



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



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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.

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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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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

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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 caregiver for enrollment. Patients and caregivers who did not log into the website within two weeks of consent were called by study staff up to

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