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Religion and Spirituality in Surrogate Decision Making for Hospitalized Older Adults

Kristin N. Geros, MPH[1], **Steven S. Ivy, PhD**[2,3], **Kianna Montz, MA**[4], **Sara E. Bohan**[5], and **Alexia M. Torke, MD, MS**[1,2,3,4]

[1]Indiana University School of Medicine, Indianapolis, IN

[2]Fairbanks Center for Medical Ethics, Indiana University (IU) Health, Indianapolis, IN

[3]Daniel F. Evans Center for Spiritual and Religious Values in Health Care, IU Health, Indianapolis, IN

[4]IU Center for Aging Research, Regenstrief Institute, Inc., Indianapolis, IN

[5]Butler University Physician Assistant Program, Indianapolis, IN

Abstract

We conducted semi-structured interviews with 46 surrogate decision makers for hospitalized older adults to characterize the role of spirituality and religion in decision making. Three themes emerged: (1) religion as a guide to decision making, (2) control, and (3) faith, death and dying. For religious surrogates, religion played a central role in end of life decisions. There was variability regarding whether God or humans were perceived to be in control; however beliefs about control led to varying perspectives on acceptance of comfort-focused treatment. We conclude that clinicians should attend to religious considerations due to their impact on decision making.

Keywords

proxy; surrogate decision making; religion; spirituality

Background

There is growing evidence that religion and spirituality play an important role in medical decision making. Several studies have found that patients who rate themselves higher on various dimensions of religious experience tend to favor more aggressive care at the end of life (Balboni et al., 2007; Phelps et al., 2009; Sullivan, Muskin, Feldman, & Haase, 2004; Van Ness & Larson, 2002). For example, studies of cancer patients have found that positive

Corresponding Author: Alexia M. Torke, MD, MS, IU Center for Aging Research, 410 W. 10th St., Indianapolis, IN 46202, atorke@iu.edu.

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religious coping is associated with a higher use of life-sustaining care in the last week of life (Phelps et al., 2009), and religious support from one's faith community or the medical team may impact the decision-making process in complex ways (Balboni et al., 2013).

During hospitalization, older adults may face difficult decisions such as when to continue or withdraw life-sustaining therapy at a time when they have lost decision making capacity due to acute illness, delirium (Inouye, 2006), or dementia (Hebert, Dubois, Wolfson, Chambers, & Cohen, 2001). It is estimated that 40% of all hospitalized adults (Raymont et al., 2004) and 47% of those 65 and older (Torke et al., 2014) are unable to make decisions. Close to death, 30% of older adults who require medical decisions lack capacity to make them (Silveira, Kim, & Langa, 2010). In such cases, family members or other surrogate decision makers, are often asked to participate in making major medical decisions.

Given the importance of religion to patient medical decisions, it is possible that religious and spiritual beliefs will play an important role in surrogate decision making as well. Previous studies have noted that beliefs about the value of life, patterns of religious coping, and/or the support and guidance of a religious community are important to surrogates (Braun, Beyth, Ford, & McCullough, 2008; Elliott, Gessert, & Peden-McAlpine, 2007) and have identified faith as one of several important factors in decision making (Boyd et al., 2010; Zier et al., 2008). One study found that over 50% of the public believes that divine intervention could save a family member from a major trauma even when physicians have determined care is futile (Jacobs, Burns, & Bennett Jacobs, 2008). A study of cancer patients found that both patients and their caregivers rank faith in God as the second most important factor in decision making after the physician's recommendation (Silvestri, Knittig, Zoller, & Nietert, 2003). In spite of its importance, we know little about how surrogates incorporate religion and spirituality into the specific decisions about medical treatment. We used open-ended interviews to better understand the role of these factors for family member surrogates making major medical decisions on behalf of hospitalized older adults.

Methods

Study Design

We conducted individual, semi-structured interviews with surrogate decision makers of hospitalized older adults. The study was approved by the Indiana University-Purdue University Institutional Review Board.

Setting and Participants

Participants were recruited through a larger, prospective observational study of surrogate decision making (Fritsch, Petronio, Helft, & Torke, 2013; Torke et al., 2012; Torke et al., 2014). We recruited adults age 65 and over from the hospitalist and medical intensive care unit services of an urban, public hospital and a university-affiliated tertiary referral center in the Indianapolis area. Research team members were notified of new admissions via the electronic medical record for all hospitalized adults age 65 and over. A brief interview was then conducted with the patient's primary inpatient physician to determine study eligibility, defined as a hospitalization of at least 24 hours, medical team consideration of a major

medical decision during the first 48 hours of current hospital admission, and presence of a surrogate decision maker due to patient impaired cognition from any cause. For this study, major medical decisions were defined as those concerning 1) procedures and surgeries; 2) life-sustaining treatments including code status and intubation; and 3) hospital discharge to a skilled nursing facility or similar institution (Torke, Simmerling, Siegler, Kaya, & Alexander, 2008). Informed consent was obtained from the surrogate decision maker or the patient, based on the treating physicians' judgment of capacity to consent.

Data Collection

We approached the primary surrogate decision maker for patients who were judged by their physician as being partially or totally unable to make medical decisions. Surrogate interviews were conducted within one month of the patient's hospital admission. If the patient died before the interview, we waited two months before approaching the surrogate, as has been done in other studies (Mitchell et al., 2006). A semi-structured interview guide (Table 1) was used and included questions about the experience of decision making and communication within the hospital, as well as specific questions relating to religion and spirituality. Interviews were conducted by one of the investigators (AMT, KM) or by a trained research assistant (SB), in the hospital or the surrogate's home.

Our approach to data collection followed an iterative process that interspersed data collection with analysis, and modification of the sampling and data collection strategy based on initial findings. This iterative approach is consistent with standard qualitative research methods (Giacomini & Cook, 2000; Lindlof & Taylor, 2002). The first 35 interviews asked generally about factors important in decision making but did not specifically mention spirituality and religion. We found that religion and spirituality were often briefly mentioned but not addressed in detail by participants. Because of prior research evidence and our clinical experience suggesting that faith is often an important factor in medical decision making, we revised our interview guide to include specific questions about these topics.

After seven additional interviews, we further modified our sampling process to include only surrogates whom physicians identified as being the sole decision maker in order to have representation from this group. Based on our preliminary finding that religion played a much larger role on decisions related to life-sustaining treatments, we then limited the types of medical interventions to those pertaining to life-sustaining treatments. We conducted 4 additional interviews until reaching theme saturation, for a total of 46 interviews.

Data Analysis

Interviews were digitally audio-recorded and transcribed verbatim. Four investigators (AMT, KM, KG, SB) read and independently coded each transcript using approaches to coding guided by grounded theory (Strauss & Corbin, 1998). All investigators met to review the emerging categories, organize codes into major themes, and discuss any discrepancies until a consensus was reached. At each meeting theme saturation was assessed and eventually obtained when new interviews no longer yielded new themes.

We took the following measures to ensure credibility within our study: all data was independently coded by multiple investigators; an interdisciplinary team was used for

analysis that included a practicing physician with bioethics training (AMT), a medical student with a public health background (KG), and a theologian with leadership experience within a large university healthcare organization (SI); and finally, we used an iterative process of data collection and analysis that continued until no new themes emerged.

Results

We approached 119 eligible surrogates for our interviews and conducted a total of 46 interviews (Table 2). The most frequent reason for refusal was not having enough time. Our participants were 76% female, 50% white and 50% African American, and most commonly daughters. Only20% of surrogates had a living will documenting prior preferences for care at the end of life. Religion was discussed in 21 of the first 35 interviews and in all subsequent interviews. Forty-one were conducted within 30 days of admission, and 5 were delayed due to patient death (range 98–117 days from hospital discharge).

We identified three major themes related to the role of religion and spirituality in decision making: (1) religion as a guide to decision making, (2) control, and (3) faith, death and dying.

Religion as a Guide to Decision Making

Many individuals described the importance of their own religious beliefs and faith during the decision making process. However, even people who self-reported as “religious” only regarded certain decisions as requiring spiritual guidance, particularly those that the surrogate perceived to be related to life and death. One man described his approach to making a decision about his mother’s code status (Table 3, Quote 1):

> [I] went to church, early service, and, uh, I asked to speak with one of the pastors. And, uh, so my wife and I went and talked to them about, you know, making those life or death decisions.

He then went on to describe a previous decision to put his mother in hospice as *“*separate*”* from religion (Quote 2):

> You know, it’s just to provide care.

During this interview, the surrogate mentioned that he felt pressured by the hospital staff to make a decision about code status before he was able to have a religious consultation.

One woman struggled with how to reconcile her Catholic faith with decisions about her mother’s pacemaker (Quote 3). This surrogate perceived the initiation of the pacemaker as morally different than turning it off, and she saw the latter as inconsistent with her Catholic faith. While she perceived stopping the pacemaker as generally unacceptable, she also could imagine circumstances, such as great suffering, in which stopping the pacemaker may be consistent with her faith.

Those who felt strongly about using religion during their decision making often sought guidance from clergy to make sure their choices were consistent with their faith. It seemed

that surrogates most often consulted their personal religious leaders. However, some involved the hospital chaplains in their discussions.

Surrogates who defined themselves as spiritual rather than religious did not invoke faith beliefs directly when making decisions. They discussed their spirituality more generally (Quote 4):

> I think spirituality has a lot to do with healing.

Control

Surrogates' perspectives varied on whether they perceived God or human beings as being in control of the patient's outcome. We found several examples of how this sense of control impacted the decision making process.

God in Control—Many surrogates felt that a person's time of death was under God's control, and some expressed a belief this was predetermined by God (Quote 5, 6). Some surrogates felt that God answers prayer and appeals through prayer could impact the health outcomes of their loved ones. Others talked about God's purpose in their role as caregiver (Quote 7).

Shared Control—Some surrogates ascribed control to a combination of God and human efforts. One woman commented (regarding her mother; Quote 8):

> She's strong so God will pull her through.

This seemed to describe belief in both the patient's strength and the will of God. Similarly, another surrogate described a conversation with a physician as she contemplated ventilation for her mother (Quote 9). In this case, letting God take over seemed to involve stopping certain medical therapies. The surrogate also described the physician's discomfort with making the decision about when to stop aggressive care.

The same surrogate who struggled with her Catholic faith and decisions regarding her mother's pacemaker perceived that two priests who affirmed her decision were providing confirmation from God (Quote 10). The surrogate took ownership of the decision, while at the same time perceiving that the priests' visits provided confirmation that her decision was consistent with God's wishes.

Surrogates often prayed for help as they tried to make decisions for their loved one, expressing a sense of their own role in decision making as well as a hope for divine guidance (Quotes 11, 12).

Human Control—Other surrogates felt that the patient was in control of the situation based upon the previous expression of desired healthcare wishes. Even surrogates who placed an emphasis on the role of God seemed to ultimately defer to the patient's wishes when they were known. For example, after several consultations with his own clergy about disconnecting his mother's ventilator, a surrogate described the following (Quote 13):

> And I says, well, Mom, are you telling me that you're ready to die? Is that your decision? And then she shrugged her shoulders. So, then I felt pretty confident that she really understood what I was saying.

In the end, this surrogate justified the decision to disconnect the ventilator based on his mother's own preferences.

Faith, Death and Dying

We found two important but contrasting themes about death and the dying process. Some people spoke about acceptance of the eventual death of their loved one based on their faith. A surrogate spoke about accepting the death of his father, a church deacon, in the following manner (Quote 14):

> Well, I just know that…or I feel that he's lived a life where…if he passes, then he will be with the Lord.

Others described how this mind-set helped them as they made difficult medical decisions. This surrogate decided to pursue a DNR order for her mother (Quote 15).

> …I feel that that will be the best decision for her and if her heart was to stop beating, I feel like that God was calling her home… To me, that's God's doing so I wouldn't want to mess with God's plan.

A surrogate in a similar situation was focused on death as an end to her mother's suffering (Quote 16). In contrast, other surrogates described how their faith led them to focus on the survival of their family member. Some surrogates felt that being faithful meant hoping for the patient's recovery (Quote 17). For many, recovery was attributed to God's will (Quote 18). One surrogate felt that withholding care was in opposition to her religious beliefs (Quote 19). She relayed a discussion where her family was considering choosing a DNR status for her mother. The surrogate challenged her family's desire to change a code status to DNR by asking them, "Don't you believe in miracles?" She expressed that changing the code status was a sign of inadequate faith.

Discussion

This interview study of surrogates making medical decisions for hospitalized older adults found that religious considerations were important elements of decision making for many surrogates, especially when making life and death decisions regarding code status or withdrawal of care. Our findings add to the growing literature suggesting that religion and faith may be important for surrogate decision making (Boyd et al., 2010; Zier et al., 2008). We also found that allowing time and guidance from religious leaders is important to the decision making process of some surrogates. This builds on prior work suggesting spiritual care is important to ICU family members (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Wall, Engelberg, Gries, Glavan, & Curtis, 2007) and should be a part of quality care for critically ill patients(Clarke et al., 2003; Davidson et al., 2007).

An important theme that emerged from our interviews was the perceived role that God played in the outcomes of medical care. Specifically, surrogates varied in whether they

ascribed control of the situation to God or to people, including the patient, clinicians and themselves. Surrogates expressed belief in varying levels of control, ranging from full belief in God's ability to intervene to a belief in human control. This variation in beliefs about control can be understood using Pargament's typology of religious coping styles. Some surrogates perceived both that God played a role and that their actions mattered, consistent with Pargament's *collaborative religious coping*; others expressed that the time of a patient's death was entirely in God's hands, suggesting *passive religious deferral* (Pargament, Koenig, & Perez, 2000).

We found several instances where the surrogate expressed preferences for the patient's care that were based on the surrogate's own religious beliefs, but deferred to the patient's own preferences when those were known. This suggests that surrogate beliefs are often balanced against or superseded by patient preferences. This is consistent with standard ethical guidelines for surrogate decision making that advocate relying on substituted judgment, in which the surrogate attempts to make the decision the patient would have made (Buchanan & Brock, 1990). Based upon our study, it would seem that patient autonomy and substituted judgment is influential even for those who are concerned with aligning their decisions with their faith. In many cases, the surrogates expressed that patient and surrogate had similar religious beliefs, such that the surrogate's statement of beliefs may have been endorsed by the patient. However, our semi-structured interviews found evidence that surrogates' own beliefs about religion and spirituality have an impact on some medical decisions. Surrogate religious belief is a source of value that is not included in standard frameworks for surrogate decision making (Buchanan & Brock, 1990). It is important for ethicists and clinicians to consider the appropriate role for these beliefs in major decisions, given our finding that they are a part of the decision making process for some surrogates, and may lead to different decisions than if the surrogate were relying only on the patient's wishes or best interests.

We found that religious beliefs impacted decisions about end of life care in complex ways. Two of our surrogates who attributed a high degree of control to God had very different interpretations of this control; one hoped for a miracle and wanted to pursue more aggressive treatment, while the other perceived stopping aggressive treatments as shifting control from physicians to God by "letting God take over." Although prior studies have demonstrated that those who are religious are more likely to desire more aggressive medical care overall, there is also evidence for very diverse perspectives in prior studies. In a study of cancer patients, the vast majority of all patients, including those with high religious coping, received hospice and avoided life-sustaining interventions at the end of life (Phelps et al., 2009). Another study found patients with a high degree of religiosity or spirituality were equally likely to have an advance directive or do not resuscitate order as their less religious peers (Karches, Chung, Arora, Meltzer, & Curlin, 2012). A qualitative study found that some patients use religious language to describe how they would reject further life-sustaining treatments or desire hospice or palliative care for themselves because of their belief in heaven or their belief that avoiding medical technology is consistent with a divine plan (Branch, Torke, & Brown-Haithco, 2006; Torke, Corbie-Smith, & Branch, 2004).

Most participants in this study were Christian, a religion for which death and the afterlife are central elements of theology. Christianity offers the contrasting themes of the inherent value

of human life and the death of the body as the beginning of eternal life (Rees, 2001). Our largely Christian sample described both of these views. This variation has also been noted amongst religious African-Americans who may either struggle against death or perceive death as going “home”, two contrasting views of death that are both consistent with their faith (Crawley et al., 2000). Although there is evidence that religious individuals prefer more aggressive care on average, the evidence for diverse perspectives should lead clinicians to inquire individually about a surrogate’s religious views and how they might influence decision making (Sulmasy, 2009).

There were limitations to our study. It was conducted in two hospitals in a single metropolitan area, and their identified religion was almost exclusively Christianity. Our population only consisted of those with an African-American or white race. Fewer than half of approached subjects agreed to be interviewed; it is possible that there were differences in the religious and spiritual beliefs of eligible surrogates who declined. This qualitative research focuses on identification of important themes described by participants, but we were not able to establish the most common or prevalent beliefs.

In conclusion, our qualitative study of surrogate decision makers found that surrogates making medical decisions for a close family member or friend often invoke their religious beliefs, especially when facing end of life decisions. Further study is needed to determine if allowing time and support for religious considerations would improve the quality of medical decisions. Second, preferences for aggressive or palliative care cannot be anticipated based on the presence of strong religious beliefs. This may be challenging for the clinician as it may require more time and more detailed communication; however, it is worth noting that this mainly occurs when life and death decisions are to be made. We believe further interventions are needed to study the impact of religious counseling and support to families of seriously ill patients.

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Biographies

Kristin Geros has a Masters of Public Health and is a medical student at Indiana University. She has conducted research addressing emergency room visits for older adults and the role of religion and spirituality in medical decision making.

Steven Ivy is Sr. Vice President for Values, Ethics and Social Responsibility at Indiana University Health. He has a Masters of Divinity (1977) and Ph.D. (1985) degrees from The Southern Baptist Theological Seminary in Louisville, Kentucky. His teaching and writing have focused on medical ethics, religion and medicine, crisis ministry and pastoral perspectives on human development.

Kiana Montz is a research coordinator at the IU Center or Aging Research, where she implements studies addressing medical decision making with a focus on adult patients who are unable to make their own medical decisions.

Sarah Bohan is a physician assistant student at Butler University. She previously worked as a research assistant at the IU Center for Aging Research.

Alexia Torke is a physician and researcher addressing medical decision making for older adults, especially those who cannot make their own medical decisions. She has an MD degree from Indiana University and a Master of Science in Health Studies from the University of Chicago. She is director of the Evans Center for Spiritual and Religious Values in Healthcare.

Table 1

Interview Guide

Decisions for Elders with Cognitive Impairment and Dementia Interview Guide for Surrogates	
Introduction	
1	Tell me about (patient) and what brought him/her to the hospital.
2	Tell me about any especially memorable events that happened as a part of this hospital stay.
3	In the time that (patient) was most recently in the hospital, could you tell me a little about the positive experiences? Now tell me about the negatives…
Information Disclosure	
4	During the time (patient) was in the hospital, how did you find out what was happening?
Relationship Building	
5	What was your first impression of the hospital staff?
6	Was there anyone at the hospital you could rely on? Why or why not?
7	Tell me a little about how things have been for you since (patient) was in the hospital?
Religion and Spirituality	
8	How did your religious or spiritual beliefs play a role in your experience when (patient) was in the hospital?
9	What religious or spiritual practices helped you in these times?
Decision Making (Repeat questions 10–17 for up to 3 decisions.)	
10	One decision that (patient's) physicians have considered is (target decision). What, if any, conversations with the doctors or other hospital staff can you recall about this decision?
11	Do you recall any other decisions you had to make while (patient) was in the hospital?
12	What part did you play in making the decision?
13	How did you decide what to do?
14	For some people, spiritual and religious beliefs are important for making decisions.
15	In the end, did you think the right decision was made? Why or why not?
Possible Interventions	
16	Can you think of anything that could have been done to help you make this decision for (patient)?
Decision Making Outcomes	
17	When you look back on this decision, what do you thing think would be the best possible outcome for (patient)? What about for you? *(Repeat for up to 3 decisions)*
18	Do you think (patient) was fully able to make the decision him/herself, partially able to made the decision, or not at all able to make the decision?
General Outcomes	
19	When you look back on (patient's) time in the hospital, what seems most important to you?
General Interventions	
20	Can you think of anything that could have been done to make the hospital experience better for you or (patient)?
Additional Information	
21	Is there anything else you would like to tell me about your experience when (patient) was in the hospital?

Table 2

Characteristics of Surrogate Decision Makers (n=46)

Characteristic	Finding	Percentage
Gender		
Female	35	76%
Male	11	24%
Race		
White	23	50%
African-American	23	50%
Religious Affiliation		
Baptist	13	28%
Lutheran	2	4%
Other Protestant/Christian	22	48%
Catholic	5	11%
None	4	9%
Relationship to patient		
Spouse	3	7%
Daughter	26	57%
Son	9	20%
Niece	2	4%
Nephew	1	2%
Sister	2	4%
Grandson	1	2%
Cousin	1	2%
Friend	1	2%
Decision maker		
Surrogate only	20	43%
Surrogate and patient	26	57%
Advance Directives		
Living Will	9	20%
Health Care Representative	19	41%

Table 3

Themes and Representative Quotes

Theme	*Quote Number*	Interview Number	*Representative Quotation*
Religion as a Guide to Decision Making	1	46	[I] went to church, early service, and, uh, I asked to speak with one of the pastors. And, uh, so my wife and I went and talked to them about, you know, making those life or death decisions.
	2	46	Regarding a decision to enroll in hospice: You know, it's just to provide care.
	3	45	The Catholic church has, I think, very good guidelines, strict may… they may be, about protecting the sanctity of life. And for me, to turn off her pacemaker is tantamount of withdrawing life support. … I don't want somebody coming in doing a full resuscitation on her. I know she is ready to go, I know what her wishes are, but at the same time there's something in place there. … Now if she were in extreme pain and medicated by pain management… …if she was unable to be awakened because she was just in a deep sleep, having actually no quality of life whatsoever, then I would consider it. If that would help make her transition easier.
Control: God in Control	4	43	I think spirituality has a lot to do with healing.
	5	46	Before you're born, He says, you know, He's already counted your days……her thing was she wanted to go in her sleep. …and 48 hours later, she had passed in her sleep. So, she basically got her, got her prayer answered. I got mine because I didn't have to make the decision.
	6	36	I said, when it's your turn, you'll go. And I said, asking for it might help; but, I said, I doubt it. I said, He has a time for everybody.
	7	40	You know, God don't make no mistakes, you know, and what he put on each individual, all three of us, you know, is his will, you know what I'm saying? So, I learned to accept whatever happen or whatever occur in this. I can't do anything about it.
Control: Shared Control	8	39	She's strong so God will pull her through.
	9	24	And also I talked to that doctor because my mother did not want extraordinary means. She wanted us to go so far, and then after it was God's will, let God take over. So I asked him, at what point do we stop? At what point…I said, tell me, at what point do we stop? And he really hesitated because I don't think he really wanted to tell me at what point I would need to stop.
	10	45	I think God showed me that my decision was right. The same day when I was crying and really kept praying was this the right decision, two priests came to visit me, two separate different priests came. They said they understood my position and I wasn't wrong.
	11	41	Did a lot of praying that God would lead me in the right direction on all of this and just comforting knowing that he is with me and helping me through this…
	12	31	I said, you know, trust Him and just follow Him because, you know, decisions that you have to make, make sure you pray first and let Him lead your decision to cut off her leg or decision to take her to hospice. It was a decision I had to make but I had to make it through his guidance.
Control: Human Control	13	46	And I says, well, Mom, are you telling me that you're ready to die? Is that your decision? And then she shrugged her shoulders. So, then I felt pretty confident that she really understood what I was saying.
Faith, Death and Dying	14	37	Well, I just know that…or I feel that he's lived a life where…if he passes, then he will be with the Lord, so that's the way I feel about it.
	15	9	… I feel that that will be the best decision for her and if her heart was to stop beating, I feel like that God was calling her home. To me, that's God's doing so I wouldn't want to mess with God's plan.

Theme	*Quote Number*	**Interview Number**	*Representative Quotation*
	16	28	And you know, I knew that somebody would be there for her. I knew her mom would be there to take her in. So you know, it's not a hard decision. I knew she lived a good life. She was a Christian, and I wanted her to be happy again. On earth, she wasn't a real happy woman.
	17	39	I just keep faith in God that she's gonna be all right.
	18	6	I had recruited a lot of other people to be praying for her as well. Which I think, God's healing touch was instrumental in her getting better.
	19	29	Regarding a family member's decision to change code status to Do Not Resuscitate: Don't you believe in miracles?