Palliative and Supportive Care (2015), **13**, 815–825.

doi:10.1017/S1478951514000388

Family communication and decision making at the end of life: A literature review

CARA L. WALLACE, L.M.S.W.
University of Texas at Arlington, Arlington, Texas

(Received February 20, 2014; Accepted March 4, 2014)

ABSTRACT

Objective: Patients and families coping with a terminal illness are faced with a number of decisions over the course of their disease. The role that family communication plays in the process of decision making is an important one. The objectives for this review are to examine the current state of empirical literature on the relationship between family communication and decision making about end-of-life care, to identify gaps, and to discuss implications for policy, practice, and future research.

Method: Articles were identified using systematic keyword searches within the following relevant databases: Academic Search Complete, CINAHL Plus, Communications and Mass Media Complete, ERIC, PsychINFO, MEDLINE, SocINDEX, and ProQuest.

Results: The three bodies of relevant literature that emerged during this review include: (1) the importance of family communication at the end of life (EoL); (2) family decision making at the EoL; and (3) the interrelationship of communication (both within the family and with healthcare professionals) and decision making at the EoL. While the literature highlights the role of communication between medical professionals and the patient or family members, there is very little focus on the process of how family communication among the family members themselves contributes to decision making at the end of life.

Significance of results: Barriers to end-of-life care are important considerations for helping patients to access timely and appropriate services. Understanding the pertinent role of family communication as it relates to the decision for EoL care is the first step in working to provide another avenue for overcoming these barriers.

KEYWORDS: Hospice, End of life, Decision making, Family communication, Literature review

INTRODUCTION

Patients and families coping with a terminal illness are faced with a number of decisions over the course of their disease. The decision to continue further treatment versus utilization of a palliative approach, such as hospice, is often one of the most difficult and complex decisions they face. Communication between patient and family is supremely important and can serve as either a barrier or facilitator within the transition to hospice care (Waldrop & Rinfrette, 2009). Barriers and facilitators to end-of-life (EoL) care are important considerations in helping patients to access timely and appropriate services. Family is a significant factor in a patient's choice of palliative care (Zhang & Siminoff, 2003), and they tend to place greater importance on communications related to EoL care within their family than with healthcare professionals (Meeker & Jezewski, 2005). The objectives for our review are to examine the current state of empirical literature on the relationship between family communication and decision making about end-of-life care, to identify gaps, and to discuss implications for policy, practice, and future research.

One study that drew great attention to the need for improved communication and for EoL care in general, funded by the Robert Wood Johnson Foundation, was the Study to Understand Prognoses and

---

Address correspondence and reprint requests to: Cara L. Wallace, 4000 Vernon Way, University of Texas at Arlington, Fort Worth, Texas 76244. E-mail: Cara.wallace@mavs.uta.edu

Preferences for Outcomes and Risks of Treatment (SUPPORT). The SUPPORT study was conducted in two phases between 1989 and 1994 and documented multiple problems for adults dying during acute hospitalization (Connor, 2009). The goal of that study was to "improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying" (SUPPORT Principal Investigators, 1995, p. 1591). Phase 1 of the study included 4,301 patients within five teaching hospitals and focused on the following objectives: describing outcomes, developing prognostic models, identifying shortcomings of care, establishing adjustment methods, and designing an intervention. The results documented "substantial shortcomings in communication, decision making, and outcomes" (p. 1593). Phase 2 of the study provided an intervention focused on improving communication and decision making by providing physicians with prognostic models to assist in estimating likelihood of disability or death, in addition to the use of a clinical nurse trained to meet with patients and families in order to discuss and document wishes. The results of phase 2 did not produce any significant differences between the control (care as usual) and intervention groups (randomized by physician group) across any of the five outcomes studied, one of which included patient–physician agreement on CPR preferences (SUPPORT Principal Investigators, 1995). Ultimately, the results of the study demonstrated that providing additional information to physicians alone did not make for any difference in outcomes of care (Schroeder, 1999) or in increased communication between patients and physicians, as it appeared that physician behavior remained unchanged (SUPPORT Principal Investigators, 1995).

Since the SUPPORT study, there has been a push to improve EoL care, and foundations have provided opportunities for research and education (Bern-Klug, 2004). As a result, much of the literature within EoL care has focused on barriers to care and decision making at the end of life; only a few studies have explored the important role of family communication. Much of the focus has been on improving health communication with providers, another important variable. However, understanding the pertinent role of family communication as it relates to the decision on EoL care is the first step in working to provide another avenue for overcoming these barriers.

In considering the relationship between family communication and decision making, one must also consider the impact of culture. Ballard-Reisch and Letner (2003) highlight the role of both culture and family communication within the management of cancer. Shrank and colleagues (2005) demonstrate the importance of the underlying beliefs and values of patients and family members in attaining optimal EoL communication. Important dimensions for these cultural factors are discussed in the relevant sections throughout this review.

Awareness of barriers within different cultures is important in helping to increase access, as barriers impact decision making for EoL care. For example, cited cultural barriers within the African-American community include religious/spiritual value conflicts (such as the belief in a cure or the role of suffering), distrust in the healthcare system (Bullock, 2011; Schmid et al., 2010; Shrank et al., 2005), and belief in the importance of preservation of life over quality of life (Shrank et al., 2005). Barriers for immigrants include geographical distance from family members, language differences, a lack of insurance, fear of deportation, and discrimination (Smith et al., 2009). Though a comprehensive discussion on cultural barriers to EoL care is beyond the extent of the present review, some cultural aspects related to understanding the constructs and relationship between family communication and decision making are included.

SEARCH METHODS AND INCLUSION CRITERIA

For inclusion within this literature review, studies had to be empirically based and published in a peer-reviewed journal or dissertation database. Initially, selected literature had to address both family communication and decision making as observed constructs and had to be within the context of terminal illness or end-of-life care. Due to varying structures of healthcare options at the EoL across countries, reviewed literature was limited to within the United States. After discovering a scarcity of empirical literature that addressed both family communication and decision making at the end-of-life, the criteria were expanded to include secondary articles relating to each of these constructs separately, yet still within the context of EoL care. These secondary areas were included to provide greater depth within this review but are not exhaustive of the current literature in these separate areas. Instead, a synthesis of the relevant literature related to the interrelationship of family communication and decision making is presented. The articles in the secondary areas were similarly identified with the initial articles using the search methods described directly below.

Articles were identified using systematic keyword searches within the following relevant databases: Academic Search Complete, CINAHL Plus, Communications and Mass Media Complete, ERIC, PsychINFO, MEDLINE, SocINDEX, and ProQuest (searches conducted during June of 2013). No timeframe limitations were implemented within the searches; however, resulting articles were published within the past 30 years, with the majority in the past decade. Key search terms included "family communication," "communication," "family," "end of life," "end-of-life care," "decision making," "patient family communication," "health communication," and "terminal illness." Initially, articles were screened by abstract only and saved into files by topic. After search completion, full articles were screened using the above-identified inclusion criteria. Reference lists of key articles were also explored for additional relevant literature. The three bodies of relevant literature that emerged during this review include: (1) the importance of family communication at the EoL, (2) family decision making at the EoL; and (3) the interrelationship of communication (both within the family and with healthcare professionals) and decision making at the EoL. Primary research methodologies that are useful in understanding these relationships are also described.

IMPORTANCE OF FAMILY COMMUNICATION AT THE END OF LIFE

Within palliative care, the patient and family are recognized as the unit of care (Connor, 2009), versus focusing on the patient alone. One approach, family-focused grief therapy, recognizes the importance of intervening with families preventatively during palliative care based upon types of family functioning, resulting in reduced distress for bereaved family members (Kissane et al., 2006). Outside of palliative care, some argue that family-centered care or collaborative approaches that involve family members are more appropriate than the traditional client-centered approach (Hardwig, 1990; Hidecker et al., 2009). While patient autonomy is a core value in Western medicine, other cultural groups may not share this value, suggesting an even greater need for involvement of family members (Ballard-Reisch & Letner, 2003; Volker, 2005). Research has shown that whites are more likely to prefer autonomous decision making than blacks (Bullock, 2011) and are likely to be more exclusive regarding whom to include in discussions, whereas blacks are more inclusive, often extending participants beyond family to close friends and spiritual leaders (Shrank et al., 2005). A number of studies have also shown family-centered models of decision making as preferred by Mexican and Korean Americans (Ballard-Reisch & Letner, 2003). Merging person-centered planning with family-focused care is offered as one suggestion for enhancing EoL care and transitions for patients with intellectual disabilities (Kirkendall et al., 2012). Family members are most likely to be the designated person within caregiving; in addition to this involvement, family influence plays a dominant role in a person's development of values, health attitudes, and behaviors (Pecchioni et al., 2006), all of which are key variables in decision making (Shrank et al., 2005).

With the prominent role of family during illness and at the end of life, family communication is an important consideration. Segrin and Flora (2005) define communication as "a transactional process in which individuals create, share, and regulate meaning" (p. 15). Though multiple definitions of family communication exist, the one accepted in the context of this review is "the act of making information, ideas, thoughts, and feelings known among members of a family unit" (Olson & Barnes, 2003, p. 1). Much of the literature on family communication provides insight into its importance at the end of life. This portion of the review examines the content of EoL conversations, important outcomes of family communication, and the challenges within family communication.

CONVERSATIONS AT THE END OF LIFE

Both patients and caregivers desire more communication at the end of life (Fried et al., 2005). Even though multiple studies suggest the absence or difficulty of family communication at the EoL (Boehmer & Clark, 2001; Fried et al., 2005; Gotcher, 1995; Zhang & Siminoff, 2003), others provide insight into the content of final conversations between family members. Final conversations are defined as any communication between the time of diagnosis and death (Keeley, 2007). Badr and Taylor (2006) characterized four different areas of relationship talk that emerged from separate interviews with patients and their spouses. The quality of the relationship, relationship memories, planning for the future, and problem solving all became topics of conversation during the cancer experience (Badr & Taylor, 2006). Messages about love, personal and relational identities, faith, routine interactions, and the difficulty of past relationships are conveyed in final conversations between dying patients and their family members (Keeley, 2007). Conveying love, gratitude, forgiveness, and farewell in conversations at the EoL are also considered important (Byock, 1996).

The impact of conversations directly related to EoL topics was a significantly stronger indicator than agreement between patient and family members about the need for communication (Abbey, 2009). In other words, whether patients and families agree on the desired amount of talking does not matter as much as whether the conversation occurs at all. Results from Wittenberg-Lyles and colleagues (2012) support this finding in that "conformity in family communication [does] not equate with family agreement or open communication" (p. 25).

OUTCOMES OF FAMILY COMMUNICATION

A number of studies have considered the impact of family communication on patient and/or family functioning through a variety of approaches. Increases in the frequency of, level of honesty in, and satisfaction with family communication along with emotional support had positive impacts on effective adjustments of terminally ill patients (Gotcher, 1993). Other studies considered the positive effect of family communication on psychosocial adjustment resulting in increased communication about the relationship (Badr & Taylor, 2006). In the opposite direction, a lack of communication between patients and family members was found to present an increased risk of poor adjustment for prostate cancer patients (Boehmer & Clark, 2001). The ability to express emotion, like within the definition of family communication provided above, was associated with a decrease in pain for cancer patients (Dalton & Feuerstein, 1989). Increased discussion of EoL topics was also associated with less distress and enhanced quality of life (Abbey, 2009).

Communication constraints, which developed due to a desire to protect patients or family members, has been documented as a predictor of family conflict (Kramer et al., 2010). Many studies have considered the impact of family communication on the caregivers instead of on the patients themselves. EoL conversations have multiple positive functions for bereaved family members, such as affirmation of their relationship with the patient, sense of closure of the relationship, validation of beliefs, and reconciliation (Keeley, 2007). Self-efficacy and increased length of caregiving were associated with greater perceived levels of open communication by caregivers, while emotional exhaustion and depression of caregivers were associated with lower perceived levels of open communication (Bachner & Carmel, 2009).

CHALLENGES IN FAMILY COMMUNICATION

In addition to positive outcomes, challenges in family communication at the end of life cannot be ignored. Across multiple studies, findings show a large prevalence of patients and families that experience communication difficulties. In a study that surveyed 193 terminally ill patients and their caregivers, 39.9% of caregivers desired more communication along with 20.2% of patients (Fried et al., 2005). Within the same study, 37.3% of caregivers and 22.3% of patients reported that communication was difficult. Two thirds of a sample of 26 lung cancer patient–caregiver dyads reported communication problems (Zhang & Siminoff, 2003), while in a sample of 78 breast cancer patients and their significant others, one fourth reported strained communication (Lichtman et al., 1987).

The nature of terminal illness itself causes the potential for communication difficulty due to the physical progression of illness, which diminishes the ability of patients to communicate normally (Planalp & Trost, 2008; Stone et al., 2012). Patient impairments, alongside the geographical distance between family members, are situational factors that influence difficult communication (Stone et al., 2012). Other natural responses to terminal illness, such as a wide range of emotions (Planalp & Trost, 2008; Zhang & Siminoff, 2003), denial (Planalp & Trost, 2008), and family conflict (Kramer et al., 2012; Planalp & Trost, 2008) also make family communication more challenging. Relational influences—for example, role changes and the influence of multiple family members—are cited as increasing communication difficulty (Stone et al., 2012). Avoidance, belief in the power of positive thinking, and psychological distress (Zhang & Siminoff, 2003) along with the belief that talking about concerns might hasten death or reoccurrence (Lichtman et al., 1987) are other variables that contribute to complexity in communication.

FAMILY DECISION MAKING AT THE END OF LIFE

Research on decision making at the end of life has invariably discovered family members to be at the center of things (Cohen et al., 2010; Hiltunen et al., 1999; Karasz et al., 2010; Tschann et al., 2003). Though Hiltunen and colleagues (1999) anticipated studying accounts of patients' decisional conflict in their review of narrative accounts from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), they found that the majority of decisions were actually made by family members. The presence of family members at the time of death when compared to patients who died alone is an indicator for greater presence of do-not-resuscitate (DNR) orders, documentation of withdrawn treatments, and use of pain medication prior to death (Tschann et al., 2003). These findings suggest that family involvement increases the use of comfort care within the hospital for dying patients, also implying that family members play a role in making these decisions.

While it is often assumed within the American healthcare system that patients will make care decisions when they are alert and able to, multiple cultures prefer family decision making, or collectivism and interdependence, versus individualism and independence (Candib, 2002; Johnstone & Kanitsaki, 2009). In a milestone study regarding culture and the end of life, Blackhall and colleagues (1995) found great variation across cultures within the United States (Korean, Americans, Americans, and African Americans) about whether or not a patient should be told of their diagnosis (47, 65, 87, and 88%, respectively) or about a terminal prognosis (35, 48, 63, and 69%). Ultimately, suggestions for providing culturally competent care at the EoL involve the inclusion of family and assessment on the role of cultural preferences related to decision making and other values and beliefs (Bullock, 2011; Stein et al., 2009).

Eight informal roles for family members across four differing intensive care units emerged during an ethnographic study spanning from 2001 to 2004: primary caregiver, primary decision maker, family spokesperson, out-of-towner, patients' wishes expert, protector, vulnerable member, and healthcare expert. Each of these roles was tied to the decision-making process for families at the end of life, often creating a complicated dynamic (Quinn et al., 2012). Within this context of decisional conflict (Hiltunen et al., 1999), a decision-making process was identified involving several stages: recognition of a dilemma, a period of vacillation, moving to a turning point, and letting go. Additional challenges in decision making for families included the need for multiple decisions throughout the process, the multiple perspectives of family members, and the presence of family members at different stages within the decision-making process at any given time (Hiltunen et al., 1999). A second identified process for family decision making at the EoL includes cognitive, affective, and interpersonal steps guiding family members to understand a patient's condition, identify a patient's preferences for treatment, and continue familial roles, respectively. These processes ultimately help family members to understand a patient's unlikelihood of recovery, enabling them to make a decision (Swigart et al., 1996).

PROXY DECISION MAKING

As noted above, family members are often called upon to make decisions with or on behalf of patients with advanced illness (Meeker & Jezewski, 2005). Though historically medical decision making was in the hands of physicians who were sworn to the Hippocratic Oath (Meeker & Jezewski, 2005), current models are based upon a model of rational choice, which emphasizes a patient's stated wishes first, followed by substituted judgment about what a patient would decide, and, last, the patient's best interest (Drought & Koenig, 2002; Karasz et al., 2010; Meeker & Jezewski, 2005). One of the challenges with this model is the overwhelming lack of implementation of "advance directive" and "living will" paperwork, designating someone's choices at the EoL (Bomba et al., 2011; Fagerlin & Schneider, 2004; Glass & Nahapetyan, 2008; Lang & Quill, 2004). Minorities are often cited as completing advanced directives at even lower rates than Caucasians (Bullock, 2011; Cohen et al., 2010; Volker, 2005). In observation of the decision-making process between staff and family members of 26 patients, Karasz et al. (2010) suggested that consideration of best interest took precedence over a patient's wishes. Additional arguments against the use of living wills in decision making include the unpredictability of complex conditions and potential choices, ambiguous understanding of one's wishes prior to facing the need for decisions, and the ability of proxies to interpret their loved ones' documented choices (Fagerlin & Schneider, 2004). An evaluation of published reports from the SUPPORT study showed that the likelihood of a surrogate understanding their loved ones' preferences was barely better than chance (Covinsky et al., 2000).

Prior to the need for proxy decision making, multiple studies have considered whether or not patients and their designated proxy matched with regard to EoL preferences (Ditto et al., 2001; Parks et al., 2011; Schmid et al., 2010). In a systematic review examining family decision-making experiences, Meeker and Jezewski (2005) found that proxies demonstrated low to moderate accuracy in predicting choices. Proxy accuracy was significantly higher when a spouse or partner served as proxy versus an adult child or other, and increased accuracy across proxy types was associated with lower family conflict (Parks et al., 2011). Other variables that increased accuracy included conditions of forced choice and directed use of substituted judgment (Meeker & Jezewski, 2005).

THE INTERRELATIONSHIP BETWEEN COMMUNICATION AND DECISION MAKING

The literature on health communication is heavily focused on the relationship between patients or their family members and healthcare practitioners (Zhang & Siminoff, 2003). Though the purpose of this review is to explore how interaction within a family relates to decision making, it is important to examine the more general context of the relationship between health communication and decision making as well. This section of the review considers the relationship between communication with healthcare providers and end-of-life decision making, the relationship between advance directives (as an instrument for decision making) and family communication, and, finally, literature that links family communication and decision making at the EoL.

COMMUNICATION WITH HEALTHCARE PROVIDERS

One study found that inadequate communication with physicians was the most significant barrier influencing quality at the end of life (Eues, 2007). In a study examining 100 patients already enrolled in a hospice program, 30% were not aware of their diagnosis and 62% had no awareness of their prognosis (Andruccioli et al., 2007). Other studies have discussed physicians' inability to communicate clearly about diagnosis and prognosis with patients for a variety of reasons. Hospice experts identified physicians' personal discomfort with death and lack of training and experience in EoL care as barriers to communication and work with dying patients and their families (Friedman et al., 2002). Another suggested that the reason is that physicians are reluctant to inform patients about impending death due to anxiety about their own mortality (Feifel, 1969, as cited in Neimeyer et al., 2004). Higher death anxiety in physicians has been related to greater difficulty disclosing prognoses (Kvale et al., 1999) along with consideration of more factors before breaking bad news to patients (Eggerman & Dustin, 1985). An additional concern is that minority patients may receive this information at an even lower rate. Thornton (2008) found that, after reviewing data from the SUPPORT study, physicians reported having prognostic conversations with only 41% of African Americans compared to 58% of white patients.

Other barriers that contribute to problematic communication between practitioners and patients include our death-denying culture, patient denial, and the focus within the American healthcare system on cure (Hickman, 2002). Ultimately, patients and families cannot talk or make decisions about something they are not even aware of. Hickman (2002) suggested that inclusion and involvement of family members is one way to overcome barriers and enhance decision making at the end of life.

In contrast to the literature that documents physicians' lack of communication, many empirical studies have attempted to evaluate the effectiveness of the communication that does in fact occur. In interviews with family members who experienced loss of their loved one in an acute hospital, Radway and colleagues (2009) found that decision making in family meetings was one of the three salient experiences that related to emotional burden for caregivers. Additional identified barriers to effective provider–family communication include multiple or alternating physicians in acute settings (Baggs et al., 2012), inadequate time conversing with family, inconsistent use of multidisciplinary teams, and lack of frequent communication (Ahrens et al., 2003). Promoting excellent communication between physicians and family members is one way to lessen caregiving burdens (Rabow et al., 2004). Normal communication typically happens in an informal fashion and not until care providers have already reached a consensus that restoration or survival is unlikely (Lilly & De Meo, 2000) or until a decision has to be made (Hines et al., 1997). The use of communication interventions involving interdisciplinary team meetings shortly following admission and daily communication from consistent team members has been shown to decrease the length of stay in critical care, to lower hospital costs, and allow for earlier access to palliative care (Ahrens et al., 2003; Lilly & De Meo, 2000).

ADVANCE PLANNING AND END OF LIFE PREFERENCES

While "advance directives" are meant to be useful in decision making, the complementary variable of communication provides additional benefits. In fact, planning for care at the EoL and making decisions are "fundamentally relational" (Jennings & Morrissey, 2011). Meeker and Jezewski (2005) found that group decision making among a family was preferred over use of an individual surrogate, indicating the need for communication between family members. Open family communication was found to be an indicator for improved congruence in care preferences between terminally ill patients and their caregivers by Gardner and Kramer (2009). Family members who discussed patients' advance directives with them also reported greater confidence in their ability to serve as a proxy, even though it did not improve accuracy in predicting patients' choices (Ditto et al., 2001). Overall, family communication about EoL preferences serves a greater purpose for decision making than completion of advanced directives alone. Barriers to these discussions, also discussed above under challenges in family communication, include fear of death, trust in others to make decisions, and challenging family dynamics. Prior experiences of death, acknowledgement of the reality of death, and spirituality are facilitators of family communication about EoL preferences (Elliott et al., 2009).

FAMILY COMMUNICATION AND DECISION MAKING

Unfortunately, there are no consistent patterns in how family communication and decision making are studied in relation to one another, though both family and communication are regularly considered in relation to decision making. Babcock and Robinson (2011) present a model of "seven core components of communication and decision making" that includes specific interventions for counselors to assist the family unit in navigating the process of decision making. The seven components include getting ready to work with the family and other systems, assessing the situation, managing conflict, providing information, identifying roles, processing familial responses, and follow through. While this model provides a framework for helping families to communicate during the decision-making process, the processes specific to how the patient and family members communicate among themselves were not considered.

Waldrop and Meeker (2012) investigated the role of family in their study on understanding decision making surrounding hospice enrollment. In order to be enrolled in the study, patients had to score 40 or above on the Palliative Performance Scale (PPS), indicating an ability to communicate. Family members were also involved in the interviews, due to the authors' understanding of family involvement within the decision-making process. Using the conflict theory model (CTM) of decision making as a framework to guide the study, explained further below, the authors discovered that the decision-making process prior to hospice encounter varied among cancer diagnoses and other chronic illnesses. Their study's results provide a useful framework for understanding differences in the process of family decision making for hospice by diagnosis, but the role of communication within the family surrounding this process was not explored.

Scott (2010) employed a theoretical perspective of multiple goals to consider how the quality of family communications about EoL decision making is more important than its quantity. Outside ratings of communication from observing family communication were positively associated with reports from patients and their loved ones on satisfaction with the conversation and decision-making efficacy. More research related to informal communication between older adults and their family members (Hopp, 2000) is certainly needed.

METHODOLOGY AND RESEARCH DESIGN

Research at the end of life presents multiple challenges. One of the first is in regard to the vulnerability of terminally ill patients. Worries about terminally ill patients' participation in research include their debilitating physical and psychosocial symptoms, dependency on others for care, and potential cognitive impairment or inability to provide consent (Fine, 2003; Reyna et al., 2007). However, the concern over patients' vulnerable state and inability to participate in research has stunted the growth of evidenced-based knowledge about EoL care (Casarett, 2005; Gysels et al., 2012). In a systematic review of 20 studies considering the impact of EoL research on participants, positive outcomes were seen across each of the different studies, and very few experienced any distress (Gysels et al., 2012). While certainly the focus on potential risk to terminally ill patients should not be minimized, it is also important to recognize the benefit of such research to dying patients, their families, and the field of EoL care at large when appropriate measures are taken to limit risks (Fine, 2003).

In addition to discussion about vulnerable patients, inclusion in research is a secondary consideration about the challenges faced with participation that can impact the research design. For example, recruitment and retention of participants, attrition, and poor health status impacting data collection are all challenges (Addington-Hall, 2007). Due to the relative newness of palliative care research and the subjective constructs often studied, optimal measurement techniques are not agreed upon, making validity a particular challenge (Casarett, 2005). Longitudinal designs are difficult due to high rates of attrition or dropouts, and quasi-experimental and experimental designs are difficult as they may be "too regimented for clinicians accustomed to flexible, patient-centered care" (Head & Ritchie, 2004, p. 40). Some clinicians even worry whether randomization in relation to EoL care is even ethical (Connor, 2009). Though pure experimental models are always desirable, other approaches are also appropriate and valuable (Head & Ritchie, 2004). In fact, with the nature of palliative care utilizing a team approach, it is natural that EoL research also be approached across interdisciplinary fields using a combination of qualitative and quantitative designs (Addington-Hall, 2007; Lloyd et al., 2011).

The SUPPORT study, described earlier, demonstrated that collection of large amounts of quantitative data utilizing a randomization design is possible in EoL research. The feasibility of such a study, though, is an important consideration. While funding was obtained through the Robert Wood Johnson Foundation, a huge funding source within EoL research, the study was their most expensive venture, costing more than $29 million (one of their normally funded projects generally involves less than $500,000) (Schroeder, 1999). Another feasibility concern in research at the end of life is with hospice patients, where the average length of stay is short, causing concern over involving them in a process of informed consent and data collection (Head & Richie, 2004). In prospective studies, even patients who are able to consent upon enrollment may lose that ability at a later point within the study (Casarett, 2005). These challenges are all aspects that need consideration within the methodology of a research study.

Though there has been recent growth in EoL research efforts, they are still overall considered to be relatively small in comparison to other topic areas, leaving many "unanswered questions" (Addington-Hall, 2007, p. 2). Much of the research on decision making and family communication at the end of life is exploratory and descriptive, demonstrating there is still much we do not know about these constructs. Qualitative research methods are common, utilizing focus groups (Bullock, 2011; Cohen et al., 2010; Elliott et al., 2009) and guided or semistructured interviews (Badr & Taylor, 2006; Gardner & Kramer, 2009; Keeley, 2007; Stone et al., 2012), with grounded theory (Badr & Taylor, 2006; Bullock, 2011; Radwany et al., 2009; Wittenberg-Lyles et al., 2012) and/or content analysis (Bullock, 2011; Waldrop & Meeker, 2012) in the data analysis. Cross-sectional designs are common (Kramer et al., 2010; Waldrop & Meeker, 2012), as longitudinal data are difficult to obtain due to the short prognoses of terminally ill patients. Quinn and colleagues (2012) utilized a prospective ethnographic approach to study trends in decision making within four ICUs over an extended period of time from 2001 to 2004. Some studies are retrospective and utilize bereaved family members to portray the EoL experience (Stone et al., 2012). Critiques of this approach include that it does not capture the experiences from the perspective of the terminally ill patients themselves. The amount of time passed from the experience may also have influenced how bereaved family members remembered it.

Due to the exploratory and descriptive nature of studies on decision making and/or family communication at the end of life, measurement tools and scales are not extensively used. The Life Support Preferences Questionnaire (LSPQ) has been employed in quantitative studies about decision making as a measure for treatment preferences when considering proxy accuracy in predicting patients' choices (Parks et al., 2011; Schmid et al., 2010). In both quantitative and qualitative designs, questions about and the presence of advanced directives were often used as an indicator for decision making (Bullock, 2011; Schmid et al., 2010; Tschann et al., 2003; Young & Rodriguez, 2006). Qualitative studies have also considered the process of decision making from the multiple perspectives of patients, family members, or clinicians (Elliott et al., 2009; Gauthier & Swigart, 2003; Quinn et al., 2012). In studies considering family communication at the end of life, self-report measures are most commonly used (Harris et al., 2009). While these tools provide flexibility to family researchers, they collect general impressions of communication versus actual occurrence of behaviors (Metts & Lamb, 2006). The use of previously validated scales to study family communication at the end of life is uncommon.

GAPS AND IMPLICATIONS

While family communication is recognized as a barrier to transition to hospice care, the research surrounding this connection is limited. Research related to the role of familial communication within the decision-making process is warranted, along with further research about how families communicate about their illness in general (Harris et al., 2009). Little is known about the decision-making process for hospice (Chen et al., 2003). While a number of studies describe family members' feelings that communication and information are insufficient, what is meant by communication is not adequately discussed. How this fits together with the way families communicate among themselves seems to be an important consideration that remains overlooked. Also, much of the literature considered within this review is specifically related to cancer and does not apply across the total spectrum of terminal illnesses at the end of life. While cancer patients continue to make up close to half the patients served in palliative programs, these studies do not provide an inclusive picture of other types of patients served by EoL care. A methodological gap includes the use of a recognized measurement scale on either decision making or family communication that is validated for use with terminally ill patients.

Understanding the role of family relationships and types of communication in decision making at the end of life will help clinicians identify and provide support to families who may be struggling to make decisions. Failing to recognize the role of family communication within this process could cause further delay in access to end-of-life care and lessen the overall quality of and satisfaction with the experience.

REFERENCES

Abbey, J.G. (2009). *Communication about end-of-life topics between terminally ill cancer patients and their family members*. Doctoral dissertation. New York: Fordham University.

Addington-Hall, J.M. (2007). Introduction. In *Research methods in palliative care*. J.M. Addington-Hall et al. (eds.), pp. 1–9. New York: Oxford University Press.

Ahrens, T., Yancey, V. & Kollef, M. (2003). Improving family communications at the end of life: Implications for length of stay in the intensive care unit and resource use. *American Journal of Critical Care*, *12*(4), 317–323.

Andruccioli, J., Montesi, A., Raffaeli, W., et al. (2007). Illness awareness of patients in hospice: Psychological evaluation and perception of family members and medical staff. *Journal of Palliative Medicine*, *10*(3), 741–748.

Babcock, C.W. & Robinson, L.W. (2011). A novel approach to hospital palliative care: An expanded role for counselors. *Journal of Palliative Medicine*, *14*(4), 491–500.

Bachner, Y.G. & Carmel, S. (2009). Open communication between caregivers and terminally ill cancer patients: The role of caregivers' characteristics and situational variables. *Health Communication*, *24*(6), 524–531.

Badr, H. & Taylor, C.L.C. (2006). Social constraints and spousal communication in lung cancer. *Psycho-Oncology*, *15*(8), 673–683.

Baggs, J.G., Schmitt, M.H., Prendergast, T.J., et al. (2012). Who is attending? End-of-life decision making in the intensive care unit. *Journal of Palliative Medicine*, *15*(1), 56–62.

Ballard-Reisch, D.S. & Letner, J.A. (2003). Centering families in cancer communication research: Acknowledging the impact of support, culture and process on client/provider communication in cancer management. *Patient Education and Counseling*, *50*, 60–66.

Bern-Klug, M. (2004). The ambiguous dying syndrome. *Health & Social Work*, *29*(1), 55–65.

Blackhall, L.J., Murphy, S.T., Frank, G., et al. (1995). Ethnicity and attitudes toward patient autonomy. *The Journal of the American Medical Association*, *274*, 820–825.

Boehmer, U. & Clark, J.A. (2001). Communication about prostate cancer between men and their wives. *Journal of Family Practice*, *50*(3), 226–231.

Bomba, P.A., Morrissey, M.B. & Leven, D.C. (2011). Key role of social work in effective communication and conflict resolution process: Medical orders for life-sustaining treatment (MOLST) program in New York and shared medical decision making at the end of life. *Journal of Social Work in End-of-Life & Palliative Care*, *7*(1), 56–82.

Bullock, K. (2011). The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care*, *7*(1), 83–98.

Byock, I.R. (1996). The nature of suffering and the nature of opportunity at the end of life. *Clinics in Geriatric Medicine*, *12*(2), 237–252.

Candib, L.M. (2002). Truth telling and advance planning at the end of life: Problems with autonomy in a multicultural world. *Families, Systems & Health*, *20*(3), 213–228.

Casarett, D. (2005). Ethical considerations in end-of-life care and research. *Journal of Palliative Medicine*, *8*(1), S148–S160.

Chen, H., Haley, W.E., Robinson, B.E., et al. (2003). Decisions for hospice care in patients with advanced cancer. *Journal of the American Geriatrics Society*, *51*(6), 789–797.

Cohen, M.J., McCannon, J.B., Edgman-Levitan, S., et al. (2010). Exploring attitudes toward advance care directives in two diverse settings. *Journal of Palliative Medicine*, *13*(12), 1427–1432.

Connor, S.R. (2009). *Hospice and palliative care*, 2nd ed. New York: Taylor & Francis.

Covinsky, K.E., Fuller, J.D., Yaffe, K., et al. (2000). Communication and decision-making in seriously ill patients: Findings of the SUPPORT project. *Journal of the American Geriatrics Society*, *48*(5), S187–S193.

Dalton, J.A. & Feuerstein, M. (1989). Fear, alexithymia and cancer pain. *Pain*, *38*(2), 159–170.

Ditto, P.H., Danks, J.H., Smucker, W.D., et al. (2001). Advance directives as acts of communication: A randomized controlled trial. *Archives of Internal Medicine*, *161*(3), 421–430.

Drought, T.S. & Koenig, B.A. (2002). "Choice" in end-of-life decision making: Researching fact or fiction? *The Gerontologist*, *42*, 114–128.

Eggerman, S. & Dustin, D. (1985). Death orientation and communication with the terminally ill. *Omega: Journal of Death and Dying*, *16*(3), 255–265.

Elliott, B.A., Gessert, C.E. & Peden-McAlpine, C. (2009). Family decision-making in advanced dementia: Narrative and ethics. *Scandinavian Journal of Caring Sciences*, *23*(2), 251–258.

Eues, S.K. (2007). End-of-life care: Improving quality of life at the end of life. *Professional Case Management*, *12*(6), 339–344.

Fagerlin, A. & Schneider, C.E. (2004). Enough: The failure of the living will. *Hastings Center Report*, *34*(2), 30–42.

Fine, P.G. (2003). Maximizing benefits and minimizing risks in palliative care research that involves patients near the end of life. *Journal of Pain and Symptom Management*, *25*(4), S53–S62.

Fried, T.R., Bradley, E.H., O'Leary, J., et al. (2005). Unmet desire for caregiver–patient communication and increased caregiver burden. *Journal of the American Geriatrics Society*, *53*(1), 59–65.

Friedman, B.T., Harwood, M.K. & Shields, M. (2002). Barriers and enablers to hospice referrals: An expert overview. *Journal of Palliative Medicine*, *5*(1), 73–84.

Gardner, D.S. & Kramer, B.J. (2009). End-of-life concerns and care preferences: Congruence among terminally ill elders and their family caregivers. *Omega: Journal of Death and Dying*, *60*(3), 273–297.

Gauthier, D.M. & Swigart, V.A. (2003). The contextual nature of decision making near the end of life: Hospice patients' perspectives. *The American Journal of Hospice & Palliative Care*, *20*(2), 121–128.

Glass, A.P. & Nahapetyan, L. (2008). Discussions by elders and adult children about end-of-life preparation and preferences. *Preventing Chronic Disease*, *5*(1), A08–A08.

Gotcher, J.M. (1993). The effects of family communication on psychosocial adjustment of cancer patients. *Journal of Applied Communication Research*, *21*(2), 176–188.

Gotcher, J.M. (1995). Well-adjusted and maladjusted cancer patients: An examination of communication variables. *Health Communication*, *7*(1), 21–33.

Gysels, M.H., Evans, C. & Higginson, I.J. (2012). Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: A critical interpretive synthesis of the literature. *BMC Medical Research Methodology*, *12*(123), 1–17.

Hardwig, J. (1990). What about the family? *Hastings Center Report*, *20*(2), 5–10.

Harris, J., Bowen, D.J., Badr, H., et al. (2009). Family communication during the cancer experience. *Journal of Health Communication*, *14*, 76–84.

Head, B. & Ritchie, C. (2004). Researching end-of-life care: Challenges, strategies, and opportunities. *Home Healthcare Nurse*, *22*(1), 37–44.

Hickman, S.E. (2002). Improving communication near the end of life. *American Behavioral Scientist*, *46*(2), 252–267.

Hidecker, M.J.C., Jones, R.S., Imig, D.R., et al. (2009). Using family paradigms to improve evidence-based practice. *American Journal of Speech–Language Pathology*, *18*(3), 212–221.

Hiltunen, E.F., Chase, S.K. & Medich, C. (1999). Decisional conflict in families making end-of-life treatment decisions. In *Classification of nursing diagnoses: Proceedings of the thirteenth conference*. M.J. Rantz & P. LeMone (eds.), pp. 467–470. Glendale, CA: CINAHL Information Systems.

Hines, S.C., Babrow, A.S., Badzek, L., et al. (1997). Communication and problematic integration in end-of-life decisions: Dialysis decisions among the elderly. *Health Communication*, *9*(3), 199–217.

Hopp, F.P. (2000). Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: Results from a national study. *The Gerontologist*, *40*(4), 449–457.

Jennings, B. & Morrissey, M.B. (2011). Health care costs in end-of-life and palliative care: The quest for ethical reform. *Journal of Social Work in End-of-Life & Palliative Care*, *7*(4), 300–317.

Johnstone, M. & Kanitsaki, O. (2009). Ethics and advance care planning in a culturally diverse society. *Journal of Transcultural Nursing*, *20*(4), 405–416.

Karasz, A., Sacajiu, G., Kogan, M., et al. (2010). The rational choice model in family decision making at the end of life. *Journal of Clinical Ethics*, *21*(3), 189–200.

Keeley, M.P. (2007). "Turning toward death together": The functions of messages during final conversations in close relationships. *Journal of Social and Personal Relationships*, *24*(2), 225–253.

Kirkendall, A.M., Waldrop, D. & Moone, R.P. (2012). Caring for people with intellectual disabilities and life-limiting illness: Merging person-centered planning and patient-centered, family-focused care. *Journal of Social Work in End-of-Life & Palliative Care*, *8*(2), 135–150.

Kissane, D.W., McKenzie, M., Bloch, S., et al. (2006). Family focused grief therapy: A randomized, controlled trial in palliative care and bereavement. *American Journal of Psychiatry*, *163*(7), 1208–1218.

Kramer, B.J., Kavanaugh, M., Trentham-Dietz, A., et al. (2010). Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer. *The Gerontologist*, *50*(2), 215–225.

Kvale, J., Berg, L., Groff, J.Y., et al. (1999). Factors associated with residents' attitudes toward dying patients. *Family Medicine*, *31*(10), 691–702.

Lang, F. & Quill, T. (2004). Making decisions with families at the end of life. *American Family Physician*, *70*(4), 719–723.

Lichtman, R.R., Taylor, S.E. & Wood, J.V. (1987). Social support and marital adjustment after breast cancer. *Journal of Psychosocial Oncology*, *5*(3), 47–74.

Lilly, C.M. & De Meo, D.L. (2000). An intensive communication intervention for the critically ill. *American Journal of Medicine*, *109*(6), 469–475.

Lloyd, L., White, K. & Sutton, E. (2011). Researching the end-of-life in old age: Cultural, ethical and methodological issues. *Ageing and Society*, *31*, 386–407.

Meeker, M.A. & Jezewski, M.A. (2005). Family decision making at end of life. *Palliative & Supportive Care*, *3*(2), 131–142.

Metts, S. & Lamb, E. (2006). Methodological approaches to the study of family communication. In *The family communication sourcebook*. L.H. Turner & R. West (eds.), pp. 83–105. Thousand Oaks, CA: Sage Publications.

Neimeyer, RA., Wittkowski, J. & Moser, R.P. (2004). Psychological research on death attitudes: An overview and evaluation. *Death Studies*, *28*(4), 309–340.

Olson, D.H. & Barnes, H. (2003). *Family communication scale*. Minneapolis: Life Innovations.

Parks, S.M., Winter, L., Santana, A.J., et al. (2011). Family factors in end-of-life decision-making: Family conflict and proxy relationship. *Journal of Palliative Medicine*, *14*(2), 179–184.

Pecchioni, L.L., Thompson, T.L. & Anderson, D.J. (2006). Interrelations between family communication and health communication. In *The family communication sourcebook*. L.H. Turner & R. West (eds.), pp. 447–468. Thousand Oaks, CA: Sage Publications.

Planalp, S. & Trost, M.R. (2008). Communication issues at the end of life: Reports from hospice volunteers. *Health Communication*, *23*(3), 222–233.

Quinn, J.R., Schmitt, M., Baggs, J., et al. (2012). Family members' informal roles in end-of-life decision making in adult intensive care units. *American Journal of Critical Care*, *21*(1), 43–51.

Rabow, M.W., Hauser, J.M. & Adams, J. (2004). Perspectives on care at the close of life. Supporting family caregivers at the end of life: "They don't know what they don't know." *The Journal of the American Medical Association*, *291*(4), 483–491.

Radwany, S., Albanese, T., Clough, L., et al. (2009). End-of-life decision making and emotional burden: Placing family meetings in context. *The American Journal of Hospice & Palliative Medicine*, *26*(5), 376–383.

Reyna, Y.Z., Bennett, M.I. & Bruera, E. (2007). Ethical and practical issues in designing and conducting clinical trials in palliative care. In *Research methods in palliative care*. J.J. Addington-Hall et al. (eds.), pp. 27–41. New York: Oxford University Press.

Schmid, B., Allen, R.S., Haley, P.P., et al. (2010). Family matters: Dyadic agreement in end-of-life medical decision making. *The Gerontologist*, *50*(2), 226–237.

Schroeder, S.A. (1999). The legacy of SUPPORT: Study to understand prognoses and preferences for outcomes and risks of treatments. *Annals of Internal Medicine*, *131*(10), 780–782.

Scott, A.M. (2010). *Family conversations about end-of-life health decisions*. Doctoral dissertation. University of Illinois at Urbana-Champaign.

Segrin, C. & Flora, J. (2005). *Family communication*. Mahwah, NJ: Lawrence Erlbaum Associates.

Shrank, W.H., Kutner, J.S., Richardson, R., et al. (2005). Focus group findings about the influence of culture on communication preferences in end-of-life care. *Journal of General Internal Medicine*, *20*, 703–709.

Smith, A.K., Sudore, R.L. & Perez-Stable, E.J. (2009). Palliative care for Latino patients and their families: Whenever we prayed, she wept. *The Journal of the American Medical Association*, *301*(10), 1047–1057.

Stein, G.L., Sherman, P.A. & Bullock, K. (2009). Educating gerontologists for cultural proficiency in end-of-life care practice. *Educational Gerontology*, *35*, 1008–1025.

Stone, A.M., Mikucki-Enyart, S., Middleton, A., et al. (2012). Caring for a parent with lung cancer: Caregivers' perspectives on the role of communication. *Qualitative Health Research*, *22*(7), 957–970.

SUPPORT Principal Investigators (1995). A controlled trial to improve care for seriously ill hospitalized patients. *The Journal of the American Medical Association*, *274*(20), 1591–1598.

Swigart, V., Lidz, C., Butterworth, V., et al. (1996). Ethical issues. letting go: Family willingness to forgo life support. *Heart & Lung*, *25*(6), 483–494.

Thornton, J.D. (2008). African Americans get less EoL discussion. *Medical Ethics Advisor*, *24*(7), 82–83.

Tschann, J.M., Kaufman, S.R. & Micco, G.P. (2003). Family involvement in end-of-life hospital care. *Journal of the American Geriatrics Society*, *51*(6), 835–840.

Volker, D.L. (2005). Control and end-of-life care: Does ethnicity matter? *The American Journal of Hospice & Palliative Medicine*, *22*(6), 442–446.

Waldrop, D.P. & Meeker, M.A. (2012). Hospice decision making: Diagnosis makes a difference. *The Gerontologist*, *52*(5), 686–697.

Waldrop, D.P. & Rinfrette, E.S. (2009). Making the transition to hospice: Exploring hospice professionals' perspectives. *Death Studies*, *33*, 557–580.

Wittenberg-Lyles, E., Goldsmith, J., Demiris, G., et al. (2012). The impact of family communication patterns on hospice family caregivers: A new typology. *Journal of Hospice and Palliative Nursing*, *14*(1), 25–33.

Young, A.J. & Rodriguez, K.L. (2006). The role of narrative in discussing end-of-life care: Eliciting values and goals from text, context, and subtext. *Health Communication*, *19*(1), 49–59.

Zhang, A.Y. & Siminoff, L.A. (2003). The role of the family in treatment decision making by patients with cancer. *Oncology Nursing Forum*, *30*(6), 1022–1028.