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End-of-life Decision Making in the Context of Chronic Life-limiting Disease a Concept Analysis and Conceptual Model

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Abstract

Background: Conceptual ambiguities prevent advancements in end-of-life decision making in clinical practice and research.

Purpose: To clarify the components of and stakeholders (patients, caregivers, healthcare providers) involved in end-of-life decision making in the context of chronic life-limiting disease and develop a conceptual model.

Method: Walker and Avant's approach to concept analysis.

Findings: End-of-life decision making is a process, not a discrete event, that begins with preparation, including decision maker designation and iterative stakeholder communication throughout the chronic illness (antecedents). These processes inform end-of-life decisions during terminal illness, involving: 1) serial choices 2) weighed in terms of potential outcomes 3) through patient and caregiver collaboration (attributes). Components impact patients' death, caregivers' bereavement, and healthcare systems' outcomes (consequences).

Discussion: Findings provide a foundation for improved inquiry into and measurement of the end-of-life decision making process, accounting for the dose, content, and quality the antecedent and attribute factors that collectively contribute to outcomes.

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Introduction

An estimated 43–83% of deaths will be preceded by an end-of-life decision (Bopp, Penders, Hurst, Bosshard, & Puhan, 2018; Silveira, Kim & Langa, 2010; Verkissen et al., 2018). Chronic life-limiting diseases are among the leading causes of death in the United States (Centers for Disease Control [CDC], 2017), and include those chronic conditions from which death is likely to occur (May et al., 2016; Steinhauser et al., 2011). These illness trajectories encompass a chronic phase that lasts a year or more and a terminal phase with either episodic functional decline in the last year of life (e.g., heart disease) or marked functional decline in the last three months of life (e.g., cancer) (CDC, 2018; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). This suggests that chronic life-limiting diseases offer the possibility of time to prepare for and make informed end-of-life decisions, yet patients and caregivers are ill equipped to do so (Allen et al., 2012; Applebaum et al., 2014; Braun, Naik, & McCullough, 2009; Liu et al., 2014).

Despite persistent calls to improve end-of-life decision making, a common vocabulary surrounding end-of-life decision making is lacking (Ahluwhalia et al., 2018; Aziz, Miller, & Curtis, 2012; Institute of Medicine [IOM], 2015). End-of-life decision making is enmeshed with related concepts in clinical practice and research. For example, advance care planning (ACP) has been defined as an act of preparation for later “in-the-moment” decision making (Sudore & Fried, 2010), but healthcare providers continue to conflate these two concepts in clinical practice (Izumi & Fromme, 2017). Tendencies to implement ACP during the terminal illness phase may also contribute to patients’ and caregivers’ perceptions that end-of-life decision making is synonymous with ACP (Johnson, Butow, Kerridge, & Tattersall, 2016). Research similarly conflates these concepts, operationalizing end-of-life decision making outcomes with ACP variables (Braun, Beyth, Ford, Espadas, & McCullough, 2014; Oczkowski, Chung, Hanvey, Mbuagbaw, & You, 2016). These conceptual discrepancies hinder advances in clinical practice and end-of-life decision making research (National Institute of Nursing Research [NINR], 2013).

The paucity of end-of-life decision making conceptual models further confounds conceptual clarity and creates measurement challenges. While two conceptual models exist (Kim et al., 2017; Sinuff et al., 2015), each lack explication of the unique components of the decision making process. Other models focus on related topics (e.g., goal-concordant care) or other populations (e.g., parents of pediatric cancer patients) (Rishel, 2010; Sanders, Curtis & Tulskey, 2018). Further, decision making at the end-of-life is conceptually unique (Emanuel & Scandrett, 2010), making classic models of decision making (e.g., logic-based) (Schwartz, 2016; Turpin & Marais, 2004) insufficient in describing the psychosocial factors that affect end-of-life decision making. Moreover, shared-decision making models typically frame decision making as a patient-healthcare provider process (Siminoff & Step, 2005; Stacey et al., 2010). Yet, evidence suggests that up to 78% of caregivers will be involved in end-of-life decisions (Hirschman Corcoran, Straton, & Kapo, 2010; Vermorgen et al., 2018). Thus, end-of-life decision making models need to account for the distinct roles of patients, caregivers, and healthcare providers (Bélanger, Rodrigues, & Groleau, 2011; Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010).

Concept analyses help to clarify the nature and components of ambiguous phenomena (Walker & Avant, 2019). These clarifications contribute to more rigorously constructed operational definitions and more informed research hypotheses (Walker & Avant, 2019). Thus, this concept analysis aimed to: 1) identify the unique components (attributes, antecedents, consequences) of end-of-life decision making in the context of chronic life-limiting disease, 2) describe stakeholder (patient, caregiver, healthcare provider) roles with respect to each component, 3) propose a refined definition, and 4) develop a conceptual model.

Methods

This concept analysis followed the Walker and Avant (2019) approach. The original eight steps were modified, excluding the two steps that involve a presentation of model and contrary cases, methodological adaptations that have been advocated by other authors (Weaver and Mitcham, 2008) and utilized in prior concept analyses (DeBastiani & De Santis, 2018; Halstead, De Santis, & Williams, 2016). This ensured that the analysis and results were grounded in the literature and emblematic of real cases, not constructed cases (Rodgers, 2000). This resulted in a six step approach: 1) select the concept, 2) determine the aims, 3) describe all uses of the concept in the literature, 4) determine the defining attributes, 5) determine the defining antecedents and consequences, and 6) identify the empirical referents (Walker & Avant, 2019).

The search strategy was iterative. First, a validated palliative care search phrase (Rietjens et al., 2019) was combined with a decision making search phrase in the PubMed, MEDLINE (OVID), and CINAHL Plus databases. Next, keyword searches using “end-of-life decision making” and “decision making theory” were also conducted in Google Scholar and a university-based library search engine. Articles were included if they were in English, peer-reviewed, and published since 1990 (i.e., after the Patient Self Determination Act). Dictionaries and resources from professional organizations (e.g., white papers; clinical practice guidelines; patient education materials) were also searched. Further, reference lists of included articles were searched.

Search results were reviewed and articles included if the article either defined, measured, or helped to explain the antecedents, attributes, or consequences. We focused on chronic life-limiting diseases broadly, as opposed to narrowing to “serious illness” (Kelley, 2014; Kelley & Bollens-Lund, 2018), so that the analysis would hold relevance for a larger population, with potential for identifying modifiable antecedents earlier in the disease trajectory. Providing further rationale for examining end-of-life decision making more broadly across various chronic life-limiting diseases was evidence of similar patient experiences living with and dying from these diseases (Barnato, Cohen, Mistovich, & Chang, 2015; Steinhäuser et al., 2011). Articles that exclusively addressed neurodegenerative disorders were excluded as these patients experience fundamentally different decision making contexts (Karlawish, 2017). Articles that dealt exclusively with cases of sudden death, physician-assisted death, or a pediatric/adolescent population were excluded. Overall, 141 sources were included. Data were synthesized utilizing definitions set forth by Walker & Avant (2019) (Table A, Appendix).

Findings

Study Characteristics

Among the 141 included sources, 131 were published research literature and 10 in other sources (3 dictionaries, 2 clinical practice guidelines, 1 white paper, 3 sources from professional or governmental organizations, and 1 evidence-based clinical support tool). Most published research articles were from the United States ($n = 105$, 80%) and comprised diverse designs (44 quantitative, 26 qualitative, 8 mixed methods, 1 protocol, 23 reviews, 11 theoretical or conceptual works, 3 case studies, and 15 position statements or commentaries). The quantitative, qualitative, and mixed methods studies ($n = 78$, 59%) included a rich representation of stakeholders (Table 1). This consisted of 1,115,137 patients (mean_w = 80.7 years; 58% male), 4,079 caregivers (mean_w = 55.4 years; 33% male), and 588 healthcare providers.

Concept Uses

Existing definitions of the components of end-of-life decision making (“end-of-life” and “decision making”) and the compound terms of “end-of-life decision making” and “end-of-life decisions” were explored (Table B, Appendix). “End-of-life” was generally a period of time in which life expectancy was a matter of months and preceded by a deterioration in health (Council of Europe [COE], 2014; end-of-life, n.d.; Hui et al., 2014; Whellan et al., 2014;). “Decision making” was a collaborative process of making a choice from multiple options while being able to evaluate the pros and cons of those options (Braun et al., 2009; decision making, n.d., a; decision-making, n.d., b; Siminoff & Step, 2005). Explicit definitions of “end-of-life decision making” and “end-of-life decisions” were usually described in terms of discrete choices to initiate, withhold, or withdraw treatment at the end-of-life (American Cancer Society [ACS], 2019; Adams, Bailey, Anderson, & Docherty, 2011; Campos-Calderón et al., 2016; Braun, Ford, Beyth, & McCullough, 2010; Pardon et al., 2012; Vermorgen et al., 2018).

Despite these commonalities, definitions vacillated between describing end-of-life decision making as a circumscribed event versus a process. Most positioned end-of-life decision making as a circumscribed event (the “what” of the decision making) (Adams et al., 2011; Braun et al., 2010; Campos-Calderón et al., 2016; Happ, Swigart, Tate, Hoffman, & Arnold, 2007; McMahan, Knight, Fried, & Sudore, 2013; Smith-Howell, Hickman, Meghani, Perkins, & Rawl, 2016; van der Heide et al., 2003; Weissman et al., 2004; Wendler & Rid, 2011), rather than a process (the “who” and “how” of the decision making) (Sinuff et al., 2015; Thelen, 2005; Waldrop et al., 2015). Further, few definitions described any temporal element (the “when” of the decision making) (Sinuff et al., 2015; Waldrop et al., 2015). These features contrasted with the more unfolding nature of general definitions of “decision making.”

These discrepancies necessitated conceptual and temporal distinctions (with respect to the chronic illness trajectory) to situate the remainder of the concept analysis. “End-of-life decisions,” by virtue of being at the “end-of-life,” were conceptualized as circumscribed events contextually bound to the terminal illness phase. In contrast, “end-of-life decision

making,” by virtue of encompassing the “decision making” process, was conceptualized to more broadly include the processes of care that led up to and informed (antecedents) the actual “end-of-life decisions” (attributes) and the outcomes of those decisions (consequences). Thus, the broader process of end-of-life decision making was conceptualized to span the chronic, terminal, and bereavement phases of the illness trajectory. Evidence was further synthesized using this lens.

Concept Attributes

The attributes represented actual decisions in the terminal illness phase, and consisted of: 1) collaboration, 2) weighing of options, and 3) serial choices. Patients and caregivers were the primary stakeholders.

Collaboration.—End-of-life decisions were consistently described as a collaborative enterprise between patients and caregivers (Cristina et al., 2017; Fritsch, Petronio, Helft, & Torke, 2013; Nunez et al., 2015; Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006; Winzelberg, Hanson, & Tulskey, 2005). The literature highlighted a shift in decision making control, from healthcare providers during the chronic illness phase (Ejem et al., 2018) to patients and caregivers during the terminal illness phase (Hirschman et al., 2010; Rosenfeld, Wenger, & Kagawa-Singer, 2000). This may be due to the more personal nature of end-of-life decisions, in that, these decisions are primarily informed by and considered in terms of the patient’s needs, values, and preferences, rather than by healthcare provider expertise (American Psychological Association [APA], 2017; IOM, 2015; Rosenfeld et al., 2000; Scheunemann, Cunningham, Arnold, Buddadhumaruk, & White, 2015; Ventres et al., 1999). Consequently, healthcare providers were not described with active decision making roles at the end-of-life, but as “guidance counselors” in negotiating family conflict, “information brokers” in providing technical guidance, “implementers” in executing decisions, and “supporters” in affirming choices (Adams et al., 2011; Braun et al., 2010; COE, 2014; Cristina et al., 2017; El-Jawahri et al., 2017; Gallagher et al., 2015; Hirschman et al., 2010; Melhado & Byers, 2011; Nunez et al., 2015; Osborn et al., 2012; Quill & Brody, 1996; Rosenfeld et al., 2000).

The nature of the patient and caregiver collaboration was not static and fluctuated during the terminal illness phase based on the disease circumstances, the patient’s decision making capacity, decision making styles, and the caregiver’s relationship to the patient (Ejem et al., 2018; Fritsch et al., 2013; Kon, 2010; Moye & Marson, 2007; Nunez et al., 2015). In situations where the patient’s decision making capacity was preserved, collaboration was possible with active involvement from both the patient and caregiver, with caregivers functioning as decision partners (Gray, Nolan, Clayman, & Wenzel, 2019; Waldrop et al., 2015). If the patient experienced a loss of decision making capacity, collaboration occurred by proxy, meaning the patient remained a party in the decisions as a function of the previously communicated or documented preferences (Braun et al., 2009; COE, 2014; Fritsch et al., 2013). With well-known preferences, caregivers functioned in an enforcer role by making a “substituted judgment” (Braun et al., 2009; Chaet, 2017). However, when preferences were uncertain, caregivers were compelled to make caregiver-driven decisions solely based on a “best interest standard” (Braun et al., 2009; Chaet, 2017), circumstances

which were described as more burdensome for caregivers (Braun et al., 2008; Dionne-Odom, Willis, Bakitas, Crandall, & Grace, 2015b).

Weighing of options.—For informed end-of-life decisions to occur, the literature described a process of weighing of options, which involved providing patients and caregivers with a full range of options. This moved beyond a simple menu of choices to incorporate the patient's values, medical facts, the odds associated with choices, healthcare provider recommendations, options to elect no treatment even when options remained, or explicit indications that all treatment options were exhausted (Allen et al. 2012; Hargraves, LeBlanc, Shah, & Montori, 2016; Lu, Mohan, Alexander, Mescher, & Barnato, 2015; Mack et al., 2012; Reinke et al., 2008; Song et al., 2013; Torke, Petronio, Sachs, Helft, & Purnell, 2012). Further, it was not the actual content of the option (i.e., the intervention itself) that guided the decision, but its expected outcome. For example, patients were documented to weigh options by considering how the options may impact caregivers (Song & Sereika, 2006). Caregivers were documented to weigh options in light of whether the intervention would restore the patient's quality of life, maintain the patient's consciousness, or help the patient to avoid pain (Braun, Beyth, Ford & McCullough, 2008; Dionne-Odom et al., 2015b; Nunez et al., 2015; Rosenfeld et al., 2000).

Serial choices.—Making an end-of-life decision was not described as *one* discrete choice, but encompassed a *multitude* of choices that guided care during the terminal illness phase (Campos-Calderón et al., 2016; Happ et al. 2007; Reinke et al., 2008; van der Heide et al., 2003). Examples included initiating treatment to relieve symptoms (e.g. pain), initiating disease directed or life-sustaining treatment (e.g., dialysis, mechanical ventilation), stopping treatment (e.g., deactivating an implantable cardioverter defibrillator), withholding treatments (e.g., do-not-resuscitate order), or making transitions (e.g., electing hospice) (Campos-Calderón et al., 2016; van der Heide et al., 2003). Such choices reflected important tradeoffs between the quality and quantity of life (Teno, Fisher, Hamel, Coppola, & Dawson, 2002).

Concept Antecedents

The antecedents represented the processes of care in the chronic illness phase that led up to and informed the actual end-of-life decisions (attributes). These consisted of: 1) decision maker designation, and 2) communication. Patients, caregivers, and healthcare providers were all stakeholders in these antecedents.

Decision maker designation.—The importance of a designated decision maker was recognized by patients, caregivers, and healthcare providers alike (Izumi & Fromme, 2017; Sinuff et al., 2015; Steinhauser, Voils, Bosworth, & Tulsky, 2015; Sudore & Fried, 2010; Virdun et al., 2015). While ACP provides a means of formally designating a decision maker (i.e., an individual who makes healthcare decisions on the patient's behalf) (United States Department of Health and Human Services [USDHHS], 2008), evidence demonstrated that nearly two thirds of patients did not formally do so (Rao, Anderson, Lin, & Laux, 2014; Yadav et al., 2017). For this reason, this antecedent factor was conceptualized to encompass either formal (ACP), informal (naturally occurring conversations), or default (state law)

processes to designate a decision maker. Thus, ACP was a potential, but not a required antecedent. Timely designation was emphasized as particularly relevant considering 36–70% of patients with chronic life-limiting diseases lacked decision making capacity at the end-of-life (Kolva, Rosenfeld, & Saracino, 2018; Silveira et al., 2010; Vermorgen et al., 2018; Winzelberg et al., 2005). The literature also supported the need for designated decision makers to understand the role, become informed of the patient's preferences, and establish leeway in decision making (i.e., the extent to which previously documented preferences are merely informative, weighty, or binding) (Berger, DeRenzo & Schwartz, 2008; Ma et al., 2016; McMahan et al., 2013; Sudore & Fried, 2010). Articulating leeway in decision making was especially important, as it allowed for more adaptive decision-making when previously documented wishes did not coincide with the present clinical reality (Berger et al., 2008; McMahan et al., 2013).

Communication.—Communication across the chronic illness phase was framed as an “instrument” that allowed patients to “...think, talk, and feel their way through which treatment option makes intellectual, practical, and emotional sense” (Hargraves et al., 2016, p. 628). Similar exploratory processes preceding decision making have been described in other decision making theories (Turpin & Marais, 2004). Consistent with recommended practices (IOM, 2015), communication that occurred in “digestible pieces” across the chronic illness phase helped to establish trust and more meaningful interactions (Mullaney, Melillo, Lee, & MacArthur, 2016; Quill & Brody, 1996). Communication interactions came in varying forms (Bernacki et al., 2015; Hebert, Prigerson, Schulz, & Arnold, 2006), but typically began with an *end-of-life preference* exploration earlier in the chronic illness phase, later progressing to more targeted communication about *prognosis* and *goals of care* (Izumi & Fromme, 2017; Bernacki et al., 2015).

End-of-life preferences. This type of communication typically constituted the prospective articulation of the patients' preferences for life-sustaining treatment. Patients, caregivers, and healthcare providers all recognized the need to cultivate a shared understanding of these preferences (Ma et al., 2016; Mack et al., 2012; Norton et al., 2019; Sanders, Curtis, & Tulskey, 2018; Torke et al., 2012). Yet, caregiver engagement in this communication was not routine (Caswell et al., 2015; Pardon et al., 2012; Vermorgen et al., 2018), negatively impacting caregivers at the time of decision making (Braun et al., 2008; Norton et al., 2003; Smith-Howell et al., 2016). In contrast, when end-of-life preferences were discussed over time, caregivers developed an understanding of how the patient's preferences evolved (Sudore & Fried, 2010), enabling more accurate preference predictions at the end-of-life (Waller et al., 2018). Critical timepoints in the chronic illness phase (e.g., exacerbation) were identified as opportune moments for this repeated exploration (Booker et al., 2018; Klindtworth et al., 2015; Reinke et al. 2008).

Prognosis. Patients, caregivers, and healthcare providers described the importance of prognosis-based communication (Bernacki et al., 2015; Braun et al., 2014; Hui et al., 2014; Rosenfeld et al., 2000; Virdun et al., 2015). Prognostication helped patients and caregivers achieve a temporal understanding of the pattern of the illness before a time when a medical crisis necessitated an end-of-life decision (Etkind, Bristowe, Bailey, Selman, & Murtagh,

2017; Glare & Sinclair, 2008; Norton et al., 2019; Weissman, 2004). Building this type of situational awareness has been described in other decision making theories (Turpin & Marais, 2004; Schwartz, 2016). In this way, prognostication functioned as a significant catalyst in acknowledging the terminal illness state (Enzinger, Zhang, Schrag, & Prigerson, 2015; Ahn et al., 2013), a critical tool for ensuring more informed end-of-life decisions (Alonso, Hupcey, & Kitko, 2017; Campos-Calderón et al., 2016; Cristina et al., 2017; Drought & Koenig, 2002; Lamont, 2005; Waldrop et al., 2015). Despite this need, difficulty with prognostication was recognized as it required periodic reformulation across the chronic illness phase, and sometimes resulted in prognostic discordance (Alonso et al., 2017; Back, Arnold, & Quill, 2003; Caswell, Pollock, Harwood, & Porock, 2015; Geerse et al., 2019; Gramling et al., 2016a; Watts, 2012).

Goals of care.: Goals of care communication involved discussing priorities of care in the context of a worsening illness trajectory (Bernacki et al., 2015). This communication was couched in the patient's values system and required the patient to balance the trade-offs of particular treatments with functional and quality of life limitations (Bernacki et al., 2015; Pope, 2018; Quill & Brody, 1996; Scheunemann et al., 2015; Sinuff et al., 2015; Sudore & Fried, 2010). These discussions allowed healthcare providers to give feedback on whether the patient's and caregiver's goals were realistic or whether they required reformulation (Whellan et al., 2014). This process of reframing goals across the chronic illness provided a means of ensuring goal-concordant care at the end-of-life (Emanuel & Scandrett, 2010; Weissman, 2004).

Concept Consequences

The consequences were the result of both the end-of-life decisions (attributes) and the preparation for those decisions (antecedents), holding implications for: 1) the quality of patients' deaths, 2) caregiver bereavement outcomes, and 3) healthcare system outcomes.

Quality of patients' deaths.—The actual content of end-of-life decisions impacted the quality of patients' deaths. Decisions to initiate or continue life prolonging treatment despite a terminal illness state were associated with a poorer patient quality of life at the end-of-life (Wright et al., 2008), and generally consistent with poorer quality deaths (Wilson & Hewitt, 2018). In contrast, decisions for comfort-focused care in light of a terminal illness state were associated with better quality of life at the end-of-life (Wright et al., 2008), and generally consistent with better quality deaths (Meier et al., 2016). These findings underscored a tendency to use the content of an end-of-life decision as a proxy for the quality of death. Such patterns were not always reliable (Rolnick et al., 2020), and ignored the contributions of other potentially salient attributes of end-of-life decisions (i.e., nature of the collaboration, the weighing of options process, and the multitude of choices) that factor into the quality of patients' deaths.

The preparation that led up to the end-of-life decisions also impacted the quality of patients' deaths. Without adequate communication during the chronic illness, decision making crises (i.e., decisions marred by uncertainty) occurred in the terminal illness phase (Norton et al., 2019; Klindtworth et al., 2015; Steinhauser et al., 2000). Under these conditions, end-of-life

decisions tended to focus on more aggressive therapies, in type, intensity, and quantity (Ahluwhalia et al., 2015; Hoverman et al., 2017; Mack et al., 2012; Mullaney et al., 2016; Scheunemann, McDevitt, Carson, & Hanson, 2011), and patients with chronic life-limiting conditions largely did not desire such therapies (Aldridge & Bradley, 2017; Barnato et al., 2007; Bischoff et al., 2013; Khan et al., 2014; Teno et al., 2002; Wright et al., 2008).

Caregiver bereavement outcomes.—End-of-life decision making also impacted caregivers during bereavement. Decision content (e.g., to withdraw life-prolonging treatment) contributed to feelings of guilt, anxiety, or depression in at least one third of caregivers, while others experienced a sense of agency, satisfaction, or relief, particularly when decisions were preference-matched (Garrido & Prigerson 2014; Nunez et al., 2015; Smith-Howell et al., 2016; Wendler & Rid, 2011). The process leading up to decisions also influenced caregivers' appraisals (Stein, Folkman, Trabasso, & Richards, 1997). Poorer quality of, reduced quantity of, or lack of caregiver engagement in communication were all associated with greater decision regret, less satisfaction with care, and poorer mental health during bereavement (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; McDonough et al., 2004; Melhado & Byers, 2011; Smith-Howell et al., 2016; Song et al., 2015).

Healthcare system outcomes.—End-of-life decisions also held consequences for healthcare systems. Intensive service utilization at the end-of-life (e.g. hospital admissions, late hospice use) led to increased resource use and costs (Sullivan, Li, Wu, & Hewner, 2017; Teno et al., 2002). Despite often offering limited benefit, these types of care decisions were increasingly common among patients with chronic life-limiting diseases (Aldridge & Bradley, 2017; Cardona-Morrell et al., 2016; French et al., 2017; Parr et al., 2010; Song, Ward, Hanson, Metzger & Kim, 2016; Teno et al., 2013). The processes leading up to these decisions also held significance, where communication (e.g., goals-of-care) reduced intensive service utilization, and consequently healthcare system cost at the end-of-life (Starr et al., 2019; Zhang et al., 2009).

Concept Definition and Model

Synthesizing the reviewed literature, a refined conceptual definition and model (Figure 1) was developed. End-of-life decision making is considered a process, not a discrete event, that involves three phases: 1) preparation (antecedents), 2) decisions (attributes), 3) and outcomes (consequences). The preparation involves the preemptive designation of a decision maker and iterative patient, caregiver, and healthcare provider communication across the chronic illness. These preparatory processes converge to inform end-of-life decisions during the terminal illness phase. These decisions involve a series of choices where options must be weighed in terms of their potential outcomes collaboratively by the patient and caregiver. Taken together, end-of-life decisions and the preparatory processes hold consequences for the quality of patients' deaths, caregivers' bereavement, and healthcare systems. Examining the dose, content, and quality of the preparation and decisions phases, and their impact on outcomes, holds relevance for research.

Concept Empiric Referents

The conceptual definition and model make clear that comprehensive measurement of end-of-life decision making requires accounting for the dose, content, and quality of both the antecedent and attribute factors (Table 2). These new measurement considerations help to account for the complexities of end-of-life decision making and avoid tendencies to reduce this process to the content of a discrete care choice in the terminal illness phase (Bischoff et al., 2013; Campos-Calderón et al., 2016; Cardona-Morrell; Wright et al., 2008), thus, providing a foundation for addressing emerging research and clinical practice needs (Bélanger, 2017; IOM, 2015; Myers, 2017; Tulskey et al., 2017). Existing measures do not allow for the measurement of these more comprehensive features of end-of-life decision making (Nielsen et al., 2016). For example, the Decisional Conflict Scale (O’Conner, 1995) measures difficulty with decision making, which is only one facet. It also has been suggested that subscale modifications of this measure are needed in end-of-life research (Song & Sereika, 2006), but these modifications have not been consistently utilized (El-Jawahri et al., 2010). Further, measures of shared decision making reflect a patient-healthcare provider decision-making dyad, rather than a patient-caregiver dyad (Elwyn et al., 2013; Makoul & Clayman, 2006), and do not account for the range of collaboration possible when patient decision making capacity is considered (i.e., fully patient-driven to caregiver-driven decisions) (Chaet, 2017; Emanuel & Scandrett, 2010; Kon, 2010).

Discussion and Recommendations

This concept analysis of end-of-life decision making in the context of chronic life-limiting disease provides clarity on the components of and the stakeholders involved in the end-of-life decision making process. The resulting conceptual definition and model demonstrate the central opportunity healthcare providers have to influence end-of-life decision making is *not* at the time of the decision-making, but in the preparation phase. Thus, the antecedent factors function as the clinically modifiable targets that have the highest potential for improving the end-of-life decision making process as a whole. Eliciting decision maker designation and participating in communication function as proactive ways to prepare patients and their caregivers for end-of-life decisions; and patients are often relying on healthcare providers to initiate these actions (Clayton, Butow, Psych & Tattersall, 2005; Hoverman et al., 2017; Waller et al., 2018). These broader preparatory processes of care do not occur exclusively through ACP, making ACP an insufficient proxy for this preparation.

The model also suggests that caregivers play at least an equal, and potentially more important role in end-of-life decision making, where patient decision making capacity may require caregivers to assume varying decision making roles (decision partner, enforcer, caregiver-driver). Caregiver engagement in the preparatory processes across the chronic illness phase is paramount for caregivers to adequately serve in these decision-making roles at the end-of-life. Yet caregiver engagement in these processes is difficult to capture. While formal communication, like that documented in palliative care consultations, may state whether a caregiver was present, these notes typically do not reveal the extent of the caregivers’ involvement in or understanding of what was communicated. More comprehensive inquiry into the total dose of preparatory processes caregivers receive is

needed (Dionne-Odom et al., 2015a; van Eechoud et al., 2014). This will help to more fully understand whether caregivers were compelled to make end-of-life decisions in the presence or absence of adequate preparation (Braun et al., 2009), and how these decision-making circumstances impact bereavement.

This concept analysis has limitations. Given the expanse of the end-of-life decision making literature, it is possible that this concept analysis and resulting conceptual model does not account for all possible facets of the end-of-life decision making process. The conceptual model is also not representative of the minority of end-of-life decision making contexts where patients lack both decision making capacity and surrogates (Effiong & Harman, 2014) or when patients exclusively defer decision making to healthcare providers (Bélanger et al., 2011). Additionally, most individuals in the stakeholder groups were White, indicating that the conceptual model may not wholly represent the breadth of racial and ethnic perspectives that factor into end-of-life decision making. However, due to inconsistent reporting of demographic data, the proportion of racial-ethnic minorities could be underestimated. Further, it was beyond the scope of this concept analysis to fully describe the underlying effect of stakeholder-level and environmental factors on end-of-life decision making. While some of these influences are described (Table C, Appendix), further explanation of these features is needed in future work.

Conclusion

This concept analysis has helped to clarify the unique components of end-of-life decision making in the context of a chronic life-limiting disease. The refined definition and model emphasize the process of end-of-life decision making across the chronic illness trajectory, which includes a preparation, decisions, and outcomes phase. The model indicates that end-of-life decisions do not constitute one discrete choice, but a multitude of choices that are contextually bound to the terminal illness phase. Preparatory factors in the chronic illness phase serve as the essential tools for informing and improving these decisions. The model also points to the central role of caregivers, indicating a pressing need to focus clinical attention on and accurately measure caregiver's engagement in this process. Fully quantifying the dose, content, and quality of the preparation and decisions components will lend to a more comprehensive understanding of the phenomena and its impacts. This concept analysis serves as a foundation for advancing end-of-life decision-making science by fostering a shared understanding of the concept and driving more informed inquiry into and measurement of the processes that affect end-of-life decisions.

Appendix

Table A.

Concept Analysis Component Definitions

Component	Definition
Concept Uses	all ordinary or scientific uses of term, which include both implicit and explicit use of the term
Antecedents	"...are those events or incidents that must occur or be in place prior to the occurrence of the concept." ^d

Component	Definition
Attributes ^b	"...the cluster of attributes that are the most frequently associated with the concept and that allow the analyst the broadest insight into the concept." ^d are the characteristics that typify a concept ^b and help differentiate it from similar phenomenon and cannot be an antecedent or a consequence
Consequences	"...are those events or incidents that occur as a result of the occurrence of the concept...the outcomes of the concept" ^d
Empiric Referents	"...are classes or categories of actual phenomena that by their existence or presence demonstrate the occurrence of the concept itself." ^d

^aWalker & Avant, 2019, pp. 173, 178, 179;

^bWalker & Avant, 2005

Table B.

Uses of End-of-life Decision Making Terminology

Concept	Source	Definition	Reference
"End-of-life" Terms			
End-of-life	Dictionary	"a final period (hours, days, weeks, months) in a person's life, in which it is medically obvious that death is imminent or a terminal moribund state cannot be prevented"	Segen's Medical Dictionary n.d. "end-of-life"
	Literature review ^a	"patients with progressive disease with months or less of expected survival"	Hui et al. 2014, p. 86
	Literature review	"a downhill trajectory [where there is a high risk for] mortality within the ensuing 6–12 months"	Whellan et al. 2014, p.123
Terminally ill	Operational definition	Life expectancy of less than 6 months	Kolva et al. 2018
End-of-life situations	Expert opinion ^b	"...those [situations] in which a severe deterioration in health, due to the evolution of a disease or another cause, threatens the life of a person irreversibly in the near future."	Council of Europe 2014, p. 8
End-of-life issues	Literature review	Advance directives and hospice care	Klindtworth et al. 2015
	Expert opinion	Advance directives, advance planning, negotiating treatment decisions	Norton et al. 2003
End-of-life care	Expert opinion	"Refers generally to the processes of addressing the medical, social, emotional, and spiritual needs of people who are nearing the end of life. It may include a range of medical and social services, including disease specific interventions as well as palliative and hospice care for those with advanced serious conditions who are near the end of life."	Institute of Medicine 2015, p. 386
	Expert opinion	"...care during the finals days or hours of life"	Watts 2012, p. 2359
End-of-life care discussion	Operational definition	Discussion about hospice, resuscitation, advance care planning, palliative care, or venue for dying	Mack et al. 2012
"Decision making" Terms			
Decision making	Dictionary	"the act or process of deciding something especially with a group of people"	Merriam-Webster n.d. "decision-making"
	Dictionary	"[t]he thought process of selecting a logical choice from the available options. When trying to make a good decision, a person must weigh the positives and negatives of each option, and consider all the alternatives. For effective decision making, a person must be able to forecast the outcome of each option as	Business Dictionary n.d., "decision making"

Concept	Source	Definition	Reference
		well, and based on all these items, determine which option is the best for that particular situation.”	
	Theory	involves several stages, “(1) <i>Recognition</i> of the situation as a decision problem (e.g. the cancer is in an advanced stage); (2) <i>Formulation</i> of how the problem is separated from or combined with other concerns (e.g. the need for physical, psychosocial, or family care); (3) <i>Alternative generation</i> or the identification of resources (e.g. what is available and accessible); (4) <i>Information Search</i> (e.g. prognosis, endpoints of care); (5) <i>Judgment/choice</i> (e.g. the decision to enroll in hospice or not); (6) <i>Action</i> or what happened after the decision and, (7) <i>Feedback</i> about the outcomes of a decision.”	Carroll & Johnson, 1990 as cited in Waldrop et al. 2015, p. 3
	Literature review	“Decisions must be made when the patient or surrogate has more than 1 course of treatment from which to choose. The patient or surrogate evaluates the alternative treatment options on the basis of the patient’s values, and then the patient or surrogate voluntarily elects the preferred course of treatment.”	Braun et al. 2009, p. 251
	Literature review	“is necessarily a sociocommunicative process whereby people enter into a relationship, exchange information, establish preferences, and choose a course of action.”	Siminoff & Step 2005, p. 599
	Expert Opinion	“...is conceptualized as a dynamic process that occurs over time rather than at a specific point by which people make choices between alternatives”	Waldrop et al. 2015, p. 3
Garbage can model of decision making	Literature review	“it assumes a pluralist environment with multiple actors, goals and view [...] emphasizes the fragmentedness of chaotic nature of decision making”	Turpin & Marais, 2004, p. 146
Logical incrementalist view of decision making	Literature review	“a step-by-step process of incremental action and keeps the strategy open to adjustment”	Turpin & Marais, 2004, p. 145
Individual differences perspective of decision making	Literature review	“focuses the attention on the problem solving behavior of the individual [...], as influenced by the [individual’s] decision-making style, background and personality”	Turpin & Marais, 2004, p. 146
Naturalistic decision making	Literature review	“decision making as it occurs in real-world settings”	Dionne-Odom et al. 2015b, p. 332
	Literature review	“Investigating and understanding decision-making in its natural context”	Turpin & Marais, 2004, p. 146
Multiple perspective approach to decision making	Literature review	involves, “an attempt to ‘sweep in’ all possible perspectives [(technical, organization, or individual)] on a problem”	Turpin & Marais, 2004, p. 147
Organizations procedures view of decision making	Literature review	“seeks to understand decision as the output of standard operating procedures invoked by organization subunits”	Turpin & Marais, 2004, p. 145
Political view of decision making	Literature review	“a personalized bargaining process, driven by the agendas of participants rather than rational processes [with deference] to the organization’s goals values and relevance of information”	Turpin & Marais, 2004, p. 145
Rational model of decision making	Literature review	“comprises a number of steps, [...] intelligence: finding occasions for a decision; design: inventing, developing and analyzing possible courses of action; choice: selecting a particular course of action from those available; and review: assessing past choices”	Turpin & Marais, 2004, p. 144
Bounded rationality model of decision making	Literature review	“admitting that the rational [person] does not always have complete information, and that optimal choices are not always required. [...] Alternatives are searched for and evaluated sequentially. If an alternative satisfies certain implicitly or explicitly stated minimum criteria, it is said to ‘satisfice’ and the search is terminated”	Turpin & Marais, 2004, p. 145

Concept	Source	Definition	Reference
"End-of-life decision making" Terms			
High quality medical decisions	Literature review	"are informed, concordant with the patient's values, and mutually endorsed by patients, surrogate, and providers."	Torke et al. 2012, p. 55
Health-related decision making during prolonged critical illness	Expert opinion	"choices about initiating, continuing, or discontinuing treatment, diagnostics, or therapeutic care activities. Health-related decisions include choices about mechanical ventilation and other therapies, such as invasive diagnostic procedures and placement of central lines and nutritional access devices that may or may not require written informed consent, and about discharge placement. Financial or legal decisions, such as appointing a power of attorney or signing financial documents to enable insurance payment for health care, were considered health-related in the context of prolonged critical illness."	Happ et al. 2007, p. 363
Serious medical decisions	Expert opinion	Involve, "life-prolonging treatment, such as mechanical ventilation, care in an intensive care unit, major surgery, or chemotherapy"	McMahan et al. 2013, p. 356
Clinical decisions at the end-of-life	Literature review	"decisions to use potentially life-prolonging treatments for emergency conditions such as respiratory failure and decisions for situations that are non-emergent and typically involve the use of treatment modalities that emphasize quality of life"	Weissman 2004, p. 1739
Final decision making	Caregivers	"tasks required when caregivers recognized that time was slipping away" and included advance directives, do-not-resuscitate orders, funeral arrangements, or financial arrangements "the need to ease the patients concerns by handling business matters, funeral plans, or unresolved issues"	Waldrop et al. 2005, pp. 631, 634
Hospice decision making	Cancer patients and Caregivers	A process that involves the <i>recognition of advance cancer and information and communication</i> . The process involves an interaction between <i>formulation of awareness</i> and <i>alternative generation</i> in order to evaluate the hospice decision	Waldrop et al. 2015
End-of-life treatment decisions	Literature review	Life-prolonging treatments or comfort-focused care	Smith-Howell et al. 2016
	Expert opinion	"choosing to initiate, withhold, continue, or withdraw life-sustaining treatment"	Wendler & Rid 2011, p. 337
Decisions to initiate an end-of-life care pathway	Expert opinion	"marks the transition to the terminal phase of palliative care" and involves "dealing with ambiguity, reaching professional consensus and engaging patients and families"	Watts 2011, pp. 2365, 2359
Medical end-of-life decisions	Expert opinion	"in principle, include: whether to withhold or withdraw potentially life-prolonging treatment—e.g., mechanical ventilation, tube-feeding, and dialysis; whether to alleviate pain or other symptoms with, for example, opioids, benzodiazepines, or barbiturates in doses large enough to hasten death as a possible or certain side effect; and whether to consider euthanasia or doctor-assisted suicide [...].Medical end-of-life decisions can take place in any setting at which patients die—that is, in hospitals, nursing homes, hospices, and at home"	van der Heide et al. 2003, p. 345
End-of-life decision making	Literature review	"centered basically in crucial measures associated with medical aspects, such as sedation, withdrawal of medication, refusal of admission to the intensive care unit (ICU), the omission or withdrawal of antibiotics, hydration, or the use of mechanical ventilation" or care decisions that, "can make the difference between comfort and discomfort"	Campos-Calderón et al. 2016, p. 2
	Expert opinion	"decisions about initiating, withholding, or withdrawing life sustaining treatments"	Braun et al. 2010, p. 3

Concept	Source	Definition	Reference
	Expert opinion	"is the process that healthcare providers, patients, and patients' families go through when considering what treatments will or will not be used to treat a life-threatening illness" and comes in several forms, including advance directives, do-not-resuscitate orders, withholding or withdrawing life sustaining therapies, and comfort care	Thelen 2005, p. 29
	Operational definition	Completion of advance directives	Silveira et al., 2010
End-of-life communication and decision making	Expert opinion	"...a clinical interaction, which includes discussion of death and dying (e.g., as part of the progression of illness or a potential outcome of treatment). It is not limited to the terminal stages of dying and includes discussions about care with patients who have advanced chronic diseases as well as discussions with healthy people who are planning for care related to unexpected illnesses. The communication and decision making comprises the following process steps or elements: 1) advance care planning (ACP); 2) Goals of care discussions and related decisions; and 3) Documentation of these discussions and decisions/plans."	Sinuff et al. 2015, p. 1079
End-of-life decision making in acute care	Expert opinion	"is complex, involving difficult decisions, such as whether to initiate or discontinue life support, place a feeding tube or a tracheostomy, or initiate cardiopulmonary resuscitation (CPR) in the event of a cardiac arrest."	Adams et al. 2011, p. 1
End-of-life decisions	Literature review	"potentially life-shortening medical [decisions] including non-treatment decisions (withholding or withdrawing medical treatment) and increasing drug administration to relieve pain and other symptoms, or less common procedures such as physician-assisted suicide and euthanasia"	Vermorgen et al. 2018, p. 1378
	Literature review	"medical decisions that possibly shorten life...., mostly non-treatment decisions and intensified pain and symptom alleviation and sometimes, although rarely, euthanasia or physician-assisted suicide"	Pardon et al. 2012, p. 516
	Literature review	"an interactive process among providers, patients, and their support systems, influenced by each stakeholder and contextual factors in the environment in which the interactions unfold"	Frost et al., 2011, p. 1174
	Expert opinion	"...are those you can make now about how you wish to be cared for and treated when you are dying. End-of-life decisions can include whether to accept or refuse treatments that might prolong your life. An advance directive is one way to let others know about your decisions based on your values and priorities."	American Cancer Society 2019 "advance directives"
Related Terms			
Shared decision making	Expert opinion	"a patient-clinician interaction that offers conversation, not just information, and care not just choice [... where] the patient and clinician create a course of action that is best for the individual patient and his or her family"	Hargraves et al. 2016, p. 627
	Expert opinion	"is the process through which clinicians and patients share information with each other and work toward decisions about treatment chosen from medically reasonable options that are aligned with the patients' values, goals, and preferences."	Allen et al. 2012, p. 1929
	Expert opinion	"an interpersonal, interdependent process in which the healthcare provider and the patient relate to and influence each other as they collaborate in making decisions about the patient's healthcare. [...] Three essential elements must be present for shared decision making to occur. First, both the health care provider and the patient must recognize and acknowledge that a decision is, in fact, required. Second, they must both	Légaré et al., 2013, p.277 This version of the definition was also adopted by the National Consensus Project for Quality

Concept	Source	Definition	Reference
		know and understand the best available evidence concerning the risks and benefits of each option. Third, decisions must take into account both the provider's guidance and the patient's values and preferences"	Palliative Care, 2018
Communication model of shared decision making	Literature review	"decisions depend on (a) antecedent factors that have potential to influence communication, (b) jointly constructed communication climate, and (c) treatment preferences established by the physician and the patient"	Siminoff & Step 2005, p. 599
Shared medical decision making	Expert opinion	Decision making among the patient, family, and health care provider that upholds patient-centered medical care	Glare & Sinclair 2008

^aLiterature review – author derived definition with supporting citations;

^bExpert opinion – author derived definition without supporting citations

Table C.

Stakeholder Influencing Factors^{a,b}

Stakeholder	Preparation Phase	Decisions Phase
Patient		
Individual characteristics	Medical	
<ul style="list-style-type: none"> • Age/life stage • Gender • Race/Ethnicity • Language • Education • Income • Acculturation 	<ul style="list-style-type: none"> • Type of chronic life-limiting illness diagnosis • Severity/stage of illness at diagnosis • Temporal pattern of illness <ul style="list-style-type: none"> – Rate of disease progression – Prior response to treatment • Comorbid disease • Symptom burden 	<ul style="list-style-type: none"> • Variable rate of functional decline in terminal illness trajectory • Comorbid disease • Symptom burden (particularly pain)
	Psychosocial	
	<ul style="list-style-type: none"> • Pre-existing mental illness • Prior experiences with loss/death • Values <ul style="list-style-type: none"> – Value for autonomy/self determination – Goals of care (quantity vs. quality of life) • Emotional readiness (e.g., fear, hope for improvement, disposition to 'focus on the positives') • Prognostic uncertainty • Perceived burden to caregiver • Expectation that health care provider will initiate end-of-life discussions 	<ul style="list-style-type: none"> • Decisional capacity • Decision control preference • Fulfillment of dying role (e.g., legacy formation) • Trust/confidence/satisfaction/therapeutic alliance with health care provider

Stakeholder	Preparation Phase	Decisions Phase
	<ul style="list-style-type: none"> Trust/confidence/satisfaction/therapeutic alliance with health care provider 	
	Spiritual	
	<ul style="list-style-type: none"> Religious/spiritual beliefs Cultural beliefs Existential maturity (i.e., peaceful acceptance of mortality) 	<ul style="list-style-type: none"> Religious/spiritual beliefs Cultural beliefs Existential maturity (i.e., peaceful acceptance of mortality)
	Practical	
	<ul style="list-style-type: none"> Financial concerns/arrangements Funeral arrangements Knowledge, preferences, perceptions of, and practices toward advance care planning 	<ul style="list-style-type: none"> Financial concerns/arrangements
Caregiver(s)		
Individual characteristics	Medical	
<ul style="list-style-type: none"> Age/life stage Gender Race/Ethnicity Language Education Income Acculturation 	<ul style="list-style-type: none"> General caregiver health Knowledge of the dying process 	<ul style="list-style-type: none"> Knowledge of the dying process Understanding of current medical circumstances/receipt of honest information about patient's condition Perception of patient's suffering/symptoms/comfort/quality of life
	Psychosocial	
	<ul style="list-style-type: none"> Pre-existing mental illness Prior experiences with loss/death Anticipatory grief Caregiver values Caregiver relationship to patient (e.g., spousal) Family dynamics (e.g., trust, conflict) Emotional readiness (e.g., fear, hope for improvement) Perceived patient expectations of caregiver role Perceived burden of end-of-life discussions Burden of caregiving 	<ul style="list-style-type: none"> Caregiver values Family dynamics (e.g., trust, conflict) Emotional capacity for decision making Willingness to participate in decision making Caregiver's understanding of decision making role (decision partner, substituted judgment, or best interest standard) Perceived patient expectations of caregiver's decision making role/Amount of leeway in decision making granted by patient

Stakeholder	Preparation Phase	Decisions Phase
	<ul style="list-style-type: none"> Trust/confidence/satisfaction/therapeutic alliance with health care provider 	<ul style="list-style-type: none"> Cultural norms in decision making (e.g., familial roles in decision making; group decision making) Decision making self-efficacy Decision control preference/Perceived level of control over care Gist impression (perception of recovery) Distressing emotions (uncertainty) Moral intuition Perception of patient's values/preferences Trust/confidence/satisfaction/therapeutic alliance with health care provider
	Spiritual	
	<ul style="list-style-type: none"> Religious/spiritual beliefs Cultural beliefs Existential maturity (i.e., peaceful acceptance of mortality) 	<ul style="list-style-type: none"> Religious/spiritual beliefs Cultural beliefs Existential maturity (i.e., peaceful acceptance of mortality)
	Practical	
	<ul style="list-style-type: none"> Financial concerns/arrangements Knowledge and perceptions of advance care planning 	<ul style="list-style-type: none"> Financial concerns/arrangements
Health care providers		
Individual characteristics	Medical	
	<ul style="list-style-type: none"> Age/life stage Gender Race/Ethnicity "Geo-ethnic" origin match to patient Language Acculturation 	<ul style="list-style-type: none"> Knowledge/Educational training related to end-of-life issues/communication Years of experience Medical specialty Routine area of work in hospital (e.g., intensive care unit vs. floor unit) Delivery of primary or specialty palliative care
	Psychosocial	
	<ul style="list-style-type: none"> Bias in recommendations 	<ul style="list-style-type: none"> Quality of communication at time of decision making (e.g., the way options

Stakeholder	Preparation Phase	Decisions Phase
	<ul style="list-style-type: none"> Assumptions about the amount of information patients desire 	are framed when discussed)
	Spiritual	
	<ul style="list-style-type: none"> Religious/spiritual beliefs Cultural beliefs 	<ul style="list-style-type: none"> Religious/spiritual beliefs Cultural beliefs
	Practical	
	<ul style="list-style-type: none"> Perceived lack of time or resources to conduct ACP 	
Environment		
	Healthcare system context	
	<ul style="list-style-type: none"> Rotating shifts of health care professionals (e.g., physician teams, nurse scheduling) <ul style="list-style-type: none"> Continuity in care Practice culture/ Institutional norms <ul style="list-style-type: none"> Proactive culture toward end-of-life preparation Norms related to advance care planning and end-of-life conversations Availability of decisional support tools for patients or health care providers Transportability of advance care planning documents across healthcare systems 	<ul style="list-style-type: none"> Practice culture (e.g., practice toward palliative care consultation/ involvement) <ul style="list-style-type: none"> Tendency to default to life-sustaining treatments Accessibility/ Availability of inpatient or outpatient hospice services, chaplaincy Location (e.g., acute [intensive care unit] vs. community-based [hospice] setting for decision) Quality of environment (e.g. secure environment to ask questions; physical space for family discussion/ conferences; availability of healthcare professionals to answer questions)
	Policy Context	
	<ul style="list-style-type: none"> Institutional policy and procedures Reimbursement structures Impact of state law on advance care planning practices 	<ul style="list-style-type: none"> Institutional policy and procedures Reimbursement structures Impact of state law on advance care planning implementation

^aStakeholder influences were organized according to medical, psychosocial, spiritual, and practical domains (Hebert, Prigerson, Schulz, & Arnold, 2006)

^bSynthesized from: Abbott et al., 2001; Allen et al., 2012; Barnato et al., 2015; Barnato et al., 2017; Bires et al., 2018; Booker et al., 2016; Braun et al., 2008; Cain et al., 2018; Dionne-Odom et al., 2015b; Emanuel & Scandrett, 2010; Frost et al., 2011; Gerhart et al., 2016; Gray et al., 2019; Howard et al., 2018; Kelley et al., 2010; Lu et al., 2015; McMahan et al.,

2013; Melhado & Byers, 2011; Mullaney et al., 2016; Nunez et al., 2015; O'Hare et al., 2010; Osborn et al. 2012; Rao et al., 2014; Reinke et al., 2008; Scheunemann et al., 2015; Schulz et al., 2015; Smith-Howell et al., 2016; Steiner et al., 2018; Steinhauser et al., 2000; Thelen, 2005; van Eechoud et al., 2014; Virdun et al., 2015; Watts, 2012; Weissman, 2004; Whellan et al., 2014; Winzelberg et al., 2005

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Highlights

- End-of-life decision making is a *process*, not a discrete event, spanning the chronic illness.
- It involves three phases: preparation, decisions, outcomes; caregivers are vital throughout.
- Preparation occurs in the chronic illness, and decisions (which are many) in the terminal illness
- Preparation includes clinically modifiable factors for improving end-of-life decision making.
- Measurement of the *process* is needed; including the *dose*, *content*, and *quality* of all factors.

Figure 1. Conceptual Model of End-of-life Decision Making in the Context of Chronic Life-limiting Disease

Within each triangle are the antecedents (preparation phase), attributes (decisions phase), and consequences (outcomes phase) of end-of-life decision-making, which are situated across the chronic illness, terminal illness, and bereavement phases, respectively. The circular arrows between the antecedents and attributes account for the fluctuating nature of end-of-life decision making, where some terminal illness trajectories (e.g., heart failure) may force patients and caregivers to navigate between cyclical end-of-life decision contexts (e.g., a potentially terminal disease exacerbation) and preparation contexts (e.g. recovery from exacerbation). Consequently, the model features stacked preparation and decisions phase triangles to illustrate the cumulative effect of preparation and the serial nature of decisions that factor into end-of-life decision making outcomes. At each phase of the decision making process, interactions among the three stakeholders (patient, caregiver, healthcare provider) are depicted. Bolded arrows depict rich interactions and active involvement, whereas gray arrows depict guidance only. Multiple driving and/or resisting forces play into this process and are described in Table C of the Appendix.

Table 1.**Participant Distribution According to Stakeholder Groups**

Participants^a	Qualitative Studies	Mixed Methods Studies	Quantitative Studies	Total
Total Participants	<i>N</i> = 1,226	<i>N</i> = 992	<i>N</i> = 1,118,532	<i>N</i> = 1,120,750
	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i> (%)
<u>Patients</u>	429	517	1,115,137	1,116,083 (99) ^b
Age, weighted mean, y	68.9	68.5	80.7	80.7 ^c
Male Sex	221	208	648,953	649,382 (58.2) ^d
Racial-Ethnic Minorities				
Total	144	100	126,937	127,181 (11.4) ^e
Minority (general)	1	50	39	90
Black	107	23	103,199	103,329
Hispanic	30	14	14,000	14,044
Asian	6	12	1,451	1,469
Other	0	1	8,248	8,249
Chronic Diseases				
Heart failure	53	0	45	98
Cancer	71	359	8,057	8,487
COPD ^f	45	0	40	85
End stage renal disease	109	0	41,703	41,812
End stage liver disease	6	0	22	28
Mixed chronic diseases	145	158	1,065,270	1,065,573
<u>Caregivers</u>	609	227	3,243	4,079 (< 1) ^g
Age, weighted mean, y	59.3	48.7	55.1	55.4 ^h
Male Sex	149	63	1,135	1,347 (33) ⁱ
Racial-Ethnic Minorities				
Total	136	103	411	735 (18) ^j
Minority (general)	17	1	208	226
Black	86	26	223	335
Hispanic	14	37	40	91
Asian	16	23	15	54
Other	3	16	10	29
Caregiver status				
Active caregivers	507	197	1,237	1,941
Bereaved caregivers	102	30	2,006	2,138
<u>Healthcare providers</u>	188	248	152	588 (< 1) ^k
Physicians	37	173	152	362
Nurses	103	0	0	103

Participants ^a	Qualitative Studies	Mixed Methods Studies	Quantitative Studies	Total
NP/PA ^l	0	14	0	14
Social workers	10	0	0	10
Chaplains	6	0	0	6
Hospice volunteers	8	0	0	8
Mixed HCPs ^m	24	61	0	85

^aFor mixed samples, participant numbers represent only those with chronic life-limiting disease;

^b53 studies involved patients, two of which accounted for 968,675 patients;

^c17% of patient studies did not report on age;

^d% of patient studies did not report on sex;

^e30% of patient studies did not report on race;

^fchronic obstructive pulmonary disease;

^g33 studies involved caregivers;

^h21% of caregiver studies did not report on age;

ⁱ21% of caregiver studies did not report on sex;

^j27% of caregiver studies did not report on race;

^k12 studies involved healthcare providers;

^lnurse practitioners/physician assistants;

^mhealthcare provider

Table 2.**Measurement Considerations**

	Measurement Features	Measures
Preparation Phase (Antecedents)		
Decision maker Designation	<i>Dose</i> – number of designated decision makers	Advance directive documentation (e.g., healthcare surrogate/proxy designation) Verbal patient or caregiver report
	<i>Content</i> – the amount of leeway in decision making the patient desires the designated decision maker to have	Advance directive documentation Verbal patient report Typology of leeway in decision making ^a : <ul style="list-style-type: none"> • Binding • Weighty, but not binding • Merely informative
	<i>Quality</i> – relationship of designated decision maker to patient; timing of designation; designated decision maker's understanding of the patient's wishes	Advance directive documentation Verbal patient or caregiver report Match between caregiver report and patient's stated/ documented preferences
Communication <ul style="list-style-type: none"> • End-of-life Preferences • Prognosis • Goals of Care 	<i>Dose</i> – the number of conversations across the chronic illness phase	EMR ^b
	<i>Content</i> – type of communication (end-of-life preferences, prognosis, goals of care)	EMR (e.g., code status designation, documentation of goals, advance care planning note, palliative care note, hospice referral) ^c Advance directive documentation POLST/MOLST ^d Analysis of naturally-occurring conversations
	<i>Quality</i> – level of patient and caregiver engagement in communication; patient and caregiver understanding of the communication; timing of the communication	EMR (e.g., notes indicating who was present and their involvement/understanding) Quality of Communication ^e Feeling heard and understood ^f
Decision Phase (Attributes)		
Collaboration	<i>Dose</i> – number of decisions which involved or did not involve collaboration	EMR (e.g., healthcare provider notes) Patient or bereaved caregiver report
	<i>Content</i> – types of decisions which involved or did not involve collaboration	EMR (e.g., healthcare provider notes) Patient or bereaved caregiver report
	<i>Quality</i> – the degree of collaboration between the patient and caregiver: <ul style="list-style-type: none"> • fully patient-driven • patient-driven with caregiver guidance • decision partners • enforcer • fully caregiver-driven 	EMR (e.g., healthcare provider notes) Patient or bereaved caregiver report Adapted versions of: <ul style="list-style-type: none"> • Degree of Sharing Scale^g • CollaboRATE^h • Shared decision making continuumⁱ
Weighing of Options	<i>Dose</i> – the number/range of options offered to the patient and caregiver	EMR (e.g., healthcare provider notes) Patient or bereaved caregiver report
	<i>Content</i> – types and framing of options offered (e.g., listing of options or options combined with supporting information - expected outcome/ recommendations)	EMR (e.g., healthcare provider notes) Patient or bereaved caregiver report

	Measurement Features	Measures
	<i>Quality</i> – patient and caregiver understanding of the options; patient and caregiver conflict in weighing options	Patient or bereaved caregiver report Decisional Conflict Scale ^j
Serial Choices	<i>Dose</i> – number of decisions made in the terminal illness phase	EMR (healthcare provider notes; healthcare utilization outcomes) Bereaved caregiver report
	<i>Content</i> – types of decisions made in the terminal illness phase	EMR (healthcare provider notes; healthcare utilization outcomes) Bereaved caregiver report
	<i>Quality</i> – whether the decisions were informed; decisions as preference matched or goal-concordant	EMR (e.g., healthcare provider notes; healthcare utilization outcomes) Bereaved caregiver report Typology of decision(s): <ul style="list-style-type: none"> • Informed decision • Marginal decision^k • Default decision^l

^aBerger, DeRenzo & Schwartz, 2008;

^belectronic medical record;

^cThese indicators are associated with high quality end-of-life care and novel measurement strategies (e.g., natural language processing) may be useful to examine their presence (Lindvall et al., 2019; Sanders et al., 2020)

^dphysician or medical orders for life-sustaining treatment;

^eEngelberg, Downey & Curtis, 2006;

^fGramling et al., 2016b;

^gMakoul & Clayman, 2006;

^hElwyn et al., 2013;

ⁱKon, 2010;

^jO'Conner, 1995, Song & Sereika, 2006;

^kEmanuel & Scandrett, 2010;

^lBraun, Naik, & McCullough, 2009