

The Cancer Specific Advance Directive

Scott R. Berry, M.D., F.R.C.P.C.¹

Peter A. Singer, M.D., M.P.H., F.R.C.P.C.²

¹University of Toronto Joint Centre for Bioethics; Department of Medical Oncology, Toronto-Sunnybrook Regional Cancer Centre, Toronto, Ontario, Canada.

²Department of Bioethics, University of Toronto Joint Centre for Bioethics; Department of Medicine, University of Toronto; Department of Medicine, The Toronto Hospital, Toronto, Ontario, Canada.

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Address for reprints: Peter A. Singer, M.D., M.P.H., F.R.C.P.C., University of Toronto Joint Centre for Bioethics, 88 College Street, Toronto, Ontario, Canada M5G 1L4.

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BACKGROUND. Advance directives are an important part of end of life care, but current advance directive documents do not address the specific issues facing cancer patients. The authors' purpose was: 1) to develop a cancer specific advance directive, 2) determine whether oncology outpatients find this directive more acceptable than a generic advance directive, and 3) describe oncology outpatient preferences for life-sustaining treatment.

METHODS. A cancer specific advance directive ("The Cancer Living Will"; the full text of the updated version is available at the University of Toronto Joint Centre for Bioethics website [URL: www.utoronto.ca/jcb]) was developed in four steps: 1) literature search, 2) key informant interviews, 3) focus groups, and 4) evaluation of face and content validity. Subsequently, 91 volunteer oncology patients were given copies of the cancer specific advance directive and the generic advance directive ("The University of Toronto Centre for Bioethics Living Will") from which it was adapted. Acceptability of the advance directive was measured by determining the participants' preferred directive. Participants recorded their treatment preferences in both the cancer specific and generic advance directives.

RESULTS. Of 60 patients who returned their questionnaires, 50 expressed a preference for the advance directive. Thirty-two patients (64%; 95% confidence interval (CI), 49-77%) preferred the disease specific Cancer Living Will and 18 patients (36%; 95% CI, 23-51%) preferred the generic Centre for Bioethics Living Will. Most participants who preferred the Cancer Living Will did so because it was more specific and relevant to their situation.

CONCLUSIONS. The authors have developed and evaluated a cancer specific advance directive that they believe can be recommended for clinical use with cancer patients. *Cancer* 1998;82:1570-7. © 1998 American Cancer Society.

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One of the most distressing situations faced by oncologists, their patients, and patients' families occurs when a patient who must make a decision regarding life-sustaining treatment is mentally incompetent to do so. Advance directives (ADs) are potentially helpful in such situations because they indicate who a person would want to make treatment decisions on his behalf, and/or what treatments a person would or would not want in various situations.^{1,2}

Current AD documents,³⁻⁷ or the forms prepared by lawyers and governments, are generic. Intended for the general public, generic ADs contain hypothetical, often irrelevant choices and inadequate prognostic information for cancer patients. Compared with generic ADs, disease specific ADs, designed specifically for people who have a particular disease, have several potential advantages.⁸ First, they present patients with scenarios and treatments that the patient is likely to confront. Second, because the group of patients completing the AD document is more homogenous, more specific prognostic information can be presented. Finally, because the patient already

has experience of the illness that may lead to those choices, the choices themselves are less hypothetical.

There have been relatively few studies of ADs in the context of cancer and they all involve generic ADs. Samal and Kraut provided ADs to 25 breast cancer patients and found that only 3 had previously completed an AD and only 1 other patient completed an AD after 1 year of follow-up.⁹ Ewer and Taubert reported that 16% of medical admissions over a 1-year period to the Intensive Care Unit at the M. D. Anderson Cancer Center had ADs.¹⁰ Stephens reported that in his retrospective study of 64 patients who had completed ADs at the Kansas University Cancer Center, 70% had positive attitudes toward ADs because of their ability to help preserve autonomy and relieve relatives of the “burden” of making difficult decisions.¹¹ Virmani et al. studied a group of cancer patients with an expected 5-year survival of $\leq 50\%$ and found that patients who had completed an AD were nearly twice as likely to have discussed future health plans with their physicians compared with the group who had not completed ADs.¹² To our knowledge, this study is the first to develop and evaluate a cancer specific AD and to describe the treatment preferences of cancer patients.

The purpose of this study was to: 1) develop a cancer specific advance directive, 2) determine whether oncology outpatients find it more acceptable than a generic AD, and 3) describe oncology outpatient preferences for life-sustaining treatment.

METHODS

Development of the Cancer Living Will

The Cancer Living Will (CLW) is adapted from the University of Toronto Centre for Bioethics Living Will (CFBLW).⁵ The CFBLW contains chapters of questions and answers regarding ADs, information regarding the legal status of ADs, information regarding health care decisions, information regarding personal care decisions and the AD form itself. The AD chapter includes both a proxy directive (i.e., the portion that indicates who a patient would like to make decisions for them) and an instruction directive (the portion that indicates what treatments the person would want in the future). The instruction directive contains a grid (Fig. 1) in which a person can indicate which treatments he would or would not want in each of the different health states by indicating yes, no, undecided, or treatment trial in each cell of the grid.

The CLW was developed in four steps. First, we reviewed the literature on the prognosis of specific health states in cancer and drafted a version of the CLW incorporating this information. Second, we conducted key informant interviews with physicians,

nurses, and social workers involved with the care of cancer patients; comments made during the interviews were used to revise the CLW. Third, we evaluated the face and content validity of the CLW using an expert panel, the Medical Affairs Committee of the Canadian Cancer Society (Ontario Division); the respondents made many useful suggestions for improving the CLW. Fourth, we conducted a focus group discussion with five lay volunteers (all but one either had cancer or had a close family member with cancer) from the Cancer Society’s Patient Services Committees from across Ontario; all focus group members gave suggestions for improving the CLW.

The primary difference between the CFBLW and the CLW is the chapter containing information regarding health care decisions that incorporates descriptions of “health states” in which the AD may be needed and treatments that might be required while in those health states. The description of health states and treatments in the CLW specifically refers to issues in the care of people with cancer whereas the CFBLW is more general. For instance, in the CLW, the description of “Current Health” (which includes the description of acute and potentially reversible illnesses that the person might experience) includes descriptions of hypercalcemia and febrile neutropenia whereas the CFBLW mentions cardiac arrest and pneumonia. A listing of the health states and treatments in both living wills is contained in Figures 1A and 1B. The full text of updated versions of both ADs is available at the University of Toronto Joint Centre for Bioethics website (URL: www.utoronto.ca/jcb).

Evaluation of the CLW

Study design

A volunteer sample of oncology outpatients was identified by their physicians at an urban regional cancer center and an urban tertiary care hospital with a general oncology clinic. Supervising physicians or oncology clinic nurses reviewed patients attending participating clinics, identified eligible participants, and approached them to learn whether they would be willing to participate in the study. If the patient was willing, they met with a study assistant and received a detailed information sheet regarding the study. Patients who agreed to participate provided informed consent and viewed an educational video about ADs. They then received a package containing two AD documents (the CLW and CFBLW) and three questionnaires (the Advanced Directive Choice Questionnaire [ADCQ] and two copies of the Advanced Directive Acceptability Questionnaires [ADAQ]) that allowed them to rate each AD and express a preference for one of the ADs. The patients reviewed the documents at home and

	CPR	VENT	RADS	CHEMO	SURGERY	BLOOD	ANTI-BIOTICS	TUBE FEEDING
CURRENT HEALTH								
BRAIN DISEASE MILD DISABILITY								
BRAIN DISEASE MODERATE DISABILITY								
BRAIN DISEASE SEVERE DISABILITY								
PAIN SYNDROME								

A

	CPR	VENT	DIALYSIS	SURGERY	BLOOD	ANTI-BIOTICS	TUBE FEEDING
CURRENT HEALTH							
MILD STROKE							
MODERATE STROKE							
SEVERE STROKE							
MILD DEMENTIA							
MODERATE DEMENTIA							
SEVERE DEMENTIA							
PERMANENT COMA							
PAIN SYNDROME							

B

FIGURE 1. (A) Cancer Living Will instruction grid. For each combination of health state and treatment, the person completing the living will writes one of four choices: Yes (if he wants the particular treatment in that health state), No (if he does not want the particular treatment in that health state), Undecided (if he is undecided whether he wants the particular treatment in that health state), and Trial (if he wants a trial of the particular treatment in that health state). CPR; cardiopulmonary resuscitation; Vent: ventilator; Rads: radiation; Chemo: chemotherapy; Blood: blood transfusion. (B) Centre for Bioethics Living Will instruction grid. For each combination of health state and treatment, the person completing the living will writes one of four choices: Yes (if he wants the particular treatment in that health state), No (if he does not want the particular treatment in that health state), Undecided (if he is undecided whether he wants the particular treatment in that health state), and Trial (if he wants a trial of the particular treatment in that health state). CPR: cardiopulmonary resuscitation; Vent: ventilator; Blood: blood transfusion.

discussed them with their proxy(ies), physician, or any other person they wanted to involve in the process. They completed both ADs and questionnaires and returned the study materials by mail in a postage-paid envelope. The ADs completed were retained by the researchers, but participants could request a blank copy of the AD of their choice for their personal use. Participants who had not returned the materials after 1 month were contacted by phone to remind them to return the materials. The study was approved by the institutional ethics review board at each center. Patients were enrolled between April 1995 and May 1996.

Participants

Participants were excluded if they were age < 16 years, not fluent in English, could not read, were incapable

of completing an AD (as measured by a Standardized Mini-Mental Status test score of < 23),¹³ would experience undue emotional distress from completing an AD (in the opinion of their physician), or refused participation in the research.

Interventions

Two ADs were used in this study: the CFBLW and the CLW, as described earlier.

Outcome measures

Acceptability of the ADs was measured using the ADCQ and ADAQ. The ADCQ asks respondents, "We are interested in which of the two living wills you liked best. If you had to choose one of these two living wills, which one would you choose to complete?" and elicits

the reasons for their choice. The ADAQ contains 14 items rated on a 5-point ordinal scale from excellent to poor.¹⁴ It has been evaluated for face/content validity by an interdisciplinary panel of experts; in a previous study, internal consistency reliability of the ADAQ, measured using Cronbach's alpha, was 0.93.

Data analysis

The primary outcome of the evaluation portion of this study was patient's choice of AD. The proportion of participants who would choose each AD (among the group of patients who received both) was described, along with the 95% confidence interval (CI) (two-tailed). In addition, we recorded and described participants' open-ended responses regarding why they preferred one or the other AD.

The secondary outcome was comparison of ADAQ scores for the CLW versus the CFBLW. The total score on the ADAQ was calculated by adding scores on each individual item, dividing by the highest possible total score, and multiplying by 100, to yield a percent value. (Items were rescored to a 0-4 scale so that higher numbers will indicate greater acceptability and the range of the total score will be 0-100%.)

Sample size

It was feasible to identify 91 eligible patients (60 of whom completed the study materials) during the study period.

RESULTS

Development of the CLW

Five of six key informants interviewed said they would use the CLW for patients they were involved with. In assessing face and content validity, 10 (8 doctors and 2 nurses) of the 12 medical members of the expert panel responded, and 8 stated that the CLW fulfilled its purpose of documenting "the wishes of people living with cancer regarding the use of life-sustaining treatments and their wishes regarding a proxy decision maker." Among the five lay volunteers in the focus group discussion, there was unanimous approval of the CLW.

Evaluation of the CLW

There were 91 patients enrolled in the evaluation portion of the study, 60 of whom returned their questionnaire package, representing a response rate of 66%. Characteristics of respondents and nonrespondents are summarized in Table 1. Respondents did not differ significantly from nonrespondents except in terms of the numbers who had completed a living will previously. Approximately 38% of the respondents had completed a living will previously compared with 10%

of the nonrespondents ($P = 0.008$). Although we do not have complete data, 9% of patients screened were enrolled, and 51% of the screened patients were not even approached because the supervising physician or oncology clinic nurse stated that the patient would experience undue distress.

Of the 60 respondents, 50 made a choice on the ADCQ. Of the ten respondents who did not make a choice, five left the questionnaire blank, three chose both the CLW and CFBLW or stated that they could see no difference between them, and two returned the packages uncompleted because they found the content of the living wills "depressing" or "disturbing."

Of the 50 respondents who made a choice on the ADCQ, 32 (64%; 95% CI, 49-77%) chose the CLW and 18 (36%; 95% CI, 23-51%) chose the CFBLW. Gender, age, type of cancer, education, presence of metastases, presence of other illnesses, or self-description of health status did not affect AD choice.

Of the 32 participants who chose the CLW, 25 did so because it was more specific and relevant to their situation. For instance, one respondent commented that "I found the CLW to be more specific and informative with respect to my personal situation and interests. Because it outlines some of the specific scenarios a cancer patient could encounter it has more significance than the other living will." Another patient said that "...the choice of radiation or chemo to control pain, for instance, is a significant choice, and I am happy it was included."

Of the 18 participants who chose the CFBLW, 13 did so because it was more detailed/comprehensive and dealt with issues other than cancer that they felt were important. For instance, one participant said "The cancer living will was too focused on cancer—it assumes that cancer will cause incapacitation—what if I get Alzheimer's? What if I am in an accident and end up in a coma?"

Of the 52 people who completed ADAQs for both living wills, the mean percentage scores did not differ. The mean score was 73.4 (standard deviation [SD] 15.3) for the CLW and 73.0 (SD 15.2) for the CFBLW. The acceptability ratings for the individual item scores for the two ADs are shown in Table 2. The majority of the ratings were in the very good to good range. There were no significant differences in scores between the CLW and CFBLW on any of the items.

Description of Treatment Preferences

Fifty-six of the 60 respondents (93%) completed the CLW, 53 (88%) completed the CFBLW, and 52 (87%) completed both. Treatment preferences recorded in the CFBLW and the CLW are shown in Figures 2 and 3.

TABLE 1
Participant Characteristics

	All patients enrolled (N = 91)	Respondents (N = 60)	Nonrespondents (N = 31)
		Mean (SD)	
Age (yrs)	58 (11)	59 (12)	58 (11)
Standardized Mini-Mental Status test score	29 (1)	29 (1)	29 (1)
		Number (percentage)^b	
Female	72 (79)	45 (75)	27 (87)
Ethnic origin			
North American/European	80 (88)	51 (85)	29 (94)
Asian	4 (4)	3 (5)	1 (3)
French Canadian	6 (7)	5 (8)	1 (3)
Native	1 (1)	1 (2)	0 (0)
Type of cancer			
Breast	53 (58)	34 (57)	19 (61)
Lung	16 (18)	11 (18)	5 (16)
Colorectal	10 (11)	7 (12)	3 (10)
Head and neck	4 (4)	4 (7)	0 (0)
Gu/Gyne	3 (3)	2 (3)	1 (3)
Esophagus/Stomach	2 (2)	0 (0)	2 (6)
Non-Hodgkin's Lymphoma	1 (1)	0 (0)	1 (3)
Melanoma	1 (1)	1 (2)	0 (0)
Carcinoid	1 (1)	1 (2)	0 (0)
Metastases	34 (37)	22 (37)	12 (39)
Other illnesses	26 (29)	19 (32)	7 (23)
Description of health at time of enrollment			
Excellent	24 (26)	15 (25)	9 (29)
Very good	20 (22)	14 (23)	6 (19)
Good	25 (28)	19 (32)	6 (19)
Fair	19 (21)	10 (17)	9 (29)
Poor	3 (3)	2 (3)	1 (3)
Hospitalized 2 Years prior to enrollment	55 (60)	37 (62)	18 (58)
Previous ICU admission	21 (23)	14 (23)	7 (23)
Highest year of schooling completed			
Less than high school	3 (3)	2 (3)	1 (3)
Some high school	10 (11)	7 (12)	3 (10)
High school graduate	17 (19)	11 (18)	6 (19)
Some college or university	17 (19)	9 (15)	8 (26)
College or university graduate	30 (33)	24 (40)	6 (19)
Postgraduate/professional degree	14 (15)	7 (12)	7 (23)
Had heard of advance directives or living wills before	82 (90)	55 (92)	27 (87)
Completed advance directive or living will before	26 (29)	23 (38)	3 (10) ^a

SD: standard deviation; Gu: genitourinary; Gyne: gynecologic; ICU: Intensive Care Unit.

^a $P < 0.05$ for comparison between respondents and non-respondents.^b Percentages may not total 100% due to rounding.

TABLE 2
Scores on Individual Items of the Advance Directive Acceptability Questionnaire

Item	CLW mean (SD) (N = 54–56)	CFBLW mean (SD) (N = 50–52)
General information	1.77 (0.76)	1.77 (0.81)
Simplicity of language	1.66 (0.72)	1.64 (0.69)
Amount of detail	2.19 (1.01)	2.08 (0.94)
Length	2.35 (0.94)	2.22 (0.86)
Design or layout	2.16 (0.88)	2.08 (0.82)
Description of situations	1.89 (0.87)	2.02 (0.87)
Description of treatments	1.89 (0.82)	2.04 (0.80)
Easy to give instructions about treatments	2.59 (1.07)	2.73 (1.06)
Easy to appoint proxy	1.86 (0.96)	1.86 (0.94)
Raised potentially disturbing issues	2.13 (0.93)	2.04 (0.80)
Gives control over future medical care	2.20 (0.92)	2.20 (0.97)
Allowed you to express your values	2.09 (0.84)	2.14 (0.94)
Allowed you to express your wishes	2.04 (0.87)	2.08 (0.98)
Overall	2.13 (0.89)	2.12 (0.85)

CLW: Cancer Living Will; CFBLW: University of Toronto Centre for Bioethics Living Will; SD: standard deviation.

Ratings on the Advance Directive Acceptability Questionnaire items are as follows: 1 = excellent; 2 = very good; 3 = good; 4 = fair; 5 = poor.

Figure 2 summarizes the responses on the CLW. Health states and severity of illness had a greater influence on preferences than did treatments. For instance, preferences across health states in the CLW varied widely from 87% of respondents wanting cardiopulmonary resuscitation in their current health state, 76% in brain disease with mild disability, 48% in brain disease with moderate disability, to 6% in brain disease with severe disability. By contrast, in current health, the preferences ranged from 72% of respondents wanting tube feeding to 96% wanting antibiotics. Similar trends were observed in patient preferences in the CFBLW (Fig. 3).

DISCUSSION

Development of the CLW

The CLW was developed using a four-step process that emphasized input from health care providers involved in the care of cancer patients and lay people who had cancer or had cared for someone with cancer. The process ensured that the health states described were relevant to people with cancer and that the descriptions included published prognostic data that would be useful for decision making. We confirmed that health care professionals would use the CLW with their patients and that patients would understand it. By getting detailed feedback from the participants in interviews and focus groups we were able to refine the CLW, which, to our knowledge, is the

first cancer specific AD ready for clinical use. The full text of the updated cancer living will is available at the University of Toronto Joint Centre for Bioethics website: www.utoronto.ca/jcb.

Evaluation of the CLW

A total of 64% of oncology patients preferred the cancer specific AD. Patients preferred a cancer specific AD because of its specificity to their clinical situation, confirming the theoretic advantages of a disease specific AD.⁸ Disease specific ADs have one major theoretic disadvantage compared with generic ADs: cancer patients sometimes die of some other cause, such as an automobile accident. Among the patients who preferred the CFBLW, this was primary reason for their preference. We recommend offering patients both a cancer specific and generic AD and allow them to choose which would better suit their needs.

It is possible that some patients would prefer to complete both living wills to achieve the advantages of both the specificity of the CLW and the comprehensiveness of the CFBLW. We would not recommend such a combination for routine use because it would be quite complicated, but it might be the right course of action for some patients. If a patient chooses to complete both, it would be important that he completes only both instruction directive grids but not two formal legal documents, to avoid the confusion this might cause.

Although we cannot exclude that patients consider the two ADs to be equivalent, we can be 95% confident that at least 49% of patients prefer the CLW (this is the lower limit of the 95% CI). Even if 49% were the “true” result, rather than our “best estimate” of 66%, our conclusion regarding the CLW would be unchanged.

Finally, why did the ADCQ (our primary outcome) show a difference between the two ADs whereas the ADAQ (our secondary outcome) did not? We believe this discrepancy is related to the better discriminating power of asking people to compare two ADs at once and state a global choice as to which they prefer (ADCQ) compared with asking people to rate different aspects of each AD individually and then comparing the sum of those ratings.

Description of Treatment Preferences

To our knowledge, this is the first study to describe cancer patients' preferences for life-sustaining treatment. Health states and severity of illness have a greater influence on preferences than do treatments. Similar trends were observed in dialysis and human immunodeficiency virus patient preferences in other studies by our group.^{15,16} We recommend that discus-

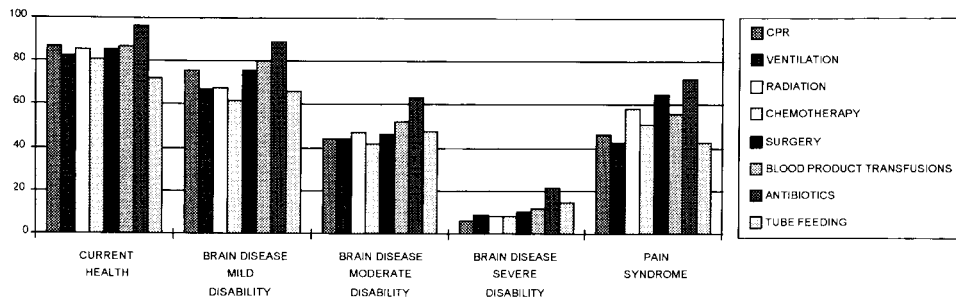


FIGURE 2. Treatment preferences on the Cancer Living Will. The height of each bar represents the proportion of respondents who wanted the specified treatment in the specified health situation. The number of participants answering each health situation-treatment choice ranges from 51 to 154. CPR: cardiopulmonary resuscitation.

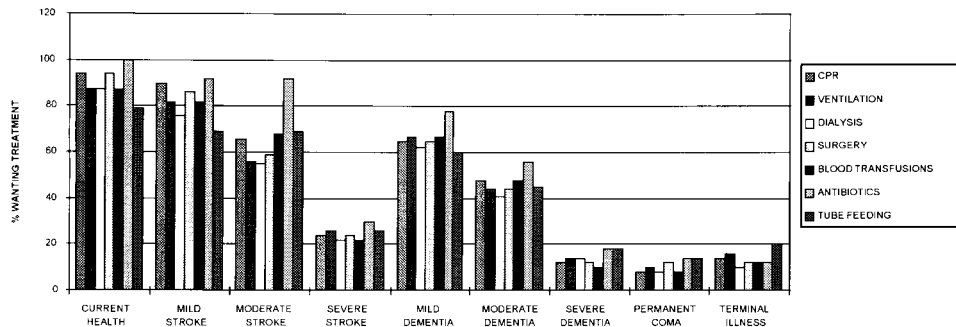


FIGURE 3. Treatment preferences of the University of Toronto Centre for Bioethics Living Will. The height of each bar represents the proportion of respondents who wanted the specified treatment in the specified health situation. The number of participants answering each health situation-treatment choice ranges from 47 to 50. CPR: cardiopulmonary resuscitation.

sions with patients during the advance care planning process should highlight the descriptions of health states.

It is interesting to note that preferences for treatment in this population on the terminal illness scenario on the generic CFBLW were much lower than preferences for treatment generally on the CLW. This suggests that these patients did not consider themselves to be terminally ill and that the equation of terminal illness with cancer in generic living wills would be inappropriate.

Limitations

This study has four main limitations. First, participants were not sampled randomly but volunteered; however, the AD choice of those who would not volunteer to complete an AD is of limited interest. Second, a significantly higher proportion of respondents had completed an AD compared with nonrespondents; however, the response of a group seemingly more interested in advance care planning may be more useful in the comparison between the two ADs. Third, only approximately 9% of patients screened were enrolled; however, there is no reason to believe the patients not enrolled would make a systematically different choice between the two ADs or that their pattern of life-sustaining preferences would be different from those enrolled. Moreover, the finding that 50% of the screened patients were excluded by their oncology health providers because of possible emotional distress is clinically

important because it raises the possibility that providers are overprotecting cancer patients who might want to pursue advance care planning. Finally, the generalizability of our findings is limited by the observation that AD documents are only one element of advance care planning, a “process of communication among patients, health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions.”¹⁷⁻¹⁹ Moreover, we did not examine the effect of ADs on clinical decisions after patients become incapable.²⁰

Conclusions

A cancer specific AD has been developed. Oncology outpatients find the cancer specific AD to be at least as acceptable as a generic AD. The detailed descriptions of cancer specific health states in the CLW have a significant influence on treatment preferences. Advance care planning programs for outpatients in cancer clinics should include a cancer specific AD.

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