



Contents lists available at ScienceDirect

Gynecologic Oncology

journal homepage: www.elsevier.com/locate/ygyno

Values and worries of ovarian cancer patients

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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.

ARTICLE INFO

Article history:

Received 27 June 2017

Received in revised form 24 August 2017

Accepted 27 August 2017

Available online xxxx

Keywords:

Ovarian cancer

Treatment decision making

Values

Worries

Gynecologic oncology

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 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.

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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

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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

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	

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

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

^c Chi-square test for the difference by age group.

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

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