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Development and pilot of an advance care planning website for women with ovarian cancer: A randomized controlled trial

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Abstract

Objective—Few available tools facilitate cancer patients and physicians' discussions of quality of life and end-of-life. Our objective was to develop a web-based tool to promote advance care planning for women with ovarian cancer.

Methods—Women with ovarian cancer, their families, clinicians and researchers met to identify ways to improve cancer care. A prototype website was created to address advance care planning, focusing on advance healthcare directives (AHD) and palliative care consultation. Patients were recruited from a gynecologic oncology clinic for a pilot randomized controlled trial. Primary outcomes included completion of an AHD and palliative care consultation.

Results—At study completion, 53 women with ovarian cancer were enrolled and 35 completed the study. The mean age at enrollment was 57.9 ± 9.5 years; most were newly diagnosed or at first recurrence. There were no statistical differences in completion of AHD ($p = 0.220$) or palliative care consultation ($p = 0.440$) between intervention and control groups. However, women in the intervention group showed evidence of moving toward decision making regarding AHD and palliative care and lower decisional conflict. Women assigned to the intervention, compared to control website, were highly satisfied with the amount ($p = 0.054$) and quality ($p = 0.119$) of information and when they accessed the website, used it longer ($p = 0.049$). Overall website use was lower than expected, resulting from several patient-related and design barriers.

Conclusions—A website providing information and decisional support for women with ovarian cancer is feasible. Increasing frequency of website use requires future research.

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Keywords

Ovarian cancer; Website; Education; Quality-of-life; End of life

Introduction

Ovarian cancer is the most lethal gynecologic malignancy, with an estimated 5-year survival of 45%, decreasing to 18% for Stage IV [1]. The median age at diagnosis is 63 years, with most women presenting with Stage III/IV disease. Common disease and treatment effects include fatigue, pain, bloating, bowel disturbances, nausea and vomiting, anorexia, and distress [2]. Symptoms are reported as undertreated in 16–49% of ovarian cancer survivors [3].

Palliative care is an interdisciplinary specialty addressing quality of life (QOL) issues for patients with life-limiting illnesses and their families [4]. Advanced cancer patients who have received palliative care consultation demonstrate improved symptom control and satisfaction [5]. The American Society of Clinical Oncology recommends palliative care be offered early for patients with metastatic cancer and/or those with high symptom burden [6]. Earlier introduction has been shown to increase symptom relief and support for transitioning from a focus on cure to care [7]. Despite recommendations, palliative care is not a consistent standard of care during cancer treatment and often is accessed late in disease progression. These limitations emphasize the need to develop advance care planning (ACP) interventions for cancer patients.

Obtaining information and making decisions about palliative and end-of-life care are integral to ACP. While patients desire ACP discussions with physicians, these frequently do not occur [8]. Typically ACP includes completing an advance healthcare directive (AHD), where patients document choices for care if/when they are unable to speak for themselves, imperative for those facing serious illness. Retrospective studies of deceased advanced cancer patients found that only 19% had a documented AHD [9] and 54% of gynecologic oncologists deferred these discussions until the patient experienced a major decline in functional status [10].

Decision-making for ovarian cancer patients and their physicians is poorly understood [11]. Research has suggested that women perceive involvement in treatment decision-making to be associated with higher QOL [12]. Studies indicate that about 60% prefer to share decision-making with their doctors, are interested in receiving information from physicians and appreciate information in many media formats [13]. Improved information pathways promote patient participation in cancer-care decisions and have included decision aids [14,15] and tailored messaging [16]. A review of 72 cancer-related decision aids described benefits of aids in conveying knowledge about treatment and other decisions [17]. To be effective, these need to be tailored to the user type (patient, caregiver, provider) [18] and for each individual [19]. For women with ovarian cancer, decision instruments about therapy [11] and genetic testing for cancer risk have been introduced [20]. No specific aid to facilitate ACP decision-making exists.

For people with chronic diseases, programs combining health information and social and/or decision support can significantly enhance knowledge, social support, and outcomes [21]. Computer and web-based programs can deliver decision aids and information to more people than traditional formats, provide social media features for support, and facilitate behavior change in cancer care. Applications in cancer palliative care have been limited; an exception is a recent study of a pancreatic cancer website providing usability and initial satisfaction data [22].

In this study we developed and pilot-tested a website for women with Stage III/IV or recurrent ovarian cancer and their caregivers to promote ACP, specifically completion of an AHD and participation in Palliative Care consultation. Additionally we determined the feasibility and acceptability of this intervention and provide preliminary data for future research.

Methods

Preliminary design event

The research team conducted a day-long “design event” (April 2010), during which clinical, information and decision experts and ovarian cancer patients and their families discussed ideas for improved cancer care. Using a structured process facilitated by moderators, 41 participants (22 patients and family members) identified key concepts including improved connectivity to the care team, presentation of information in varied formats, care navigation/coordination tools, education and support in the “white space” between visits, and resources to support shared decision-making with a palliative care focus.

Prototype system development and usability testing

An iterative process was used to create a prototype website. The front end was developed using Microsoft .NET framework with Ajax to bring together the HTML and CSS. The back-end utilized IIS (Internet Information Services for Microsoft Windows Servers), a SQL database and SSL encryption.

Core intervention components included distress monitoring, questions recorded to ask providers, an information library written by the research team, and goal-setting options. Special attention was given to including and formatting materials to promote social support and communication. Information was comprehensive and accurate about care throughout the course of ovarian cancer. Recommended readings were presented based on users' disease stage. Information was further tailored by presenting topics at three levels, each with increasing information (Fig. 1), recognizing users vary in learning style especially when presented with potentially threatening information [23]. The website system also included social media features such as a shared journal and discussion forum.

The general approach was based on theories of informed [24,25] and shared decision-making [24–26]. Ovarian cancer care information and decision support were designed to apply from diagnosis to end-of-life as women's decisions and goals change. Decision-making was promoted by educating women about methods and styles, introducing shared decision making, and encouraging discussions with caregivers, family, and providers [27].

Participants were provided with an interactive PDF of the Ottawa Personal Decision Guide [28] to help them weigh risks and benefits of a medical decision. Specific to our study goal, the website included an AHD appropriate for the state of Minnesota and guide [29]. Lastly, the Palliative Care staff was introduced using brief biographies and users were encouraged to make an appointment.

A companion caregiver intervention website was created with the same general features and content as the patient website. However, caregivers were guided to topics specific to caregivers, had a separate discussion forum, and could view a summary page of their companion's (patient) questions and distress levels. Including caregivers as part of the trial represented recognition that ACP does not occur in isolation and communicating with and support from family plays an integral role.

In the control arm, a single caregiver/patient control website was created containing all usual care information documents converted to PDFs and organized into general topics. Prior to this project, these documents were provided to patients in paper format only as part of a welcome folder. The control website represented an electronic method of centralizing information for patients and caregivers compared to the traditional standard of care. All women in both groups still received the welcome folder in paper format.

Initial usability tests were performed on intervention and control websites using standard methodology [30] prior to implementing the randomized trial. Five users, including women with ovarian cancer, a caregiver, and clinicians, performed tasks from specifically designed use-case scripts created to test all features. Using talk-aloud methodology, issues with usability were identified and website revisions were made accordingly.

Study population and recruitment strategy

Following University of Minnesota Institutional Review Board approval, women with Stage III/IV or recurrent epithelial ovarian, primary peritoneal or fallopian tube cancer were recruited from the University of Minnesota's Gynecologic Oncology clinic between September 2012 and February 2013, with survey and medical record data collection through May 2013. Women with recurrent disease were over-sampled to achieve balance between women with newly diagnosed and recurrent disease. Participants in the design event or website usability testing and those not having computer access were ineligible. One patient/caregiver pair was consented from outside the clinic, finding the study on clinicaltrials.gov.

Patients were consented in the clinic and invited to nominate a care-giver for enrollment. Patients and caregivers who did not log into the website within two weeks of consent were called by study staff up to two times to encourage use. All participants received \$50 gift cards after completing the study.

Study design

We conducted a randomized controlled trial (RCT) to pilot test the intervention website among women with ovarian cancer and their care-givers. Upon initial login, participants completed a pre-study survey. Randomization was 1:1 for the intervention and control groups and blocked by disease status (newly diagnosed, remission, first recurrence, multiply

recurrent). Randomization was programmed within the website following pre-survey completion. Caregivers were given the same randomization assignment as their companion. Participants were asked to access the website 2–3 times per week for 60 days and then complete the post-study survey.

The original goal was to obtain complete data on 80 women with ovarian cancer. We expected approximately 25% of the participants would have completed an AHD at the time of the baseline assessment [31]. With a sample size of 80 and assuming the control group would have only a marginal increase in this proportion to 30% and the intervention group would have a significant increase in the proportion to 55% during the 60-day study, we would achieve 80% power to detect this difference using a two-sided Fisher's Exact test and a significance level of 0.05.

Measures

Demographics including age, race/ethnicity, education, income, marital status, computer experience were collected at baseline for all participants and disease characteristics, including disease stage and status, treatment status, and cancer history for patients. Health literacy was obtained using the Medical Term Recognition Test (METER), a measure with possible scores ranging from 0 to 70, with higher scores indicating greater literacy [32].

Primary study outcomes for patients were completion of an AHD and consultation with Palliative Care, assessed by self-report using a modified form of the Stage of Change (SOC) questionnaire [33]. The SOC has demonstrated satisfactory validity and reliability in measuring health decision-making, including end-of-life decisions [33]. Patients were categorized into 1 of 3 stages of change regarding an AHD: pre-contemplation (no intention to complete), contemplation (intention to complete in next 2 months), or action (completed). Electronic medical records were used to verify AHD completion. Similar questions were asked regarding Palliative Care consultations with the addition of a fourth step, adding whether women were seeking information from their physician (contemplation). Decisional conflict regarding meeting with Palliative Care was measured post-study using the 16-item Decisional Conflict Scale (DCS) [34]. The DCS assesses uncertainty in making health-related decisions and consists of a total and five subscale scores, with higher scores indicating more decisional conflict [35].

Website use and satisfaction data were collected. The website recorded the number of times participants accessed the website and user activity, such as opening documents, visiting areas of the website, and using tools. Post-intervention satisfaction with the website was assessed using questions on usability, usefulness, and content quality, all measured on a 5-point Likert scale.

Statistical methods

Demographic and clinical characteristics were summarized and analyzed by randomized group using chi-squared tests, Fisher's Exact tests and t-tests as appropriate. Data collected on caregivers are not presented due to low recruitment. Primary analyses focused on comparing changes from pre- to post-intervention (60 days) by randomized group using an intention-to-treat analysis approach [36]. The change in proportions and means between

randomized groups were compared using Fisher's Exact tests and t-tests, respectively. Data were analyzed with and without the patient consented from outside the clinic. No significant differences were noted; therefore, she was left in the analysis as she met all eligibility criteria.

Results

Recruitment and participation

Website engagement was lower than expected and therefore the number of active participants was fewer than planned. Final enrollment included 53 women with ovarian cancer, 35 (66%) of whom started the study (Fig. 2). Women starting the study were more likely to be newly diagnosed or at first recurrence ($p = 0.094$) and younger ($p = 0.052$); those who did not participate cited feeling of being overwhelmed and not having time. Caregiver recruitment and participation was challenging; 17 caregivers consented however 6 completed the study.

Demographic and clinical data for ovarian cancer participants are detailed in Table 1. No statistically significant differences were observed between randomization groups.

Decision making

There was no statistical difference in completion of an AHD between intervention and control groups ($p = 0.220$). Notably, 2 (12.5%) women in the intervention group who completed the study provided their previously completed AHD to the clinic following the study, compared to 0 in the control group (Fig. 3a). At baseline, however, 3 (23.1%) of the control group had an AHD in their medical record, compared to 1 (6.3%) in the intervention group.

Likewise, there was no significant change in decision-making regarding palliative care ($p = 0.440$). In the intervention group, 3 (18.8%) women moved from not planning to meet with or wondering about meeting with Palliative Care to planning to meet with them; no women reported this change in the control group (Fig. 3b). The total DCS score was lower in the intervention group compared to the control (42.5 ± 24.0 vs. 48.6 ± 23.9), however the difference was not statistically significant ($p = 0.519$). A similar trend occurred for each subscale, though none were significantly different (data not shown). These trends suggest higher decision-making certainty for the intervention group.

Use and satisfaction

Use of both websites by patients was lower than expected. While the majority of those completing the baseline survey used the website at least once (93% control group, 100% intervention group), the median number of log-ins per person was 4.5 in both groups. This varied widely within group, with some women accessing a few times and others accessing over 10 times during the 60-day study. The mean time per session differed significantly between groups, with the control participants accessing on average 15.9 ± 8.7 min per session and the intervention participants 19.9 ± 14.6 min per session ($p = 0.049$).

Open ended patient comments from the post-study survey are summarized in Table 2. Some users of both sites found the website not relevant and a significant portion required numerous reminders of their password. For the control website, a lack of motivation to use the website regularly was reported. For the intervention website, barriers included difficulty of use, too few participants for the discussion forum, and lack of real-time connectivity to their provider.

Overall, women were moderately satisfied with both websites (Table 3). Women in the intervention website were highly satisfied with the amount ($p = 0.054$) and quality ($p = 0.119$) of information and over 90% in both groups would recommend their respective website to others, which did not differ by website ($p = 1.00$).

Discussion

Our web-based intervention for women with ovarian cancer was received with high satisfaction regarding quality and quantity of information provided suggesting that this is a promising direction even for older women at challenging points in their cancer care. Careful interpretation of decision outcome results suggests that technology-enabled interventions may improve advance care decision-making.

Website use is a note worthy issue in the development process of this field [37]. Low use in our study might be due to participants' age or treatment. Results of prior studies of age and web-based health interventions have been inconsistent, with some finding that age influenced use, a review found no consistent age effect on acceptance [38] and a recent study found that older participants(>50 years) were more likely to be users [39]. Low use in our study might be associated with timing: most participants were in active treatment. Demanding chemotherapy treatment and its side effects, such as fatigue and cognitive changes might have interrupted use, preventing sufficient opportunity within 60-days to use a complex web-based system. While gift cards and a dedicated study coordinator were intended to incentivize, no means to guide users through the website was provided nor was the technology simple to use.

While participants accessed their respective websites less often than requested, high dropout rates and non-usage are typical of other computer and web-based studies [40]. A similar website (WebChoice), evaluated by women with breast and men with prostate cancer, found only 64% of those agreeing to participate logged on at least twice over the course of one year [41]. These researchers found similar variations in use and perceived usefulness by disease status as our study; those further from diagnosis perceived the website as less useful. It is important that web-based health interventions focus on encouraging increased and prolonged use [42].

Finally, direct, immediate communication between participants and providers might have increased use and decision-making. Clinicians as well as family members have an important role in ACP discussions, including promoting positive attitudes and hope [43]. The website was intended to enhance provider-patient communication and decision making. Clinician providers were included in our initial design event, in usability testing, and within the

website in our designing and formatting materials to promote patient–clinician communication. In the WebChoice study, the highest rated component was receiving an answer from a nurse [41], suggesting web-based technology supports but does not replace patient–provider communication. A recent RCT suggested provider email and/or telephone prompts can increase use of a website cancer prevention intervention [44].

One area for improvement in our study would be to more directly address decision-making. We provided web-based information without prompts, triggers to action, or a “critical path” for users to follow [37], all of which might have increased task completion. Including many features also might have clouded the ACP focus. Future initial usability testing prior to a website trial could invite users to prioritize features, subsequently selecting and including only high-priority features and thereby further tailoring the website to the specifically designated trial population. The control website itself was rated as ‘very useful’, possibly affecting our ability to find significant between-group differences but demonstrating the high receptivity by women with ovarian cancer to receiving cancer-care information electronically. Future research could implement a delayed RCT whereby the control group waits to have access to the full intervention (true “usual care” control). Lastly caregivers were not successfully engaged and typically play a central role in ACP [45]. Independent of website use, not engaging family members as study co-participants might have weakened our results, as noted in previous gynecological cancer intervention studies [46].

There are numerous study limitations. The smaller than expected sample size reduced power for primary analyses. The study is vulnerable to selection bias. It was conducted at a single academic gynecologic cancer clinic which sees predominately educated, white, insured women, and while women with little computer experience participated, individuals without computer access were not eligible. Women with ovarian cancer were included as important stakeholders in the original design and usability testing phases, but not as the website intervention was developed. Finally, due to a small budget, we were unable to mitigate some usability issues identified prior to the pilot.

We successfully developed and pilot-tested a website designed to provide information and decisional support for women with ovarian cancer. Improving access to ACP for those with serious and chronic health problems remains a clinical challenge that requires innovative interventions that can be tested in the clinical arena for patients with cancer.

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Highlights

- A web-based intervention was designed to encourage decision-making surrounding advance care planning for women with ovarian cancer.
- A pilot RCT demonstrates its promise in facilitating creation of advance healthcare directives and consultation with palliative care specialists.

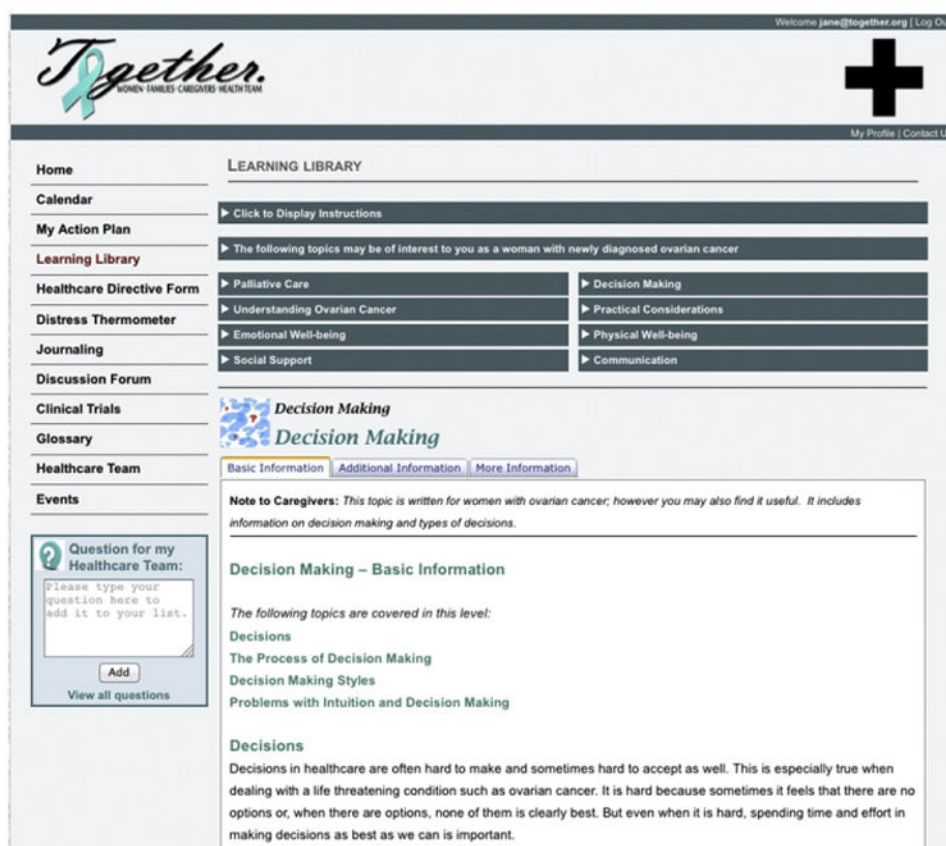


Fig. 1.
Example screenshots of intervention website.

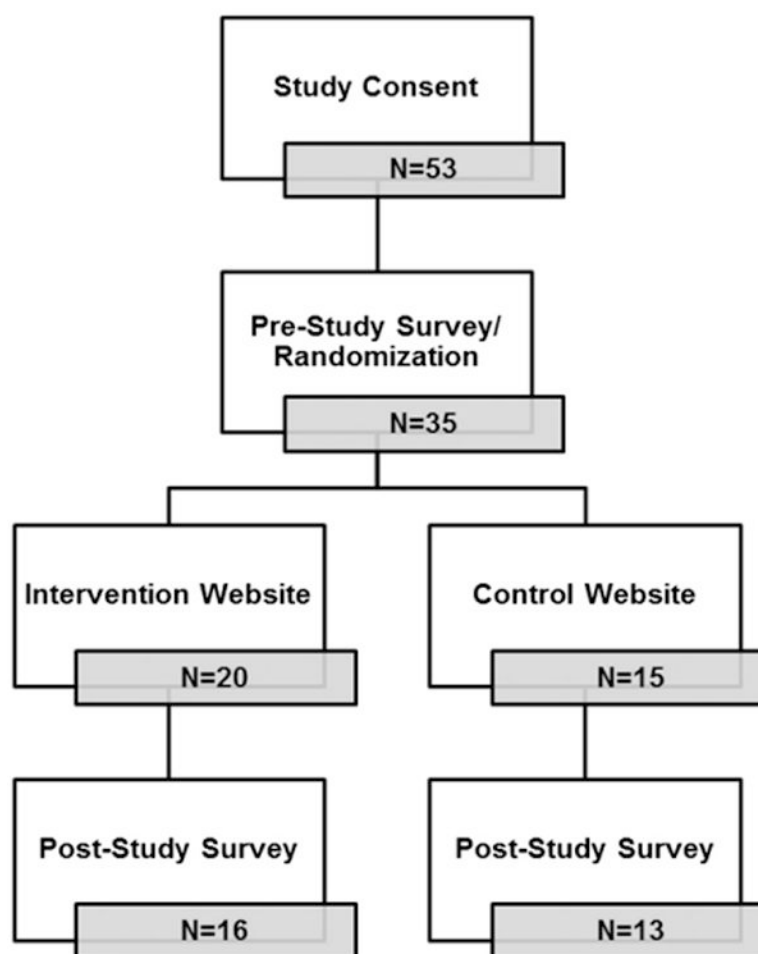


Fig. 2. Enrollment and randomization of women with ovarian cancer. Flow of subjects through study.

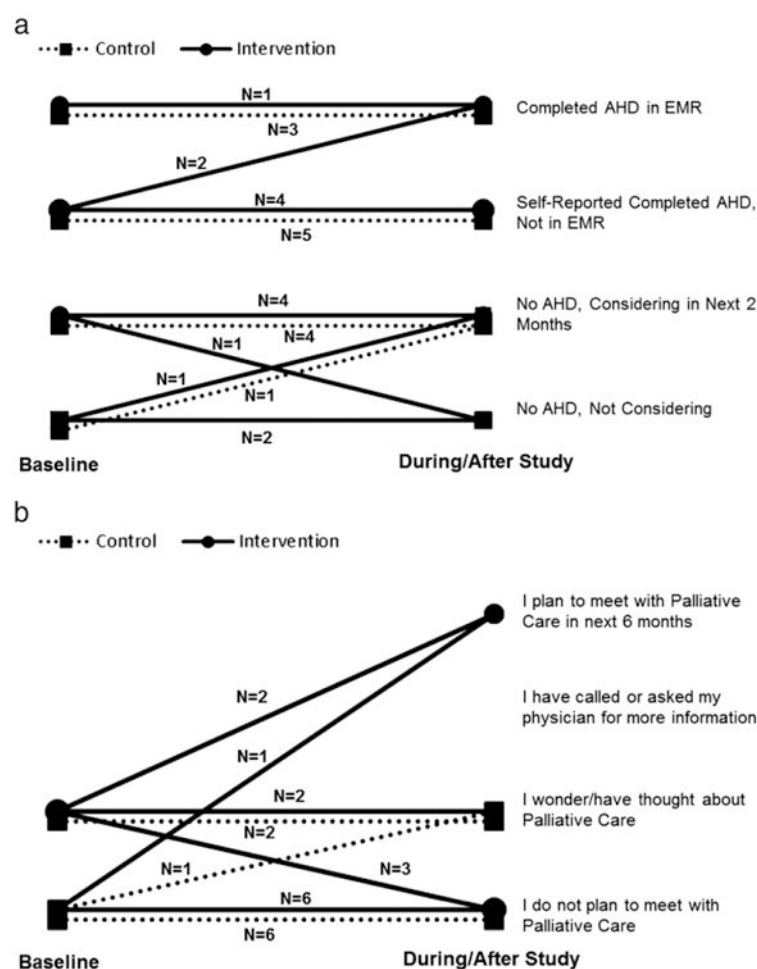


Fig. 3. Decision-making by study group among completers. Decisions surrounding (a) completion of an Advance Healthcare Directive (AHD) and (b) Palliative Care Consultation are presented pre and post-study by randomization group. The circles and solid lines represent the intervention group and the squares and dotted lines represent the control group.

Table 1

Baseline demographics and clinical data of participants with ovarian cancer by randomization group.

Variable	All participants			Control		Intervention		
	N	%		N	%	N	%	
Race/ethnicity								
White, Non-Hispanic	30	90.9	11	78.6	19	100.0		
Other	3	9.1	3	21.4	0	0.0		
<i>Missing</i>	2		1		1			
Highest education								
High school graduate or less	7	20.6	1	7.1	6	30.0		
Some college	15	44.1	8	57.1	7	35.0		
College graduate/professional school	12	35.3	5	35.7	7	35.0		
<i>Missing</i>	1		1		0			
Work outside of home								
Yes	23	67.7	11	78.6	12	60.0		
No	11	32.4	3	21.4	8	40.0		
<i>Missing</i>	1		1		0			
Marital status								
Single	4	11.8	2	14.3	2	10.0		
Married/partnered	22	64.7	11	78.6	11	55.0		
Divorced	6	17.7	0	0.0	6	30.0		
Widowed	2	5.9	1	7.1	1	5.0		
<i>Missing</i>	1		1		0			
Disease status								
Newly diagnosed	11	31.4	3	20.0	8	40.0		
Remission	8	22.9	4	26.7	4	20.0		
First recurrence	11	31.4	5	33.3	6	30.0		
Multiply recurrent	5	14.3	3	20.0	2	10.0		
Active cancer treatment during study								

Variable	All participants			Control			Intervention		
	N	%		N	%		N	%	
Yes	21	60.0	7	46.7	14	70.0			
No	14	40.0	8	53.3	6	30.0			
History of other cancer									
No	28	80.0	12	80.0	16	80.0			
Yes	7	20.0	3	20.0	4	20.0			
Rating of computer skills									
Poor	3	9.4	0	0.0	3	17.8			
Fair	10	31.3	6	40.0	4	23.5			
Good	14	43.8	7	46.7	7	41.2			
Very good	5	15.6	2	13.3	3	17.7			
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)			
Age (years)	35	57.9 (9.5)	15	55.5 (8.4)	20	59.6 (10.0)			
METER (out of 70)	35	66.4 (2.7)	15	67.9 (1.6)	20	65.3 (2.9)			

Table 2

Participants with ovarian cancer reported barriers to website use by group.

Control
<i>Relevance to participants</i>
<ul style="list-style-type: none">“I have been done with treatment for 3 years... You need to provide more informationfor those that have completed”
Lack of incentive to use website regularly
<ul style="list-style-type: none">“I had already found much of the information on the website elsewhere.”
Intervention
<i>Relevance to participants</i>
<ul style="list-style-type: none">“I wish I would have had this info when I was first diagnosed.”
Difficult to use, computer skills required higher than many patients' skill level
<ul style="list-style-type: none">“Had a hard time logging in and finding website.”
Not enough participants for discussion forum
<ul style="list-style-type: none">“I wish there would have been more participants to chat with about ovarian cancer.”

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Table 3

Use and satisfaction with website by study group.

	Control		Intervention		p-Value
	N	Mean (SD)	N	Mean (SD)	
Overall satisfaction					0.468
Very satisfied	3	23.1	3	20.0	
Somewhat satisfied	4	30.8	4	26.7	
Neutral	3	23.1	7	46.7	
Somewhat dissatisfied	3	23.1	1	6.7	
Very dissatisfied	0	0.0	0	0.0	
Ease of use					0.386
Very Satisfied	5	38.5	6	40.0	
Somewhat Satisfied	5	38.5	3	20.0	
Neutral	2	15.4	6	40.0	
Somewhat dissatisfied	1	7.7	0	0.0	
Very dissatisfied	0	0.0	0	0.0	
Content quality					0.119
Very Satisfied	5	38.5	5	33.3	
Somewhat satisfied	1	7.7	5	33.3	
Neutral	3	23.1	5	33.3	
Somewhat dissatisfied	3	23.1	0	0.0	
Very dissatisfied	1	7.7	0	0.0	
Amount of information on website					0.054
Too little	8	61.5	3	21.4	
About right	5	38.5	11	78.6	
Too much	0	0.0	0	0.0	
Website was at right level for my computer skills.					0.792
Strongly agree	3	23.1	3	20.0	
Agree	7	53.9	6	40.0	
Neither agree nor disagree	2	15.4	5	33.3	
Disagree	1	7.7	1	6.7	

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Intervention		Control		p-Value
N	Mean (SD)	N	Mean (SD)	
0	0.0	0	0.0	0.0
Strongly disagree				