Published in final edited form as:

West J Nurs Res. 2018 December ; 40(12): 1861–1884. doi:10.1177/0193945917723010.

Theories of Health Care Decision Making at the End of Life: A Meta-Ethnography

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Abstract

The aim of this meta-ethnography is to appraise the types and uses of theories relative to end-of-life decision-making and to develop a conceptual framework to describe end-of-life decision making among patients with advanced cancers, heart failure, and amyotrophic lateral sclerosis (ALS) and their caregivers or providers. We used PubMed, Embase, and CINAHL databases to extract English-language articles published between January 2002 and April 2015. Forty-three articles were included. The most common theories included decision-making models (n=14) followed by family-centered (n=11) and behavioral change models (n=7). A conceptual framework was developed using themes including: context of decision-making, communication and negotiation of decision-making, characteristics of decision makers, goals of decision-making, options and alternatives, and outcomes. Future research should enhance and apply these theories to guide research to develop patient-centered decision-making programs that facilitate informed and shared decision-making at the end of life among patients with advanced illness and their caregivers.

Keywords

end-of-life; decision making; framework; patients with advanced illness; meta-ethnography

As the global population ages, quality end-of-life care is a serious public health concern for patients, caregivers, and health care providers (United Nations, 2015). Recent technological advances in health care have increased the number of choices that patients and their families face when deciding on treatments and care at the end-of-life (The Organisation for Economic Co-operation and Development [OECD] Better Life Index, n.d.). Aligned with these trends, in September 2014, the Institute of Medicine released a consensus report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Institute of Medicine [IOM], 2014), emphasizing the responsibility clinicians,

researchers, and policy makers have for offering affordable, sustainable, high-quality care for individuals who are nearing death. The National Institute on Aging also endorses the importance of quality end-of-life care across the illness trajectory as evidenced in a report titled *End-of-life: Helping with comfort and care* (National Institute on Aging [NIA], 2012). This report highlighted that end-of-life care not only involves the final moments before death, but also encompasses the support, comfort, and palliative care for a dying individual with one or more advanced conditions (NIA, 2012).

In the United States, federal funding for end-of-life care research has grown more than tenfold between 1997 (\$4,233,000) and 2010 (\$61,547,000) (National Institutes of Health, 2013). Institutes such as the National Institute of Nursing Research have strongly advocated for end-of-life research and continue to expand efforts to increase end-of-life research funding (National Institute of Nursing Research, 2016). These increases in end-of-life research dollars will result in more end-of-life studies. In order to support the design of quality end-of-life studies for researchers and to offer clinically relevant, sustainable, high-quality end-of-life care throughout the continuum an illness trajectory, a theoretical understanding of the multiple factors that influence the end of life care decision process (culture, communication, hope) and the influence of the process on end of life care outcomes (e.g. treatment options, decision regret) is needed. Despite attention to health care decision making and the critical role of theory in end-of-life care research, very little is known about theories relative to the context, process, and outcomes of end-of-life decision making.

National Attention to Decision Making at the End of Life

The complex needs of persons at the end-of-life and their families call for better communication among patients, their families, and their healthcare providers to offer better patient-centered health care services. Shared decision making, that is, decision making that involves patients and providers, patients and families, or patients, families and providers, has been suggested as an ideal model of health care decision making in a situation where multiple treatment options are available (Almyroudi, Degner, Paika, Pavlidis, & Hyphantis, 2011; Barry & Edgman-Levitan, 2012; Charles, Gafni, & Whelan, 1997). To promote this type of decision making, in January of 2016, the Centers for Medicare and Medicaid Services (CMS) approved payments to support advance care planning discussions by physicians, nurse practitioners and physician assistants with patients and families (Office of the Federal Register, 2016). Though CMS's support for consultation on advance care planning helps patients express their values and preferences related to end-of-life care, the complexities involved in this care require ongoing discussions throughout the trajectory of illness.

A Meta-Ethnographic Approach to Synthesizing Theories

Theory, defined as “creative and rigorous structuring of ideas that projects a tentative, purposeful, and systematic view of phenomena (Chinn & Kramer, 2004, p.58),” provides a comprehensive explanatory framework for a set of observations (Campbell et al., 2014). Middle-range theories are most commonly used in empirical research to identify major concepts in phenomena under study and to test relationships among these concepts

(Campbell et al., 2014). Theoretical reviews are increasingly being undertaken in the health sciences to gain insight into how multiple concepts relate to one another within complex health phenomena across a range of theories and disciplines (Toye et al., 2014). These reviews can have various purposes (Campbell et al., 2014). For example, one might take one or more existing theories and propose a new theory based on a review of research that adds a new dimension to the theory. Another common type of theoretical review involves selecting several common theories undergirding intervention research aimed at a common problem. For example, Lorenc et al. (2014) conducted a theoretical review of interventions on delay in patients with chest pain seeking professional medical help. The review provided insight into the concepts and assumptions underpinning interventions, and elucidated factors that may affect the efficacy of interventions (Lorenc et al., 2014). This type of review is used to test the most effective aspect of interventions. Still another variant of theoretical review involves conducting a systematic review of research literature to examine a common phenomenon and describing the theories that guide this research. The various theories and their constructs are compared and combined using a meta-ethnographical approach and thematic analysis (Campbell et al., 2014; Noblit & Hare, 1988). For instance, Rosenthal and Nolan (2013) used meta-ethnography to synthesize the qualitative studies about parental ethical decision making in the neonatal intensive care unit. The authors translated concepts that were addressed in separate studies into one another, exploring similarities and contradictions, and organizing the concepts into new theory (Rosenthal & Nolan, 2013). In the context of end-of-life decision making, in response to the growing demand to understand end-of-life care, Belanger et al. (2011) conducted a systematic review and offered insight into an understanding of the complexity of the shared decision-making process in care at the end of life. However, a growing number of studies has been published since Belanger et al. (2011) completed their literature search (up to May 2009). In addition, an understanding of the theoretical underpinnings important to end of life decision making is missing in the review.

Purpose

To this end, the purpose of the present review was to: (1) examine and synthesize theories that either were developed from or guided research examining health care decision making at the end of life, and (2) develop a comprehensive conceptual framework of end-of-life decision making.

Methods

Design

Meth-ethnography – an inductive, interpretive synthesis approach – is frequently used qualitative evidence synthesis approach in health care-related research (France et al., 2014; Noblit & Hare, 1988). We used a meta-ethnographical approach with thematic synthesis to examine the theories guiding and emerging from research on health care decision making at the end-of-life (Noblit & Hare, 1988; Thomas & Harden, 2008). Noblit and Hare (1988) outlined a seven-step approach for synthesizing the findings of the selected studies: (1) getting started; (2) deciding which articles are relevant to the topic of interest; (3) reading the studies; (4) determining how the studies are related; (5) translating the studies into on

another; (6) synthesizing translations; and (7) expressing the synthesis. In our meta-ethnography, expressing the synthesis was completed through thematic synthesis of the selected articles, as described by Thomas & Hare (2008) and steps four to seven in the Noblit and Hare's (1988) approach were used iteratively as the thematic synthesis was performed.

Definition of Theory

In choosing articles for our meta-ethnography that had a theory focus, we adapted Chinn and Kramer's (2004) definition of theory: "creative and rigorous structuring of ideas that projects a tentative, purposeful, and systematic view of phenomena (p.58)." Specifically, we viewed theory as comprising of multiple concepts which are related to one another, with the goal of describing and explaining a particular phenomenon or predicting outcomes (Reed & Shearer, 2009). In this article, we grouped theories with models and theoretical/conceptual frameworks, as long as our definition of theory has been fulfilled.

Search Strategy

With the assistance of a professional health science librarian, we undertook a comprehensive search of the electronic databases, PubMed, Embase, and Cumulative Index to Nursing and Allied Health Literature (CINAHL), to find articles exploring end-of-life decision making among patients with advanced cancers, heart failure, and amyotrophic lateral sclerosis (ALS). These illnesses were chosen in order to represent two distinct illness trajectories (Murray, Kendall, Boyd, & Sheikh, 2005): a trajectory with a steady progression towards death (i.e., amyotrophic lateral sclerosis, [ALS] and cancer); and a trajectory with an unpredictable course and more sudden death (i.e., heart failure). We used a combination of keywords: 'terminal care,' 'decision making,' 'cancer,' 'heart failure,' and 'amyotrophic lateral sclerosis' to find English-language journal articles published between January 2002 and April 2015. Our initial search was performed in 2012 with the aim of identifying relevant articles published within the past 10 years. We subsequently updated this search to find other relevant articles published between 2013 and April 2015. More detailed information on search terms is provided online as a table (Online Supplementary Table 1).

Review Process

The review process is presented as a figure in Online Supplementary Figure 1. We identified 2282 articles from three electronic databases after removing 1794 duplicates. All citations were then uploaded to the web-based DistillerSR systematic review software system ("Distiller SR,") which is designed to help researchers uphold an open and transparent review process and easily audit the review results. Using the software system, two reviewers (KK and MF) independently screened 2282 titles and abstracts. A total of 330 (14%) articles were included for full text review after excluding 1952 articles due to no relevance to end of life decision making. Members of the team (KK, KH, JX, MK, HP, & MF) were paired and assigned a list of full text articles to independently review. Inclusion criteria were as follows: (1) data-based articles, (2) sample included patients with advanced cancers, heart failure (HF), and/or ALS, or family caregivers of patients with advanced cancer, HF, and/or ALS, (3) article focused on decision making between the patient and caregiver, patient and provider, or caregiver and provider, (4) articles specifically involving end-of-life decision

making, and (5) articles explicitly addressing a theory (model or theoretical/conceptual framework) as part of the study design or the development of a theory. Any discrepancies between the paired reviewers were reconciled during bi-weekly team meetings. We excluded 287 articles for the following reasons: (1) non-research articles (e.g., editorial and commentary; n=35), (2) articles that did not include patients with advanced cancers, heart failure, and/or ALS or their caregivers (n=11), (3) articles that did not involve end-of-life decision-making (n=18), and (4) articles that did not cite a theory (n=223). A total of 43 articles met our inclusion criteria.

Data Extraction

The team developed a standardized data extraction form based on a series of team discussions. Each of the paired reviewers, independently completed the data extraction form to classify the articles (quantitative, qualitative, or mixed methods design) and summarized the selected articles (e.g., study objectives, sample characteristics, and name of theory). Any discrepancies between the paired reviewers were discussed at team meetings until consensus was reached. Data were then exported from the DistillerSR to an excel file for data synthesis.

Data Synthesis: Constructing the New Conceptual Framework

After the initial data extraction, a summary table was created to assist in the coding of themes, with the purpose of developing a new conceptual framework. A table was created, which included the name of the theory in each article, type of theory (e.g. behavioral, family-centered – theory including concepts associated with the family and applied to patients and their families), main concepts of the theory, whether the theory was related to the process and/or outcomes of decision-making, and how the theory was applied in the publication. Two members of the team were assigned to each article to validate the coding. Discrepancies were resolved through discussion at team meetings and the development of consensus.

Using thematic synthesis described by Thomas and Harden (2008), categories of theoretical concepts were compared and similar categories were combined into themes. Relationships among the themes were derived from the relationships found in the reviewed literature and through team discussion and consensus. Subsequently, a conceptual framework was created depicting these themes and their relationships to one another.

Quality Rating – Use of Theory

Of the 43 studies included in this meta-ethnography, one study conducted a literature review (Amalraj, Starkweather, Nguyen, & Naeim, 2009). Seven studies developed a theory based on grounded theory methodology (Edwards, Olson, Koop, & Northcott, 2012; Horne, Seymour, & Payne, 2012; Kohara & Inoue, 2010; Meeker, 2011; Mehta, Cohen, Carnevale, Ezer, & Ducharme, 2010; Michael, O'Callaghan, Baird, Hiscock, & Clayton, 2014; Ohnsorge, Gudat, & Rehmann-Sutter, 2014). Of the remaining 35 articles, nine qualitative studies used a deductive coding method based on the selected theory to guide the qualitative analysis (de Graaff, Francke, van, & van, 2012; Drevdahl & Dorcy, 2012; Elliott & Olver, 2011; Ferrell et al., 2003; Gardner, 2008; Mehta, Cohen, Ezer, Carnevale, & Ducharme,

2011; Sharf, Stelljes, & Gordon, 2005; Volker & Wu, 2011; Waldrop & Meeker, 2012). Each theory used in these studies can be found in Table 1. Detailed information on the included studies is provided online as a table (Online Supplementary Table 2). The degree to which the remaining 26 studies used theory varied. We utilized the four-level approach by Painter, Borba, Hynes, Mays, and Glanz (2008) to categorize these 26 studies into the following levels: (1) the study was informed by theory: a theoretical framework is mentioned but no application of the framework is present; (2) the study applied theory: a theoretical framework is mentioned and constructs are applied in study components; (3) the study tested theory: a theoretical framework is mentioned, more than half of the constructs in the theory are measured, and explicitly tested; and (4) the study created theory: a new or revised theory is created based on constructs that are measured and tested in the study. For level three, it was acceptable for us if the study measured and tested at least one construct in the theory. The first author (KK), assigned these 26 articles to the appropriate level: informed by theory, applied theory, testing theory, and creating theory. No articles reviewed were classified as “creating theory.” Studies that used grounded theory were not automatically categorized as creating theory articles because according to Painter et al. (2008), creating theory meant that the study created a theory as well as measured and tested the theory constructs within one article. The second author (KH) then evaluated KK’s decisions. Discrepancies between the two authors were discussed and reconciled during team meetings.

Results

Description of Included Articles

Of 43 selected articles, 17 studies were qualitative (e.g., Edwards et al., 2012; Horne et al., 2012; Michael et al., 2014; Ohnsorge et al., 2014), 23 were quantitative (e.g., Back & Huak, 2005; Heyland et al., 2006; Koedoot et al., 2003; Noguera et al., 2014; Yun et al., 2011), and three were mixed methods (Gattellari, Voigt, Butow, & Tattersall, 2002; Murray, O’Connor, Fiset, & Viola, 2003; Nolan et al., 2008). More than half of the studies focused on patients with advanced illness and families and/or providers (dyads) (e.g., de Graaff et al., 2012; Ferrell et al., 2003; Henoch et al., 2012; Nolan et al., 2008; Ohnsorge et al., 2014; Waldrop & Meeker, 2012). Twelve focused exclusively on patients (e.g., Heyland et al., 2003; Maida et al., 2010; Mo et al., 2012; Sharf et al., 2005; Smith et al., 2011; Volker & Wu, 2011), while nine focused exclusively on families (e.g., Bakitas et al., 2008; Klinkenberg et al., 2004; Meeker, 2011; Mehta et al., 2010; Nolan et al., 2009; Yun et al., 2011).

The most frequently used theories were decision making (n=14), family centered (n=11), and behavioral change theories (n=7). The theories focused on a wide variety of topics such as: improving quality of patient care, health care communication, psychology, health beliefs, and patient decision making. Thirty-three theories were mainly related to the process of decision-making, four were related to the outcomes of decision-making (Drevdahl & Dorcy, 2012; Rose et al., 2004; Smith et al., 2011; Tang et al., 2005) and six were related to both the process and outcomes (e.g., Gattellari et al., 2002; Kohara & Inoue, 2010; Mo et al., 2012). As shown in Table 1, two studies were informed by theory (Back & Huak, 2005; DesHarnais et al., 2007), nine applied theory (e.g., Gattellari et al., 2002; Nolan et al., 2009; Nolan et al., 2008; Siminoff et al., 2006; Vogel et al., 2013; Walczak et al., 2015), and 15 tested theory

(e.g., Henoch et al., 2012; Heyland et al., 2006; Koedoot et al., 2003; Mo et al., 2012; Noguera et al., 2014; Ozanne et al., 2009; Tang et al., 2005; Yun et al., 2011). None of the studies created theory.

Conceptual Framework for Individual and Family End-of-Life Decision Making

The concepts addressed within the theories are presented as a table (Online Supplementary Table 3). Using the concepts in Online Supplementary Table 3, we developed The Conceptual Framework for Individual and Family End-of-Life Decision Making (Figure 1) to visually depict the dimensions of end-of-life decision making across a serious illness trajectory. This multilevel framework offers a more comprehensive guide for the ways in which patients with advanced illness and their caregivers and/or health care providers make a decision regarding complex health problems at the end of life. In particular, this conceptual framework is based on the underlying assumptions that: (1) health care decision making occurs in the context of cultural and social expectations, as well as established health care systems; (2) desirable decision processes and decision outcomes depend on patient-family-provider interactions; and (3) the decision making is cyclical and iterative where decision outcomes influence future decision process and outcomes.

Key themes and findings

The following section is a summary of the key themes in the conceptual framework: the context of decision making, communication and negotiation of decision-making, characteristics of decision makers, goals of decision-making, options and alternatives, and outcomes of decision-making.

Context of decision making—Context of decision making was defined as factors related to the healthcare system, family, culture, and/or personal values, uncertainty, and autonomy. As shown in Online Supplementary Table 3, twenty-seven studies used theories that included contextual factors of decision making (e.g., Ferrell et al., 2003; Gardner, 2008; Hinderer et al., 2015; Ohnsorge et al., 2014; Smith et al., 2011; Waldrop & Meeker, 2012). Among these theories, 15 were related to the healthcare system (e.g., Drevdahl & Dorcy, 2012; Ferrell et al., 2003; Klinkenberg et al., 2004; Siminoff et al., 2006; Smith et al., 2011; Stein et al., 2013), 14 were related to family, cultural, and/or personal values (e.g., Back & Huak, 2005; Bakitas et al., 2008; de Graaff et al., 2012; Elliott & Olver, 2011; Mehta et al., 2011; Siminoff et al., 2006), five were related to uncertainty (Drevdahl & Dorcy, 2012; Gardner, 2008; Kohara & Inoue, 2010; Smith et al., 2011; Waldrop & Meeker, 2012), and three were related to autonomy (Hinderer et al., 2015; Stein et al., 2013; Tang et al., 2005).

Communication and negotiation of decision making—Communication and negotiation of decision making was defined as communication of health information and negotiation of decision making among patients, families, and healthcare providers. Thirty-two studies included theories related to communication and negotiation of decision making (e.g., DesHarnais et al., 2007; Elliott & Olver, 2011; Gattellari et al., 2002; Heyland et al., 2006; Maida et al., 2010; Meeker, 2011; Mehta et al., 2011; Michael et al., 2014; Nolan et al., 2008; Ozanne et al., 2009; Vogel et al., 2013; Walczak et al., 2015). The focus of communication and negotiation of decision making varied. For example, theories in this

category were used to describe patient-provider communication (de Graaff et al., 2012; Ferrell et al., 2003; Heyland et al., 2003; Maida et al., 2010; Rose et al., 2004); communication between family caregivers/surrogate decision makers and patients (Amalraj et al., 2009; Drevdahl & Dorcy, 2012; Meeker, 2011; Mehta et al., 2010), barriers to communication (Amalraj et al., 2009), and negotiation of care decisions (de Graaff et al., 2012; Drevdahl & Dorcy, 2012; Ferrell et al., 2003; Gardner, 2008; Heyland et al., 2003).

Characteristics of decision makers—Characteristics of decision makers were defined as emotional, psychological, and other characteristics (e.g. desire for involvement, cognition) of decision makers. Twenty studies had theories that described characteristics of decision makers (e.g., Amalraj et al., 2009; Hinderer et al., 2015; Kramer et al., 2010; Mo et al., 2012; Nolan et al., 2009; Volker & Wu, 2011; Yun et al., 2011). Characteristics of decision makers included: emotional factors such as fear (e.g., Ferrell et al., 2003; Koedoot et al., 2003; Murray et al., 2003; Rose et al., 2004), psychological factors such as anxiety (e.g., Ferrell et al., 2003; Hinderer et al., 2015; Kramer et al., 2010; Stein et al., 2013; Volker & Wu, 2011; Yun et al., 2011), self-efficacy (e.g., Nolan et al., 2009; Nolan et al., 2008; Sharf et al., 2005), health belief (e.g., Ferrell et al., 2003; Gardner, 2008; Rose et al., 2004; Sharf et al., 2005), desire for involvement (Amalraj et al., 2009; Koedoot et al., 2003; Mo et al., 2012; Sharf et al., 2005), and cognition (Hinderer et al., 2015; Volker & Wu, 2011).

Goals of decision making—Goals of decision making were defined as the outcomes desired by patients, caregivers/surrogate decision makers, and healthcare providers. Twenty-one studies used theories that addressed goals of decision making (e.g., Back & Huak, 2005; Bakitas et al., 2008; Edwards et al., 2012; Elliott & Olver, 2011; Mehta et al., 2011; Michael et al., 2014; Siminoff et al., 2006). Goals for decision making included: patient quality of life (Ferrell et al., 2003; Hensch et al., 2012; Mo et al., 2012; Ohnsorge et al., 2014; Rose et al., 2004), achieving a “good”/peaceful death (Bakitas et al., 2008; Edwards et al., 2012; Klinkenberg et al., 2004; Murray et al., 2003; Rose et al., 2004), honoring patient wishes (Edwards et al., 2012; Elliott & Olver, 2011; Horne et al., 2012; Koedoot et al., 2003; Michael et al., 2014; Noguera et al., 2014; Nolan et al., 2008; Rose et al., 2004; Sharf et al., 2005; Stein et al., 2013), finding hope/meaning (Gardner, 2008; Kohara & Inoue, 2010; Kramer et al., 2010), and enhancing dignity and family harmony (Back & Huak, 2005; Siminoff et al., 2006). Many theories also focused on decreasing patients’ symptoms including pain (Mehta et al., 2010; Rose et al., 2004; Sharf et al., 2005), agitation and dyspnea (Mehta et al., 2010), and meeting patients’ needs (Kramer et al., 2010) including spiritual needs (Nolan et al., 2009).

Options and alternatives—Options and alternatives were defined as the choices patients and family members/surrogate decision makers had to choose among to achieve their goals. Fifteen publications had theories that addressed options and alternative decisions (e.g., Edwards et al., 2012; Heyland et al., 2003; Horne et al., 2012; Meeker, 2011; Michael et al., 2014; Noguera et al., 2014; Nolan et al., 2009; Nolan et al., 2008; Ohnsorge et al., 2014; Ozanne et al., 2009; Waldrop & Meeker, 2012). Specific options and alternatives identified included location of end-of-life care such as home or hospital (Murray et al., 2003), treatment options such as curative-focused vs. supportive-focused care (Ferrell et al., 2003;

Koedoot et al., 2003; Kohara & Inoue, 2010; Rose et al., 2004; Sharf et al., 2005), and the processes used to weigh options (de Graaff et al., 2012; Drevdahl & Dorcy, 2012; Ozanne et al., 2009; Waldrop & Meeker, 2012).

Outcomes of decisions—Outcomes of decisions were defined as elements of included theories that described the patients', families', or healthcare providers' reaction to an end-of-life decision. Eight theories/frameworks included information related to the outcomes of decisions (Drevdahl & Dorcy, 2012; Heyland et al., 2006; Kohara & Inoue, 2010; Mehta et al., 2010; Noguera et al., 2014; Smith et al., 2011; Waldrop & Meeker, 2012; Yun et al., 2011). Some theories/frameworks included outcomes-related to patient and caregiver satisfaction with the decision (Kohara & Inoue, 2010; Mehta et al., 2010) and regret with the decision (Drevdahl & Dorcy, 2012; Heyland et al., 2006; Smith et al., 2011).

Discussion

This systematic review reports the first known synthesis of theories used in studies related to decision making at the end of life, and proposes a new comprehensive, multi-disciplinary conceptual framework of end-of-life decision making that describes key concepts and their relationships among one another. Our multilevel framework offers a more comprehensive guide for understanding the ways in which patients with advanced illness and their caregivers and/or healthcare providers make a decision regarding complex health issues at the end of life.

While the included theories varied in their dimensions of end-of-life decision making, informed and shared decision making models (Charles et al., 1997; Charles, Gafni, & Whelan, 1999) that focused on the degree to which patients participated in the decision making process were the most commonly cited theories. Although there is a growing emphasis on the cultural context of end-of-life care for persons with cancer, heart failure, and ALS, few of the theories examined included dimensions of culture, family, or personal values as these pertain to decision making. It is possible that focusing on these dimensions was uncommon because many of the studies examined were conducted in the United States, Canada, and Europe, where patient autonomy is accorded a high value in health policy and practice of health professions. In contrast, many non-Western cultures value the inclusion of family in end-of-life decision making over patient autonomy (Back & Huak, 2005; Tang et al., 2005). In these cultures, end-of-life decisions are rarely made by the individual patient. This has important implications for patients with cancer, heart failure, and ALS and their caregivers, since not understanding or facilitating cultural norms around end-of-life decision making can lead to conflict between the patient/family and health care team. One potential solution is an interdisciplinary team approach to better understand and facilitate patient decision making. Although there are potential challenges to achieving high-functioning, interdisciplinary care teams, including differences in theoretical positions (Connor, Egan, Kwilosz, Larson, & Reese, 2002), the interdisciplinary team approach may better facilitate patient decision making, as multiple health care providers can help address the various personal, sociocultural, and spiritual dimensions of decision-making. Our interdisciplinary conceptual framework can provide a foundation for research around end-of-life decision-

making by including patients, caregivers and cultural concepts and synthesizing concepts originated from multiple disciplines such as psychology and sociology.

We excluded nearly nine in ten articles in the title and abstract review because the articles did not explicitly incorporate theory into the study design. This is concerning, considering the merits of using theory in empirical research. For example, hypothesis testing with theory-driven instruments and analyses is crucial for strengthening the validity of study findings. Twenty-four out of 35 quantitative research articles that were included in this review applied or tested at least one concept of a theory, yet the articles did not clearly address how concepts were operationalized. McQuiston and Campbell (1997) highlighted the benefits of substruction, “a hierarchical model that progresses from the abstract to the concrete, relating key concepts, propositions and operationalizations,” in order to assure the congruence of both the conceptual and operational components of the theory tested. Theory testing research using substruction can be a powerful tool to contribute to the body of knowledge in the field of end-of-life decision research.

Studies have revealed that decision making is a cyclical, iterative process with a number of steps needed to reach a desired outcome (Cristancho et al., 2016; Segal, 1982). Decision making across the end of life trajectory is also a cyclical, iterative process where the decision process and decision outcomes are equally important to study. For instance, within the context of advanced illness, the process of decision making at the end of life may lead to positive or negative decision outcomes, and the experiences with particular decision processes and/or outcomes may inform future decisions throughout the illness trajectory. Despite the critical importance of understanding both process and outcome components of decision making, the majority of articles in this study predominantly focused on the decision-making process. Only eight articles used theory to focus on the outcomes of end-of-life decision making such as regret, satisfaction, and conflict. This is concerning because it is essential to understand how patients and their caregivers reflect on the outcome of their decisions in order to achieve high-quality, end-of-life care across the continuum of the illness trajectory. Future research should examine how patients and caregivers view the outcomes of care at the end of life as well as the decision-making process, thereby offering a tailored approach to informed and shared decision making processes by patients and their caregivers,’ based on reflection of past decisions.

This systematic review has limitations. First, although we conducted a rigorous electronic search using three comprehensive databases, there is a possibility relevant articles were missed. However, we conducted a systematic search using relevant MeSH terms after consulting with a trained health science librarian to reduce this chance. Second, we included studies conducted among patients with cancer, heart failure, and ALS. We did not report theories used in end-of-life decision-making among subgroups of patients by race, gender, educational level etc.; thus it is difficult to evaluate how a theory can be used in subgroups of patients. In addition, since the review was limited to studies focusing on patients with these three diseases, the findings cannot be generalized to patients with other diseases. Lastly, the Painter et al. (2008) classification system has been rapidly used by a wide range of researchers from diverse disciplines. However, we acknowledge that the classification system’s definition for the creation of theory may be different from other definitions of what

creating a theory entails. Despite these limitations, this systematic review has strengths. This is the first systematic review to evaluate the use and development of theory in published articles on end-of-life decision-making. We also developed The Conceptual Framework for Individual and Family End-of-Life Decision Making that consists of six key themes: the context of decision making, communication and negotiation of decision-making, characteristics of decision makers, goals of decision-making, options and alternatives, and outcomes of decision-making. This new conceptual framework has the potential to offer guidance for nuanced decision making research with a wide variety of applications. The framework could be applied to a variety of illnesses (e.g., cancer, heart failure, ALS), illness trajectories (e.g., unpredictable vs. steady decline), groups of individuals (e.g., families, caregivers, health care providers), and studies with specific decision making objectives (e.g., process and/or outcome oriented study). Future research should enhance and apply the framework to guide research to develop patient-centered decision-making programs that facilitate informed and shared decision-making at the end of life among patients with advanced illness and their caregivers.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Conceptual Framework for Individual and Family End-of-Life Decision Making

Table 1.

Summary of the studies that used theory

Source	Study aims	Methodology and Sample	Theory*	Theory use
Studies that mainly focused on patients and used decision making models				
Desharnais (2007; USA)	Test the effects of physician-patient communications regarding health care decision making at the end of life	Cross-sectional; 22 Physicians and 71 cancer patients with either congestive heart failure or advanced cancer, with < 6 months to live	Donabedian's framework to explore barriers for patients seeking health care (Process)	Informed by theory
Elliott (2010; Australia)	What do cancer patients at the end of life report about choosing to refuse CPR?	Qualitative approach; 28 adult advanced cancer patients and attending palliative or oncology clinics of a teaching hospital	Paternalist, consumerist, & shared decision making models (Process)	Shaped the results
Ferrell (2003; USA)	Explore the decision making of patients with advanced disease and surgeons	Content analysis; 10 advanced cancer patients and 3 oncology surgeons	Clinical decision making in palliative surgery (Process)	Informed by theory
Gattellari (2002; Australia)	Are patients with terminal cancer appropriately informed and invited to participate in care decisions?	Mixed methods; 118 cancer patients with incurable disease	Informed and shared decision-making models (Process + outcome)	Applied theory
Heyland (2003; Canada)	Examine the patient's preferred role in decision making and his/her provider's perception of this preference	Prospective cohort study: 135 patients with congestive heart disease, cirrhosis, chronic pulmonary disease, or metastatic cancer	Heyland et al.'s framework for decision making near the end of life (Process)	Applied theory
Koedoot (2003; Netherlands)	What is the patient's chemotherapy treatment preference? What factors predict the actual decision outcome?	Prospective; 140 patients with metastatic cancer for whom palliative chemotherapy was a treatment option	Unnamed conceptual model developed by authors (Process)	Testing theory
Maida (2010; Canada)	Investigate patients' preferences surrounding commonly-offered active and aggressive medical treatments	Cross-sectional; 380 advanced cancer patients referred to a regional palliative medicine consultative program	Shared, paternalistic, consumer decision making models (Process)	Testing theory
Mo (2011; Korea)	How are cancer patients involved in decision making, and how does this impact quality of life/quality of death?	Cross-sectional; 93 terminal cancer patients recruited from 31 inpatient palliative care centers	Unnamed conceptual model developed by authors (Process + outcome)	Testing theory
Murray (2003; Canada)	What are decision-making needs of women with terminal illness?	Mixed methods; 20 terminally ill women	O'Connor et al.'s Ottawa decision support model (Process)	Testing theory
Noguera (2014; multiple countries)	Examine the decision-control preferences, level of informational disclosures, and satisfaction reports of Hispanic patients	Cross-sectional; 387 patients with advanced cancer referred to palliative care services	Passive decisional control models, traditional/paternalistic models of medical decisional control (Process)	Testing theory
Ozanne(2008; USA)	Do metastatic breast cancer patients have advance directives, and, if so, with whom have they talked about these?	Longitudinal; 32 women with metastatic breast cancer and 21 providers	Shared decision making model (Process)	Testing theory

Source	Study aims	Methodology and Sample	Theory*	Theory use
Rose (2004; USA)	Examine relationships between survival estimates, quality of life predictions, treatment preferences, and outcomes?	Cross-sectional; 720 middle-aged and 696 older patients with advanced cancer	Conceptual model for near end-of-life decision making developed by the authors (Outcome)	Testing theory
Smith (2011; USA)	Test effects of decision aids for patients with cancers contemplating chemotherapy	Experimental; 27 advanced breast, lung, colorectal, and prostate cancer patients	Ottawa decision support framework (Outcome)	Applied theory
Vogel et al. (2013; USA)	Test the effect of a website on advance directives and palliative care consult	Experimental; 35 women with stage III/IV or recurrent ovarian cancer	Informed and shared decision making models (Process)	Applied theory
Family centered approaches				
Back (2005; Singapore)	Examine extent of non-disclosure of cancer diagnosis, and resulting decisions	Prospective audit; 369 consecutive new patients referred to a radiation oncologist	Freedman's family centered model (Process)	Informed by theory
Bakitas (2008; USA)	Examine the experience of family proxies in end of life care	Cross-sectional; 125 family proxy respondents of deceased cancer patients	Teno et al.'s patient-centered, family-focused model (Process)	Testing theory
de Graaff (2012; Netherlands)	How do the care styles of families and providers impact patients' communication and decision making experiences?	Qualitative thematic and contextual analysis; 83 respondents; 6 patients, 30 relatives and 47 providers	Janzen's Therapy Management Group (Process)	Shaped the results
Gardner (2008; USA)	Explore patterns of relationship, support, and communication in married couples	Thematic analysis; 35 advanced cancer patient/partner dyads	Symbolic interactionism and family systems theories (Process)	Shaped the results
Heyland (2006; Canada)	What is the information need of older inpatients at the end of life and their family members?	Cross-sectional; 439 older inpatients with end-stage cancer and advanced medical diseases and 160 caregivers	Shared decision-making model (Process + outcome)	Testing theory
Hinderer (2015; USA)	Explore patient and proxy decision related to mechanical ventilator withdrawal in 3 scenarios	Cross-sectional; 59 patients with cancer, stroke, and heart failure and 51 inexperienced proxies	Buchanan et al.'s surrogate decision making and Fin et al.'s contractual-covenantal hypothesis (Process)	Testing theory
Kramer (2010; USA)	What are the factors involved in family conflict as reported by family members?	Cross-sectional; 155 deceased lung cancer patients and their family members	Kramer et al.'s explanatory matrix of family conflict (Process)	Testing theory
Siminoff (2006; USA)	Develop and validate an instrument to assess the level of family discord in late-stage cancer treatment	Instrument development and validation; 43 patients with advanced stage non-small cell lung cancer and 67 family caregivers	Kissane et al.'s Family focused grief therapy model (Process)	Applied theory
Stein (2013; Australia)	Test the effect of written information and a discussion on the timely signing of DNR orders and location of death	Experimental; 120 patients with metastatic cancer and 87 caregivers	Shared decision-making model (Process)	Applied theory
Tang (2005; Taiwan)	Examine the extent of agreement between cancer patients and their caregiver	Cross-sectional; 617 dyads of terminally ill cancer patients—family caregivers	A model of family autonomy vs. patient autonomy (Outcome)	Testing theory

Source	Study aims	Methodology and Sample	Theory*	Theory use
Behavioral change models				
Waldrop (2012; USA)	How do patients and families decide about hospice enrollment and timing?	Qualitative approach; 36 patients and 55 caregivers who had recently made the decision to enroll in hospice	Janis and Mann's conflict theory model of decision making (Process)	Shaped the results
Klinkenberg, (2004; Netherlands)	Describe medical care preferences of older patients at the end of life	Cross-sectional; 270 proxy respondents of 342 deceased persons	Bandura's self-efficacy theory (Process)	Testing theory
Nolan (2008; USA)	What are preferences of ALS patients to involve family in end-of-life decisions?	Mixed methods; 16 patient-family dyads of patients with ALS	Bandura's Self-efficacy theory (Process)	Applied theory
Nolan (2009; USA)	Develop and validate a scale to measure caregiver confidence in making decision with/for a terminally ill loved one	Instrument development and validation; 30 family members of patients with ALS and pancreatic cancer	Bandura's Self-efficacy theory (Process)	Applied theory
Sharf (2005; USA)	Explore why lung cancer patients refused further diagnosis and treatment advice.	Grounded theory; 9 patients who have a diagnosis of non-small cell lung cancer	Health Belief Model and self-efficacy theory (Process)	Guided interview questions
Volker(2011; USA)	How does a group of diverse advanced cancer patients explain control preferences at the end of life?	Hermeneutic, phenomenological approach; 20 adults with an advanced cancer diagnosis	Lewis's conceptual typology of control (Process)	Shape the results
Walczak (2015; Australia)	Can a nurse-administered program facilitate patient-family discussion of the plan of care at the end of life?	Thematic analysis with an inductive approach; 31 advanced cancer patients and 11 family caregivers	Self-determination theory of health-related behavior change (Process)	Applied theory
Yun (2011; Korea)	Can a decision aid help families discuss terminal prognoses?	Experimental; 444 family caregivers of patients with cancer	Trans theoretical model (Process)	Testing theory
Other theories				
Drevdahl (2012; USA)	What are the connections between transitions, decision making, and decisional regret?	Qualitative exploratory longitudinal study; 25 patients undergoing stem cell transplant and 20 caregivers	Regret theory (decision regret); transitions theory (Outcome)	Shaped the results
Henoch (2011; Sweden)	What are the perceptions of quality of care and relationships between patients with cancer and their family members?	Cross-sectional; Dyads with patients with lung cancer and their families (N=51)	Wilde et al.'s quality from the patient's perspective (Process)	Testing theory
Mehta (2011; Canada)	How do family caregivers manage cancer patients' pain in the home setting?	Grounded theory; 24 family caregivers of patients with advanced cancer	Mehta et al.'s the puzzle of pain management (Process)	Shaped the results

Note:

* Theories that are related to decision making have been included.

** Abbreviation: ALS, amyotrophic lateral sclerosis