
REVIEW ARTICLE

Family decision making at end of life

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ABSTRACT

Objective: To enhance understanding of the phenomenon of family surrogate decision-making at the end of life (EOL) by means of a systematic review and synthesis of published research reports that address this phenomenon.

Methods: Garrard's (1999) methods for conducting a systematic review of the literature were followed. Fifty-one studies focusing on family decision-making experiences, needs, and processes when assisting a dying family member were selected following electronic database searches and ancestry searches.

Results: In studies using hypothetical scenarios to compare patients' choices and surrogates' predictions of those choices, surrogates demonstrated low to moderate predictive accuracy. Increased accuracy occurred in more extreme scenarios, under conditions of forced choice, and when the surrogate was specifically directed to use substituted judgment. In qualitative explorations of their perspectives, family members voiced their desire to be involved and to accept the moral responsibility attendant to being a surrogate. Quality of communication available with providers significantly influenced family satisfaction with decision-making and EOL care. Group or consensual decision-making involving multiple family members was preferred over individual surrogate decision-making. Surrogates experienced long-term physical and psychological outcomes from being decision-makers.

Significance of results: Functioning as a surrogate decision-maker typically places great moral, emotional, and cognitive demands on the family surrogate. Clinicians can provide improved care to both patients and families with better understanding of surrogates' needs and experiences.

KEYWORDS: Surrogate decision-making, End of life decision-making, Family decision-making, Terminal care, Systematic review

INTRODUCTION

Individuals with advanced illness commonly rely upon family members to assist them with health care choices and to make decisions for them when they are unable to self-determine their care. Functioning as a surrogate decision maker typically places great moral, emotional, and cognitive demands on the family surrogate. Nurses can more effectively assist both patients and family members when they understand family decision-making processes. The purpose of this review is to synthesize

the empirical evidence regarding the phenomenon of family surrogate decision making at the end of life. A brief overview of the contextual aspects of end of life (EOL) decision making in American society precedes the review of empirical evidence.

METHOD

Garrard's (1999) methods for conducting a systematic review of the literature were followed. The electronic databases, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, and Bioethicsline, CancerLit, and Cochrane Database of Systematic Reviews were searched using key words ethical decision making, family decision making, and surrogate decision making in combi-

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nation with terminal care, palliative care, hospice care, terminally ill patients, and end of life care. Results were limited to English language reports of empirical studies. Ancestry searches were also conducted to identify further pertinent resources. One hundred sixty (160) abstracts were reviewed and 56 primary research reports selected for inclusion in the systematic review. Studies selected for review addressed research purposes that focused on decision-making experiences, needs, and processes when assisting a dying family member.

OVERVIEW OF SOCIAL AND HISTORICAL CONTEXT FOR EOL DECISION MAKING

Improving end-of-life (EOL) care is a national research and practice priority. The central issues related to EOL decision making today have emerged over the past two to three decades. Historically, the Hippocratic oath guided medical decision making. Although this guideline engendered paternalistic decision making by physicians, physician dominance was constrained by the acknowledgment that medicine and the healer's power were finite, and that the physician was responsible to cease attempts to combat illness when those efforts were no longer effective. In more modern times, the paternalism of the Hippocratic oath persisted but progress in medical science resulted in fewer natural limits on medicine's powers and abilities. Death came to be regarded as medical failure. Resulting excesses in treatment helped fuel patients' fears of an overly medicalized dying, of protracted and useless pain and suffering. Increasing concern with self-determination and preservation of individual autonomy characterized a cultural shift in health care. The requirement for informed consent was one outgrowth of this shift in cultural values. As technological interventions have become more numerous, sophisticated, and effective, the nature of dying has changed. More potentially life-sustaining interventions are available, and more people encounter protracted states of ill health in which they are unable to make health care choices for themselves. While there has always been some need for surrogate decision-making in health care, the need is now much more frequent and the decisions typically more complex.

Surrogate Decision-making

Patient self-determination is the widely accepted standard for health care treatment choices for adult patients. Since Judge Cardozo's decision in 1914 in

a case involving surgery without the patient's consent, the guideline for informed consent has become widely accepted and applied for competent adults (High, 1994). Controversy persists, however, concerning choices for the persons experiencing lack of capacity to make their own decisions. Current thinking, as reflected in both the President's Commission (1983) and the Hastings Center Report (1987) subscribes to the following hierarchy for guidance in decision-making: advance directive principle, substituted judgment standard, and lastly, the best interests standard. The advance directive principle directs that if knowledge of the patient's previously expressed desires is available, that knowledge should guide decisions. If no formal or informal advance directive is available, a surrogate decision maker is called upon to choose as the patient would choose if able to do so in the current situation, i.e., to make a substituted judgment. Finally, absent all knowledge of what the patient would want, choices are to be made using a best interests standard. In the last case, choices should be those most likely to lead to the best outcomes for the patient, maximizing benefits and minimizing suffering or other burdens.

This hierarchy of decision-making standards is consistent with the culturally pre-eminent valuing of patient autonomy and seeks to rank order the alternate routes when autonomous decision making is not possible. Despite efforts to increase rates of completion and utilization of advance directives, most Americans have not formulated instructional or proxy directives. According to Robinson (2001), only 10% to 20% of Americans have completed advance directives. Persons more vulnerable because of illness or advanced age are somewhat more likely to have prepared advance directives, but numbers remain low even in these populations. Lynn and Teno (1998) report that approximately 25% of those who are elderly or seriously ill have advance directives.

When advance directives do exist, their implementation is frequently difficult. With instructional directives, for example, there may be a lack of clear congruence between health states addressed in the directive and the patient's clinical situation. The advance directive then is inadequate to the decision at hand. Given the complexity of advanced illness as well as the element of uncertainty present in most clinical decisions, it is very difficult for all possible scenarios to be anticipated and provided for in an instructional advance directive. For these reasons, current thinking tends to favor creation of a directive that names an agent for health care decisions (Lynn & Teno, 1998).

In the creation of any advance directive, there is still considerable risk that the person completing

the directive lacked an adequate understanding of its meaning, and a comparable risk that those implementing the directive may lack sufficient perception of its intent (Lynn & Teno, 1998). Teno et al. (1998) found that advance directives influenced care in fewer than half the situations studied. Where they did influence care, they did so by leading to negotiation with a surrogate and an eventual shift in the nature of care.

Based in an autonomy model of respect for persons and concomitant respect for their right of self-determination, substituted judgment is valued above other ways of proceeding with health care decision-making. However, if substituted judgment is more of an abstract and ideal concept than it is a practical possibility or reality, this value may be misplaced.

FINDINGS

This systematic review of surrogate decision making at the end of life includes findings from several types of studies which are relevant to our understanding of the needs, experiences, and influences upon family surrogates. We will first summarize studies investigating the ability of surrogate decision makers to accurately predict choices of family members. Several studies utilizing hypothetical vignettes are synthesized, and surrogate accuracy in one large clinical study is reported. Next qualitative investigations of family members' decision-making processes and their perceptions of important EOL values and needs are reported. Available evidence describing the effects on family surrogates of having functioned in this role as well as evidence regarding outcomes influenced by family involvement in EOL care is summarized.

Surrogate Accuracy

The earliest investigations of surrogate decision making were focused on an attempt to assess how accurately surrogates could predict patient choices. In this view, autonomy is not protected if the proxy decision makers choose differently than the persons themselves would choose. The broad question being addressed is whether substituted judgment is possible. These studies have typically used independent, structured interviews of pairs of patients and surrogates for data collection. Hypothetical vignettes are presented, and subjects are asked what they would choose in such a situation whether for themselves (patients) or for the other person (surrogates). Vignettes varied in severity of the clinical situation, and interventions varied in intensity and invasiveness.

In the concordance studies, researchers have most often explored predictive accuracy of surrogate decision makers for elderly patients (Uhlmann et al., 1988; Ouslander et al., 1989; Zweibel & Cassel, 1989; Tomlinson et al., 1990; Seckler et al., 1991; Ditto et al., 2001) and have often focused on life-support decisions, especially those related to resuscitation and mechanical ventilation. Several studies report comparative data describing the accuracy of family members and health care providers (Uhlmann et al., 1988; Ouslander et al., 1989; Seckler et al., 1991). For example, in the earliest published study of surrogate accuracy, Uhlmann et al. (1988) compared the accuracy of spouses with that of physicians in predicting the choices of elderly, non-terminally ill outpatients for resuscitation and mechanical ventilation in three different states of health. Calculating percent agreement and kappa coefficients, these investigators found that physicians' accuracy was not greater than chance in 5 of the 6 situations. Spouses' accuracy was not greater than chance in 3 of the 6 scenarios. (Kappa coefficient is a measure of concordance beyond chance, and ranges from 0 for agreement consistent with chance to 1 for perfect agreement or -1 for perfect disagreement.) There is no indication in this study that patients' and surrogates' understanding of resuscitation and mechanical ventilation were assessed.

In an attempt to expand upon the above study, Zweibel and Cassel (1989) assessed predictive accuracy of next-generation proxies (child, niece, nephew) selected by the physician. Data were gathered regarding choices of life-sustaining interventions, such as chemotherapy and tube feeding, as well as resuscitation and mechanical ventilation. The percentage of discrepant responses were calculated for five interventions, and ranged from 24% to 50%. Interpretation of these findings is limited by a relatively small sample size ($N = 55$ pairs) and by allowing subjects to select a "don't know" response, and then excluding those responses from the data analysis. This exclusion further truncated the sample size.

The Seckler et al. (1991) study was methodologically strong in that patient mental status and patient comprehension of the nature and meaning of resuscitation were assessed. However, this study was limited by the scoring of responses on a 5-point Likert scale. Such scoring allowed "uncertain" as a response. When the kappa coefficient was calculated, "uncertain" was treated as "yes" for resuscitation. While there may be some clinical justification for this approach (i.e., if you are uncertain at the critical moment, you will be resuscitated), there is evidence that better data can be obtained through

forced choice (Sulmasy et al., 1994; Sulmasy et al., 1998). Clinically, of course, resuscitation is a yes or no decision.

In summary, early concordance studies consistently revealed low to moderate accuracy between the patient's choice and the surrogate's prediction of that choice (Uhlmann et al., 1988; Zweibel & Cassel, 1989; Seckler et al., 1991; Hare et al., 1992; Suhl et al., 1994). While physicians have sometimes wanted to use this information to justify greater reliance on a best interests standard, physicians' choices are nearly always more discrepant from the patients' than those of family surrogates (Uhlmann et al., 1988; Ouslander et al., 1989; Seckler et al., 1991).

Two investigations led by Daniel Sulmasy have provided a fuller understanding of issues related to predictive accuracy of surrogates (Sulmasy et al., 1994; Sulmasy et al., 1998). The earlier study functioned as a pilot ($N = 50$ patient-surrogate pairs) for the more recent study. In Sulmasy's 1998 study, the sample size was determined by a clearly explained power analysis and consisted of 300 patient-surrogate pairs. Fifty patient-surrogate pairs were recruited for each of five life-threatening diagnoses. A comparison group consisting of 50 general medical patients and their surrogates was also included. Thus, these investigators primarily studied a population (those with terminal diagnoses) for whom surrogate decision making was most likely imminent but included a comparison group as well. The salience of end-of-life decision making would be expected to be greater for those with life-threatening diagnoses than for elderly patients in general, as emphasized in earlier investigations.

Legal surrogates were recruited for participation in this study. In most cases, this legal surrogate was the same as the moral surrogate (i.e., the person the patient would have chosen). Subjects were asked to respond to 10 possible interventions in each of 3 scenarios. The researchers calculated a scale score entitled SAMPPS (Surrogate Accuracy in Matching Patient Preferences Scale Score) during data analysis. Both studies employed forced choice. Surrogates' predictive accuracy was higher (as compared to earlier studies) when subjects were required to make a "yes" or "no" response, rather than answering by means of a Likert scale, and having the opportunity to select "uncertain." Complex clinical decisions are often characterized by uncertainty, but ultimately choices must be made. Forced choice affords a better opportunity to assess surrogate accuracy. In the 1998 study, the overall accuracy of surrogates was 66%.

Only rarely in this body of patient and surrogate concordance studies did a researcher assess sub-

jects' extent of understanding of the interventions presented in the vignettes (Seckler et al., 1991), creating further questions about the validity of findings. With a few exceptions (Zweibel & Cassel, 1989; Seckler et al., 1991; Sulmasy et al., 1994), the concordance studies also suffer from a limitation shared by end of life research in that participants were predominantly white, middle-class, and fairly well-educated. Little is known about the views of other cultural subgroups despite the multi-cultural nature of American society at this time.

Because likely outcomes of treatment are often more meaningful in patient decision making than specific interventions, Fried et al. (2003) assessed surrogates' predictive accuracy, as compared to patients, using various health states and asking patients whether that outcome from treatment would be acceptable. They found 80% agreement in current health, states with mild symptoms, and coma. States involving more severe symptoms yielded lower agreement. Unfortunately, these investigators asked surrogates to choose based on what they believed was best for the patient. Thus, although surrogates were directed to use a best interests standard, they were evaluated against a substituted judgment standard.

All studies involving hypothetical scenarios have a fundamental methodological limitation in that both the patient and surrogate (whether family member, physician, or other health care provider) are responding to fictional scenarios and making choices about whether various interventions would be desired or refused. Thus, both the patient and surrogate are reliant on what they imagine the patient would want in some yet to be experienced and unknowable situation. Zweibel and Cassel (1989) believe that this factor does not compromise the validity of the comparative data assessed in such studies. However, given the complex nature of health care decision making, such an impairment of validity is probably inevitable. Vignettes provide a brief outline of a particular clinical situation and brief descriptions of possible interventions. Thus, responses rely on a kind of imagining that does not characterize contemporaneous surrogate decision-making situations. The information available to both patient and surrogate is not only limited in quantity, it is also limited in form, i.e., the information is only verbal. Actual clinical decision making is informed by visual, auditory, and, at least for the patient, kinesthetic knowledge.

Variables Affecting Surrogate Accuracy

Researchers have sought to identify the factors associated with differing levels of surrogate accuracy

in predicting patient choices. In their exploration of surrogates' ability to predict choices for or against life-sustaining interventions by elderly patients, Tomlinson et al. (1990) compared accuracy of prediction with and without a specific instruction to the proxy to use substituted judgment. Family members were more accurate than chance in matching the patient's decision *only* when they had been explicitly instructed to choose as they believed the patient would choose.

Sulmasy et al. (1998) identified factors associated with surrogate accuracy by examining correlations between various independent variables and the SAMPPS score. As would be expected, accuracy was higher for more invasive procedures as well as in the direst of the scenarios (i.e., a situation of permanent coma). Interestingly, accuracy was not related to whether the surrogate decision-maker was the patient's preferred spokesperson. Accuracy was decreased in those situations where the patients (in marked contrast to their physicians' perceptions) believed their life expectancy to be longer than 10 years. In those situations, lack of information and/or denial on the patient's part may account for some of the discrepancy between choices of the patient and predictions of the surrogate. In an as yet unexplained correlation, surrogate accuracy was diminished for patients who regularly attended religious services (Sulmasy et al., 1994) and in situations where the surrogate regularly attended religious services (Sulmasy et al., 1998).

Predictive accuracy of family surrogates was always higher in the "current health" scenario, as compared to more hypothetical scenarios, when the design of the study included both (Uhlmann et al., 1988; Seckler et al., 1991; Ditto et al., 2001). This finding supports the contention discussed above that assessing predictive accuracy on the basis of brief, verbal, hypothetical vignettes omits elements critical to decision-making.

One of the most consistent and clinically useful findings from this body of concordance studies was that prior discussion of EOL issues between patients and surrogates improved surrogate accuracy (Suhl et al., 1994; Sulmasy et al., 1994; Sulmasy et al., 1998). A recent study by Ditto and colleagues (2001) brings this relationship into question. These authors report a large clinical trial to examine the effectiveness of instructional advance directives to improve surrogate accuracy. Patient and surrogate pairs ($N = 401$ pairs) were randomly assigned (within blocks) to one of five conditions. Included were the control condition and four intervention conditions where patients completed either a scenario-based or values-based advance directive, and did or did not discuss the information from the

directive with the surrogate. In the advance directive without discussion groups, patients completed one of the forms of advance directive, and this written document of their wishes was available to the surrogate both before and during the time they were responding to the predictions questionnaire. Patients in the two other intervention groups not only completed a directive but also discussed its contents with their proxy.

None of the interventions in Ditto's study resulted in improved surrogate accuracy. Several ideas are worth considering regarding these results. Perhaps the instrument lacked sufficient sensitivity to measure improvements in surrogate accuracy. These investigators did not use forced choice, despite empirical evidence, as noted above, that doing so improves accuracy. Also, those consenting to the long-term and fairly intensive participation requirements for this study (three interviews of 1 to 2 hours each over two years, and additional interviews if hospitalized during the study) were persons already interested in advance planning for health care, conceivably leaving less room for improvement in the measurable understanding of another's wishes. Furthermore, as suggested above, the process of patient-surrogate relationship and decision-making is most likely too complex to reduce to assessment through brief, verbal scenarios and treatment choices. Although the discussion interventions, as conducted in this study, did not increase measured accuracy of surrogates' predictions, the discussion interventions did significantly increase the patient's perception that his or her surrogate had a good understanding of care preferences, for those patients with no prior advance directive (Ditto et al., 2001). This outcome is important to consider even in the absence of measurable improvements in accuracy.

Other Aspects of Surrogates' Predictive Accuracy

Some investigators conducting concordance studies have used a Likert scale to assess surrogates' perceptions of their own accuracy. Surrogates' confidence in their choices has been found to be higher than their measured accuracy (Uhlmann et al., 1988; Tomlinson et al., 1990; Hare et al., 1992). Perhaps surrogates who believe they already have a good understanding of their family member's wishes are less likely to engage in intensive discussion and exploration of those wishes. There is some evidence that surrogates' predicted choices match more closely with their own treatment preferences than with those of the family member whose wishes they are attempting to predict (Fagerlin et al., 2001).

Another concern of researchers in this area of surrogate predictive accuracy has been to assess the direction of errors when surrogate decision-makers fail to match patient preferences. In several studies, surrogates were more likely to choose interventions that the patient refused than to withhold wanted care (Uhlmann et al., 1988; Tomlinson et al., 1990; Suhl et al., 1994; Ditto et al., 2001). Some authors regard this as a 'safer' error. Other investigators found inaccuracies equally divided between choosing in favor of unwanted care and withholding care the patient would choose (Seckler et al., 1991; Sulmasy et al., 1998).

In some concordance studies, the criteria employed by decision-makers as well as accuracy of prediction have been investigated. Libbus and Russell (1995) asked both patients and surrogates to rank order the criteria used to make their choices. While patients considered the ability to care for themselves as most significant, surrogates rated amount of pain as their first criterion in whether to choose or forego treatment. Patients ranked burden on family third; surrogates did not list this choice at all. These data on discrepant criteria employed to make a decision are similar to those found by others (Tomlinson et al., 1990; Hare et al., 1992).

Surrogate Accuracy in Clinical Settings

The SUPPORT study (Study to Understand Prognosis and Preferences for Treatment) provides data about the relationship between patient preferences and surrogate understanding of those preferences from a clinical study, as opposed to investigations utilizing hypothetical vignettes. Findings from SUPPORT found only moderate levels of agreement between patient preferences and surrogate perception of those preferences. The SUPPORT study was a large, multi-center, two-phase investigation that attempted to identify and later correct troublesome features of the experience of dying in American hospitals (SUPPORT Principal Investigators, 1995). One goal of the intervention phase of SUPPORT was to align decision-making with expressed preferences of patients and with likely outcomes. The investigators sought ways to improve communication among patients, providers, and families. Analysis of published reports from the SUPPORT study (Covinsky et al., 2000) reveal limited understanding on the part of surrogates regarding patients' wishes for cardio-pulmonary resuscitation. For those patients who did want to be resuscitated, 16% of surrogates believed they did not. And for those patients who desired an order stating "Do Not Resuscitate", 50% of surrogates failed to be aware of that wish. (Layde et al., 1995) Surrogates also often

were mistaken about patients' preferences for curative versus comfort focused care plans and willingness to live in a nursing home. Despite these shortcomings in predictive accuracy, 78% of patients indicated willingness for their surrogate to make treatment decisions for them if they were unable to speak for themselves. This empirical finding is congruent with bioethicists' assertion of the moral authority of family surrogates to be decision makers (Nelson & Nelson, 1995).

The issue of accuracy of prediction is only one element within a complex decision-making process. Despite limitations in the measured accuracy of surrogate predictions of patient preferences, surrogate decision making has come to be widely accepted over the past ten years. Miles et al. (1996) strongly support the validity of family surrogacy without an emphasis on accuracy, saying, "The moral authority of a family proxy need not be contingent on their ability to recount or predict a patient's choice; the trust that lies behind their selection may justify their authority" (p. 1067).

Family Decision-making Studies

Several studies have addressed family decision-making experiences and needs. The emphasis has generally been on decision-making for critically ill patients, most commonly around decisions to withdraw life-sustaining interventions.

Decision-making Processes

Tilden et al. (1995) studied the experiences of family members around decisions to withhold or withdraw life-sustaining interventions for critical care patients, seeking to identify both helpful and burdensome provider behaviors, from the perspective of family members. Participants identified quality, frequency, and availability of communication with health care providers as critical in assisting them during decision making. The factors that family surrogates considered during decision making were the family member's previously expressed wishes and quality of life, as well as legal guidelines. Achieving consensus among family members rather than having a unilateral decision maker was important to family satisfaction with the decision-making process.

Jeffers (1995) explored the lived experience of surrogate decision making related to a treatment decision for a family member. Individual decision experiences, usually related to life-sustaining interventions such as artificial nutrition and hydration, for hospitalized patients were the focus of this study. The surrogates' experiences were char-

acterized by the themes of contextualizing (situating the experience in a context of both past and future), actualizing (recognizing that one holds the decision-making responsibility alone), reviewing and resolving, and transcending.

Using grounded theory methods to explore family members' experiences with life-sustaining treatment decisions, Jacob (1998) interviewed seventeen persons who had functioned as surrogate decision makers for a family member during a critical illness. Findings in this study are reported as three major themes characterizing family decision-making processes. These themes were "arriving at a judgment, moving in concert versus disharmony, and looking back and going on" (p. 33). A similar view of decisions to withdraw and withhold life-sustaining treatment for a patient in an intensive care unit emerged from Swigart et al. (1996) prospective study of family decision-making processes. This grounded theory study generated a theoretical model of letting go, i.e., becoming willing to relinquish life support for the ill family member. According to this model, families participate in three interrelated processes: gathering information, reviewing the patient's life and discerning meaning, and maintaining relationships within the family. In the situations studied, the patient's illness was very advanced and outlook very poor. Death was consequent to the decision to withdraw or withhold active interventions. Family members were not so much asked to make choices as to assent to a recommended course of care that was comfort-focused rather than life prolonging. Grieving and coming to terms with loss were a prominent part of the process described.

In addition to the above studies of family decision making in critical care settings focused on discrete decisions to withhold or withdraw life-sustaining interventions, Meeker (2004) conducted a grounded theory investigation with surrogate decision makers whose family members had died from cancer. The basic social process of *Seeing Them Through with Care and Respect* revealed that family surrogates viewed decision making as integral to accompanying the patient through the entire EOL illness trajectory rather than discrete decisional episodes. Similar findings regarding the integrated nature of decision making are reported by Jeffers (1995). In Meeker's study, surrogate participants worked throughout the family member's illness to balance care demands with respecting the autonomy and self-determination of the ill family member. They supported and advocated for the ill family member and acted in a variety of ways designed to protect him or her from greater harm.

In attempting to study the decision-making process as a whole, Shidler (1998) provided one

specific and contextualized view of this complex and multi-faceted process. Using an ethnographic, ethnomethodological approach to investigate EOL decision making in a long-term care setting, Shidler revealed the inadequacy of examining decision making only within the patient-physician dyad or patient-proxy dyad, at least within the care setting studied. In one of the situations studied, Shidler reports, "What questionnaires and concordance studies cannot reveal is how the RN's intervention at the time of the actual treatment decision facilitated a discussion of the patient's wishes between the physician and the proxy, resulting in the change of treatment choice to one that conformed with the resident's wishes" (p. 267).

Surrogate Views

Utilizing an innovative approach for data gathering, Koch (1997) studied surrogate decision making and the concerns of surrogates through their participation in an on-line health forum. This study has the strength of providing an avenue to access data that is *outside* the health care system, or nearly so. Its only link to the formal health care system was a physician moderator who offered correction of potentially dangerous inaccuracies being shared in the discussion. A different view of surrogate decision making emerged. In contrast to the perspective in the literature of the centrality of the physician-patient relationship, Koch reported that, "all were perceived, first and foremost, as familial rather than individual or professional decisions" (Koch, 1997, p. 467). Also of note in this exploration, no surrogate decision maker expressed concerns about protecting the patient's autonomy. This is in direct contrast with the emphasis in the literature, and in legislation and policies. It may not, however, differ from what patients have said they want.

Exploring Family Needs during EOL Decision Making

In addition to the studies of family decision-making processes, investigators have asked family members, usually in a focus group format, about their needs and experiences during EOL decision making. One study of this sort was based on a program entitled *Dialogue to Action* (Jacobson et al., 1997). Researchers gathered bereaved persons into focus groups to talk about their decision-making experiences during the death of their family member (in hospital), and simultaneously collected data from members of the hospital's ethics committee. The concerns expressed and experiences described by the family members differed from the beliefs and perceptions of ethics committees' members. While

ethics committees believed families were overwhelmed with medical information, no family member reported feeling that way. Families wanted as much information as possible about what was going on with the patient and what to expect. This desire for information is consistent across many studies (Hanson et al., 1997; Pierce, 1999; Abbott et al., 2001; Meeker & Jezewski, 2004). In the Dialogue to Action program, families reported varying experiences with advance directives. Responses included relief when they were honored, anger when they were not, and in some situations, gratitude when an advance directive was *not* honored. While they were not overwhelmed with information, families often *did* feel overwhelmed with decision making.

Toll on Surrogates

Surrogate decision making is a demanding role and process that has long-term consequences for the surrogates. Evidence suggests that health care providers often find family members difficult to deal with and experience them as interfering with the provision of good care. Such findings indicate that providers fail to effectively support and assist family surrogates. According to Levine and Zuckerman (1999), one consequence of efforts to contain health care costs is that health care providers increasingly rely on family members to provide care. At the same time, providers paradoxically tend to regard families as a source of difficulty. Family members are often seen as an annoyance at best and a barrier to good care, at worst. When Levine and Zuckerman interviewed 42 staff physicians and hospital counsel regarding what was most troublesome in EOL care, the immediate and nearly universal response was “Families” (p. 149). Focus groups conducted with family caregivers shed light on their perceptions and needs. The authors reported that, “surrogates are often unclear about the real choices available and about how to participate meaningfully in decision-making” (p. 150).

In another study, Kirchoff and Beckstrand (2000) surveyed critical care nurses regarding barriers to and facilitators of good EOL care and found that, for these nurses, six of the top seven identified obstacles involved patients’ families. Specific issues included lack of understanding of the meaning of treatments, anger, and the family requesting interventions contradicted by the patient’s advance directive. Norton and Bowers (2001) found discrepant perceptions on the part of providers and proxies regarding the patient’s status and prognosis to be a source of conflict (as perceived by providers) in EOL decision-making. Forbes and colleagues (2000), in studying family decision-making processes re-

garding EOL treatments for patients with dementia being cared for in a skilled nursing facility, similarly found that an “unrecognized dying trajectory” impeded effective decision making. Family surrogates were unable to translate their understanding of their family members’ values into specific treatment choices, and suffered “relentless guilt” as they struggled with decisions (p. 256). As one family surrogate in another study (Rabow et al., 2004) stated, “The home caregiver doesn’t know what they don’t know. I didn’t know questions to ask doctors. . . .” (p. 485).

From the family’s perspective, conflict during EOL decision making arises from the relational and contextual features of the care setting. In a study by Abbott and colleagues (2001), 46% family members who had been involved in a decision to withhold or withdraw life-sustaining treatment reported experiencing conflict with providers around the decision. In nearly every circumstance, however, the conflict over a substantive decision co-occurred with conflict related to provider communication or professional behavior. Similarly, conflict experienced by family members involved in treatment withdrawal decisions was found to be associated with unmet communication and interpersonal needs (Norton et al., 2003).

A family surrogate’s preferred mode of decision making often conflicts with the model held by health care providers, creating additional toll on surrogates. Many studies of family needs during EOL decision-making report that family members valued consensus in making EOL decisions and emphasized to researchers the importance of group versus individual decision making (Meeker, 2004; Tilden et al., 1995; Swigart et al., 1996). This preference for shared decision making is in contrast to the focus in the literature and to typical clinical practice. Many of these research participants felt that the burden of functioning as sole decision makers was too great. According to High (1994), “Frequently, families expect that group decision making will be instituted, and often, that expectation coincides with the previously expressed wishes of the elderly patient” (p. 455). Despite the fact that family members often prefer to make decisions as a group, legal and bureaucratic structures are oriented toward an individual decision maker. Current clinical practice involves selecting a designated surrogate in those situations where the patient cannot make self-determined choices. Given these differing approaches, family member surrogate decision makers are called upon not only to represent the wishes of the patient but also, at times, to represent to health care providers the wishes and concerns of other family members. Bridging these

disparate decision-making models increases demands placed on the family surrogate.

In a recent effort to quantify the impact on family surrogates of making treatment withdrawal decisions (Tilden et al., 2001), investigators found high levels of stress as measured by Horowitz Impact of Events Scale and the mental/emotional state subscale of the Rand 36-Item Health Survey 1.0. Stress levels remained quite high when measured again six months following the experience.

PATIENTS' EOL VALUES

Empirical evidence suggests that often patients, especially older patients, have a greater concern with *who* will make decisions for them than with *what* is decided in a particular situation (Ott, 1999). This has been referred to as relationship-based autonomy as contrasted with the more familiar rationality-based autonomy (Robertson, 1996). Persons who formally name agents for health care decisions usually name a family member. When an agent has not been named, legally identified surrogates are family members, except in situations of legal guardianship or if no family members are available. Thus, in the vast majority of situations, the surrogate decision maker is a family member. Family members are generally believed to be the most appropriate surrogates for several reasons (High, 1994; Lynn & Teno, 1998). Usually the family members will have the greatest interest in and concern for the patient's well-being. They will also usually be the persons most knowledgeable about what the patient would want, about who that patient is as a person, and what choices would be consistent with his or her values and goals. In addition, the family is the "primary social and moral unit in our society" and "personal self-determination actually emanates from within a primary social structure of interdependencies" (High, 1994, p. 451).

The salience of family relationships is supported by findings from studies that address patient experiences, preferences, and needs. Singer and colleagues (1998) studied perceptions of advance directives in a group of long-term hemodialysis patients. While patients viewed advance directives as a way to stay in control of their care, they also viewed them as a way to protect their loved ones from excessive physical and emotional burdens. Congruent with earlier findings, investigators (Singer et al., 1999) conducting in-depth interviews to explore patients' criteria for quality EOL care found that two of the five most significant domains identified by these patients were family related. Specifically they were concerned with relieving burden placed on loved ones and with strengthening family relationships.

Further exploring preferences regarding proxy decision makers, Aikman et al. (1999) found that patients were concerned both about who should make decisions for them and also about who should not. Some wanted proxies to have considerable leeway in decision making—an indicator of trust as well as a realization of the complexity of decision making. Those who wanted instructions followed strictly placed this limitation to lessen potential burden and possible guilt on the part of the selected proxy. Thus both choices reflected the importance of relationship. Patients with awareness of advance directives who nevertheless do not follow through and prepare them often expressed confidence that their family members would make appropriate decisions for them. The majority of patients studied placed greater value on discussing EOL care with family than with physicians and were comfortable relying on family for decisions if they became incapacitated (High, 1994; Singer et al., 1998; Hines et al., 1999). Hamel and colleagues found that some participants did not complete advance directives because they believed their family members understood their wishes and would be effective decision makers for them (Hamel et al., 2002). Similarly, Dupree (2000) found that Black Americans tended to view legally executed advance directives as unnecessary because of the presence of family members.

One investigator asked patients how they would want decisions made if there was a conflict between their instructional advance directive and the surrogate's judgment at the time when a clinical decision was necessary (Terry et al., 1999). Fifty-four per cent of respondents preferred that physicians follow the directions of their surrogate decision maker. A portion (18%) of those who preferred that their instructional advance directive be followed expressed this preference as an attempt to protect the surrogate from a burdensome decision-making process. Thus, a majority of the patients in this study accorded greater prominence to relationship than to strictly interpreted individual autonomy. Older patients studied by Rosenfeld et al. (2000) described wanting both physicians and family members involved in decision making for them, with the emphasis shifting to the role of family members during the EOL phase.

Moore et al. (2003) explored what standard a sample of older adults wanted their surrogate decision-makers to use. In addition to substituted judgment and best interests standards, these researchers proposed a best judgment standard in which the surrogate also considered family needs. One third of the participants preferred this standard, and most of those had experience as a surrogate decision maker. These participants explicitly acknowledged the com-

plexity of surrogate decision making and believed a family's needs should also be represented.

What is a Good Death?

Decision making is embedded in the whole process of movement through the end of life trajectory and both influences and is influenced by the quality of EOL care. Recent studies have been undertaken to explore EOL values from the perspectives of multiple participants in EOL decision-making (including patients, family members, and healthcare providers). Studies of various participants' views of what constitutes a "good death" and what characterizes good care indirectly inform us of beliefs and values that underlie decision-making. Both seriously ill patients and family caregivers rank attention to advance care planning as a very high priority for provision of good EOL care (Yurk et al., 2002). Patients want their wishes honored and the burdens placed on loved ones limited.

Clear decision-making was one of six major contributors to a good death for patients, families, and providers in a focus group study (Steinhauser et al., 2000). Another group of investigators (Curtis et al., 2001) conducted a series of studies collecting data through focus groups to elucidate patient, family, and provider values regarding physician skills in providing EOL care. Inclusion and recognition of the family in EOL care and support of patient decision making were two of the 12 central concerns reported. These investigators (Wenrich et al., 2001; Carline et al., 2003; Wenrich et al., 2003) are attempting to identify and describe in detail the component behaviors of such commonly cited needs. This explication of broadly stated values, such as emotional support, is a necessary precursor to improving EOL education for clinicians. The frequency and consistency with which participants in EOL decision making describe the importance of clear decision-making attests to the existence of clinical practice deficits in this area and to the need for further understanding of decision-making processes.

SUMMARY

Surrogate decision making has been studied from the perspective of assessing the accuracy of surrogates' predictions in hypothetical scenarios. In hypothetical scenario decision-making studies, family surrogates cannot predict patient choices with 100% accuracy. In one randomized controlled trial, predictive accuracy was not improved by the addition of advance directives and discussion between patient and family member. Furthermore, the ques-

tions asked in nearly all of the vignette studies focused on the desirability of interventions rather than on outcomes. Outcomes have been shown to be more meaningful to patients and surrogates, and to be influential in their decision making (Rosenfeld et al., 2000). Thus, surrogate decision making has been shown to be a complex personal and interpersonal process with multiple determinants many of which remain unknown.

Family involvement is a crucial component of good EOL care. Not only do patients emphasize the importance of relationships at the end of life and nearly always want family members involved in decision making in some way, family members voice their desire to be involved and accept the moral responsibility attendant to that role. Family needs and decision-making experiences have been investigated primarily in critical care settings and most often related to decisions to withdraw active treatment. Studies exploring values of various participants in EOL care confirm the importance of improved decision making and improved integration of family members into the EOL care situation.

Recommendations

Findings from this review can assist clinicians working with family surrogates during EOL decision making. Directing family surrogates to use substituted judgment when the patient has lost decision-making capacity can simultaneously safeguard patient autonomy to the extent possible and diminish risk for surrogate guilt. Furthermore, even if advance directives fall short of providing explicit guidance to family decision makers, empirical evidence indicates that the stress and burden experienced by family decision makers are lessened when they are present. Continuing efforts to facilitate advance care planning are warranted. Respect for the preferences of those who prefer group decision making can be demonstrated by means of scheduling family meetings and through allowing surrogates time to consult with other family members. Clinicians may need to anticipate and respond to surrogates' needs for information rather than responding only to topics and questions initiated by the surrogate. Further study can assist in identifying what kinds of information are helpful to surrogates at what points in time, as well as most effective modes of delivery.

Questions left unanswered by this review point toward areas where further research is indicated. Further investigation of the influence family involvement exerts on EOL care is indicated. Chen and colleagues (2003) reported that, in the majority of instances, a decision to access hospice care is

made by the patient's family. During their retrospective cohort analysis of patients dying in one hospital over a one year time interval (Tschann et al., 2003) identified a relationship between family involvement in EOL care and the occurrence of comfort focused care plans as well as use of fewer technological interventions. These findings suggest that family involvement contributes in measurable ways to decreased patient suffering. Understanding the components of "successful" family involvement could guide clinicians in assisting all families during EOL care and decision making.

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