An Exploratory Study of the Use of Advance Directives by US Oncologists

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ABSTRACT

Purpose: This study sought to determine the rate of advance directive completion among US oncologists and factors influencing such a decision.

Methods: We surveyed 7590 members of the American Society of Clinical Oncology using a web-based questionnaire.

Results: The response rate was 8.1%. Most respondents (59%) had completed at least 1 document: 9% living will, 9% power of attorney for health care, and 41% both. Respondents who were older, men, married, with children, working in the community setting, radiation oncologists, and practicing general oncology were more likely than their counterparts to have an advance directive. Among those who had one, 95% and 36% had discussed their wishes with their loved ones and health care providers, respectively. Factors including experience at work, spouse, children, family, and religion had the most influence on respondents' decision. The majority of those without an advance directive reported either no reason or lack of time. Those who had them were more likely to report having a comprehensive review of their wishes with those closest to them, being more knowledgeable, having more routine discussions with their patients, and being more comfortable helping their patients complete one.

Conclusion: Only about half of US oncologists who responded to our survey have completed an advance directive.

BACKGROUND

Advance care planning is an important and ongoing process in which people discuss their health care goals and preferences with their loved ones and their health care providers. These discussions are intended to determine the patients' wishes regarding such issues as resuscitation and use of advanced life support at the end of life, and to help them choose appropriate health care agents who will make decisions on their behalf if they should lose the capacity to decide for themselves. To document those decisions, patients often complete an advance directive, a document that includes written instructions regarding their decisions regarding end-of-life health care.[1] The most common types of advance directives are: (1) the living will, which lists instructions for medical care; (2) the power of attorney for health care, which designates another person to make decisions on the patient's behalf; and (3) a combined document that has features of both the living will and the power of attorney for health care.[1] Without an advance directive, patients who have lost decision-making capacity might receive unwanted aggressive care, which can lead to worsened quality of life for patients and a more difficult bereavement adjustment for caregivers.[2,3]

The Patient Self-Determination Act of 1990 requires all medical facilities certified by Medicare and Medicaid to provide patients with advance directive information and to advise them of their right to accept or refuse medical treatments.[4,5] Most people have discussed their advance care planning with their family members at some point, yet less than 25% of patients have a written document that is available to their health care providers.[1] Even when patients have an advance directive, their physicians may be unaware of its existence.[4] This is true even among patients with serious illnesses such as cancer. A recent study showed that less than half of seriously ill admitted oncology patients at an urban academic medical center had an advance directive.[6] The completion rate for health care providers—even those who care for cancer patients—is not different from that of patients.[5,7,8] At our own community cancer center, only 35% of the 134 health care professionals who have face-to-face patient contacts had a written advance directive. Among those with advance directives, 66% had informed their primary care providers. More importantly, just 58% of our 13 oncologists had completed an advance directive.[8]

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Oncologists often care for patients who are near the end of their lives and, as such, it might be assumed that they are also involved with patients' end-of-life care issues and advance directive discussions. Yet neither oncologists' attitudes toward advance directives nor their completion rates have been systematically captured, analyzed, and reported. The aims of this study were to document the rate of advance directive completion among oncology physicians in the United States, to identify the factors that influenced their decision to complete an advance directive, and to find out whether those who had an advance directive had communicated its existence to their health care provider.

METHODS

The American Society of Clinical Oncology (ASCO) is the largest oncology society in the world, representing over 30,000 oncology professionals from 120 countries and encompassing all subspecialties. Using the ASCO membership book, we identified ASCO members who had an MD or equivalent degree, lived in the United States, and were actively involved in clinical oncology care. The Gundersen Clinic Human Subjects Committee/Institutional Review Board exempted the study because we did not collect any respondent identifiers in our anonymous web-based survey. Between June 2007 and December 2007, the survey (available online at: www.wisconsinmedicalsociety.org/_WMS/publications/wmj/pdf/112/4/sharma_survey.pdf) was sent to these ASCO members via e-mail. For purposes of the study, advance directive was defined as either a living will and/or a power of attorney for health care. In addition to information regarding advance directive, the survey captured demographic data (age, sex, marital status, number of children) and practice data (type, setting, specialty, location, time spent in direct patient care, and year of oncology training completion). Using the Agency for Healthcare Research and Quality survey guideline definitions, we identified incomplete surveys and excluded them from the analyses.[9] Data were analyzed using SAS statistical software, version 9.3 (SAS Institute, Inc., Cary, NC). The χ^2 test was used to compare groups.

RESULTS

We emailed the survey to 7590 ASCO members who met our inclusion criteria. Of these, 614 (8.1%) responded to the survey. We excluded 37 surveys because less than half of the research questions had been answered. The demographic and clinical practice features of the 614 respondents included in the final analysis are described in Table 1. Most were men, age 50 years or older, married with children, and community oncologists devoting over 75% of their time to caring for adult patients.

A slight majority (58.8%) of the respondents had completed at least 1 of the advance directive documents: 9.0% living will alone, 8.6% power of attorney for health care alone, and 41.2% both documents. Respondents who were older than 50 years (74.9%), were men (64.5%), were married (60.0%), had children (62.1%), worked in the community setting (65.5%), were radiation oncologists (78.1%), and practiced general oncology (62.3%) were more likely than their counterparts to have advance directives (Table 2). Among those with advance directives, 95.3% and 36.3% had discussed their wishes with their loved ones and health care providers, respectively. All (100%) of those with advance directives reported that their documents were in their medical records.

Factors such as experience at work (66.5%), spouse or domestic partner (46.3%), children (21.6%), family or friends (11.4%), and spirituality or religion (10.3%) had the most influence among respondents' decision to have an advance directive. The majority of those without one reported either no reason (52.2%) or lack of time (43.4%). See Table 3. Most (74.3%) of those without advance directives reported having discussed their wishes regarding future life-sustaining medical care with those closest to them. However, those with advance directives were more likely to report having had a comprehensive review of their wishes with those closest to them (54.9% vs 34.6%; $P < .001$), being more knowledgeable about advance directive (93.2% vs 85.0%; $P < .001$), routinely discussing advance directives with their patients (58.3% vs 49.4%; $P = .030$), and being more comfortable helping patients complete advance directives (93.0% vs 87.0%; $P = .013$). See Table 4.

DISCUSSION

Despite working in oncology or related fields and having to discuss end-of-life issues with patients, nearly half of the ASCO members who responded to the survey do not have a written advance directive. This is not surprising because previous studies have shown that health care workers have advance directive completion rates similar to those of the general population.[5,7,8] This may be a reflection of health care providers' attitudes toward advance care planning—attitudes that likely influence the advance directive completion rate of their patients. As others have suggested, physicians need to address their own fears, concerns, goals for care, and quality-of-life issues before they can address them with patients.[10]

In our study, the typical oncologist who has completed an advance directive is a married man older than 50 years who has children, practices in the community setting, and spends over 75% of the time in direct patient care. In many ways, these qualities are congruent with the most common reasons described by respondents as having a positive influence on having an advance directive—namely, work experience, family, and health concerns. These findings are reinforced by a recent survey among cancer patients and medical staff at an oncology clinic, which showed that although the overall completion rate was low (<20%), respondents who were older, in poor health, or in pain were more likely to have the intention to complete an advance directive if given the opportunity.[7]

Barriers to patients completing advance directives have been studied, but reasons for health care providers not completing them remain largely unknown and under studied.[7,8] A robust debate on the utility of advance directives persists in the medi-

Table 1. Demographic and Clinical Practice Descriptions of Survey Respondents

Characteristic	n (%)
Men	**428 (72.4)**
Age, Years	
<40	120 (20.9)
40-49	139 (24.2)
50-60	199 (34.7
>60	116 (20.2)
Marital Status	
Single	46 (7.8)
Married	513 (86.8)
Separated	5 (0.8)
Divorced	16 (3.9)
Widowed	4 (0.7)
Number of Children	
0	103 (17.5)
1-2	296 (50.3)
>3	189 (32.1)
Practice Setting	
Academic	225 (37.5)
Community with teaching	127 (21.2)
Community without teaching	224 (37.3)
Government	10 (1.7)
Other	14 (2.3)
Primary Practice	
Adult hematology-oncology	494 (82.3)
Pediatric hematology-oncology	16 (2.7)
Radiation oncology	32 (5.3)
Surgical oncology	36 (6.0)
Other	22 (3.7)
Practice Specialty (may choose more than one)	
Brain cancer	156 (25.4)
Breast cancer	260 (42.3)
Gastrointestinal cancer	222 (36.2)
General oncology	385 (62.7)
Genitourinary cancer	189 (30.8)
Gynecological cancer	147 (23.9)
Head and neck cancer	170 (27.7)
Hematologic cancer	250 (40.7)
Lung cancer	210 (34.2)
Melanoma	185 (30.1)
Palliative care	190 (30.9)
Sarcoma	153 (24.9)
Other	30 (4.9)
Practice Location (states)	
Atlantic (NJ, NY, PA)	41 (6.9)
Great Lakes (IL, IN, MI, OH, WI)	85 (14.2)
Midwest (IA, KS, MN, MO, ND, NE, SD)	71 (11.9)
Mountain (AZ, CO, ID, MT, NM, NV, UT, WY)	42 (7.0)
Northeast (CT, MA, ME, NH, RI, VT)	29 (4.9)
Pacific (AK, CA, HI, OR, WA)	119 (19.9)
Southeast (DC, DE, FL, GA, MD, NC, SC, VA, WV)	107 (17.9)
South (AL, KY, MS, TN)	34 (5.7)
West (AR, LA, OK, TX)	68 (11.4)
Time Spent in Direct Patient Care, %	
>75	378 (63.0)
50-74	111 (18.5)
25-49	51 (8.5)
1-24	48 (8.0)
None	12 (2.0)
Year Completed Oncology Training	
Before 1980	125 (21.3)
1980-1999	305 (51.9)
After 1999	133 (22.7)
None	24 (4.1)

Table 2. Characteristics of Respondents and Completion of Written Advance Directive (AD)

Characteristic	n	No. with AD (%)	*P* Value
Age, Years			
<50	299	125 (41.8)	<.001
>50	315	236 (74.9)	
Sex			
Women	163	73 (44.8)	<.001
Men	428	276 (64.5)	
Marital Status			
Married, divorced, separated, or widowed	540	324 (60.0)	.057
Single	46	21 (45.7)	
Children			
0	103	46 (44.7)	.001
>1	485	301 (62.1)	
Completion of Medical Training			
Before 1990	302	231 (76.5)	<.001
On or after 1990	235	98 (41.7)	
Practice Setting			
Academic	225	108 (48.0)	<.001
Community with teaching	127	82 (64.6)	
Community without teaching	224	148 (66.1)	
Other	24	14 (58.3)	
Primary Practice			
Adult hematology/oncology	494	292 (59.1)	.042
Pediatric hematology/oncology	16	7 (43.8)	
Radiation oncology	32	25 (78.1)	
Surgical oncology	36	19 (52.8)	
Other	22	9 (40.9)	
Practice Specialty			
General oncology	385	240 (62.3)	.021
Other	229	121 (52.8)	
Practice Location			
Midwest (Midwest, Great Lakes)	299	125 (41.8)	.587
Northeast (Northeast, Atlantic)	70	40 (57.1)	
South (South, Southeast, West)	161	97 (60.3)	
West (Pacific, Mountain)	163	73 (44.8)	
Time Spent in Direct Patient Care, %			
>75	489	288 (53.3)	.050
<75	378	233 (61.6)	

Table 3. Factors Influencing the Decision to Have an Advance Directive[a] (AD)

Factor	AD (n=361)	No AD (n=253)
Experience at work	66.5	—
Spouse or domestic partner	46.3	4.0
Children	21.6	1.2
Other family members or friends	11.4	0.4
None	15.5	52.2
Religion/spirituality	10.3	0.8
Medical condition or illness	7.5	1.2
Financial advisor/attorney	5.0	—
Media	4.4	0.0
Old age	0.4	—
Lack of time required to complete written AD	—	43.4
Healthy/young	—	5.5
Lack of discussion by primary care provider	—	4.3
Lack of value	—	1.6
Non-US citizen	—	0.4

[a]All data are presented as percentage of respondents with or without an AD who indicated the factor.

cal literature, with evidence suggesting that patient-designated and next-of-kin surrogates incorrectly predict patients' end-of-life preferences in one-third of the cases.[10-13] Another potential explanation is the influence of culture and society on patient attitudes toward advance directives. In one study, 80% of the patients in the United States had negative feelings toward end-of-life care, compared with only 45% in Japan.[14] Workplace-based interventions, such as electronic reminders or designating a department meeting once a year for advance directive completion, may boost completion rates. Our study suggests that cancer care providers might be easily persuaded to complete their advance directives because over three-fourths of respondents reported already having had end-of-life discussions with their loved ones.

Although the response rate was low, our study is the largest survey of US oncologists regarding advance directives to date. Nevertheless, caution is necessary in interpreting the results because they may not be representative of most oncologists in the United States. Because this was a web-based survey that required self-reporting, subjective interpretation of the questions and answer choices could not be avoided. Because of the exploratory nature of our study, we did not perform a multivariate analysis. Many of the variables associated with having an advance directive may also be associated with each other—for example, age, marital status, number of children, and year of completion of medical training (Table 2).

Regrettably, forces beyond the physician-patient relationship may become barriers to efforts to promote end-of-life discussions. A recent *New York Times* editorial aptly described how politics—both secular and religious—can hinder advance directive discussions between physicians and patients.[15] Nevertheless, many health care organizations, including ours—Gundersen Health System in La Crosse, Wisconsin—have been successful in implementing community-wide advance care planning.

Table 4. Discussion of Advance Directives (AD) with Family and Patients[a]

Questions	AD n=361	No AD n=253	*P* Value
Have you discussed your wishes regarding future life-sustaining medical care with those closest to you?	95.3	74.3	<.001
Which of the following best describes the level of discussion you have had with those closest to you?			
A few comments about your wishes	6.4	10.6	
A brief conversation about your wishes	16.0	18.1	
A limited exchange of ideas about your wishes	22.7	36.7	<.001
A comprehensive review of your wishes	54.9	34.6	
What is your level of knowledge regarding advance directives?			
Very knowledgeable	58.6	52.2	
Knowledgeable	34.7	32.8	<.001
Somewhat knowledgeable	6.8	13.4	
Not knowledgeable	0.0	1.6	
What percentage of your patients do you discuss an advance directive with?			
0	1.7	5.1	
1-24	16.6	23.7	
25-49	23.4	21.7	.030
50-74	28.2	32.4	
75-100	30.1	17.0	
What is your level of comfort in helping patients with an advance directive?			
Very comfortable	60.9	45.5	
Comfortable	32.1	41.5	.013
Somewhat uncomfortable	6.2	10.7	
Not comfortable	0.9	2.4	

[a]All data are presented as percentage of respondents with or without an AD indicating the level of discussion, knowledge, or comfort with ADs.

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