaths due to sudden and unexpected deaths also meant that the wishes of the dying person were not known or not achieved, as there was not enough time to enact final wishes or preferences (Borbasi et al., 2005; Costello, 2006). Distress and stress among healthcare providers, as well as family members, were related to an inability to start comfort-oriented care—such as when the death came too suddenly or when palliative care was not started early enough for a chronically or terminally ill person, so that their pain and other symptoms could not be prevented or successfully addressed (Borbasi et al., 2005; Costello, 2006; Luxardo et al., 2014). Sudden deaths also prevented important end-of-life religious and cultural rituals (Costello, 2006). Low-quality end-of-life care has thus been identified as a consequence of bad deaths.

Conflict between and among those involved in the dying process was another commonly identified outcome of bad deaths (Counts & Counts, 2004; De Jong & Clarke, 2009; Garnett et al., 2008; Good et al., 2004; Luxardo et al., 2014). This conflict could be between nurses and physicians when the nurses believed that a physician had ordered inappropriate in-hospital care (Borbasi et al., 2005; Costello, 2006; De Jong & Clarke, 2009). Conflict among family members was also cited (Counts & Counts, 2004; Good et al., 2004; Luxardo et al., 2014), as well as con-

flict between family members and the physician or nurses who were providing care for their dying family member (Costello, 2006; Garnett et al., 2008; Good et al., 2004; Luxardo et al., 2014).

Community-wide problems and social disruption or societal upheaval were additional possible outcomes of bad deaths (Counts & Counts, 2004; Posel et al., 2007). For instance, AIDS deaths in South Africa were considered bad deaths, as young people were dying, and these deaths led community members to think that their country’s social values and customs were changing for the worse (Posel et al., 2007). Shame and blame were also associated with bad deaths, with this resulting in distrust between and among community members (Counts & Counts, 2004; Posel et al., 2007). In one case, the murder of a presumed offender believed to have caused a bad death was an outcome of community strife over that bad death (Counts & Counts, 2004). Bad deaths also have led to charges of professional incompetence when healthcare providers were unable to prevent deaths or adequately explain why a sudden or premature death had occurred (Counts & Counts, 2004; Posel et al., 2007). The suspicion that family members had been incompetent or uncaring was another outcome of bad deaths, as well as suspicion of foul play (Counts & Counts, 2004).

DISCUSSION

Our attempt to gather research evidence on bad deaths revealed only 25 research articles published in the last two decades for inclusion in our review. Although this is not a large number, and most were qualitative studies with findings that cannot be generalized, these studies were helpful in demonstrating that bad deaths are a valid concern. These studies were also helpful in identifying probable causes or contributing factors and possible outcomes and consequences of bad deaths.

Although these 25 studies were conducted in 10 different countries, which indicates widespread recognition of the possibility of bad deaths, no escalation in research has occurred since publication of the first such article in 1996. With only two research reports published in 2015 and none in 2016, current research attention is not apparent. As such, an undeveloped state of the science exists, a state that would be appropriate if the palliative care movement and other developments had rendered all death and dying processes good. However, two of the reviewed studies revealed that 7.8 to 23% of deaths were considered bad (Ganzini et al., 2003; Wiegand & Petri, 2010). Moreover, bad deaths were thought more likely to occur in hospitals than in community settings (Borbasi et al., 2005). It is also important to recognize that the 25

studies included in our review were conducted out of a concern that bad deaths are possible. Consequently, more research is needed on bad deaths, including quantitative studies to establish their incidence. Until this incidence is known, bad deaths may be considered rare or unusual, and thus of little or no consequence.

Only 8 of our 25 studies focused on the perspectives of dying persons and/or their family members, with the formal caregiver perspective more often obtained. Although formal care providers are an understandable focus of research attention, since burdening dying people and their families with research participation has ethical and practical concerns, research needs to determine what makes a death bad for the dying person (Ternstedt et al., 2002). Another essential focus is the family, as they are often involved in end-of-life care and are the ones who are left to grieve.

Research is also needed to determine the extent of individual and sociocultural differences in relation to factors causing or potentiating bad deaths. Vig et al. (2002) found that common bad death factors existed according to 16 older Americans attending a geriatric clinic for nonterminal heart disease or cancer, although some differences among them also existed. Similarly, Vig and Pearlman (2004) found common factors but heterogeneous views about good and bad deaths among 26 men diagnosed with terminal heart disease or cancer. Payne et al.'s (1996) study found that major differences in bad death views existed between patients and staff. Kim and Lee (2003) found that bad death views varied among Korean nurses. Shih's (2010) discussion of bad death in Taiwan illustrated the importance of determining how culture and religion influence individual, family, and social views about the "bad death."

Regardless, unrelieved pain was revealed as a prime factor in bad deaths. Correspondingly, all four good death literature reviews identified an absence of pain as being essential for a good death (Cottrell & Duggleby, 2016; Evans & Walsh, 2002; Meier et al., 2016; Proulx & Jacelon, 2004). Other bad death factors appear to mirror those needed for good deaths (Adesina et al., 2014; van der Geest, 2004), although our literature review revealed some salient bad death attributes, ones that could be avoided to prevent bad deaths from occurring.

Our review was also helpful in revealing that bad deaths have consequences and so should be avoided. These consequences are concerning, as the dying person is often impacted by a bad death and dying process. For instance, McPherson and colleagues (2007) found that dying persons were distressed when believing that they are a burden to their family members. In fact, dying persons who are suffering

may ask for assisted suicide to end such burdens (Quill et al., 1997). Family members, caregivers, communities, and even society as a whole can also be impacted by bad deaths. As only one long-term study was found for our review (Counts & Counts, 2004), it is advisable for longitudinal or multi-year studies to be performed in order to assess the ongoing impact of bad deaths. These studies are important, as Counts and Counts' (2004) study in a developing country showed that a bad death can have serious consequences for many years after a death, as it resulted in continuing conflicts, fissures in society, and possibly more deaths. Their study also revealed that a murder took place a few years after a young woman committed suicide, the crime being a result of the social turmoil in the community arising from the bad death (Counts & Counts, 2004).

Although murder may seem a highly unusual or rare outcome of a bad death, a recent criminal conviction in the province of Alberta in Canada demonstrates otherwise. In 2016, Steven Vollrath was found guilty of kidnapping and torturing an Edmonton man who had driven a vehicle into a restaurant in 2013 and killed a 2-year-old boy. He was convicted on four charges—kidnapping, aggravated assault, possession of a dangerous weapon, and impersonating a police officer—and sentenced to 12 years in prison (Johnston, 2016). These criminal actions were thought to be committed out of revenge for the child's death and the anguish it caused his family (Johnston, 2016).

Clearly, research needs to focus on the immediate and long-term outcomes of bad deaths. These outcomes should focus on the family, as research is revealing bereavement grief to be more severe and longer in duration when the mourners consider the death and dying process to have been a bad one (King, 2004). Mourners can experience extremely severe and prolonged or even permanent grief (Holland et al., 2009; He et al., 2014; Middleton et al., 1996; Zhang et al., 2006). This grief can lead to physical and/or psychological illnesses and, indeed, early death (Shah et al., 2013).

Other outcomes are also important to assess, as our review showed that nurses are impacted by bad deaths. This is not the first time that nurses have been found to be impacted by their difficult work—moral distress among nurses is an established concern (Austin, 2012). Moral distress arising from bad deaths can lead to nurse depression and job loss, long-term toxic conflict among care team members, and other outcomes that impact the workplace (Austin, 2016).

The wide range of factors identified as causing or potentiating bad deaths and the possible impact of bad deaths suggests that routine assessment of

terminally ill people and their end-of-life contexts are needed to prevent bad deaths and promote the possibility of good deaths. These assessments must not be burdensome. Our six categories of contributing factors could form the template for this assessment, with one question each asked about concerns or needs in relation to: (1) physical pain, (2) suffering, (3) sudden and unexpected deaths, (4) prolonged dying processes or terminal illnesses, (5) disrespect of the dying person, and (6) dying while experiencing a lack of dignity. This assessment could reveal what must be avoided and what must be done to prevent bad deaths and enable good ones.

IMPLICATIONS AND RECOMMENDATIONS

This scoping review of research literature revealed only 25 studies published in the previous two decades that focused in whole or in part on the “bad death.” Although much more research is needed, some information has been gained in relation to the incidence of bad deaths, what may cause them, and what may be their possible consequences. Above all, our review indicates that bad deaths can occur whenever a good death has not been achieved, as well as when bad death factors are present. These bad death factors must be understood and addressed further.

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DISCLOSURES

The authors hereby declare that they have no conflicts of interest to disclose.

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