



Factors That Influence Elders' Decisions to Formulate Advance Directives

Crystal Dea Moore MA, MSW & Susan R. Sherman PhD

To cite this article: Crystal Dea Moore MA, MSW & Susan R. Sherman PhD (1999) Factors That Influence Elders' Decisions to Formulate Advance Directives, Journal of Gerontological Social Work, 31:1-2, 21-39, DOI: [10.1300/J083v31n01_03](https://doi.org/10.1300/J083v31n01_03)

To link to this article: http://dx.doi.org/10.1300/J083v31n01_03



Published online: 11 Oct 2008.



[Submit your article to this journal](#)



Article views: 190



[View related articles](#)



Citing articles: 19 [View citing articles](#)

Factors That Influence Elders' Decisions to Formulate Advance Directives

Crystal Dea Moore, MA, MSW
Susan R. Sherman, PhD

ABSTRACT. Nine minority and eleven White low-income community-dwelling senior adults participated in semi-structured qualitative interviews regarding end-of-life decision-making related to the completion of advance directives (e.g., living wills and health care proxies). The seniors were asked to discuss the role of their own evaluations and beliefs and their perceptions of the influence of significant others in their decisions to complete advance directives. Religious affiliation and a measure of religiosity were also examined. The participants overwhelmingly evaluated the completion of advance directives as positive, but many of the seniors reported that discussing end-of-life issues with their children was difficult. In addition, depth of religious belief figured prominently in medical treatment planning for some of the participants, particularly the minority seniors. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: getinfo@haworthpressinc.com]*

KEYWORDS. Advance directives, end-of-life decision-making, religiosity

Crystal Dea Moore is Social Welfare Doctoral Candidate, and Susan R. Sherman is Professor of Social Welfare, Rockefeller College of Public Affairs and Policy, University at Albany, State University of New York.

Address correspondence to: Crystal Dea Moore, Rockefeller College of Public Affairs and Policy, School of Social Welfare, 135 Western Avenue, Albany, NY 12222.

The authors would like to thank Don DeVirgeles, Ted Tottey, Joelle Bolam, Tammy Boyd, and Mary McCabe for their assistance in recruiting participants, and Dr. Anne E. Fortune for her thoughtful comments in the development of this manuscript.

Funding for this study was provided by the Initiatives for Women Program at the University at Albany, State University at New York.

With the increasing capabilities of medical technology to extend life, the distinction between life and death has become blurred (Mulholland, 1991). Because of severe illness, some elderly patients' lives are extended through medical life support, respirators and methods to deliver artificial hydration and nutrition. The medical conviction to preserve life and cure disease has inadvertently suspended some patients in a living death. Conscious, competent adults have the right to refuse medical care, but the matter of patient self-determination becomes muddled when an individual is unable to make informed health care decisions due to incapacity. Health care providers must grapple with legal and ethical issues involved in the decision to artificially prolong an incapacitated patient's life. In addition, such care can be extremely expensive (Scitovsky, 1994). Without clear directions as to a patient's preferences regarding life-sustaining treatment, medical expenditures can soar while a patient is artificially kept alive.

Emotional and monetary costs run high for family members when they are forced to watch a loved one be kept alive via artificial medical procedures. It is possible in some circumstances that "an irreversibly vegetative patient will remain a passive prisoner of medical technology" (Justice Brennan in *Cruzan v. Director, Missouri Department of Health*, 110 S. Ct. 2841, 2864 (1990)), and that a family can be left legally powerless to make the decision to withdraw life support. The process of dying can be prolonged and prove to be devastating for the patient's significant others. Finally, life support measures may inadvertently cause more suffering, pain, and degradation for the patient than the actual death itself.

POLICY RESPONSE TO THE ISSUE

In response to these issues and to a United States Supreme Court decision regarding the rights of an incompetent person's family to make proxy health care decisions (*Cruzan v. Director, Missouri Department of Health*, 110 S. Ct. 2841 (1990)), Congress passed the Patient Self-Determination Act (PSDA) in 1990 (P.L. 101-501, § 4206). The PSDA mandates all health care organizations that receive Medicaid or Medicare funding, including hospitals, skilled nursing facilities, home health care agencies, and HMOs, to provide all patients with written information about advance directives. This information is to be provided upon admission or enrollment in a program, and should inform

patients as to their rights to formulate advance directives and to refuse medical care, and the policies of the provider respecting the implementation of those rights. The PSDA defines advance directives as “written instructions, such as a living will or durable power of attorney for health care, recognized under State law . . . and relating to the provision of [health] care when the individual is incapacitated” (P.L. 101-501, § 4206). A living will is a written document that expressly indicates a person’s wishes with respect to specific medical treatments. A durable power of attorney for health care (in some states referred to as a health care proxy form), allows a patient to appoint an individual to make medical decisions for him or her in the case of decisional incapacity. The goals of the legislation are to maximize patient’s rights to self-determination regarding health care decisions, to protect health care providers and those who make decisions for incompetent patients from liability (High, 1991), and to increase the preparation and use of advance directives. Although a large majority of people indicate that completion of advance directives is desirable (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991), estimates of adults actually completing medical directives range from 12 to 18 percent (Emanuel et al., 1991; Gordon & Dunn, 1992; LaPuma, Orentlicher, & Moss, 1991; Singer, Choudhry, & Armstrong, 1993). If so few people have medical directives, the chances continue to be low that an incompetent patient’s wishes regarding medical treatment will be known.

FACTORS INFLUENCING ADVANCE DIRECTIVE PREPARATION AMONG THE ELDERLY

Over the past decade, scholarship addressing advance directives and their preparation has burgeoned in the medical, legal, psychological, and social work literature. Many of the reports address clinical and policy implications of the PSDA (e.g., LaPuma, Orentlicher, & Moss, 1991; Mulholland, 1991; Soskis & Kerson, 1992; Wolf et al., 1991), interventions to increase the use and preparation of advance directives (e.g., High, 1993; Luptak & Boulton, 1994; Sachs, Stocking, & Miles, 1992), the rate of agreement regarding a patient’s treatment preferences between the patient and his/her designated health care surrogate decision-maker (e.g., Sansone & Phillips, 1995; Seckler, Meier, Mulvihill, & Cammer, 1991; Zweibel & Cassel, 1989), attitudinal factors

regarding advance directives (e.g., Vandecreek & Frankowski, 1996) and the influence of significant others on the decision to complete an advance directive (e.g., High, 1990, 1991). As the literature suggests, factors influencing an individual's decision to formulate treatment directives are multifaceted and complex. The factors involved in this decision range from the macro/policy level (e.g., how and when information on advance directives is presented to patients) to micro/personal considerations (e.g., the perceived advantages and disadvantages to formulating advance directives). It is the intent of this research to examine personal and family systems influences on the decision to complete an advance directive.

Attitudinal factors and influence of significant others. The completion of such documents is an outcome of a process in which an individual must examine his/her attitudes surrounding death, a potentially anxiety provoking topic. Individuals must perceive the advantages to completing an advance directive as outweighing the disadvantages associated with that action (Vandecreek & Frankowski, 1996); hence, one's beliefs about and attitudes toward the documents could heavily influence one's behavior in preparing an advance directive. High (1990, 1991) argues that many elderly have an aversion to executing legal documents such as health care proxies and living wills; instead, they prefer to rely informally on the "character and good faith of a family member" (High, 1990, p. 307) to make medical decisions for them in the event they become unable to make decisions for themselves.

Sociocultural variables. Researchers suggest that those who choose to execute advance directives tend to be well educated and White (Fried, Rosenberg, & Lipsitz, 1995; High, 1993; Luptak & Boulton, 1994). High (1991) intimates that the completion of medical treatment directives may be largely a middle-class phenomenon and suggests there is a need for more research addressing the impact of race/ethnicity and social class on the execution of such documents. Another factor potentially influencing one's decision to complete an advance directive is religious affiliation/religiosity. Although no research was found that primarily focused on the role of religion in the formulation of advance directives, some studies do peripherally mention the role of religion in end-of-life decision-making. In an intervention study conducted by Luptak and Boulton (1994), designed to increase the use of advance directives, some of the individuals who chose not to complete

an advance directive cited religious reasons. Another study (Sansone & Phillips, 1995) found that the religious affiliation of the elder's residential facility (Catholic versus Jewish) was significantly associated with the decision to complete an advance directive. In a study of factors influencing elderly hospitalized patients' preferences for life sustaining treatment, 47% of those interviewed reported that their end-of-life treatment preferences were influenced by their religious beliefs (Cohen-Mansfield, Droge, & Billig, 1992). This current research seeks to fill the void in the literature surrounding the role of religion in end-of-life decision-making by explicitly examining religious affiliation and religiosity as they are related to an elder's decision to formulate an advance directive.

FOCUS OF CURRENT RESEARCH

The current research explored factors that influence an elder's decision to complete an advance directive through qualitative semi-structured interviews with White and minority low-income community-dwelling elderly who are in relatively good health (i.e., the well elderly). These target groups were chosen because the literature on advance directives under-represents the well elderly and is deficient with respect to cultural and class diversity. A qualitative method was chosen over a quantitative one so that the research participants could spontaneously discuss their own personal beliefs and attitudes about the decision to complete an advance directive, thereby contributing to the understanding of what advance directives *mean* to older adults. Once a sense of meaning from the participants' perspectives is derived, further research can be conducted to expand on the themes that are important to the elderly themselves, thereby giving helping professionals more information in their quests to serve this client group and their needs related to end-of-life decision making.

The conceptualization of the decision-making process in this research is guided by Ajzen and Fishbein's (1980) reasoned action theory, a model of the decision-making process. Briefly, the model posits that an intention to perform a behavior (the primary determinant of any behavior) is influenced by attitudes and norms regarding the behavior alternatives. Beliefs about the behavior and the evaluation of the advantages and disadvantages of performing the behavior comprise the attitude component of the model. Normative factors involve

the perception of significant others' potential influence over selection of various behavior alternatives. Demographic variables such as socioeconomic status and ethnicity impinge upon behavior in that they influence attitudes and norms which in turn influence intentions and corresponding behaviors.

The model of reasoned action, generally calling for quantitative measurement procedures that are determined a priori by the researcher, is applied loosely in this context to conceptualize factors regarding end-of-life decisions. In this qualitative study, the model is employed as a means to organize the various aspects of the individual's belief system and perceived influences of significant others as related to the decision to complete an advance directive. In essence, the theory is used as a "conceptual template with which to compare and contrast results, rather than [being used] as a priori categories into which to force the analysis" (Morse, 1994, p. 221). In this context, attitudinal and normative factors influencing the decision to complete an advance directive are explored. Attitudinal factors include (a) beliefs about advance directives, including level of knowledge one has regarding treatment directives, (b) perceived advantages of advance directives, and (c) perceived disadvantages of advance directives. Normative factors encompass the role of one's family and doctor in the decision to formulate treatment directives. Ethnicity, religious affiliation, and a measure of religiosity are also examined in terms of their influence on the decision to complete the documents. No a priori hypotheses are offered; instead, the data are examined and presented in terms of emergent themes.

METHOD

Participants

Information was collected in the form of semi-structured interviews from 20 community-dwelling seniors ranging in age from 58 to 78 years. This purposive sample was drawn from two sources: volunteers for the New York State Senior Companion Program and residents of senior housing units in the Capital District of New York. Senior Companions are low-income seniors who volunteer to spend time with developmentally disabled adults and were chosen because of the first

author's previous affiliation with the program. Coordinators of the Senior Companion Program were approached for assistance in recruiting volunteers from their specific programs. A total of eleven Senior Companions were interviewed. Eight were from Northern New York State and were interviewed at the program headquarters. The remaining three Senior Companions in the sample were from the Capital District of New York state and were interviewed in their homes. The other nine members of the sample were drawn from three congregate senior housing sites in the Capital District and were also interviewed in their homes. The social workers employed by the housing units were approached and asked to identify seniors who might be interested in being interviewed. Interviews for all participants lasted between 30 to 60 minutes, interviews were audio taped, and participating seniors were remunerated \$20 for their time. The participants were interviewed by the first author, a White 33 year-old woman.

Efforts were made to collect data from as a diverse a sample as possible. Of the participants, eleven were White, eight were Black, and one was Hispanic. It should be noted that obtaining access to minority seniors proved difficult. Due to the Senior Companion sub-sample being predominantly White (only one minority individual was interviewed from that group), it was necessary to recruit minority seniors from the housing sites. Even after being contacted by the social worker at the housing site and agreeing to speak with the researcher, approximately 50% of the minority seniors declined to be interviewed when contacted over the phone by the researcher. In addition, one Black Senior Companion contacted also refused participation. In contrast, no White seniors refused to be interviewed after being contacted by the researcher.

The sample included 16 women (6 Black, 1 Hispanic, and 9 White) and 4 men (2 Black and 2 White). Three seniors were between 58 and 64 years of age, five between 65 and 69, another seven between 70 and 73 years, and five were between the ages of 76 and 78. Eleven members of the sample were Catholic, and nine were Protestant. When asked to rate their overall health as either excellent, good, fair, poor, or very poor, all but two participants reported their health status as being fair or better; one indicated her health was poor, and another reported her health as being very poor. Eight seniors were widows, four were currently married, four divorced, two had never been married (both women), and two were separated from their spouses. Sixteen of the

seniors had children, and four had no children. In terms of the participants' level of formal education, one had no formal education, two had a seventh grade education, three had some high school, nine were high school graduates, four had some college, and one was a college graduate. All but three had either worked in blue collar positions or were married to blue collar workers. Eleven of the seniors had a current yearly household income less than \$10,000 per year, seven had an income between \$10,000 and \$14,999, and two seniors reported their income between \$15,000 and \$19,999. All of the seniors in the sample were retired.

This sample was selected to include predominantly lower income, working class seniors as well as minority seniors. It is a Christian sample drawn from the Capital District and North Country of New York state. Most of the Whites in the sample were drawn from the Senior Companion pool in the North County where many have resided all of their lives, and the minority sample came from the Capital District, many of whom grew up outside that area. The sample was not intended to represent the general population of those over 65, and this should be considered when evaluating the results of the analysis.

In reference to the participant's previous knowledge about advance directives, two had no information, five had heard of a living will but were not entirely clear on its purpose, five had some information about advance directives (had either read a pamphlet, seen a television spot about the documents, or spoke with a family member who had completed an advance directive), two had considerable knowledge about living wills and health care proxies from seminars on the topic, and six seniors had completed an advance directive (all six were women, two White and four Black). During the course of the interview, the interviewer explained to all participants what advance directives are and answered any questions they had.

Interview

The topics discussed in the semi-structured interviews included: amount of information the participant had regarding advance directives; perceived advantages and disadvantages of advance directives (i.e., living wills and health care proxies); beliefs about one's family's perception of the participant completing an advance directive; the degree of discussion with one's family regarding end-of-life medical treatment wishes; and the participant's perception of his/her doctor's role in com-

pleting advance directives. Participants were encouraged to elaborate on the topics, and the interviewer probed responses when indicated. In addition to questions related directly to advance directives, demographic information was collected from participants, and the seniors were given a 10-item religiosity scale originated by Hoge (1972) and revised by Thorson and Powell (1990). The scale, Intrinsic Religious Motivation Scale (IRM), measures “depth of [religious] belief rather than frequency of religious behaviors or activities, extrinsic motivations such as socialization, or denominational preference” (Thorson & Powell, 1990, p. 382). Cronbach Alpha for the scale was .85 in Thorson and Powell’s sample, and a factor analysis revealed a unidimensional factor structure. The scale is appropriate for diverse cultural and religious traditions. Respondents were asked to rate 10 statements on a five-point Likert scale indicating the degree to which they agreed with the item. The IRM was administered during the first half of the interview. Three negatively phrased items were reverse scored.

The items on the IRM include the following: My faith involves all of life; in my life, I experience the presence of the Divine; one should seek God’s guidance when making every important decision; my faith sometimes restricts my actions; nothing is as important to me as serving God as best as I know how; I try hard to carry my religion over into all my other dealings in life; my religious beliefs are what really lie behind my whole approach to life; it doesn’t matter so much what I believe as long as I lead a moral life; I refuse to let religious considerations influence my everyday affairs; and I feel there are many more important things in life than religion.

RESULTS AND DISCUSSION

The interviews were transcribed by the first author and examined for emergent themes. Negative case analysis (examination and incorporation of case exceptions to the general themes) was utilized to account for the variability of all interview responses. The results are presented according to the categories in the reasoned action theory framework.

Evaluations of and Beliefs About Advance Directives

Overwhelmingly, the seniors interviewed had positive evaluations of advance directives. The main advantage they discussed is their

belief that formulation of the documents would prohibit them from being placed on artificial life support. The desire not to be “put on machines” was a recurrent spontaneous theme mentioned by almost all of the seniors. Most participants viewed advance directives as a means to ensure one would not be placed on life support if there were no chance for a “decent recovery,” as one participant put it. One woman who had formulated both a health care proxy and a living will mentioned that the completion of the documents meant she had some input in the process of her own death. She said, “I felt like I had some control over what would happen to me even though I [may] not [be conscious] to make the decision . . . I just want to be going peacefully and with as much dignity as possible.” The seniors expressed a strong collective desire to not have their lives artificially prolonged. Many believed an important advantage to the formulation of the documents was the avoidance of a lengthy, painful death process.

A majority of the seniors felt that being placed on artificial life support would not only be detrimental to themselves, but a significant burden to their families as well. One 63 year-old man indicated, “If I’m in a coma on life support, I’m taking a lot of their time and stealing a lot of things from [my adult children’s] families.” Another woman reported that completing a living will would “just make it easier” for her daughter to deal with coping with treatment decisions for her mother. This participant further commented, “She’ll have enough to contend with because I’ll be leaving it in her hands . . . I want to leave her with everything practically done so she doesn’t have to do anything besides get me buried.”

Another advantage mentioned by at least three of the participants was related to the cost containment of expensive life-prolonging medical treatments. One woman felt very strongly about this issue. She indicated, “[The hospitals] are the ones that are benefiting with respirators and keeping people alive . . . If they know they can’t save you it is their advantage to keep you on machines.” She saw a living will and health care proxy as a means to stop the hospitals from profiting from terminal illness.

Most of the respondents saw few if any disadvantages to the formulation of treatment directives; however, one potential disadvantage to the formulation of a living will voiced by six of the seniors concerned the possibility that the execution of the documents could force medical professionals to terminate life support when there could be a

chance for the patient's recovery. One 63 year-old man was concerned that he might not be able to anticipate all of the medical circumstances that he might face in the future. He quite eloquently characterized this disadvantage to the living will by saying, "[I]f I wrote down don't do this and don't do that, [due to] me not having medical knowledge, I might be digging my own grave." Other participants echoed the same sentiments, indicating that a potential disadvantage to completing a living will is the fact that being temporarily put on machines can save lives. For example, having a living will that states "no respirators" could thwart attempts for resuscitation and recovery. One 78 year-old woman said, "The only [disadvantage] I see is that they might not keep me alive if there was a possibility I could recover." Another disadvantage indicated by a 71 year-old woman was related to people changing their minds about treatment decisions. If one does have a change of heart, the living will must be updated, and she saw this as a drawback. The disadvantages to living wills explicated by the participants in this study (difficulty in anticipating future medical circumstances, use of vague language in the documents, possibility that one's medical treatment preferences may change in the future) have also been documented in the professional literature (Wolf et al. 1991).

Although not directly discussed by the participants, it appeared that lack of information regarding advance directives was a potential barrier to their completion. Twelve of the twenty seniors interviewed had little or no information regarding the formulation of treatment directives prior to being interviewed. Some of the seniors had never even thought about the topic before they had agreed to be interviewed. A portion of the interviews was spent directly educating the seniors about the documents so that each participant had a correct definition of the terms "living will" and "health care proxy." In addition, it was hoped that giving the participants this information would provide them with sufficient knowledge to formulate treatment directives in the future if they wished. Once given the information, at least three of the seniors (all were Black individuals) indicated they would definitely be completing a health care proxy in the near future. One of these participants was a 58 year-old woman. Her self-rated health status was very poor; she said she needed a lung transplant. She had never heard of these documents prior to the interview, and reported she was concerned about medical treatments should she become unable to make her own decisions. Upon completion of the interview, she asked the

interviewer for assistance in completing a health care proxy. This is an example of the power of education surrounding these issues. Without appropriate information on the topic, many seniors do not have the tools to formulate the documents even if they wanted to.

Influence of Significant Others on the Decision to Complete an Advance Directive

For many, the role of the family seemed to figure prominently in the decision to complete a treatment directive. Although most participants had quite positive attitudes toward the documents, consideration of family led to some seniors preferring either the living will or health care proxy. Four participants expressed strong preferences for the living will over the health care proxy. Two White women (both of whom had living children) indicated that they were not close to their families, and would not feel comfortable designating people who were not familiar with the details of their lives. One of these women, a 65 year-old divorcee, also cited her independence as an additional factor influencing her negative evaluation of the health care proxy, saying “I’m too much of an individual . . . I don’t want a proxy. I want my own decision.” In addition, she did not share a close relationship with her children and felt if she appointed them to make medical treatment decisions for her, they would act as surrogate decision-makers purely out of obligation, which she found disturbing. A 76 year-old Black woman who preferred the living will over the health care proxy pointed out that she had no children, husband, or close family members (geographic proximity) to appoint, so explicitly spelling out her treatment preferences was the best option for her. She said, “For me, without a family, [I would] have to depend on the people in the hospital . . . If I’m sick, I want to be taken care of pleasantly [and] not being pushed on [them].”

The 63 year-old Dominican woman with six children had an entirely different reason for preferring the living will. She is very close to all of her children and said of the potential appointment of one of them as a surrogate decision maker: “It’s not fair. It’s not right.” She indicated that saddling the family with that decision would be too emotionally difficult for them. The ultimate decision her family would be forced to make for her would be something they would have to live with for the rest of their lives. She felt that completing a living will would prevent these potential problems for her family. On the other hand, other

seniors felt that having a health care proxy would be helpful to their children. They believed that having their family watching them “lingering” on machines would be extremely difficult for their loved ones, and having a legal document that allows a family member to discontinue life support would be the best for all concerned.

Some participants indicated that their adult children may actually object to their completing an advance directive, because the children could not and/or would not be able to acknowledge the ultimate demise of their parent. At least eight of those interviewed said one or more of their children were reticent or outright refused to discuss this issue. When one White 63 year-old woman who had completed both a living will and health care proxy asked her son to read and familiarize himself with the documents, he initially refused. Another White woman became upset and cried during the interview when asked about the degree of discussion she has had with her children regarding end-of-life issues. She tearfully said, referring to her attempts at communication with her children, “It’s a subject that when it comes up, it’s changed.”

Even among those seniors who were successful at having a discussion with at least one of their children, some indicated that their sons and/or daughters were uncomfortable when approached about the topic of the parent’s death. For most of these parents, these discussions were brief and occurred only on one or two occasions and were brought about by an illness or hospitalization of the parent. Apparently, this topic is not discussed in the context of day-to-day healthy living, and being faced with possible death due to illness is often how families are forced to communicate about it. Some offspring and parents were able to overcome the discomfort and reticence to discuss a parent’s end-of-life decision-making. Five of the minority participants and two of the White seniors had discussed the issue with their children to the point that the parent was confident his or her children could competently make health care decisions for them. Among the seniors in this sample, race appears to be related to the degree of communication between parents and adult children regarding end-of-life treatment preferences.

In comparison to the influence of the family, it appears that doctors do not figure prominently in the decision to complete an advance directive. Only one member of the sample, a White 70 year-old woman, had ever discussed advance directives with a doctor. Her

doctor had mentioned it to her because her sister, also a patient of the doctor's, had recently completed both a living will and health care proxy. The doctor thought she might also be interested in completing the documents. In reference to the doctor's suggestion, the participant remarked, ". . . I did think about it, I've just never done it. You think about it, but it's just like anything else—you thought about it but [you don't] do it." A majority of the sample indicated they would be comfortable if their doctors brought up advance directives during a routine visit. Three individuals, two Black men and a Black woman, felt that if a doctor would bring this up to them during a visit, it would be indicative that something was very wrong. One gentleman remarked, "[If] the doctor walks up to you and says, 'I'd like to talk to you about a living will,' well, am I ready to die? That would be the first thing most people would think." These three seniors indicated that education about advance directives is better brought up outside a doctor's office. If a doctor did initiate a discussion on this topic in the context of a routine office visit, it could be a cause for alarm.

Characteristics of Those Who Had Completed Advance Directives

As previously indicated, six members of the sample had completed an advance directive. All six were women. Two had never been married, one was divorced, two were widows, and one was separated from her spouse. Four of the women were Black, and the other two were White. Two of the women (both White) indicated that they had decided to complete a health care proxy (with specific treatment instructions) in response to a death in each of their families. One witnessed a relative lingering on life support and decided she definitely did not want that to happen to her. The other woman's son died from AIDS. Her son had left explicit verbal instructions to his mother about the circumstances of his death, but there was still some disagreement within the family regarding the situation. She wanted her wishes to be explicitly known to avoid any problems for the family surrounding her own death.

Being childless and having few living family members prompted two of the women in the sample to complete an advance directive. One widowed woman felt strongly about "not being a burden" on anyone. She decided that a way to avoid this possibility was to formulate a living will which indicated she did not want any artificial means to

prolong her life. The other woman formulated an advance directive at the urging of a sister-in-law who had been educated about the documents at a workshop. This woman had never been married and wanted to complete a health care proxy that designated her sister-in-law, one of her few remaining family members, as her surrogate.

The final two women (both were Black) completed a health care proxy after they had attended an advance directive workshop given by an elder law attorney at their local senior center. Prior to this workshop, neither of the women knew about treatment directives, thus education about the issue proved to be an important factor in their decision. Although previous research has suggested that well educated, middle-class Whites are more likely to complete an advance directive (Fried, Rosenberg, & Lipsitz, 1995; High, 1993; Luptak & Boulton, 1994), this research indicates that low-income seniors will also engage in end-of-life planning with the appropriate education.

Role of Religion and Ethnicity

To examine the role of religious affiliation/religiosity in the decision to complete an advance directive, the median score on the Intrinsic Religious Motivation (IRM) scale was calculated. Scores on the IRM ranged from 18 to 36 (higher scores indicating higher levels of intrinsic religiosity), and the median was 29.83. Two groups of participants were formed, those scoring below the median and those scoring above. The interviews were then examined by group to ascertain any differing emergent themes. This examination produced interesting results in the areas of race, religious affiliation, degree of spontaneous religious comments, whether or not one had formulated an advance directive, and degree of communication with children regarding end-of-life issues. Each of these areas is discussed in turn.

Race, religious affiliation, and religiosity interacted in this sample. Of the nine participants scoring below the IRM median, eight were Catholic and one was Protestant. Of these eight Catholics, seven were White and one was Black; the Protestant participant was White. For those eleven participants scoring above the median, three were Catholic and eight were Protestant. Of these three Catholics, one was Black, one Dominican, and one White. For the eight Protestants scoring above the median, six were Black and two were White. Generally speaking, those scoring below the IRM median tended to be White and

Catholic; those scoring below were somewhat more likely to be minority individuals affiliated with Protestant denominations.

The interviews were examined for participant remarks that were religious in nature. In the lower scoring group, none of the seniors spontaneously mentioned religion or God. All but two seniors in the higher scoring group elaborated on their religious beliefs with respect to end-of-life decision-making throughout the interview. For some individuals, particularly the minority participants, end-of-life decision-making is couched in a religious context.

Some of the seniors' desire not to "be hooked up to machines" appears to be related to a perspective summed up aptly by a 65 year-old Black woman, "I don't want anybody trying to save me because I think I have lived my days when I [am close to death]. When God says He is ready for you, you got to go. So I figure if anything happens to me, God is ready." Many of those interviewed mentioned "God's will" in relation to their negative evaluation of artificial life support. One 73 year-old Black woman remarked, "No one man is going to save you. God is the one that is going to take you." A 65 year-old Black woman who had recently refused to allow her physician to implant a pacemaker for her said, "I'll keep going [until] God stops me." Another 65 year-old White woman conveyed, "I don't . . . want to live like a vegetable. I don't think God wants that either." When discussing God and extraordinary medical treatments, one 65 year-old Black man said, "If He wants to save me and keep me on the earth a little bit longer, I will be here." Some of these seniors also expressed confidence that God would ensure that their passing would be peaceful. The Dominican woman indicated, ". . . God knows how much you can take. [When] God knows I can't take anymore, He's going to call for me. Because you serve God your whole life, [He] will take you when you've had enough."

Higher scores on the IRM and a belief in God's will was also related to the actual completion of an advance directive. Five of the six seniors who had completed a treatment directive scored above the median on the IRM. All of these participants elaborated on their faith and trust in God, and mistrust of human medical technology. Their confidence that God would protect them in the dying process coupled with a strong belief in an afterlife possibly made end-of-life planning more comfortable and desirable for these seniors. This suggests that strong religious beliefs are related to one's comfort level in relation to plan-

ning for one's own death. This speculation has been confirmed by other research: Thorson and Powell (1990) demonstrated that death anxiety was inversely related to religiosity.

This "comfort level" regarding death related issues also may have influenced the discussions the participants had with their adult children regarding end-of-life decision-making. Four participants who scored above the median on the IRM had discussions on more than one occasion with at least one of their adult children surrounding end-of-life issues. Of those who scored below the IRM median, only one participant had an extended dialogue with an adult child regarding treatment decisions. This may suggest that older adults with deeper religious convictions may experience less death anxiety which in turn may predispose them to be comfortable in communicating with others about issues related to their own death. In addition, the religious values imbued to their children may make their adult children more open to such communications from their aging parents.

Based on this study, it is impossible to say exactly how religious beliefs, communication with adult children regarding end-of-life decision-making, and the formulation of advance directives are related. One problem to be addressed in future research is how to disentangle the variables race and religion, which interacted in this sample. But the data presented here do intimate that religion, communication with family members, and the execution of medical treatment direction are related. One's spirituality may increase one's comfort level surrounding death issues, thereby facilitating an elder's ability to initiate discussion with adult children and to actually execute medical directives. A factor that may influence the relationship among these variables is the level of anxiety one feels surrounding his or her own inevitable demise. This provocative issue warrants further scrutiny.

SOCIAL WORK IMPLICATIONS AND CONCLUSIONS

Listening carefully to the meaning that elders' ascribe to the formulation of advance directives indicates that there are several factors that influence the process of end-of-life decision-making. Social workers who work with older adults can be instrumental in helping seniors come to terms with this complex issue. Given the multi-faceted nature of end-of-life decision-making, social workers need to be cognizant that formulating an advance directive is an individual *pro-*

cess that may require an extended dialogue. It is an emotionally-charged topic for many people, and workers involved in educating and/or helping elders to formulate treatment directives need to be aware that writing a living will or completing a health care proxy form means more than the simple execution of another legal document. Individual preferences for one type of document over another also needs to be explored with the client, as an elder's relationship with his or her family can impact the type of desired advance directive.

Social workers, armed with their ability to intervene on various system levels, are uniquely suited to aid older adults in beginning a dialogue with the extended family about end-of-life issues. As this research indicates, discussion topics related to a parent's ultimate death can be difficult for parents and adult children. Workers can assist seniors in developing strategies to communicate with their loved ones about this important issue.

Finally, one of the most important findings of this study is related to the importance of religion in end-of-life matters. A dialogue that includes an elderly client's religious beliefs relative to death and dying appears to be of the utmost importance. Social workers who are instrumental in assisting elders in formulating advance directives need to be mindful of and open to the integral role religious beliefs play for many elders in planning for medical treatment at the end of life.

REFERENCES

- Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. New Jersey: Prentice Hall.
- Cohen-Mansfield, J., Droge, J.A., & Billig, N. (1992). Factors influencing hospital patients' preferences in the utilization of life-sustaining treatments. *The Gerontologist*, 32, 89-95.
- Cruzan v. Director, Missouri Department of Health, 110 S. Ct. 2841 (1990).
- Emanuel, L., Barry, M., Stoeckle, J., Ettelson, L., & Emanuel, E. (1991). Advance directives for medical care—a case for greater use. *The New England Journal of Medicine*, 324, 889-895.
- Fried, T., Rosenberg, R., & Lipsitz, L. (1995). Older community-dwelling adults' attitudes toward and practices of health promotion and advance planning activities. *Journal of the American Geriatrics Society*, 43, 645-649.
- Gordon, G., & Dunn, P. (1992). Advance directives and the Patient Self-Determination Act. *Hospital Practice*, 27, 39-42.
- High, D. (1990). Who will make health care decisions for me when I can't? *Journal of Aging and Health*, 2, 291-309.

- High, D. (1991). A new myth about families of older people? *The Gerontologist*, *31*, 611-618.
- High, D. (1993). Advance directives and the elderly: A study of intervention strategies to increase use. *The Gerontologist*, *33*, 342-349.
- Hoge, D. (1972). A validated intrinsic religious motivation scale. *Journal for the Scientific Study of Religion*, *11*, 369-376.
- LaPuma, J., Orentlicher, D., & Moss, R. (1991). Advance directives on admission: Clinical implications and analysis of the Patient self-Determination Act of 1990. *Journal of the American Medical Association*, *266*, 402-405.
- Luptak, M., & Boulton, C. (1994). A method for increasing elders' use of advance directives. *The Gerontologist*, *34*, 409-412.
- Morse, J. (1994). Designing funded qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Mulholland, K. C. (1991). Protecting the right to die: The Patient Self-Determination Act of 1990. *Harvard Journal on Legislation*, *28*, 609-630.
- Patient Self-Determination Act of 1990, P.L. 101-508, § 4206, 104 Stat. 1388.
- Sachs, G., Stocking, C., & Miles, S. (1992). Empowerment of the older patient? A randomized, controlled trial to increase discussion and use of advance directives. *Journal of the American Geriatrics Society*, *40*, 269-273.
- Sansone, P., & Phillips, M. (1995). Advance directives for elderly people: Worthwhile cause or wasted effort? *Social Work*, *40*, 397-401.
- Scitovsky, A. A. (1994). "The high cost of dying" revisited. *The Milbank Quarterly*, *72*, 561-591.
- Seckler, A., Meier, D., Mulvihill, M., & Cammer-Paris, B. (1991). Substituted judgment: How accurate are proxy predictions? *Annals of Internal Medicine*, *115*, 92-98.
- Singer, P., Choudhry, S., & Armstrong, J. (1993). Public opinion regarding consent to treatment. *Journal of the American Geriatrics Society*, *41*, 112-116.
- Soskis, C., & Kerson, T. (1992). The Patient Self-Determination Act: Opportunity knocks again. *Social Work in Health Care*, *16*, 1-18.
- Thorson, J., & Powell, F. (1990). Meanings of death and intrinsic religiosity. *Journal of Clinical Psychology*, *46*, 379-391.
- Vandecreek, L., & Frankowski, D. (1996). Barriers that predict resistance to completing a living will. *Death Studies*, *20*, 73-82.
- Wolf, S., Boyle, P., Callahan, D., Fins, J., Jennings, B., Lindemann-Nelson, J., Baroness, J., Brock, D., Dresser, R., Emanuel, L., Johnson, S., Lantos, J., Mason, D., Mezey, M., Orentlicher, D., & Rouse, F. (1991). Sources of concern about the Patient Self-Determination Act. *The New England Journal of Medicine*, *325*, 1666-1671.
- Zweibel, N., & Cassel, C. (1989). Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. *The Gerontologist*, *29*, 615-621.

DATE MANUSCRIPT RECEIVED: 09/29/97

DATE MANUSCRIPT SENT FOR BLIND REVIEW: 10/10/97

DATE MANUSCRIPT RE-RECEIVED

IN ACCEPTABLE FORM: 02/09/98