

Hard Choices: The Gynecologic Cancer Patient's End-of-Life Preferences

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Few reports in gynecologic literature have addressed patient preferences about terminal care. In light of the current discussions about end-of-life decision-making, a study was designed to assess the desires of patients with gynecologic cancer. A questionnaire was completed by 108 patients under treatment for gynecologic cancer at the University of Michigan Medical Center and by 39 patients from the routine gynecology clinic at the same institution. Participants were asked about their reactions to a poor prognosis, their desires for the location of terminal care, and their preferences for withdrawing or withholding life-sustaining technologies. Five percent of these cancer patients anticipated giving up the fight against their disease. Seventy-eight percent specifically expressed resolve to continue the fight against their disease. Feedback from these patients about their end-of-life preferences served to define the concept "fight." A majority preferred to receive care at home. Ninety percent of these cancer patients could envision their conditions deteriorating to the point that they would not want ventilator support. Thirty-four percent could envision refusing surgery for another life-threatening condition; 37%, a time when artificial nutrition would be refused; 22%, a time when antibiotics would be rejected. This study suggests that limiting the use of artificial respiratory support while continuing the use of artificial nutrition and hydration support would be consistent with the preferences of gynecologic cancer with end-stage disease. © 1994 Academic Press, Inc.

INTRODUCTION

Maximizing patient self-determination and liberally accommodating patient treatment preferences are now established commitments in medical decision-making [1]. However, literature reviews continue to point out that few studies have actually sought to ascertain the preferences of patients facing the specific decisions associated with life-threatening conditions [2,3]. The literature that exists on patient preferences has focused on whether and

how much to inform a patient [4,5], on quality of life [6,7], on do-not-resuscitate orders [8,9], on a patient's psychosocial vulnerabilities and needs [10,11], on the perceptions of elderly patients [12-15], and on physician understanding of patient perceptions [16-18].

In light of the importance now given to patient self-determination in the management of life-threatening conditions (including patient requests for and public discussion of physician-assisted death), insight into the ways patients address end-of-life decisions remains critical. However, generalizations about patient preferences at the end of life are difficult to draw. Studies have proposed contrasting descriptions. For instance, Lo *et al.* asked 152 patients, each of whom had conditions that could leave them incapable of making decisions, to suppose that they had severe memory loss without chance of recovery [19]. Seventy-three percent indicated they would refuse intensive care; 71% would refuse cardiopulmonary resuscitation; 75% would refuse a feeding tube; 53% would refuse antibiotics or hospitalization for pneumonia. Danis *et al.* studied 160 patients who had experienced medical intensive care [2]. Seventy percent of the patients and families were completely willing to undergo intensive care again to achieve even 1 month of survival.

We have attempted to look at end-of-life decision-making from the perspective of gynecologic cancer patients. Little literature has developed around the preferences of this patient group. In a 1982 study, Gallup *et al.* addressed gynecologic cancer decision-making from a physician perspective [20]. Our study has sought a patient perspective.

SUBJECTS AND METHODS

Respondents to this study came from the patients seen by the Oncology Service of the Department of Obstetrics and Gynecology at the University of Michigan Medical

Center (Ann Arbor, MI). The members of the comparison group came from the department's Gynecology Service. After Institutional Review Board approval was obtained, data were collected between August 1989 and May 1991. All participating patients gave informed consent.

A self-administered questionnaire was developed for this study. The final wording of the questions reflected the results of a thorough literature review [21] and the input from staff members clinically involved with the study population. In addition to demographic items, the questionnaire posed 16 multiple choice questions and 4 true-false questions. Participants needed 20-30 min to complete the questionnaire.

Respondents were asked to envision being informed by their physicians that efforts to cure or control the spread of their disease were failing. They were then asked to predict their desire (if any) for continued therapy, their preferred location of subsequent care, and what (if any) types of further technological interventions they would prefer withheld or withdrawn. Each item on the questionnaire had an open-ended opportunity for the patients to add opinions not contained in the designated options.

The questionnaire was distributed randomly to cancer patients (all of whom were English-speaking) during clinic appointments or hospital stays. Approximately 50% of the patients invited to participate chose to participate. No demographic or medical information was available concerning the patients who refused to participate. The majority of the participants completed the questionnaire during the time of initial contact. A few chose to return the questionnaire by mail.

To form a comparison group, the questionnaire was also distributed randomly to women without cancer who were waiting for routine gynecologic examinations. Approximately 75% of these women agreed to participate. Most of these participants also completed the questionnaire during the time of initial contact.

The data from the cancer patients have been categorized according to patients whose disease was active or inactive. Responses from the patients for whom the cancer was active have been further stratified into three categories of patients: newly diagnosed, undergoing therapy, or facing end-stage disease.

Since some participants did not respond to all of the items on the questionnaire and since the information about medical status was not available for the few patients whose informed consent signatures were not legible, the denominators occasionally varied. Analyses were done using the Pearson χ^2 test with significance set at 0.05 (Systat, Ver. 5.1, Systat Inc.).

The data for this report were generated by three items from the questionnaire (see Appendix). The remaining data will be addressed in future reports.

TABLE 1
Demographic Data

Variables	Cancer patients (%)	Control group (%)
Age (years)	(n = 107)	(n = 39)
<40	21	44
41-55	29	28
56-70	39	28
70+	11	—
Ethnic group	(n = 105)	(n = 36)
Caucasian	92	89
African-American	7	11
Hispanic	1	—
Marital status	(n = 108)	(n = 39)
Married	68	69
Single	10	15
Widowed	11	5
Divorced	11	10
Education	(n = 105)	(n = 39)
<High school	17	5
High school diploma	40	54
Some college	25	21
College degree	9	18
Graduate school	10	3
Faced (other) life-threatening condition(s)	(n = 93)	(n = 30)
Yes	27	13
No	73	87
Religious preference	(n = 91)	(n = 32)
Christian	97	84
Jewish	3	13
Islamic	—	3
Children living at home	(n = 108)	(n = 39)
Yes	19	26
No	81	74
Disease status	(n = 100)	NA
Newly diagnosed	9	
Undergoing therapy	22	
Post-Rx doing well	55	
Facing end-stage disease	14	

RESULTS

Table 1 presents selected demographic and medical data about the participants. A total of 108 gynecologic cancer patients agreed to participate. A total of 39 cancer-free women constituted the comparison group. The patient group and the comparison group had similar demographic profiles, except that the patient group was older (54 years of age vs 45 years of age) and had more personal experience with life-threatening conditions other than cancer.

1. Reaction(s) to Poor Prognosis

Participants were asked to predict (or describe, in the case of the cancer patients actually facing end-stage dis-

TABLE 2
Reaction(s) Should Treatment Be Failing

Item	Total (%) (n = 100)	Disease inactive (%) (n = 50)	Disease active* (%) (n = 44)	New patient (%) (n = 9)	Under therapy (%) (n = 21)	End-stage disease (%) (n = 14)	Comparison group (%) (n = 39)
Volunteer	40	40	45	56	57	21	33
Give up	5	6	5	—	10	—	3
Help	39	42	36	11	33	57	49
Fight	78**	78	75	78	67	86	56
Unorthodox	18	14	23	11	33	14	28

* The "disease active" column totals the "new patient," "under therapy," and "end-stage disease" columns.

** $P = 0.01$, when cancer patients were compared with the comparison group.

ease) how they would react should they learn that treatment to cure or contain their conditions seemed to be failing. Their options were: (A) to volunteer for any medically available treatment, however experimental; (B) to give up the fight; (C) to help family and/or friends deal with the situation; (D) to fight even harder against the illness; (E) to seek cure through medically unorthodox means. They were encouraged to mark as many reactions as were applicable. Table 2 reports their responses.

Five percent of the cancer patients expected to resign themselves to inevitable death if they learned that their disease could not be cured or contained. Three percent of the comparison group expected similar resignation. Seventy-eight percent of the cancer patients indicated they would fight even harder against the illnesses. This resolve to continue to fight was significantly greater than that expressed by the comparison group (78% vs 56%, $P = 0.01$). The expressions of resolve to continue to fight rather than to give up did not decline when the responses were analyzed according to disease status. In fact, the highest majority (86%) of patients who expected to continue to fight against their disease came from those patients actually facing end-stage disease.

How the patients actually facing end-stage disease would "fight" was unclear, given their comparative lack

of expressed preparation to volunteer for experimental treatments (21%) or to try unorthodox alternatives (14%). They were the most likely patients (57%) to respond to the report of a poor prognosis by helping family members cope.

2. Preference for Location of Care

Participants were asked whether, should treatment to cure or contain their illnesses seem to be failing (or already have failed, in the case of patients with end-stage disease), they would prefer to be cared for: (A) at home, (B) as an inpatient at a hospital, (C) as an outpatient at a hospital, or (D) by some other arrangement (e.g., hospice facility). Table 3 reports their responses.

Fifty-seven percent of the cancer patients, regardless of disease status, preferred to be treated at home. Fifty-four percent of the comparison group expressed a similar preference. By contrast, 22% of the cancer patients and 11% of the comparison group preferred to be cared for as inpatients. The cancer patients indicated significantly less preference for outpatient care than did the comparison group (14% vs 30%, $P = 0.042$). They expressed least desire (7%) for care to be delivered in other settings (e.g., hospice facility).

TABLE 3
Preferences for Location of Care

Item	Total (%) (n = 97)	Disease inactive (%) (n = 49)	Disease active* (%) (n = 42)	New patient (%) (n = 9)	Under therapy (%) (n = 19)	End-stage disease (%) (n = 14)	Comparison group (%) (n = 39)
Home	57	55	62	56	63	64	54
Inpatient	22	27	14	11	5	29	11
Outpatient	14**	16	12	11	21	—	30
Other	7	2	12	22	11	7	5

* The "disease active" column totals the "new patient," "under therapy," and "end-stage disease" columns.

** $P = 0.042$, when cancer patients were compared with the comparison group.

3. Withholding or Withdrawing Life-Sustaining Technology

Participants were asked if a time could come in their illnesses (or if the time had come, in the case of patients with end-stage disease) when they would want any of the following procedures withheld or withdrawn: (A) mechanical respiratory assistance (ventilation); (B) surgery for another life-threatening condition; (C) antibiotics for infection; (D) technology (e.g., a feeding tube) that delivers nutrition and hydration. Tables 4 and 5 report their responses.

Twenty-four percent of the cancer patients indicated that they would reduce all of these decisions to one categorical decision—either requesting (5%) or rejecting (19%) all life-sustaining technologies. The rest distinguished among the technologies.

Accordingly, 43% of these cancer patients anticipated preferring that only ventilation support be withheld or withdrawn. Sixteen percent could envision refusing nutrition and hydration technology as well as ventilation support. Ten percent expected to refuse ventilation support and surgery for other life-threatening conditions that might develop. Two percent thought that they would only want antibiotics withheld or withdrawn. Another 2% predicted that they would refuse surgery only for another life-threatening condition. A final 2% would refuse all but antibiotics.

COMMENT

We realize that studies dependent on data collected via a questionnaire can be biased by the selection and wording of the questions and that self-reported data, reflecting a respondent's perceptions at the time of participation, cannot predict changes in patient preference as the disease process continues. The use of a vignette, although a valid method for assessing patient attitudes, cannot fully capture the complexities of decision-making at the end of life.

These data describe women with gynecologic cancer,

TABLE 5
Decision-Making Variations Pertaining to Withholding or Withdrawing Life-Sustaining Technology

Variation	Percentage
Employ all technologies	5
Employ or continue no technologies	19
Withhold or withdraw ventilation only	43
Withhold or withdraw ventilation and nutrition/hydration support	16
Withhold or withdraw ventilation and withhold surgery	10
Withhold or withdraw antibiotics only	2
Withhold or withdraw surgery only	2
Withhold or withdraw all but antibiotics	2

treated at the University of Michigan, who were willing to reveal their end-of-life preferences. This population was virtually all English-speaking and Caucasian females. Both the study sample and the comparison group were representative of this population. Taking these limitations into account, we think this study's data address four important aspects of the management of patients with gynecologic cancer.

First, this study offers a perspective on the interpretation of polls (e.g., a 1990 Detroit Free Press poll, a 1990 *Time/CNN* poll, a 1991 State of Washington poll) that consistently find that a majority of Americans favor the legalization of physician-assisted death. Five percent of the cancer patients and 3% of the comparison group that we studied thought they would give up their fight against the disease when medical means of treatment were judged to be failing. It would be reasonable to assume that a number less than 5% would actually request physician-assisted death. The majorities reported to favor the legalization of physician-assisted death may then be expressing support for a choice which they themselves are not likely to make [22].

Second, we regard it clinically significant that these patients expected that they would continue to use the "fighter" metaphor even when faced with end-stage disease. This retention of the fighter metaphor may confuse clinicians for whom the fight has to do with attempts to

TABLE 4
Withholding or Withdrawing Life-Sustaining Technology

Item	Total (%) (n = 83)	Disease inactive (%) (n = 40)	Disease active* (%) (n = 38)	New patient (%) (n = 8)	Under therapy (%) (n = 19)	End-stage disease (%) (n = 11)	Comparison group (%) (n = 39)
Ventilator	90	95	87	100	79	91	77
Surgery	34	35	32	25	42	18	44
Antibiotics	22	23	24	25	26	18	29
Nutrition/hydration	37	28	47	63	42	45	50

* The "disease active" column totals the "new patient," "under therapy," and "end-stage disease" columns.

cure or contain the disease. If no intervention to cure or contain the disease remains, then such clinicians may think it best for these patients to lay aside the fighter metaphor.

The retention of this metaphor by these patients calls for further analysis. They seem to be saying that the fight has to do with matters more fundamental than defeating a disease process. The responses of the patients who were actually facing end-stage disease are most revealing on this point. Although few were ready to turn to more experimental or unorthodox ways to combat the disease, the majority of these patients expected to focus on helping family members cope with the reality of their status.

Third, few of these cancer patients indicated the intention to have their existence unconditionally sustained. They had thought enough about dying to have formed opinions about decisions to withhold or withdraw life-sustaining technologies.

Most of these cancer patients would not reduce questions about life-sustaining technologies to "all or nothing." Instead, the majority revealed several decisional steps that they would take before giving up hope of continued life. Their most basic decision had to do with whether any life-sustaining technology should be withheld or withdrawn. The 5% who expressed the desire to receive all possible technological support without consideration of quality of existence represent a test for clinicians committed to patient self-determination, especially in light of concern about fairness in the allocation of limited health care resources [23].

The majority of these patients seem to have been represented by the frequent marginal comments about not wanting to be sustained if reduced to a "vegetable." Ninety percent could envision circumstances in which they would at least want mechanical respiratory support withheld or withdrawn. However, 63% did not view hydration and/or nutrition support as extraordinary or heroic. These data suggest that limiting the use of artificial respiratory support while continuing the use of artificial nutrition and hydration support would be consistent with the preferences of the majority of gynecologic cancer patients with end-stage disease.

Fourth, the decision about location of care has been one of the least studied aspects of care delivered to patients facing poor prognoses. Gallup *et al.* [20] reported in 1982 that 62% of the 1637 gynecologists that they studied hospitalized their terminally ill cancer patients; 21% managed their patients at home; 1% used a hospice service. By contrast, the majority of the cancer patients we studied preferred home care. Only 22% of the respondents preferred inpatient care.

Perhaps physician opinion has changed since the Gallup *et al.* study was conducted. If not, a significant contrast in the preferred site of care may exist between physicians and patients. Our data support the recommendation that physicians caring for patients with gynecologic cancer should be fully informed about innovations in home care [24]. Given that home care is either not possible or not advisable for some patients, physicians should be prepared to educate patients about hospice services [25,26].

APPENDIX: THE STUDY QUESTIONNAIRE

1. Marital status:
 - Married: ___ number of years
 - Never married
 - Widowed: ___ number of years
 - Divorced: ___ number of years
2. Children: ___ none ___ 0-6 in age ___ 7-13 ___ 14-18 ___ over 18
3. Religious preference (if any): _____
 - If Jewish: ___ Orthodox ___ Conservative ___ Reformed
 - If Christian, what denomination? _____
4. Last grade of education completed: _____
5. Vocation: _____
6. Age: _____ 7. Ethnicity: _____
8. Would you describe yourself as (circle one from each couplet):
 - A. More introverted or extroverted?
 - B. More an abstract thinker or concrete thinker?
 - C. More a feeling or thinking person?
 - D. More spontaneous or structured person?
9. What other life-threatening condition(s) (if any) have you faced?

10. Are you satisfied with the information you have received from your doctor(s) about your condition? ___ very satisfied ___ satisfied ___ not satisfied
11. Which of the following describe what you expect from your doctor(s)? (You may check more than one item):
 - "straight talk" about your illness
 - control of the progression of your illness
 - aloofness
 - a cure
 - disrespect
 - to be valued as a research subject
 - compassion
 - disinterest
 - other: _____
12. Which of the following best expresses what you want to know from your doctor(s) about your condition (you may check more than one item):
 - "tell me everything to expect"
 - "just give me the bottom line"
 - "help me deal with this a day at a time"
 - "treat me, don't teach me"
 - "leave me alone"
 - other: _____
13. Have you sought information from sources other than your doctor(s):
 - Yes ___ No ___ If yes, which of the following sources have you used:
 - medical textbooks
 - cancer society literature
 - another doctor
 - television
 - family
 - friends who have experienced your form of cancer
 - other _____
14. To what degree do you want to participate in decision-making related to your illness? ___ fully ___ where your doctor invites your participation ___ as little as possible
15. When facing new treatment decisions, would you like the doctor(s) to:
 - inform you of every option?
 - inform you of the options considered appropriate for your condition?
 - inform you of the option that has been decided to be best for you?
16. At every stage of your illness, do you want your doctor(s):
 - to give you their best medical judgment of what to expect next? ___ Yes ___ No
 - to give your immediate family this information? ___ Yes ___ No

17. Should treatment to cure or contain your illness seem to be failing, would you:
 volunteer for any available treatment, however experimental?
 give up the fight?
 help family/friends deal with the situation?
 fight even harder against the illness?
 seek cure from sources outside your doctor's care?
18. Should treatment to cure or contain your illness seem to be failing, would you prefer to be cared for: at home? as an inpatient at a hospital? as an outpatient?
 other options (e.g., hospice)
19. Rank (with 1=the most influential) the factors that have led you to the preference you indicated in question #18:
 fear family needs doctor's advice friend's advice
 security cost family preference other: _____
20. Are you familiar with the term "hospice"? Yes No
21. How familiar are you with "living wills"?
 "I have a living will."
 "I know about living wills, but I do not have one."
 "I do not know what a 'living will' is."
 "I would like to know what a 'living will' is."
22. Have you arranged for someone to make decisions in your behalf, should such a need arise? Yes No
23. If you have a 'living will' and/or a person designated to make decisions in your behalf, why have you made these arrangements? (Check as many as apply):
 to relieve family members of difficult decisions
 to avoid undesirable prolongation of life
 to protect yourself against potential excessive treatment
 to minimize the financial burden put on your family
 other: _____
24. Has having cancer left you feeling (1=acutely, 2=occasionally, 3=seldom, 4=not yet):
 abandoned isolated unable to communicate your feelings embarrassed
 afraid:
 of pain of abandonment of dying of disfigurement of total dependency
 of medical technology/machines of becoming dependent on medicines
 losing dignity or losing control (other): _____
25. Would you describe yourself as 'religious'? Yes No
26. Since having cancer, have you become more religious? Yes No
27. (If Applicable) How has religion helped you deal with your illness? (Check as many as apply):
 "more than I expected" "less than I expected"
 "by giving my suffering meaning" "by helping maintain my sense of worth"
 "by helping maintain my hopes" other: _____
28. Have you been able to talk openly and honestly about your illness with:
 your spouse Yes No your children Yes No
 your parents Yes No your best friend Yes No
 others: _____
29. Rate (1=the highest) the hopes that matter most to you as you face your illness:
 to continue your normal lifestyle to remain in control of your life
 to avoid a painful death to maintain an optimistic outlook on life
 to be cured by some miracle other: _____
30. Could a time come in your illness when you would want any of the following procedures withheld or withdrawn?
 mechanical respiratory assistance
 surgery for a life-threatening condition (other than cancer)
 antibiotics for infection
 IV fluid and/or a feeding tube
 other: _____
31. Please relate any feelings you may have that have not been addressed in this questionnaire:

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