

Are Advance Directives Followed by Surrogate Decision Makers?

Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010;362:1211–8.

Study Overview

Objective. To determine the need for decision making at the end of life, the prevalence of lost decision-making capacity, and the association between advance directives and end-of-life decision making.

Design. Retrospective cohort study.

Setting and participants. The study used data from the Health and Retirement Study, a biennial longitudinal survey of a nationally representative cohort of U.S. adults aged 51 years or older. For this study, subjects were limited to persons age 60 years or older who died between 2000 and 2006 and for whom a proxy (family member or knowledgeable informant) answered a study-directed exit interview after the subject's death.

Main outcome measures. Outcomes of interest were obtained from the responses of proxies regarding the decedent's circumstances of death. Proxies were asked whether the subject had completed a living will or durable power of attorney for health care. For subjects who had completed a living will, data were collected on preferences expressed in this document. For subjects who had appointed a durable power of attorney for health care, data were collected on who was appointed. Proxies were also asked whether decisions had to be made about the subject's care or treatment during the final days of his/her life, and whether the subject was able to participate in decisions about medical care during the final days of his/her life. For subjects who needed decision making, data were collected on the decisions made and on the person who made them. Clinical and sociodemographic factors were reported by either the subject before death or by the proxy after the subject's death.

Main results. Of the 4246 respondents to the Health and Retirement Study who died between 2000 and 2006, exit interviews with proxies were available for 3963 decedents. Of these, 3746 decedents were 60 years or older at the time of death and comprised the study sample. Subjects commonly died in the hospital (38.9% [95% confidence interval (CI), 36.8–41.1]), in their homes (27.3% [95% CI, 25.3–29.2]) or in nursing homes

(24.5% [95% CI, 22.6–26.5]). Proxy respondents were adult children (48.9% [95% CI, 45.0–53.0]), spouses (32.5% [95% CI, 30.6–34.3]) or other relatives (13.5% [95% CI, 11.1–16.1]). Proxy interviews occurred a mean (\pm SD) of 13 \pm 8.4 months after the subject's death. Of the 3746 decedents, 42.5% (95% CI, 39.9–44.5) required decision making about treatment in the final days of life. Of the subjects who required decision making, 70.3% (95% CI, 67.3–73.2) lacked decision-making capacity. In multivariate analysis of the predictors of decision-making capacity, subjects who were less likely to maintain decision-making capacity were those with cognitive impairment (adjusted odds ratio [OR], 0.42 [95% CI, 0.33–0.53]; $P < 0.001$), cerebrovascular disease (adjusted OR, 0.56 [95% CI, 0.39–0.82]; $P = 0.003$) and those residing in a nursing home (adjusted OR, 0.67 [95% CI, 0.51–0.88]; $P = 0.003$). At least 76.6% (95% CI, 75.0–78.2) of the overall population had at least 1 of these characteristics.

Of the subjects who needed decision making and lacked decision-making capacity, 67.5% (95% CI, 63.1–72.0) had an advance directive; 6.8% (95% CI, 4.6–8.9) had completed a living will only, 21.3% (95% CI, 17.9–24.8) had appointed a durable power of attorney for health care only, and 39.4% (95% CI, 35.7–43.1) had both prepared a living will and appointed a durable power of attorney for health care. Among subjects who had completed a living will, 1.9% (95% CI, 0.6–3.3) had requested all care possible, 92.7% (95% CI, 90.1–95.3) had requested limited care and 96.2% (95% CI, 94.7–97.7) had requested comfort care. Among the 435 subjects who had prepared a living will and expressed a preference for or against all care possible, there was strong agreement between stated preference and the care received ($P < 0.001$). Outcomes varied according to preferences: of the 425 subjects who did not indicate a preference for all care possible, 30 (7.1%) received it; among the 10 subjects who did indicate a preference for all care possible, 5 (50%) received it. There was also strong agreement between expressed preferences for or against limited care and the care received ($P < 0.001$). Of the 398 subjects who requested limited care, 331 (83.2%) received it; of the 36 subjects who had not requested limited care, 17 (47.2%) received it. Of the 417 subjects who had requested comfort care, 405 (97.1%) received it, and of the 29 subjects who did not request comfort care, 15 (51.7%)

received it ($P = 0.56$). In adjusted analyses, subjects who had requested comfort care were more likely to receive comfort care than subjects who had not requested it (adjusted OR, 11.57 [95% CI, 1.34–99.81]).

Among subjects who required decision making, had lost decision-making capacity, and had appointed a durable power of attorney for health care, the actual decision maker matched the appointed surrogate in 91.5% (95% CI, 89.1–93.9) of cases.

Conclusion. Surrogate decision making was often required for elderly Americans at the end of life. Subjects who had prepared advance directives received care that was associated with their preferences.

Commentary

Using national data from the Health and Retirement Study, Silveira et al highlight the frequency with which surrogate decision making occurs at the end of life. Of the 3746 adults age 60 years or older included in this study, 29.8% required decision making before death but lacked decision-making capacity. Predicting who will need surrogate decision making is difficult based on the authors' findings, as at least 1 of the characteristics associated with lost decision-making capacity—cognitive impairment, cerebrovascular disease, and residence in a nursing home—was present in over three-quarters of the study population.

Given the frequency with which surrogate decision making is needed, the authors sought to determine whether advance directives aided end-of-life decision making among those who had lost capacity. They found high rates of advance direction completion among these subjects, suggesting that such documents have become more common and accepted than they were 15 years ago, when the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) trial reported that only 21% of seriously ill hospitalized adults had an advance directive [1]. Using interview data from proxies, they also found significant concordance between the preferences expressed in advance directives and the care subjects received before death. The authors conclude that these findings support the continued use of advance directives, as both a living will and a durable power of attorney for health care appeared to have a significant effect on the provision of care in keeping with patients' wishes.

However, several limitations of this study limit our ability to draw conclusions about the benefit of advance directives. First, data were obtained from interviews conducted with proxies an average of 13 months after the subject's death and may be subject to significant recall and social-desirability bias. The authors were not able to verify that

the actual contents of advance directives matched the care received. Second, the authors had no data on the preferences of subjects without advance directives, and were thus unable to conclude whether subjects' preferences were any more likely to be honored if they had an advance directive than if they did not.

Such limitations are particularly concerning given the weight of recent evidence and expert opinion suggesting that advance directives are seriously flawed. Medical ethicists, palliative care clinicians, and health services researchers point to the fact that advance directives are seldom completed, most often not available when needed, and do not accurately reflect patient preferences in the face of real, rather than imagined, conditions [2–4]. Advance directives also fail to address the burdens encountered by surrogates asked to make decisions for an incapacitated family member [5]. Ongoing challenges in advance care planning unlikely to be addressed by increased use of standard advance directives include facilitating discussions about end-of-life treatment preferences earlier in the course of care, helping patients to define their goals, ensuring that these goals are documented in a manner that is easily available and transferable between health care settings, and aiding families in the difficult task of surrogate decision making.

Applications for Clinical Practice

Surrogate decision making before death is common. Living wills and durable powers of attorney for health care are increasingly common and appear to favorably affect the outcomes of surrogate decision making. More research is needed to determine how to best support patients and surrogates in the difficult task of decision making near the end of life.

—Review by Yael Schenker, MD

References

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