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Values and worries of ovarian cancer patients

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Abstract

Introduction—Older women with ovarian cancer (OC) are less likely to receive guideline concordant treatment. Differences in values and worries about treatment may explain why.

Methods—Women with OC in 2013–2015 were surveyed about values and worries at the time of initial treatment. Existing values (11 item, e.g., maintaining quality of life) and worries (12 items, e.g., treatment side effects) scales were adapted based on OC literature. Responses were very/somewhat/a little/not at all important or worried. Principal Component Analyses (PCA) identified groups of values and worries that best explained scales' variation. We examined proportions

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Conflict of interest

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reporting very/somewhat important/worried on 1 item in each component by age (older ≥65 years, younger <65 years).

Results—Of 170 respondents, 42.3% were older. PCA components for values were: functional well-being (3 survey items, proportion of variance explained [PoVE] 26.3%), length of life and sexual functioning (3 items, PoVE 20.1%), attitudes (3 items, PoVE 14.2%), and not becoming a burden (2 items, PoVE 13.7%). PCA components for worries were: economic (4 items, PoVE 27.2%), uncertainty (6 items, PoVE 26.0%), and family impact (2 items, PoVE 16.3%). Older women were less likely to indicate very/somewhat worried to 1 item in the economic (51.4% vs 72.4%, $p = 0.006$), uncertainty (80.6% vs. 98.0%, $p = 0.001$), and family impact component (55.6% vs. 70.4%, $p = 0.03$). No other age differences were found.

Conclusions—While worry during OC treatment decision-making may differ across age groups, values do not. Research should assess how differences in worry might affect OC medical decision-making for older and younger women.

Keywords

Ovarian cancer; Treatment decision making; Values; Worries; Gynecologic oncology

1. Introduction

Approximately 20,000 women are diagnosed with ovarian cancer annually, the deadliest gynecologic cancer with a five-year survival rate of 46% [1]. The age group of women 65 years old and older is particularly vulnerable to this cancer: incidence rates are 6 times and mortality rates are 13 times higher in the older population than in women younger than 65 [1]. The advances in treatment have improved the prognosis for ovarian cancer; however, not all women diagnosed with this disease, in particular older women, receive care congruent with current evidence-based guidelines, including the National Comprehensive Cancer Network (NCCN) guidelines [1–4].

Advanced age is a predictor of guideline incongruent care with older women being less likely to receive guideline directed treatment or receive care from specialists, i.e., gynecologic oncologists [1]. While various reasons may contribute to this disparity, one reason may be related to different treatment goals [5]. Values such as the desire to prolong life may be different across the age spectrum, with older adults being more sensitive to the effects of treatment on functionality and other impairments [6–8]. Moreover, considerations related to child-bearing, maintaining high sexual function, family, work and costs may also differ by age. Worrying about economic consequences of cancer is not uncommon: among lung and colorectal cancer patients, as many as 40% worry about the cost of treatment and more than half about time away from work [9]. Given the insurance coverage through Medicare, however, women who are 65 years old or older may differ in how they value or worry about costs of care. Understanding preferences and values, as well as worries at the time of treatment decisions, is fundamental not only to understand differences in patterns of care, but also to achieve the Institute of Medicine's vision of patient-centered care that is consistent with patients' values, needs, and preferences [1].

Currently, we know little about what women with ovarian cancer value or worry about at the time of treatment, and whether younger and older women differ in their evaluation of these factors. We begin to address this knowledge gap with a survey of 170 women who received ovarian cancer treatment in Alabama and Georgia. We aimed at identifying which values and worries were most prominent using Principal Component Analysis (PCA). Moreover, given differences that may exist by age, we examine values and worries for women who were younger vs. older than 65 years.

2. Methods

The Research to Understand Treatment Choices in Ovarian Cancer (RUTH) study aimed to understand the factors that women and their physicians consider when making decisions about ovarian cancer treatment. The RUTH study was approved by the University of Alabama at Birmingham Institutional Review Board.

2.1. Survey development

The survey collected information on demographics, symptoms leading to diagnosis, initial treatment offered and received, medical decision making, goals of treatment and prognosis, and other financial/coverage-related information. The survey instrument was adapted from the questionnaire used for the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) (<http://appliedresearch.cancer.gov/cancors/>), which surveyed lung and colorectal cancer patients to examine patient-reported outcomes and clinical and psychosocial domains pertaining to medical decision-making [10]. Questions most relevant to the intent of the survey were retained from CanCORS including questions on what patients worried about at the time of treatment. Other CanCORS questions retained were about the beliefs and barriers to doctors and specific treatments, satisfaction with care, and support.

We added questions to the survey instrument on the values that were important to women at the time of treatment, adapting them from literature on medical decision making and directly related to ovarian cancer. Specifically, we adapted questions related to fertility sparing surgery or sexual concerns, which have been shown to be important domains for women with OC [11–13].

The survey was piloted in two rounds with five ovarian cancer patients identified through the University of Alabama at Birmingham's healthcare system, and cancer survivors from an ovarian cancer support group in Birmingham, AL. The development of survey questions was informed by these discussions and the survey was modified accordingly.

2.2. Patient population and recruitment

RUTH participants were recruited from several different sources: 1) the University of Alabama at Birmingham (UAB) hospital (45.3%); 2) the University of South Alabama/Mitchell Cancer Institute (MCI) in Mobile, AL, (20.6%) and Northside Hospital in Atlanta, GA (19.4%); and 3) the Alabama Statewide Cancer Registry (ASCR) (14.7%) (Table 1). Eligible patients included women who 1) were age 21 years or older; 2) had a recent diagnosis of ovarian cancer (diagnosis within two years with stage I–IV, as defined by the

International Federation of Gynecology and Obstetrics (FIGO) or unstaged ovarian cancer); 3) were proficient in the English language and able/willing to provide their consent to participate in the telephone-based survey. Women were excluded if they were currently being treated for another primary cancer or were institutionalized (including hospice). We documented reasons for non-participation (e.g. disconnected phone/could not be reached, non-English speaker, etc.), or personal preference in declining participation.

Survey recruitment strategies had minor variations by site. At UAB and MCI, potential participants were initially contacted with a letter from the gynecologic oncology division that provided detailed information about the study and the option to decline participation by dialing a 1–800 phone number or by email. At Northside Hospital, a research nurse contacted potential participants to assess interest. The ASCR sought physicians' consent to contact patients before releasing the contact list to RUTH investigators. After receiving the information letter, all potential participants were then contacted by recruiters of the UAB Recruitment and Retention Shared Facility (RRSF). RRSF recruiters administered the eligibility screen, obtained verbal consent, and scheduled a date/time for the 60-minute structured, phone-based interview. Calls were placed at different days/times across the week and weekend, with a maximum of 7 attempts. Participants who refused to participate in the interview were coded as “final refusal” and were not contacted again.

2.3. Survey administration

All surveys were administered by the UAB Survey Research Unit (SRU) of the Center for the Study of Community Health over the 2013–2015 period. The SRU interviewers were professionally trained on proper interviewing techniques, unbiased probing, questions/skip patterns and using the Computerized Assisted Telephone Interview (CATI) system. Each interviewer received study-specific training to assure familiarity with the content. As a quality assurance measure, interviewers were randomly, electronically monitored, at minimum four times per month. Interviews were recorded through the CATI system and data were maintained in a secure format. All participants received a \$50.00 gift card for completing the survey.

2.4. Study outcomes

The main outcomes for this analysis are the values and worries expressed by RUTH participants. Respondents were asked to indicate what was important to them at the time they discussed initial treatment with the doctor. Respondents could indicate very, somewhat, a little, or not at all important on 11 value items. Similarly, respondents were asked how much they were worried about 12 worry items at the time they were making decisions about their ovarian cancer treatment. Respondents would indicate very, somewhat, a little, or not at all worried.

2.5. Analysis

Frequencies, means, and standard deviations were calculated for categorical and continuous variables, respectively. Demographic and clinical variables were stratified by age. Chi-square tests were used to test for significance of differences between those <65 years of age and those 65+ at the time of the survey.

The frequency of reporting that a value was “very” or “somewhat” important for each of the 11 value items, and the frequency of reporting “very” or “somewhat” worried for each of the 12 worry items, were calculated overall and by age groups. Logistic regression analysis, adjusting for stage and work status, were used to evaluate the differences between those <65 vs. 65+.

2.5.1. Principal Components Analysis (PCA)—We conducted PCA to identify the most prominent values and worries, and how they group together in overall themes. PCA is a multivariate statistical technique used to reduce the number of variables in a data set into a smaller number of ‘components’, or groupings of variables [14,15]. Essentially, PCA provides a method to identify different dimensions existing within a set of correlated variables. In our study, we used PCA to determine the primary components of the 11 item values scale and the 12 item worry scale.

Each of the components from PCA are linear weighted combinations of the initial scale items. The weights for each component are determined by eigenvectors (factors) of the correlation matrix. The components are ordered so that the first component explains the largest possible amount of variation in the original data. Subsequent components explain additional variation, but less variation than the first component. The proportion of the total variation in the original data set accounted by each principal component is determined by the variance of the individual component divided by the total number of items. Each component is representative of an additional dimension in the data, while explaining smaller and smaller proportions of the variation of the original variables. The higher the degree of correlation among the original variables in the data, the fewer components required to capture common information.

We dichotomized each item in the set of questions about values to “somewhat/very important” and “not important at all/not very important”; for the worry scale, we dichotomized the 12 items as “worried” and “not worried/a little worried.” We used a tetrachoric correlation matrix for each of the PCAs to account for the dichotomous nature of the data. To identify the simplest data structure, we used an unrotated and a varimax rotation (orthogonal rotation, assumes no correlation among components). To identify the relevant number of components in each of the value and worry scales, we conducted the PCA without pre-specifying the number of components. Scree plots and eigenvalues (>1) were evaluated to determine the appropriate number of components for each scale. Each component is comprised of items with factor loadings (e.g., correlations to the component) of 0.40.

We then calculated the proportion by age group of respondents who indicated “very” or “somewhat” important to at least one item in the value components, and the proportion of respondents by age group who indicated “very” or “somewhat” worried to at least one item in the worry components. We then tested for significant differences in these proportion by age group using logistic regressions adjusted for stage and work status.

3. Results

3.1. Population characteristics

One hundred and seventy women participated in the RUTH survey. The response rate among the women who could be reached was 66%. The mean age of the women was 61.8 (standard deviation 11.6) years; 42.3% were 65 years or older at the time of the survey, 24.1% African American, 38.2% with high school education or less, and 58.2% retired (Table 1). Most (82.6%) were within 18 months of the ovarian cancer diagnosis, 22.5% were diagnosed with FIGO stage I–II disease, 46.7% with stage III–IV, and the rest were not staged or the stage was missing. Women 65 and older at the time of the survey were similar to younger women except for being more likely to be retired ($p < 0.0001$) and, although not significant at a 5% level, more likely to have stage III–IV disease ($p = 0.06$).

3.2. Values

Overall, for >90% of survey participants, “maintaining a positive attitude,” “not becoming a burden to the family,” “living as long as possible,” and “maintaining quality of life,” were each “very important” values (Table 2). These values were supported by both younger and older women; older women endorsed “living as long as possible” as a “very” important value less frequently (87.5% vs 95.9%, adjusted $p = 0.04$ adjusted for stage and work status) than younger women. About 66 to 82% of women reported “maintaining the ability to do activities they enjoy”, “returning to work or other routine activities,” or “not sacrificing plans for the family” as “very” or “somewhat” important values (Table 2). Moreover, about one-third of women reported as “very” or “somewhat” important having “doctors who shared their religious beliefs,” while about 25% reported as “very” or “somewhat” important “maintaining a satisfying sexual life.” Older women were less often indicated that maintaining a satisfying sexual life was “very” or “somewhat” important (combined “very”/“somewhat” important responses: 30.6% vs 59.1%, adjusted $p = 0.001$).

3.3. Worries

Overall, about one-third of women (between 31.2 and 37.6%) indicated being “very worried” about “developing cancers later,” “not knowing what to expect,” “the side effects from treatment,” and “being financially set back because of medical expenses” (Table 2). For these items, older women were significantly less likely to indicate being “very” or “somewhat” worried about developing cancer later (combined “very”/“somewhat” worried: 61.1% vs. 78.5%, adjusted $p = 0.007$), not knowing what to expect (“very”/“somewhat” worried: 57.0% vs 74.5%, $p = 0.01$), and being financially set back by treatment costs (“very”/“somewhat” worried: 40.3% vs. 63.3%, adjusted $p = 0.046$). Older women were less likely to be “very” worried about the side effects from treatment (23.6% vs. 38.8%, adjusted $p = 0.03$). Overall, >24% indicated being “very” worried about “taking time away from the family,” the “cost of treatment” and “using all their savings or retirement funds to pay for their care.” Older women were less likely to be “very” or “somewhat” worried about the “cost of treatment” (“very”/“somewhat” worried 40.3% vs. 60.2%, adjusted $p = 0.01$) and “taking time away from work or other daily activities” (“very”/“somewhat” worried 41.7% vs. 63.2%, adjusted $p = 0.02$). Overall, <13% of respondents were “very” worried about changes in body image, having to post-pone medical care for the family, transportation, or

going through early menopause. Older women were less likely to be “very” or “somewhat” worried about changes in body image (“very”/“somewhat” worried 25.0% vs 42.8%, $p = 0.03$) and going through early menopause (“very”/“somewhat” worried 2.8% vs. 19.4%, $p = 0.009$) (Table 2).

3.4. Principal Components Analysis (PCA) results

3.4.1. Values scale—PCA results indicate up to four components were present among the 11 value questions. The first included 3 items related to functional well-being and explained 26.3% of total variance in the values scale (Table 3). The second component included 3 items on maintaining length of life and sexual functioning and explained 20.1% of the total variance. The third component included 3 items related to attitudes and explained 14.2% of the overall variance. The fourth component included two items related to not becoming a burden to the family and explained 13.7% of the variance. The proportion of respondents indicating “very” or “somewhat” important to at least one item within each value component was >98.6% for all factors with no difference by age group (data not shown).

3.4.2. Worries Scale—PCA results indicate up to three components were present among the 12 worry questions (Table 4). The first component included 4 items related to cost or economic worry and explained 27.2% of the total variance in the worry scale. The second included 6 items on the physical consequences and uncertainty imposed by the disease and explained 26% of the total variance. The third component included 3 items related to the effect of cancer on the family and explained 16.3% of the overall variance. The proportion of respondents indicating “very” or “somewhat” worried to at least one item within each worry component was 63.5% for factor 1, 90.6% for factor 2, and 64.1% for factor 3. Older women were less likely to indicate “very” or “somewhat” worried to at least one item of each worry component of economic concerns (51.4% vs 72.4%, $p = 0.006$), uncertainty (80.6% vs. 98.0%, $p = 0.001$), and cancer impact (55.6% vs. 70.4%, $p = 0.03$).

4. Discussion

In this sample of 170 women diagnosed with ovarian cancer, we identified the values and the worries that were important when making decisions about treatment. Women valued various factors in addition to prolonging life: in fact, almost all women, regardless of age, endorsed as “very important” values related to maintaining “your quality of life” and “the ability to do the activities you enjoy,” “a positive attitude,” and “not become a burden to your family.” Worries were not only about side effects of treatment or cancer recurrence: at least one out of three women were very worried about the uncertainty associated with cancer, not only as it related to physical consequences, but also as it related to economic stability. Although less than younger women, a significant proportion of older women worried about the consequences of cancer. However, it is unclear how our findings might explain the observed differences in treatment observed by others for younger and older women with ovarian cancer [1].

Understanding values and worries at the time of treatment decision making is important to allow for the best process and the best patient-centered care. It is unclear how the values and worries of cancer patients are incorporated in decision-making. In one small qualitative

study, only a few women with ovarian cancer reported having discussions regarding goals of treatment and values before treatment decisions were made [16]. In this same study, women emphasized their interest in discussing quality of life rather than progression free and overall survival [16]. This is supported by our findings that women clearly endorsed the importance of maintaining both quality and length of life, while not becoming a burden for the family. These values need to be considered carefully when making treatment choices, and women need to be encouraged to express these values in their own context. There is less information in the literature on what cancer patients worry about. Our respondents reported a high level of worry about several factors related to treatment decisions, a level that may be higher than in patients of other cancers. Among lung and colorectal cancer patients, three quarters were worried about treatment side effects when making decisions about cancer treatment, but a substantial proportion were also worried about time away from the family (50%), cost of treatment (40%), time away from work (52%), and transportation to treatment (22%) [9]. In our group of ovarian cancer patients, if “worried” was defined as in Martin et al. [9], (i.e., any respondent who reported at least some level of worry) we would find that 87.7% reported being worried about side effects, 78.8% about time away from family, 67.6% about cost of treatment, 73.5% about taking time from work, and 27.1% about transportation. These proportions are considerably higher than in Martin et al.. However, study populations are not closely comparable: Martin et al. included men and women with lung and colorectal cancer diagnoses of whom nearly half had early stage disease (stages I and II). Early stage may be when treatment decision-making can be influenced differently [9]. Further research should examine whether the extent of worry differs, and how worries may impact treatment decisions, across cancer types and stage. Overall, however, our finding that one in three women diagnosed with ovarian cancer were very worried about several factors is notable and needs to be addressed.

We did not find differences in values by age group. Our results are in line with others who have found that cancer patients, including older ones, highly value maintaining their quality of life and ability to do the activities they enjoy, as well as not becoming a burden to their families [6–8]. Our study adds to this literature findings on differences by age in what women worry about. In general, older women were less likely to report being very worried about all items we inquired about. About one in five were very worried about developing other cancers, the uncertainty that cancer brings, the side effects, and the financial consequences, compared to more than one in three younger women. Therefore, difference in worries about cancer, its treatment and its consequences, may not be enough to understand differences in treatment across age groups. It would be important to test in future research efforts whether women who have high level of worry are indeed more likely to forgo or delay cancer treatment or seek care from specialists, and to identify groups of women who may be more likely to worry, for example those with lower incomes or with multiple comorbid conditions. Additionally, whether the level of worry that influences treatment decisions differs by age is another important area of research that can provide insight into understanding differences in cancer treatment.

It is worth highlighting that concerns about costs of care and the financial implications of cancer treatment were very important for our respondents: the variance explained by these worry factors in the principal component analysis (in the three-factor solution) was the

highest for the worry questionnaire. More than a quarter were very worried about the cost of treatment, and more than two thirds (67.6%) worried a little; the latter is considerably higher than the 40% of colorectal and lung cancer patients who worried about costs in Martin et al. [9]. This may be due to several factors among which the high cost of treatment for ovarian cancer. Among young and older women, this cancer was found to be costlier than lung and colorectal cancer [17]. In addition, we surveyed women between 2013 and 2015, while the colorectal and lung cancer patients in Martin et al. were surveyed between 2003 and 2005, and thus before the economic recession of the late 2000s. Moreover, the women we surveyed were mainly from Alabama, one of the poorest states in the US: these women may be more concerned about their economic constraints overall. Regardless of the reasons, it is significant that two out of three women worried about the costs of cancer care and that economic issues were the main components of what they worried about. This is in line with current literature that calls attention to financial and economic implications as another side effect of cancer treatment [18–21]. The implications these may have for the well-being of women with ovarian cancer, and how to address them, needs to be investigated. Breast cancer survivors, for example, suggested that knowing the costs of care upfront would help in dealing with financial challenges [22]. Similar interventions may also help women with ovarian cancer.

This study has some limitations to be considered. First, participants were recruited from three hospitals in two southern states and the Alabama Statewide Cancer Registry; they may not, thus, represent all women with ovarian cancer in the US or in the Southeast. Second, women received treatment mainly at large cancer centers and may not represent women who receive care at other smaller centers. Third, the sample size is relatively small and does not allow us to conduct separate PCA by age group to assess the difference in principal components by age group. Fourth, the sample included women who survived 18 months after diagnosis. Given that patients were asked to recall back to the time of treatment decision-making, there is potential for recall bias captured in these responses.

In conclusion, our paper contributes to the understanding of values and concerns of cancer patients, in particular filling a knowledge gap about those of women with ovarian cancer across different age groups. We believe these are important considerations to assure treatment that is patient-centered and reflective of preferences of patients of all ages. While values were comparable for women across all ages, older women reported being less worried about the consequences of ovarian cancer. Further research is needed to assess how these worries and values affect the medical decision making for patients with ovarian cancer, and whether differences by age may or may not contribute to the observed differences in treatment for older women and younger women [1].

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HIGHLIGHTS

- Values of ovarian cancer patients regarding treatment do not vary by age.
- Overall, women value functional well-being, life length and sexual function
- Women also value positive attitudes and not becoming a burden.
- Although a majority do, older women are less likely to report worries than younger ones.
- Worries are related to uncertainty, and economic and family impact.

Table 1

Demographic and clinical characteristics of women with ovarian cancer who participated in RUTH.

Characteristic	All (n = 170)	Age ^b <65 (n = 98)	Age ^b 65+ (n = 72)	Chi-square ^c
	%	%	%	P
Age 24–55	25.9	–	–	
Age 55–64	31.8	–	–	
Age 65–90	42.3	–	–	
Race				0.39
White	72.3	69.4	76.4	
African American	24.1	26.5	20.8	
Other ^d	3.5	4.1	2.8	
Education				0.34
High school or less	38.2	37.8	38.9	
Some college/Tech degree	37.1	33.7	41.7	
College or more	24.7	28.6	19.4	
Employment status				<0.0001
Retired or disabled	58.2	42.9	79.2	
Employed	24.7	31.6	15.3	
Other	17.1	25.5	5.6	
Time since diagnosis >18 months	17.4	15.8	19.4	0.30
Stage				0.06
I – II	22.5	26.8	16.7	
III–IV	46.7	39.2	56.9	
Not staged or stage missing	30.8	34.0	26.4	
Number of comorbidities				0.20
None	16.5	21.4	9.7	
1–2	58.2	53.1	65.3	
3+	25.3	25.5	25.0	
Study site ^a				0.66
UAB	45.3	48.0	41.7	
MCI	20.6	21.4	19.4	
Northside Hospital	19.4	16.3	23.6	
ASCR	14.7	14.3	15.3	

^aUAB: University of Alabama at Birmingham, MCI: Mitchell Cancer Institute, ASCR: Alabama State Cancer registry.

^bAge ranged from 24 years to 90 years; mean age of the women was 61.8 (standard deviation 11.6).

^cChi-square test for the difference by age group.

^dOther race included: Hispanic, Asian and non-specified "Other race."

Values important to women, and what they worried about, when they discussed treatment with their doctors, and differences by age at the time of survey.

Table 2

	All women			Age < 65			Age 65+		
	Very	Somewhat	% reporting very or somewhat important	Very	Somewhat	% reporting very or somewhat important	Very	Somewhat	% reporting very or somewhat important
How important was it for you to:									
Maintain a positive attitude	96.5	2.3	95.9	96.5	2.3	95.9	97.2	1.4	98.6
Not become a burden to your family	94.7	1.8	96.9	94.7	1.8	96.9	91.7	2.8	94.5
Live as long as possible ^a	92.3	5.3	95.9	92.3	5.3	95.9	87.5	8.3	95.8
Maintain your quality of life	91.8	5.3	92.9	91.8	5.3	92.9	90.3	4.2	94.5
Maintain the ability to do the activities you enjoy	82.3	11.2	83.7	82.3	11.2	83.7	80.6	11.1	91.7
Return to work or usual activities	70.6	15.3	73.5	70.6	15.3	73.5	66.7	16.7	83.4
Not to sacrifice plans you had for your family	65.9	22.9	69.4	65.9	22.9	69.4	61.1	26.4	87.5
Have doctors who shared your religious beliefs	31.8	31.8	30.6	31.8	31.8	30.6	33.3	33.3	66.6
Maintain a satisfying sexual life ^{a,b}	24.7	22.3	32.6	24.7	22.3	32.6	13.9	16.7	30.6
Keep your ability to have children	5.9	1.2	6.1	5.9	1.2	6.1	5.6	0.0	6.1
Keep your uterus	2.9	3.5	4.1	2.9	3.5	4.1	1.4	2.8	4.1
How much were you worried about...									
Developing other cancers later ^{c,d}	37.6	33.5	46.9	37.6	33.5	46.9	31.6	25.0	36.1
Not knowing what to expect ^d	37.1	30.0	42.9	37.1	30.0	42.9	31.6	29.2	27.8
The side-effects from treatment ^c	32.3	35.9	38.8	32.3	35.9	38.8	32.6	23.6	40.3
Being set financially back because of medical expenses ^{c,d}	31.2	22.3	37.8	31.2	22.3	37.8	25.5	22.2	18.1
Taking time away from your family	29.4	32.3	34.7	29.4	32.3	34.7	32.6	22.2	31.9
The cost of treatment ^{c,d}	28.2	23.5	37.8	28.2	23.5	37.8	22.4	15.3	25.0
Using up savings or retirement funds to pay for cancer care	27.1	17.1	30.6	27.1	17.1	30.6	18.4	22.2	15.3
Taking time away from work or other daily activities ^{c,d}	24.1	30.0	32.6	24.1	30.0	32.6	30.6	12.5	29.2
Changes in body image ^d	12.9	22.3	17.3	12.9	22.3	17.3	25.5	6.9	18.1
Having to postpone/avoid medical care for family	10.0	12.9	12.2	10.0	12.9	12.2	14.3	6.9	11.1
Transportation to treatment	9.4	9.4	11.2	9.4	9.4	11.2	12.2	6.9	5.6
Going through early menopause ^d	5.3	7.1	8.2	5.3	7.1	8.2	11.2	1.4	1.4

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- ^aStatistically significant difference in proportions reporting very important by age ($p < 0.05$). Logistic regressions adjusted for stage and work status.
- ^bStatistically significant difference in proportions reporting very or somewhat important by age ($p < 0.05$). Logistic regressions adjusted for stage and work status.
- ^cStatistically significant difference in proportions reporting very worried by age ($p < 0.05$). Logistic regressions adjusted for stage and work status.
- ^dStatistically significant difference in proportions reporting very or somewhat worried by age ($p < 0.05$). Logistic regressions adjusted for stage and work status.

Principal Components Analysis results for the questions on values: factor loadings and variance explained.^a

Table 3

Values	Components			
	1	2	3	4
Maintain the ability to do the activities you enjoy	0.91706	-0.21845	0.01716	0.13018
Maintain your quality of life	0.82534	0.01277	0.19621	-0.02153
Return to work or usual activities	0.81168	-0.20444	0.10723	0.10846
Live as long as possible	-0.25614	0.92496	0.00709	-0.00894
Maintain a satisfying sexual life	-0.19494	0.87986	-0.16643	-0.06645
Keep your uterus	0.53379	0.59943	-0.01041	0.16069
Keep your ability to have children	0.33209	0.11977	0.75419	-0.14812
Have doctors who shared your religious beliefs	-0.14012	-0.32736	0.75026	0.23151
Maintain a positive attitude	0.28015	-0.07522	0.56836	0.52843
Not become a burden to your family	0.32363	-0.07052	-0.09647	0.75399
Not to sacrifice plans you had for your family	-0.12388	0.07000	0.14407	0.72524
Variance explained by each component	2.89803	2.21572	1.56294	1.50875
Percent of total variance explained by component (variance / number of items)	26.3%	20.1%	14.2%	13.7%

Indicated in bold are factor loadings of items that define a component.

^aRotated factor loading; Tetrachoric correlation matrix; varimax (orthogonal) rotation.

Table 4Principal Components Analysis results for the questions on worries: factor loadings and variance explained.^a

Worries	Component		
	1	2	3
Using up savings or retirement funds to pay for cancer care	0.88115	0.17152	0.23364
The cost of treatment	0.84507	0.27797	0.21274
Being set financially back because of medical expenses	0.83082	0.29038	0.36563
Transportation to treatment	0.66637	0.38224	0.00403
The side-effects from treatment	0.27847	0.80405	-0.14110
Going through early menopause	0.08647	0.68381	0.29595
Not knowing what to expect	0.32925	0.68363	0.29778
Changes in body image	0.26301	0.60818	0.23418
Taking time away from work or other daily activities	0.30516	0.57993	0.44538
Developing other cancers later	0.42510	0.57513	0.23232
Having to postpone or avoid medical care for other family members	0.28372	0.05902	0.81380
Taking time away from your family	0.12975	0.39884	0.74237
Variance explained by each factor	3.25864	3.11807	1.95028
Percent of total variance explained by component (variance / number of items)	27.2%	26.0%	16.3%

Indicated in bold are factor loadings of items that define a component.

^aRotated factor loading; Tetrachoric correlation matrix; varimax (orthogonal) rotation.