Journal of Social Work in End-of-Life & Palliative Care, 6:27–50, 2010

ISSN: 1552-4256 print/1552-4264 online
DOI: 10.1080/15524256.2010.489221

PEER-REVIEWED ARTICLES

Life-Sustaining Treatment Decisions: A Social Work Response to Meet Needs of Health Care Surrogates

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Surrogates must possess essential patient information prior to legitimately exercising legal and moral obligations to act on patients' medical care preferences. This descriptive, in vivo study examined factors influencing surrogate and proxy decisions (N = 132) following life-sustaining treatment decisions. Patient communication and self-efficacy variables accounted for approximately 38% of the variance in surrogates' perceptions of benefits/barriers associated with decision making. Guided by patients' advanced communication, respondents (97.8%) expressed high self-reliance and significant appreciation of benefits associated with their decisions. Clarifying surrogates' and providers' understanding of patient care preferences during ICU/CCU admission may facilitate better adherence to patient wishes.

KEYWORDS *end-of-life care, health care proxy, health care surrogate, Health Care Surrogate Preferences Scale, life-sustaining treatment decisions*

In nearly 80% of the 2.5 million deaths that occur in U.S. hospitals each year, surrogates make 70–90% of the decisions to withhold or withdraw life-sustaining treatment from critically ill patients in the intensive care unit (ICU; Mcgee, 2000; Prendergast & Luce, 1997; Swigart, Lidz, Butterworth,

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Received 17 January 2010; accepted 22 April 2010.

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& Arnold, 1996). Therefore, surrogates potentially influence nearly 1.5 million end-of-life treatment decisions per year. As the number of older people continues to grow, more and more Americans will likely experience this decision-maker role at some period during their lifetime.

An overall lack of advanced surrogate knowledge of patient care preferences complicates surrogate decision making. Surrogates better understand what is important to patients at the end of life when they have had detailed discussions with them. However, limited awareness about specific treatment choices and a lack of understanding of surrogate role requirements have remained largely unaddressed in prior examinations of surrogate and patient communications (Engelberg, Patrick, & Curtis, 2005; Gutheil & Heyman, 2005; Truog et al., 2001). Although differences often exist between what patients and their surrogates deem important end-of-life tasks, advanced knowledge of patient preferences has been found a necessary, but not sufficient, ingredient for surrogate action (Engelberg et al., 2005; Hines et al., 2001; Layde et al., 1995; Suhl, Simons, Reedy, & Garrick, 1994).

For many Americans, the recent uproar about so-called "death panels" (Lepore, 2009) evoked images of medical care driven by external mandates and little individualized choice. This underscored both public and political misunderstanding of the tremendous challenges faced by those making decisions in support of a loved one's medical care at life's end. In addition to highlighting the resistance and barriers associated with end-of-life discussions in American culture, this debate has emphasized Americans' fears of "dying badly" (Court, 2009). At the same time, the debate countered the status quo by bringing to light the crucial importance of explicit communication by persons charged with making respectful health care choices on behalf of a loved one whose preferences would otherwise remain unspoken.

Social work professionals providing services to surrogates or extended family members involved in decision making in the ICU generally have relied on extensive professional training and experience in delivering short-term, crisis, or other brief treatment interventions to the surrogate population. Although the very public life and death of Terri Schiavo reminded us of the potentially negative and long-lasting consequences possible in relationships among patients' survivors (Ditto, 2006), social work professionals have had few empirical findings available to guide them as they assist surrogates to discharge their duty of making treatment decisions. For that reason, this study sought to answer the question, "Did surrogates' personal attributes, or their perceptions of communications, social support, or self-efficacy directly influence their perception of the benefits and barriers associated with their life-sustaining treatment decisions?" In other words, how well did these factors predict participants' sense that they had done the right thing for their loved one?

LITERATURE REVIEW

Development of Surrogate Roles and Responsibilities

During the late 20th century, the health care surrogate role emerged as an outgrowth of three interrelated developments: application of biomedical technology to critically ill patients, development of the field of bioethics, and judicial and legislative decisions directing surrogate and proxy actions (Health Care Advance Directives Act, 2009).

In recognizing the right of parents to speak and act on behalf of family members, federal and state courts acknowledged the health care surrogate role (*Cruzan v. Director, Missouri Department of Health*, 1990; *Quinlan v. New Jersey*, 1976). These extensions of individual patient rights from competent to incompetent patients paralleled passage of the Patient Self-Determination Act (PSDA, 1990), directing that all Medicare and Medicaid patients be allowed to express their individual preferences for health care in advance of receiving medical treatment. This resulted in each state eventually moving to establish evidentiary standards that would determine specific conditions under which patients' previously expressed treatment wishes would be honored. Consequently, individual state statutes have produced a diverse surrogate nomenclature consisting of a number of interchangeable titles for patients' representatives, such as *health care surrogate, durable power of attorney for health care (DPAHC), health care proxy*, or *guardian*. This language also reflected the varying surrogate duties and processes assigned within each state (*Cruzan v. Director, Missouri Department of Health*, 1990; Health Care Advance Directives Act, 2009).

Initially, research on surrogate activity focused research attention on medical patient decision making (Smeidra et al., 1990) or on patient-surrogate treatment decision concordance to gauge surrogate accuracy in predicting patient treatment preferences (Cogen et al., 1992; Hare, Pratt, & Nelson, 1992; Seckler, Meier, Mulvihill, & Cammer-Paris, 1991). Yet, these early studies produced inconsistent findings and offered little insight into the actual surrogate decision-making process (Engelberg et al., 2005). Instead, they produced an initial view of surrogate performance that persists today: surrogates were "unreliable" patient representatives, and their decisions "are no better than random chance" (Suhl et al., 1994, p. 90).

More recent investigations have inquired into amounts and types of preliminary patient-surrogate communications, to move surrogate decision making from its initial presentation of surrogate duties limited to a simple, isolated decision, to a series of complex, multi-tasked responsibilities orchestrated by individuals who represent incapacitated patients (Buckey, 2007; Limerick, 2007; Swigart et al., 1996; Thelen, 2005; Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006). Patient-surrogate communication preceding the patient's need for medical treatment emerged as an instrumental component in surrogate decision-making studies. When surrogates knew patient wishes, they were committed to following them; when they did not, surrogates reported high levels of decision conflict and poorer post-mortem adjustments (Buckey, 2007; Carr & Moorman, 2008; Seckler et al., 1991; Wright et al., 2008).

Increasingly, examinations of surrogacy have revealed a stressfully complex assortment of tasks. When they knew little about patient care preferences, surrogates displayed an "insatiable" need for information (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001, p. 200), including human physiology, trajectory of patient illnesses, prognoses, and likely responses to treatment (Hiltunen, Medich, Chase, Peterson, & Forrow, 1999; Jacob, 1998; Swigart et al., 1996). Surrogates evaluated patients' medical and emotional conditions together with prior illness histories, and factored what patients said into their decisions (Abbott et al., 2001; Hiltunen et al., 1999, Jacob, 1998; McNabney, Beers, & Siebens, 1994; Swigart et al., 1996). Less knowledge about patient preferences increased family conflict, surrogates' personal distress, and number of treatment decisions required (Abbott et al., 2001; Hiltunen et al., 1999; Jacob, 1998; Lautrette et al., 2007).

Surrogates may feel both moral and ethical obligations to respect patient treatment wishes, regardless of their personal discomfort (Buckey, 2007; Swigart et al., 1996). Those who honored patients' wishes reported greater success in post-mortem adjustment, and those who failed to do so reported more problems after the patient died (Jacob, 1998; Lautrette et al., 2007). Surrogates attempted to make decisions congruent with patient, surrogate, and family values, while avoiding decisions likely to increase patient pain or complicate treatment (Abbott et al., 2001; Hiltunen et al., 1999; Jacob, 1998; Vig et al., 2006). Decisions to withhold treatment were often based on patients' poor prognoses, lack of mental acuity, and adverse reactions to treatment (Cogen et al., 1992; Hare et al., 1992; Layde et al., 1995; McNabney et al., 1994; Smedira et al., 1990).

Surrogates were routinely emotionally closer to patients than other family members, and often assumed a role of leadership in the family, expanding their responsibilities to care for other family members prior to, during, and following patient illness. These family leadership skills appeared to expedite decision making and included efforts to bring together family members divided in their preferences for patients' medical care and treatment (Swigart et al., 1996).

Surrogates often view physicians as primary information sources about patient condition and prognosis, leading them to expect physicians to be available and involved during decision making (Engelberg et al., 2005; Lewis et al., 2006). Physician traits, such as availability, openness, and support, enhanced surrogate trust and produced greater adherence to physicians' treatment recommendations (Abbott et al., 2001; Hiltunen et al., 1999; Jacob, 1998; Swigart et al., 1996). Conversely, and especially regarding decisions to forgo treatment, lower trust levels created greater decision-making difficulty

(Hiltunen et al., 1999; Swigart et al., 1996). Collectively, surrogates' subjective impressions of patient conditions, combined with information acquired from physicians, medical staff, and family members, aided surrogate decision making while mitigating their distress (Abbott et al., 2001; Jacob, 1998; Johnson et al., 2000; Hiltunen et al., 1999; McNabney et al., 1994; Swigart et al., 1996; Wright et al., 2008). In acquiring reliable information from multiple sources, surrogates made decisions after processing information obtained from patients and significant others; i.e., physicians, nurses, or family members (Hiltunen et al., 1999; Jacob, 1998; Johnson et al., 2000; Limerick, 2007; Swigart et al., 1996; Vig et al., 2006).

Incorporating Theory

To offset one major omission from prior studies, a conceptual model of surrogate decision making with variables based on relevant theory, the Health Belief Model was designed for this study (HBM; Rosenstock, Strecher, & Becker, 1988). The HBM has previously been applied to gauge individual preventive health, illness, and sick role behaviors and to emphasize readiness to act during periods of uncertainty. Although the HBM has not been applied to the health-related behaviors of persons acting on another's behalf, the core of this value-expectancy model can be applied to surrogates who anticipate that particular actions taken on behalf of a critically ill patient will achieve a desired outcome. Their evaluation of potential patient *benefits* and *barriers*, or disadvantages, associated with treatment choices is central to the Surrogate Decision-Making Model (see Figure 1). For example, surrogates

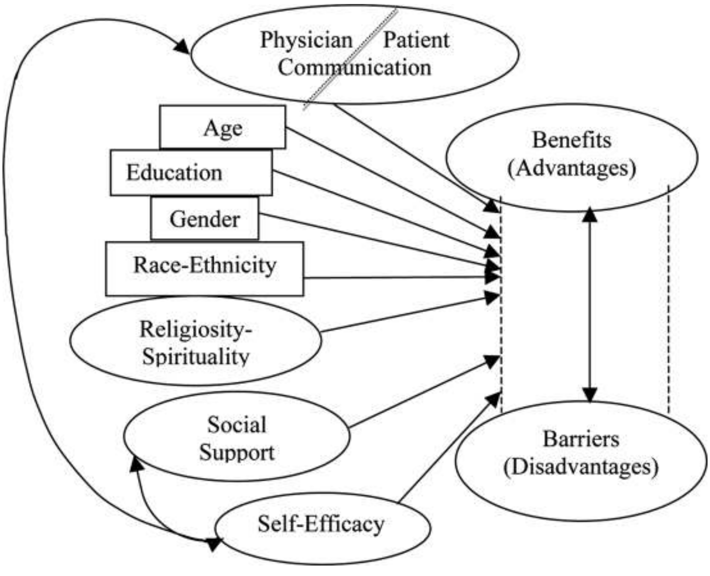

FIGURE 1 Proposed Surrogate Decision-Making Model.

may experience conflict when instituting a treatment possessing both advantages and disadvantages, such as stabilizing the patient's medical condition while simultaneously risking greater medical complications resulting from the treatment choice.

We also adapted a key group of HBM social cognitive antecedents thought to precede individual surrogate health behaviors and modify factors influencing their action: demographic characteristics (age, gender, education, and ethnicity), sociopsychological attributes and beliefs (emotional closeness to patient and perceived social support), and structural influences (patient and physician communications). Thus, the model represents the interactive, psychosocial approach to surrogate decision making as it acknowledges the social and psychological realities of individual health decision behavior. The variable of self-efficacy was later introduced to enhance the model's ability to account for greater variation in behavior (Rosenstock et al., 1988). Although self-efficacy had not been incorporated into subsequent HBM model tests as originally proposed by Rosenstock and colleagues, in other models examining health behavior it had historically accounted for as much as 20% of the variance (Abraham & Sheeran, 2000). Thus, we included it here.

Physician assessment of other HBM variables, such as threat and susceptibility of severe (patient) illness, is a unique challenge in application of the HBM to surrogate decision making. These HBM variables are portrayed via physicians' treatment recommendations, thus are not represented by surrogate decisions and were excluded from our model. Overall, the HBM represents an initial, interactive, psychosocial approach to surrogate decision making, reflecting the social-psychological reality of surrogate decision behaviors while incorporating the multiple influences potentially influencing health-related surrogate behaviors within health-related environments (Abraham & Sheenan, 2000). It offers a coherent approach to examine variables identified as being inconsistently measured in the surrogate literature, yet selectively found to influence surrogate decisions (Buckey, 2007; McNabney et al., 1994).

METHODOLOGY

While existing literature provides an initial profile of influences on surrogate decision making, methodological and conceptual limitations are often unaddressed, raising concerns about the validity of conclusions. George (2002) charges that researchers have failed to apply a uniform definition of surrogacy. Others cite difficulties associated with prospective designs attempting to examine life-threatening treatment conditions before they have actually occurred, versus retrospective studies that risk bias when survivor recall may be clouded by personal bereavement and grief (Addington-Hall & McPherson, 2001). Finally, use and alteration of measurement scales with unknown or unreported psychometric properties compromised internal and statistical conclusion validity (Cogen et al., 1992; Hare et al., 1992; Smedira et al., 1990; Suhl et al., 1994). As a result, questions remain about the credibility of findings based on questionably measured constructs.

An attempt was made to address these and related limitations in our investigation of factors influencing surrogate and proxy decisions about life-sustaining treatments. As a result, this study differs from prior efforts in a number of ways. First, a uniform definition of surrogacy, encompassing multiple statutory definitions of adults functioning in the role of treatment decision maker on behalf of a critically ill medical patient was applied. In this study, surrogacy refers to "a competent adult who has not been expressly designated to make health care decisions for a particular incapacitated individual, but who, nevertheless, is authorized pursuant to s. 765.401 to make health care decisions for such individual" or "any competent adult expressly designated by a principal to make health care decisions on behalf of the principal upon the principal's incapacity." These definitions are compatible with the recent Florida Health Care Advance Directives Act (2009, Definitions sections, ¶ 15 and ¶ 16). Second, adhering to recommendations for conducting research on end-of-life decision-making processes directly (Gessert, Curry, & Robinson, 2001), we conducted this study in real time, or while participants were actively engaged in health care surrogate decision making. People currently acting as surrogate and proxy for patients in the ICU/CCU (Critical Care Unit) were surveyed immediately after their decisions about a life-sustaining treatment and, where possible, before those decisions had been acted upon or their outcomes known; i.e., while patients continued to receive care. Thus, methodological concerns associated with the prospective–retrospective study debate were minimized as much as possible.

In addition to the conceptual framework described above, also employed were reliable, valid measurement tools; some, specifically developed and validated for use in this study (Buckey & Abell, 2004, 2009). A power analysis determined the required sample size needed to maximize the predictive power of the regression procedures employed (Hair, Black, Babin, Anderson, & Tatham, 2006). Again, the question addressed was "Did surrogates' personal attributes, or their perceptions of communications, social support, or self-efficacy directly influence their life-sustaining treatment decisions?"

Design

A real-time, descriptive, cross-sectional survey design was used to assess surrogate values, attitudes, and beliefs immediately after their decisions to initiate, withdraw, or withhold one of four life sustaining treatments: cardiopulmonary resuscitation (CPR), mechanical ventilation, tube feedings (PRN or TPR), or dialysis. We surveyed a sample of surrogates from a diverse, heterogeneous population who were active in their decision-making roles.

Sample

Respondents were adults making life-sustaining treatment decisions on behalf of incapacitated medical (ICU) patients during a current hospitalization, a prior hospitalization (such as with hospice patients), or for advanced Alzheimer's patients being cared for at home. Surrogates qualified for the study if they had made at least one life-sustaining treatment decision on behalf of a patient and then continued in the surrogate role, and if their patient continued to receive some form of medical care.

Facilities were identified where surrogates might be found. One indicator of estimated surrogate activity was the number of hospital deaths, which also included patient age, gender, and race, reported quarterly by state-licensed hospitals to Florida's Agency for Health Care Administration during the calendar years 2001–2003. Letters were sent to a broad range of hospital and other agency administrators seeking interest in study participation. Of 60 hospitals contacted, 8 administrators expressed study interest; of 18 hospices, 5 were interested, and no responses were obtained from the 55 long-term care facilities contacted. Final sample sites included three hospitals, two hospices, and two Alzheimer's and Parkinson's disease support agencies.

As the tertiary facilities engaged for this study (described below) maintain no formal records on surrogate action or on the utilization of life-sustaining treatment equipment, random sampling of study participants was not an option. Using a nonprobablity, purposive sampling approach based on the relevant characteristics of this highly specialized population (Henry, 1990), the sample blended respondents from rural with urban communities.

Measures

We used a combination of researcher-created items and standardized measurement scales to strengthen data reliability and statistical conclusion validity, and to increase the power of statistical tests employed (Tate, 1998). Of the 10 predictor variables represented in Figure 1, 4 were demographic—i.e., surrogate age, education level, gender, race-ethnicity—and 4 were single-item or summated rating scales developed for this study (physician and patient communications, religiosity-spirituality, and emotional closeness to the patient).

Existing standardized scales measured the remaining two predictor variables. Social support was measured by the 12-item Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988), and self-efficacy was measured by an adaptation of the 20-item Healthcare Surrogate Preferences Scale (HSPS; Buckey & Abell, 2004). While the original HSPS was designed to be predictive of self-efficacy (i.e., projecting what one would or could do), this view was modified for this study to ask participants to recall their judgments after the fact, following a surrogate decision. Thus, respondents had an opportunity to reflect on individual competencies required to conduct their duties while simultaneously evaluating personal beliefs about their role experience, including its tasks and responsibilities.

The Acceptance of Treatment Choice Inventory (ATCI), measuring surrogate perceptions of the advantages (benefits) and disadvantages (barriers) associated with evaluating life-sustaining treatment decisions, was used to measure the criterion variable, benefits, and barriers (Buckey & Abell, 2009). As established psychometrics are inherently sample dependent, reliability of all standardized measures were reassessed using Cronbach's alpha (α) prior to hypothesis testing.

Although this study design was primarily quantitative, it also included a single qualitative item, "Is there anything else you feel we should know about your surrogate experience?" Located at the end of the survey, this item provided respondents an opportunity to share personal views on the subject.

Data Collection

Consent for use of human subjects was obtained from University and facility institutional review boards (IRBs), facility or agency administrators, and/or Boards of Directors. Potential study participants were approached in ICUs, hospice, or community support agency service locations to complete an anonymous, self-report survey about their feelings, attitudes, and beliefs following their decision to initiate, withhold, or withdraw patient treatment. Study participation was confidential and voluntary and the consent process specified a disclaimer that participation would in no way affect patient treatment.

Participants were requested not to place personal identifying information protected under HIPPA (1996); i.e., name, patient name, age, bed or room number, or any signature on the survey. Although participants were encountered face-to-face when asked about their interest in the study, after data collection there was no way for the researcher to associate any response with any individual. Participants chose one of three methods of survey return: in person to the researcher or research associates, via facility drop boxes, or by mail. Other than survey completion, no other respondent activity was required. Counseling resources were listed in the packet to address potential respondent emotional reactivity.

Several facilities required the researcher to undergo HIPPA (2002) on-site training.The first author conducted on-site training to assist in standardizing data collection procedures for research associates who were recruited from facility staff members. Volunteer research associates were given study background and data collection procedures, including paraphrasing of verbal scripts that were used during surrogate interactions and prior to survey administration. These associates used a verbal script to announce study availability and assess study interest. HIPPA guidelines mandated that only facility staff could approach potential participants. After receiving an affirmative response, surrogates were personally presented a survey packet. Staff and potential respondents were familiarized with study procedures. After receiving facility permission to post survey notices within facilities—i.e., in the ICU waiting room, on staff bulletin boards, or in newsletters—the researcher posted notices to publicize the study, ensuring researcher availability during day, evening, and night shifts.

Two hundred forty-six survey packets were distributed to potential respondents; 135 usable surveys were returned. The overall response rate of 55% was within the range of rates documented in the literature, from 37% (community mail survey, Hare et al., 1992) to 100% (medical inpatients, Suhl et al., 1994).

Data Management

Data analyses compared raw data runs using listwise deletion with runs using mean replacement values. As results of all model variables differed notably and yielded greater numbers of statistically significant correlations using mean replacement data, the more conservative, raw data values were used in data analyses (Tate, 1998). The influence of outliers, evident in four variables, resulted in deletion of three cases, yielding the total usable sample of 132. Sample sizes for specific analyses ranged from 105 to 128, each meeting criteria for adequate power in hypothesis testing. Data analyses were performed with SPSS 14.0.

RESULTS

Respondents

The average surrogate age was 58 years ($SD = 12.5$), slightly less than the average reported age of patients (59 years). Patient ages over 89 ($n = 22$) were not reportable under HIPPA (2002) privacy regulations. Consequently, actual mean age for patients is unknown, though certainly higher than the figure reported here. Respondents were three-fourths female (78.8%), predominately white (82.5%), and reported 14.2 years of formal education ($M = 14.2$, $SD = 2.89$). Gauging themselves to be very religious or spiritual ($M = 7.49$; $SD = 2.22$) on a scale from 1 = *not at all important* to 9 = *extremely important*, most surrogates ($n = 111$, or 84.1%) felt *extremely* to *very emotionally close* to the patient. Only a minority ($n = 5$, or 3.8%) reported feeling *neutral* or *distant* toward the patient.

Spouses were the largest relationship subgroup ($n = 49$, 37.1%), followed by daughters ($n = 47$, 35.6%), sons ($n = 13$, 9.8%), and others ($n = 23$, 17.5%). Religious affiliation was primarily Protestant, 73 (55.3%), followed by Catholic, 44 (33.3%), and Jewish, 3 (2.3%). Nearly one half of respondents (*n* = 64, or 48.5%) withheld or did not begin treatment. Forty (30.3%) initiated treatment, and 28 (21.2%) withdrew treatment. The greatest number of decisions (*n* = 59, or 44.7%) were about CPR/do not resuscitate orders (DNRs); nearly one third of surrogates (*n* = 36, or 27.3%) made decisions about mechanical ventilation; nearly one fifth (*n* = 23, or 17.4%) made decisions about tube feedings. A minority (*n* = 13, or 9.8%) made decisions about dialysis; only one (.8%) failed to specify a decision. Overall, 104 (78.8%) surrogates strongly agreed with the statement, "Looking back, I can accept that my decision was the best alternative for the patient."

Surrogates reported having dealt with patient illness an average of 36.5 months (*SD* = 56.2 months); item responses ranged from 1 to 31 years, indicating the time surrogates had been actively involved with patient illness; 7 respondents failed to respond to this item. Cardiac/cardiopulmonary disease and cancer, the two most prevalent surrogate-identified patient diagnoses, paralleled the prevalence of each disease category in the general U.S. population (*n* = 24, 18.4%, respectively), followed by cerebrovascular disease (*n* = 17, 12.8%; Centers for Disease Control and Prevention, 2009). Interested readers are referred to Buckey (2007) for more information on surrogate and patient characteristics resulting from this study.

Existing and Newly Created Measures

Results of existing and new measures of study variables contained in the surrogate decision-making model are shown in Table 1. The MSPSS (Zimet et al., 1988) produced a Cronbach's coefficient alpha representing scale reliability of $\alpha = .943$ for social support (*M* = 5.96, *SD* = 1.15); the adapted HSPS (Buckey & Abell, 2004), $\alpha = .877$, for surrogate self-efficacy (*M* = 6.16; *SD* = .76). Standard error of measurement (*SEM*) coefficients were computed as indicators of measurement error for the current sample; for

TABLE 1 Measurement of Key Constructs: Patient Communication, Physician Communication, Social Support, Surrogate Self-Efficacy, and Benefits-Barriers

Measure and variable	α	*SEM*	*M*	*SD*
Existing measures				
MSPSS				
Social support	.94	.27	5.96	1.15
Adapted HSPS				
Self-efficacy	.88	.27	6.16	.76
New measures				
Physician communication	.92	.56	7.64	2.02
Patient communication	.91	.42	8.49	1.43
ATCI				
Benefits subscale	.73	.39	6.32	.76
Barriers subscale	.68	.54	1.95	.98
Benefits-Barriers composite	.69	.38	.88	.68

the MSPSS, *SEM* = .27, and for the HSPS, *SEM* = .27, results well below the threshold value of .3 (5% of 6.0 = .30), thus both variables were retained for model testing (Springer, Abell, & Hudson, 2002).

Two new, researcher-created dimensions of surrogate communication variables measured the degree of surrogates' perception of communication helpfulness, assessing first, whether communication occurred, and if so, the means by which it was shared (verbal or written) between (a) surrogates and physicians, and (b) surrogates and patients. Using a Likert scale where 1 = *not very helpful at all*, to 9 = *extremely helpful*, Physician communication (*M* = 7.64, *SD* = 2.02) resulted in a Cronbach's coefficient of $\alpha = .922$ (*SEM* = .56); and Patient communication (*M* = 8.49, *SD* = 1.43), a Cronbach's coefficient of $\alpha = .913$ (*SEM* = .42). The standard errors of measurement (*SEM*s) for physician communication were considerably above, and for patient communication only slightly above, the target threshold ($\leq .40$).

The initial validation of the 20-item Acceptance of Treatment Choice Inventory (ATCI), an evaluation of surrogate perceptions of the Benefits and Barriers associated with treatment decision choice, has been detailed elsewhere (Buckey & Abell, 2009). ATCI items combined (a) HBM constructs reflecting the individual costs-benefits analyses thought to occur during individual medical treatment decision making (Rosenstock et al., 1988), and (b) the empirical literature findings that reflected the potentially beneficial or harmful results surrogates associated with treatment decisions (Jacob, 1998; Swigart et al., 1996). Benefits scores (representing advantages surrogates associated with a treatment choice) were assigned positive values; Barriers scores (representing disadvantages surrogates associated with a treatment choice) were assigned negative values, on a 7-point Likert scale, where 7 = *very strongly agree* and 1 = *very strongly disagree*. The goal of the final ATCI composite score was to capture surrogate perceptions about whether their treatment decision would improve (produce greater Benefits) or worsen (produce greater Barriers) overall patient and surrogate situations. An overall higher score on the ATCI would indicate surrogates perceived greater advantages associated with a treatment decision; a lower score would indicate greater disadvantages associated with a treatment decision.

Final scale analysis mirrored the two originally intended subscales, with a slight modification. The Benefits subscale (*M* = 6.32; *SD* = .76) was interpreted as decision support, as final items captured concerns about surrogate perceptions of the various sources of support for a treatment decision. The Barriers subscale (*M* = 1.95; *SD* = .98) was interpreted as an inability to act in the patient's best interest, again reflecting content of items retained in the final analysis. The final Benefits-Barriers (decision support-inability to act) composite variable (*n* = 117; *M* = .88; *SD* = .68; Range: −1.20 to +2.40) was interpreted as higher scores reflecting surrogates' perceptions of Benefits (i.e., greater support for surrogate decisions). Lower scores reflected greater perceptions of Barriers. As an example, the highest ATCI composite score,

+6, indicated that these surrogates ($n = 18$) perceived greater benefits associated with their treatment decisions, while the lowest ATCI composite score, −1, indicated that this surrogate ($n = 1$) perceived greater barriers associated with her treatment decision.

The subscale reliability for Benefits (decision support; $\alpha = .726$) was clearly acceptable for individual use, yet the subscale reliability for Barriers (inability to act; $\alpha = .690$) was marginal. Given the pilot nature of this study and the absence of stronger indicators of the Barriers-Benefits composite construct, we judged the ATCI as acceptable for use in these analyses. The *SEM* for the Benefits subscale (.39) slightly exceeded the threshold value of .30 (5% of 6.0 = .30), and the Barriers subscale *SEM* (.54) exceeded the target value.

Benefits and Barriers

Simple regression was used to test hypotheses between predictor variables and the Benefits-Barriers criterion (see Table 2). After deleting three cases with excessive influence to improve model performance (Tate, 1998), patient communication accounted for 25% of the variance in Benefits-Barriers [$R^2 = .254$, $p < .001$, $F(1,110) = 37.48$]. The more conservative adjusted R^2, appropriate for comparisons containing different numbers of variables, sample sizes, or both, was essentially equivalent ($R^2_{adj} = .247$). These findings were consistent with other studies addressing surrogates' need for patient information, suggesting that surrogates may seek greater quantity and quality of information than patients are willing to provide (Abbot et al., 2001; Covinsky et al., 2000; Hines et al., 2001; Jacob, 1998, Swigart et al., 1996).

Self-efficacy accounted for approximately 22% of variance in perceived Benefits-Barriers [$R^2 = .223, p < .001, F(1,115) = 32.751; R^2_{adj} = .216$]. This find- This finding mirrored the conceptual literature on medical decision making but has not been previously reported in surrogate studies. Self-efficacy repeatedly accounts for approximately 20% of model variability when more broadly examining individual health behaviors (Abraham & Sheeran, 2000).

Nearly 5% of surrogates' self-efficacy could be accounted for by patient communication [$R^2 = .048$, $p < .013$, $F(1,126) = 6.407$ $R^2_{adj} = .041$].

TABLE 2 Bivariate Relationships: Predicting the Impact of Patient Communication and Surrogate Self-Efficacy on Perceived Benefits-Barriers of Life-Sustaining Treatment Decisions

Variable	*B*	*SE B*	B
Patient communication ($n = 112$)	.379**	.062	.504
Self-efficacy ($n = 116$)	.790**	.138	.472
Self-efficacy and patient communication ($n = 128$)	.100*	.039	.220

Note. $R^2 = .254$ and ($R^2_{adj} = .247$) for Patient communication; $R^2_{adj} = .223$ and $R^2_{adj} = .216$ for Self-efficacy; and $R^2 = .048$ and $R^2_{adj} = .041$ for Patient communication and Self-efficacy.

$^{*}p < .05$. $^{**}p < .001$.

Thus, surrogates aware of patient wishes in advance may have greater confidence in performing their surrogate duties, knowing that patients' wishes were followed. When viewed in conjunction with the statistically significant but relatively small correlation between these variables ($r = .220$), these findings suggest measurement of separate, but related, constructs (Hair et al., 2006).

Using hierarchical multiple regression (HMR) as the procedure of choice for testing conceptual models (Cohen & Cohen, 1983), the less conceptually important variables—in this case, demographic variables of age, education, gender, ethnicity, and religious-spiritual beliefs—enter the model first (Group 1), followed by physician and patient communications (Group 2), and finally, by social support and self-efficacy (Group 3; see Figure 2). Cases assessed in the HMR analysis ($n = 105$) produced a ratio of cases to predictor variables (9) of approximately 12:1, greater than the minimum 5:1 ratio, but slightly less than the ideal, approximately 15 or 20:1 (Hair et al., 2006).

As shown in Table 3, regression of the demographic variables in Step 1 did not significantly predict Benefits-Barriers ($R^2 = .031$). Introduction of physician and patient communication variables in Step 2 was significant ($R^2 = .153$, $F = 2.50$, $F[.05;\ 7,\ 97] = 6.36$, $p = .001$) reinforcing the overall strength of the relationship between patient communication and Benefits-Barriers reported in the previous simple regression model. The resulting change in R^2 ($\Delta R^2 = .122$) indicated that communication with the patient and physician accounted for approximately 12% of variability in perceived Benefits-Barriers. Lastly, after controlling for the influence of variables previously introduced, social support and self-efficacy were entered into

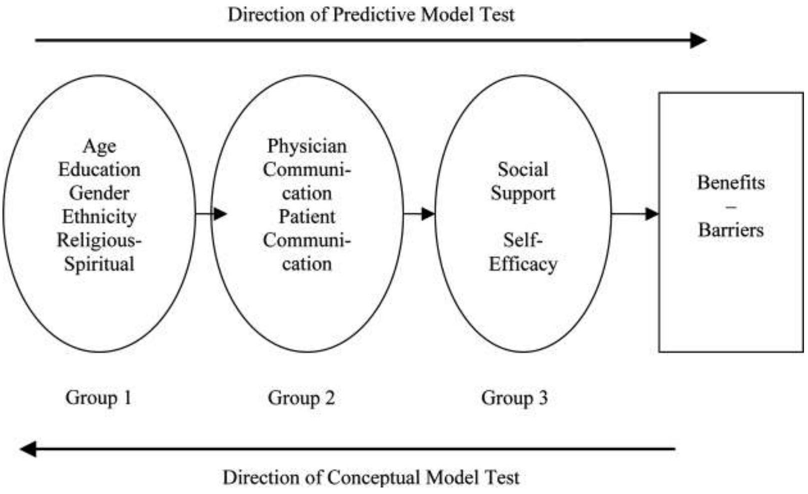

FIGURE 2 Applied Hypothesized Model of Surrogate Decision Making.

TABLE 3 Summary of Hierarchical Regression Initial ($n = 105$) and Final ($n = 104$) Surrogate Decision Models: Predicting Perceived Benefits-Barriers

Variable	*B*	*SE B*	β
Initial model			
Step 1			
Age	−.004	.011	−.041
Education	−.047	.046	−.104
Gender	−.238	.332	−.073
Ethnicity	.501	.356	.148
Religiosity-spirituality	−.008	.066	−.012
Step 2			
Physician communication	.025	.061	.038
Patient communication	.305*	.082	.350
Step 3			
Social support	−.031	.111	−.027
Self-efficacy	.628*	.185	.336
Final model			
Patient communication	.291**	.067	.362
Self-efficacy	.673**	.155	.391

Note. Step 1: $R^2 = .031$; $R^2_{adj} = -.018$. $\Delta R^2 = .031$.
Step 2: $R^2 = .153$; $R^2_{adj} = .092$. $\Delta R^2 = .122$.
Step 3: $R^2 = .252$; $R^2_{adj} = .181$. $\Delta R^2 = .099$.
Final regression model: $R^2 = .381$. $R^2_{adj} = .322$. $\Delta R^2 = .140$.
$^*p < .05$. $^{**}p < .001$.

the model in Step 3. This resulted in a statistically significant $R^2 = .252$ ($F = 3.56$, $F[.05; 9, 95] = .718$, $p = .001$). The $\Delta R^2 = .099$ (9.9%) in the final step indicates that social support and self-efficacy increased the explanatory power of the model by an additional 10%.

Post hoc diagnostics improved the fit of the regression model and resulted in statistically significant coefficients showing no multicollinearity concerns (Hair et al., 2006). Final model results, improved by deletion of one influential case ($N = 104$), are shown in Table 3. The final model changed as follows: R^2 (from .252 to .381), R^2_{adj} (from .181 to .322), and ΔR^2 (from .099 to .140). Of particular note were changes in the final model in Step 2, in which patient communication and self-efficacy explained 12.5% and 12.4% of surrogate decision making, respectively. Thus, surrogate communication with patients, and surrogate knowledge of and functionality in their roles, accounted for approximately one quarter of the variability in surrogates' perceptions of Benefits and Barriers associated with their treatment decisions. Our preliminary power analysis supported testing simple and multiple regression R^2 coefficients of medium effect size ($ES = .15$) considering all variables entered into the hierarchical model. But as indicated by the final coefficient of determination, $R^2 = .381$ ($R^2_{adj} = .322$), the overall study effect size is relatively large, given typical effect sizes in the social sciences literature that range from .25 to .50 (Cohen & Cohen, 1983).

DISCUSSION

Study findings underscore the importance of early communications between patients and their surrogates in enhancing surrogates' understanding of patient treatment preferences (Gutheil & Heyman, 2005; Karel, Powell, & Cantor, 2004). Consistent with previous research, surrogates in this study were aware of patient preferences, and they attempted to comply with them when making "tough" decisions (Buckey, 2007, p. 157; Jacob, 1998). Accordingly, this advanced understanding of patient wishes enabled them to carry out excruciating, emotionally painful life-and-death decisions reflecting their knowledge of "what Mom wanted" (Buckey, 2007, p. 140). Following patient treatment directives not only provide surrogates a degree of personal gratification and emotional relief, but may bring closure to a highly emotional, stressful life experience, a closure enhanced by acceptance of the decision made, regardless of patient outcomes. Reflecting on their personal acceptance of decisions made under real time conditions, the majority of surrogates in this study (98%) felt they made the best decision possible, a decision that they and others can "live with" (Buckey, 2007, p. 158).

Conversely, when knowledge of patient preferences for treatment is unknown, unclear, or inadequate, surrogates had to rely on additional factors, including theirs and others' values and preferences for patient treatment (Lewis et al, 2006; Limerick, 2007; Vig et al., 2006). The impact of this lack of knowledge was articulated by one respondent, age 54, acting on behalf of her husband, age 57, who openly admitted, "We'd never talked, so I didn't know what to do." (Buckey, 2007, p. 141).

Concerns associated with fulfilling the surrogate role included its pragmatic-introspective nature, which we termed the head-heart dilemma, one characterized by internal logical versus emotional struggles. Head-related activities, captured by HBM value expectancy theory, included logical thought processing and its follow-through, acting on patient wishes in order to attain the desired patient treatment decision (Limerick, 2007). One respondent separated her actual treatment decision from its personal repercussions, identifying the most difficult part of her surrogacy as "watching them go, even though I knew it was what she wanted and she was ready" (Buckey, 2007, p. 134). One respondent (who happened to be a health care professional) indicated she did "a little magical thinking" in deciding her mother's treatment, acknowledging, "Being a health care professional doesn't make these decisions any easier" (Buckey, 2007, p. 134).

As the limited availability of end-of-life quantitative measures unique to surrogate needs have inhibited progress in end-of-life investigations (George, 2002; National Institutes of Health [NIH], 2004), the attempt in this study to capture two variables—self-efficacy and benefits and barriers associated with treatment decisions—offer end-of-life researchers a possible beginning for reliable, valid measurement of surrogate decision activity. As a new variable in the surrogate decision literature, surrogate self-efficacy may expand surrogate investigations through its representation of inherent complexities in the surrogate role. The HSPS (Buckey & Abell, 2004), developed early in this research agenda, provides a reliable, valid measurement tool specifically to assess self-efficacy in the context of surrogate decisions. Preliminary scale items associated with treatment decisions developed for the ATCI (Buckey & Abell, 2009), such as rallying family support, obtaining information from others, and inward reflection on considerations leading to a final treatment decision, mirrored conceptual themes in other studies (Limerick, 2007; Swigart et al., 1996). Lastly, we have piloted evaluation of benefits and barriers perceived by surrogates. This promotes greater reliance on conceptual literature regarding surrogates' evaluative process, previously unaddressed in quantitative investigations.

Even with attention to selection of a rigorous measure such as the MSPSS subscales identifying sources of support: family, friends, and significant others (Zimet et al., 1988), the social support variable did not emerge as statistically significant, accounting for less than .8% ($sr^2 = .008$) of the $\Delta R^2 = .099$ reported in the HMR, Step 3. Prior studies identified family and others as sources of guidance during decision making (Abbott et al., 2001; Cogen et al., 1992; Hiltunen et al., 1999; Jacob, 1998; Smedira et al., 1990; Swigart et al., 1996). Considering the strong showing of ATCI items identifying surrogates' influence from and connection with others in treatment decisions, this finding was surprising. Although a positive relationship did emerge between social support and benefits ($r = .245$, $p < .001$), it may be that surrogates view support or guidance obtained during decision-making deliberations as a benefit; and beyond family and friends, investigators have not acknowledged ICU health care professionals (i.e., physicians, nurses, social workers, pastoral care) as sources of such support (D. Heyland, personal communication, November 3, 2006). Future research should attempt to define and clarify the potential role of social support by conceptualizing help received from formal care providers.

Limitations

Access to only three tertiary care facilities—one, a major University teaching hospital, along with the Hospice and service agencies (Alzheimer's and Parkinson's Association)—was a limitation (small sample size). Two hospitals declined participation primarily due to concerns about researcher contact with surrogate representatives at such an emotionally volatile time, a concern echoed one facility ethics committee. Administrators felt that engaging with researchers at such a critical time in the patient's and surrogate's experiences would adversely affect family responses on patient satisfaction surveys; thus they declined participation. It should be noted that researcher restriction by facility administrators was identified as a barrier to conducting end-of-life research in the first National Institutes of Health End-of-Life Consensus Report (NIH, 2004). Social work researchers pursuing surrogate decision research should be aware of, and prepared to deal with, potential facility resistance.

However, our experiences in this in vivo study, conducted while surrogates exercised the duties of their role, indicated that such concerns may be unwarranted. It was only after speaking with one emotionally distraught surrogate who declined participation that we discovered that a research associate had, in violation of study protocol, inappropriately approached the surrogate *prior* to his treatment decision, rather than afterward. In contrast, one mother-daughter couple expressed appreciation to us for compiling a survey, thus allowing them to reflect and affirm their decision to withdraw their loved one from the ventilator per his wishes.

Another limitation of this study was the occurrence of Terri Schiavo's death (March 2005), midway through data collection. This unforeseen event was accompanied by excessive media coverage of which participants were almost certainly aware, and posed a major threat to the internal validity of our study (Pedhauzur & Schmelkin, 1991). A visible spike in survey returns nearly tripled submissions in the 2 weeks prior through the 2 weeks following Ms. Schiavo's death, as her life-and-death struggle precipitated international attention and heightened awareness of moral and ethical dilemmas associated with surrogate decisions.

This study was conducted in Florida. Consequently, all methodological and applied issues drawn from the data are circumscribed by Florida statute (Health Care Advance Directives Act, 2009). Generalizations can only cautiously be made to other settings, though it is our belief that the broader issues regarding surrogate decisions; specifically, the evaluation of the presenting benefits and barriers that are the emphasis of this study, are more readily generalizable than particulars of law or title.

Despite these limitations, this study produced meaningful results. In addition to the new measures noted above, the findings also provide support for more intensive study of the underlying surrogate decision-making process, specifically investigating factors relevant to making, and making peace with, surrogate decisions. Our findings also support expanding measurement of the types and nature of patient-surrogate communication, highlighted as a need in the NIH (2004) report.

Implications for Social Work Practice

With previous research findings indicating a lack of surrogate awareness of and preparation for assuming their roles (Bern-Klug, Gessert, & Forbes, 2001; Moorman & Carr, 2008), the finding that increased surrogate self-efficacy enhanced perceived benefits associated with surrogate decisions can serve to guide social workers as they help surrogates prepare to carry out their dual responsibilities. These include communicating with patients to learn and understand patients' treatment preferences and implementing those preferences when patients become unable to do so.

As surrogates in this study affirmed, with little or no advance knowledge of patient preferences, surrogates cannot represent patients accurately. Therefore, social workers might begin by assessing surrogates' knowledge of patient treatment preferences early, at minimum, upon patient entry into the critical or intensive care unit, especially if patients are in imminent danger of losing consciousness/capacity for decision making. Initially, as in any crisis situation, social workers can assess and corroborate surrogates' knowledge about patient care preferences during initial patient admission, or when patient transfer to ICU/CCU is anticipated or occurs.

Secondly, social workers can increase or enhance patient-surrogate communications, if indicated. Interventions should target enhancing or clarifying previous and current communications, especially for surrogates entering the ICU/CCU situation and who have little knowledge of patient care preferences and for patients who remain communicative and cognizant of their surroundings. Doing so may establish a more secure base of information for surrogates' future use. As patients' treatment needs intensify over time, having clarified surrogate understanding of patient preferences in the beginning may prove useful.

Social workers can also develop strategies to address surrogate communication difficulties. If the patient is noncommunicative, the surrogate's or family's recounting of the most recently expressed patient treatment preferences may also aid in making future treatment decisions, especially should the most recent preferences change in the case of a marked physical decline, such as an increase in patient pain or discomfort. Social workers listening to surrogates' narratives about patients' life histories and lifestyles may offer yet another method to prepare surrogates to examine an eventual, but currently unstated question, "What would Mom want?" in a supportive, reassuring way.

Finally, social workers can enhance surrogate knowledge of patient preferences through tapping into the knowledge of others. For surrogates with extended family support systems, social workers can encourage surrogates to marshal their resources, notifying significant others in the patient's life who are available and willing to support the surrogate during patient care and in making difficult future decisions.

As an estimated 90% of patients die after decisions to withhold or withdraw treatment (Truog et al., 2001), the surrogate role is often complicated by a debilitating level of emotional and physical stress. Surrogates in this study reported being overwhelmed with the multiple tasks expected of them. Social workers can serve as liaisons between health care providers and surrogates—providing concrete, updated patient information; supporting surrogate emotional, physical, and psychological well-being through direct services; and advocating for provision of appropriate collateral services, specific interventions, or referrals for follow-up care.

To address these potential voids in surrogate self-efficacy during face-to-face interviews, social workers can topically explore surrogates' understanding of their duties. In our highly mobile society, surrogate representatives may arrive at the patient's bedside from across the country or around the world; thus, an assessment and orientation of the surrogate's understanding of what decisions may be expected and when they would most likely occur can inform both surrogate and social worker of any knowledge or information gaps to be addressed.

Filling these gaps might include sharing printed materials or online resources on topics including surrogate duties, state statutory requirements, and facility rules, regulations, or procedures that will influence surrogates' abilities to carry out their duties. Other examples to increase knowledge of surrogate role functioning may include provision for independent education, such as online resources, available through individual or facility resources, or overnight accommodations near the patient, or ICU/CCU quiet rooms designed to support family members.

As relationships are established, social workers may explore preparatory, "What if?" scenarios in surrogate discussions, or offer to help rebuild connections with distant family members. As members of interdisciplinary health care teams, social workers excel at facilitating communications (Black, 2005). Helping surrogates develop relationships with medical or health care facility staff, supporting contact among them, and providing surrogates clear, concrete information needed for making treatment decisions can be crucial in the environments of most fast-paced medical treatment facilities.

Responding to surrogate needs can extend traditional social work services into a realm that benefits surrogate and patient partnerships through critically important communication and education. By assessing and expanding what surrogates know about patient preferences early in the patient's critical care regimen, social workers can assist surrogates to clarify and articulate their understanding of patient care preferences prior to the time a surrogate decision is needed. During this process, social work efforts can focus on preparing surrogates for subsequent complex decisions, thereby averting future unnecessary or unwanted medical care and its associated costs. Thus, social work interventions can simultaneously clarify and educate surrogates on the expectations associated with the surrogate role, while continuing to assist and support surrogates during decision making in the critical care environment.

This study reinforces that advanced knowledge of patients' explicit treatment preferences guides surrogate treatment decisions, even in the face of personal surrogate distress and hardship. The degree of importance surrogates attached to honoring patient wishes was reflected in the significance of the patient communication and self-efficacy variables. The emerging benefits-barriers variable pointed to a greater reliance on theory to capture surrogate evaluations of treatment options. Focusing future investigations on how surrogates can be better prepared to know patient preferences in advance and to execute their roles within supportive, responsive medical systems may improve understanding of surrogates' decision-making experiences.

Potential respondents' emotional distress is a paramount concern in end-of-life research. This study showed that approaching surrogates with sensitivity, respect, and support during an emotionally volatile period is a viable research approach, particularly when potential respondents understand that the research may benefit others facing similar challenges in the future. Reported benefits associated with their treatment decisions suggested they derived a degree of personal satisfaction in bringing closure to a highly emotional, stressful life experience.

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