Implementation and Testing of a Web-based Tool for Improving Communication
between Ovarian Cancer Patients and their Providers through Timely Data Collection and
Use

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Dedication

The very first book I read in preparation for my dissertation work was *Mastering Communication with Seriously Ill Patients* by Anthony Back in the summer of 2011. Never did I imagine that as I completed my writing, would my work become so personal. I dedicate this work first, to my beloved Father, who passed away March 21, 2013 from multiple myeloma after great suffering. For too many reasons to list, my Dad, Julian Bilski, will forever and always be my personal hero.

Secondly, I also dedicate my work to my children - Danny, Jennifer, Caitlin and Annie. While you have been busy working to fulfill your life wishes and dreams, I have been on this journey. You are all so talented that you keep me inspired to be my best self.

Abstract

Background

Research studies show that many symptoms of ovarian cancer are not addressed adequately in the communication between patient and oncologist. To complicate matters further, this patient population has unique, complex symptom clusters which need to be managed and which themselves often complicate the communication process. The advent of secure patient portals makes possible the use of real time patient-reported outcomes (PROs) in order to improve communication between patients and their providers and enhance individual patient management by clinicians. However, there is very little current research on how real-time PROs can be used effectively to improve patient-provider communication, leading to better health care delivery and patient outcomes.

Methods

Beginning in August of 2012, a total of 53 patients from the University of Minnesota Gynecological Oncology Clinic were recruited and randomized into intervention and control groups to test a new, high-fidelity prototype created by the author for patient reported questions and concerns, as part of a website designed specifically for women with ovarian cancer. Pre/post surveys were administered electronically to obtain preliminary information on acceptability and frequency of use, perceptions of usefulness for improved communication, and self-reports of perceived reduction in anxiety about communication.

Results

No differences between the intervention and control groups were found on any of the measures. There was a high drop-out rate and low participation in overall use of the website. Significant barriers to successful patient entry in the communication tool and use of PRO's at the clinical level were found and included low patient technology skills, memory problems, symptom burden, lack of clinician engagement with the website, and no real-time response made available from a provider.

Discussion

This online communication tool was designed to facilitate communication between cancer patients and their healthcare providers; however, uptake of the tool was sub-optimal. While supportive communication tools made possible through technology can assist in meeting the communication needs of cancer patients with complex symptoms, there is much more to learn about how to effectively accomplish this. Additional research is needed on how best to meet the needs of cancer patients for information and improved communication with their oncologists, as well as longitudinal studies linking better communication to better patient outcomes.

Table of Contents

List of Tables

List of Figures

1. INTRODUCTION: BACKGROUND AND SIGNIFICANCE

1.1 Patient-reported Outcomes

As far back as 2001, an Institute of Medicine (IOM) committee issued a report, "Crossing the Quality Chasm: A New Health System for the 21st Century". The report recommended that health care information should move from a record that is "retrospective, archival, passive and inert…to an interactive, real-time, and prospective format that is continuous and paid for in a way that patients receive care when they need it and in many forms" (Institute of Medicine, 2001). This new health system should integrate and rely more on patient-reported outcomes (PROs) in clinical practice (Hesse, 2010). The IOM report was also among the first to suggest the creation of patient-centered care and defined this as organizing current care to "care through a patient, rather than [from] a provider viewpoint".

Patient-reported outcomes (PROs)--such as qualitative health-related surveys--have been used at an aggregate level in research studies to measure outcomes of specific interventions on patient populations. These have been intrinsically measured over time, and designed and used primarily to compare subgroups of the patient population of interest. Recently, however, the advent of secure patient portals added to provider websites makes possible the use of patient-reported information on a *real-time* basis for a) better communication between patients and clinicians, and b) potentially better individual patient management by clinicians.

Health internet sites are increasingly being used by patients to access information and resources to augment traditional care. Current websites for patients with cancer consist

primarily of text-based information, and have few if any applications tailored to meet patients' needs for better communication or to promote interactive communication with providers. Thus, there is very little current research on how real-time patient-reported data, in the form of questions or concerns, can be used effectively to improve health care delivery, and result in better outcomes and improved quality of life (QOL) for patients, one patient at a time.

It has been postulated (Greenhalgh, 1999 & Hesse, 2010) that PRO interventions that monitor and permit use of patients' self-reports of health issues could:

- Improve communication between patients and clinicians

- Help identify problems patients might not have raised in a clinic visit

- Aid with patient memory and ability to describe their problems

- Result in better quality of care and improved patient outcomes

The Patient Protection and Affordable Care Act (PPACA) of 2010 focused on the importance of patient-centered care, patient self-management, patient involvement in care, and shared decision-making. The Centers for Medicare & Medicaid Services is finalizing details for a new reimbursement method--required by the Health Care and Education Reconciliation Act of 2010-- that ties bonuses to successful implementation of programs to increase these processes, as well as results of patient satisfaction survey data that demonstrate significant improvement. With the advent of patient portals and the possibility to link such portals to systems used by clinicians, there is an opportunity to

eventually extend the use patients' self-reports of health issues to impact individualized patient management rather than merely inform research at the population level.

Patient reports that relay information on issues of health-related QOL and improve communication of symptoms, disease progression, and therapy side effects can prompt timely discussions between patients and their clinicians about these issues, and have the potential to change the dialog, improve the course of disease management, and ultimately improve patient outcomes.

In the last 10 years, the National Cancer Institute has provided ongoing funding to researchers to develop item banks for measuring major self-reported health domains affected by chronic illness. This has resulted in the Patient-Reported Outcomes Measurement Information System (PROMIS) Network, a National Institutes of Health Roadmap Initiative (Cella, 2007). These item banks are currently being refined to provide comparisons of symptoms across different patient populations, and include first generation measures of self-reported pain, fatigue, and emotional distress, as well as physical and social function (Yost, 2011). New tools and approaches in clinical health care settings can facilitate the completeness and accuracy of these information banks.

To date, the PROMIS Network has funded research to collect and validate cancer specific item banks for measuring QOL from seven cancers: female breast, uterine, cervical, prostate, and male and female colorectal, non–Hodgkin's Lymphoma and non–small cell lung cancer (nihpromis.org, accessed 8.1.2013). Ovarian cancer specific items have not yet been collected for validating and calibrating to this unique population for future use at the population or clinical level of care.

PRO tools or measures refer to the range of ways PROs can be collected: such as in–person interviews, written questionnaires or computer–assisted tools. The National Institutes of Health define PROs as health data that is provided by the patient through a system of reporting and additionally as, a "patient's feedback on their feelings or what they are able to do as they are dealing with chronic diseases or conditions" (nihpromis.org, accessed 8.1.2013). This randomized-controlled clinical trial was conducted to develop, implement, and pilot test a system to collect patient-reports (as questions or concerns) in free text form, and to test if this website tool could be used to share this information with their provider during a clinical encounter. Post-study, patient entries would be viewed and analyzed by item types and frequency.

1.2. Patient-reported Outcomes: Ovarian Cancer Patient Population

Oncology research studies have suggested that cancer patients could benefit significantly from real-time electronic entry of their health questions and concerns. Ovarian cancer patients, in particular, face *chronic* (incurable) cancer with multiple treatments including surgery, chemotherapy and radiation therapy. Patients suffer from many different resulting complications from these treatments, as well as from the disease symptoms themselves. It is well known that patients with ovarian cancer are commonly impacted by groups of symptoms that include fatigue, anxiety, pain, bloating, bowel disturbances, nausea and vomiting, anorexia, and depression (Nattress et al., 2006; Bankhead, 2005). In the long-term, these patients also deal with surgical menopause, gender and role identity issues, peripheral neuropathy, cognitive dysfunction, and decreased QOL related to fears of cancer recurrence, sexual dysfunction, depression, and employability (Koldjeski, 2007;

Le, 2005; Le, 2003; Lockwood-Rayermann, 2006). As QOL for these patients is generally rated by measures of pain, decreased physical function, fatigue, and emotional distress, tools are needed to record and report these symptoms at the individual patient level. This research study asserted that it is only through a well-designed PRO system that timely, accurate and valid information can be captured so that symptoms can be made fully known to, and best treated by clinicians over time.

At the clinical level of care in ovarian cancer, real-time electronically collected patient-reported outcomes have been used in very few US health organizations to date, in order to report symptoms and help organize the care process. The National Institutes of Health (NIH) has funded an oncology module at Dartmouth-Hitchcock Medical Center and at the University of California San Francisco Breast Care Center. In these two health systems, individual PROs from cancer patients are made available to clinicians in a web-based system – *Integrated Survey System* (ISS) – to collect, share and track patient-entered data. Information flows directly to the Electronic Health Record (EHR) where questions can trigger automatic e-mail alerts to specialists (Donaldson, 2008). Patient reports are reviewed at the oncology visit and have become part of the clinic visit protocol. The use of technology to implement PROs into clinical practice has proven feasible, and future plans at these two sites include remote clinical surveillance of patient health status as well as longitudinal analysis of patient data to improve patient-clinician communication and outcomes (Donaldson, 2008).

The implementation of a system for accurate and timely PROs for ovarian cancer patients has great potential to improve patient outcomes in terms of QOL. Research has found that

for approximately 16-49% of ovarian cancer patients, multiple symptoms are undertreated (Le et al., 2005). Another study (Donovan & Ward, 2005) found that 59% of patients with gynecological cancers have cancer-related fatigue that goes unreported to oncologists. Although fatigue is the greatest complaint overall, 53% of cancer patients never receive counseling from oncologists on how to treat this debilitating symptom (Garcia, 2007). Cancer patients are also reluctant to complain about pain to their oncologists for fear of being seen in an unfavorable light by their providers (Ward, 1993). To complicate matters further, oncologists often under-treat pain due to an unreasonable fear of creating addictions (Ward, 1993). Other symptoms and concerns go unreported by cancer patients due to embarrassment, a shortage of time with their clinician, and memory problems associated with chemotherapy (often referred to as "chemo-brain"). The impact of multiple symptoms upon patients is described as "symptom burden" (Cleeland, 2007), a concept that encompasses both the severity of the symptoms and the patient's perception of the impact of the symptoms.

At every stage of treatment, ovarian cancer patients rely on their health care providers to meet their information and medical needs in order to maximize their QOL. Physicians who care for patients with life-threatening illnesses face daunting communication challenges (Back, Arnold, & Tulsky, 2009). Stress, fear, and lack of information often overwhelm patients when speaking with their clinicians. At any given appointment, patients and their caregivers (family members or others) are limited in the amount of information they can take in. The use of technology to facilitate and improve

communication between patient and provider in the ovarian oncology setting could have a significantly positive impact.

Identifying the appropriate structure and incentives for use of a technological intervention that is realistic and not disruptive, however, is paramount to its success. Interfaces of care must be safe, effective, patient-centered, timely, efficient, and equitable (Taplin, 2010). The workflow of the clinician must be changed to include a review of patient self-reports that is time-efficient, and most importantly, perceived by them as valuable with immediate perceived benefits for their patients and their work.

The six core functions of patient-clinician communication overlap and interact to produce communication that can affect important health outcomes. In an educational publication for the National Cancer Institute, the following model was proposed (Epstein, 2007) for the interactions of these functions and their impact:

Figure 1.2: Six Core Functions of Patient-Clinician Communication (Epstein, 2007)

Information exchange is a key factor to making decisions, managing uncertainty, and enabling patient self-management. A physician's emotional responsiveness and ability to create a trusting relationship also influence the quality of communication with patients. Improving the patient-provider dialog is paramount to improving patient outcomes.

1.3 Implementation and Acceptance of use of PROs at the Clinical Level

Five systematic reviews of randomized controlled trials evaluating the impact and effectiveness of sending individual-level PRO data to clinicians have been published since 1999 (Valderas et al, 2008, Marshall et al, 2006, Gilbody et al, 2003, Espallargues et al, 2000, & Greenlaugh et al, 1999). None of the studies reviewed used a patient portal for real-time multiple item data entry, however, and none assessed the patients' perceptions of the process and outcomes (Greenlaugh, 2008). There has been one cohort study published (Hilarius, 2008) of touch screen data entry in an oncology clinic just prior to an appointment by patients to solicit Health-related Quality-of-Life (HRQOL) assessments. No specific guidelines were provided to either clinicians or patients as to how to use the HRQOL data. The study did report an increase in QOL discussions and increased clinician awareness of the importance of their patients' QOL, but showed only modest changes in patient management. Another study (Gaertner, et al., 2004) did validate the use of electronic *pain* diaries with cancer and non-cancer patients as feasible and more likely to be used than paper diaries for pharmacotherapy, but confined itself to this one measure. Fatigue is reported by ovarian cancer patients to be more debilitating than anxiety, pain, and nausea/vomiting (Stone, 2000). Ideally, PRO's should be

inclusive of *all* important and debilitating symptoms in order to be most clinically useful as the symptoms interact with one another and affect outcomes.

Challenges to the acceptance and implementation of PROs include concerns by oncologists regarding longer appointment times, lack of reimbursement, impact on patient flow and on patient-clinician relationships, as well as concerns about increased liability (Donaldson, 2008). Patient barriers include access to technology, literacy level, and the effect of cancer disease and treatments on patients' ability to enter data. It has been suggested that an incremental approach which starts with patient needs and focuses on how to meet those needs will be most effective (Donaldson, 2008 & Taplin, 2010). Incremental steps will allow for identifying where breakdowns occur and their consequences on patient outcomes.

A growing body of research shows that physicians' communication behavior does indeed have a positive impact on patient health outcomes and assumes great significance in the care of cancer patients (Step, 2009). Studies are needed to further examine and better understand the effects of the use of technology on patient-clinician communication, to test novel models of patient care, to better identify and manage patient expectations, to measure clinician acceptance and identify potential incentives, and develop the best processes that facilitate patient-centered care.

1.4 Study Site: University of Minnesota Gynecologic Oncology Clinic

Ovarian cancer is one of the most prevalent forms of cancer in women. It is the 5th most common cause of cancer deaths among women and causes 14,600 deaths annually. There are more than 21,000 new cases identified every year (American Cancer Society, 2008).

The University of Minnesota Gynecologic Oncology Clinic alone receives approximately 120 newly diagnosed or recurrent stages III and IV cases of ovarian cancer each year.

In the spring of 2010, a team of researchers conducted a Preliminary Design Event - a full day of interaction between gynecological oncologists, psychologists, information and decision experts, and ovarian cancer patients and their caregivers. A total of 41 participants including 22 patients and family members discussed issues and needs that should be addressed in an interactive system. Key themes that emerged included better connectivity to the healthcare team, 24/7 access to key information in a variety of formats and information types, navigation and care coordination tools, and education and support (including families) in the "white space" between visits.

Drs. Geller and Sainfort, along with a team of other researchers and clinicians, started the design plan for a prototype website, named *Together*, for use by ovarian cancer patients and their caregivers with the goal of studying information seeking style and behavior, decision-making of ovarian cancer patients with respect to palliative care, and the effectiveness of education on symptom management and monitoring. While this project was underway, a review of literature identified the initiatives (as described earlier) that pointed to the potential benefit of using PRO data at the individual patient/clinician level to improve care and eventually, patient outcomes. The literature also identified a strong need for improved communication between oncologists and their patients (Rasavi, 2003, Ong, 2000). Unstructured interviews with providers (a nurse practitioner, 2 oncologists, and a psychologist) at the University clinic were also conducted to determine the preliminary perceived value of an electronic log of patient questions being used during a

clinic appointment. Comments from all providers included that patients "ask the same questions again and again at appointments" using up valuable time. While this was likely related to chemotherapy memory problems, an electronic record for reference at any time, could minimize this problem.

With these considerations in mind, this researcher designed a tool on the website *Together* for the express purpose of improving patient-provider communication and tracking patient reported symptoms, questions, and concerns (outcomes*).* The principal investigators agreed to the augmentation of *Together* with the *Questions for My Healthcare Team* text box for communication with providers, as well as the additional research instrumentation to measure actual use and patient outcomes from its implementation. This tool focused specifically on the clinical level of care, and more specifically on the collection of PRO information entered electronically by patients *and* the use of such information between ovarian cancer patients and oncologists during a clinic visit. Collaboration with the Gynecologic Oncology Clinic was secured, as was approval from the University of Minnesota Institutional Review Board to put the system in use with ovarian cancer patients and their caregivers.

2. WEBSITE DEVELOPMENT AND COMMUNICATION TOOL DESIGN

2.1 *Together*: An Interactive Website for Women with Ovarian Cancer

The pilot secure patient website was created, tested, and revised over a period of 16 months. The project team met weekly to decide on all content and design requirements, and delivered the requirements to developers for short iterations of code and periodic

review. While the final content of the website was being created, this researcher assisted in the design of the user interface. In keeping with the ovarian cancer theme of teal, a similar color palette was chosen and display of features was formatted for similarity to other educational and interactive websites. For the primary study, intervention components included distress monitoring (a distress thermometer) and an extensive library of information with suggested *Action Items* - prompts to complete helpful reading and tasks, like exercising, journaling, or using tools in the site. The library topics were written by members of the project team accessing clinical, psychological, legal, and financial expertise.

The larger study's goals were to measure the impact of *Together* on new Palliative Care appointments/consultations and upon the completion of Advance Healthcare Directives (AHD) due to directed education and the provision of a toolkit for AHD decision-making. A legal, fillable Advance Healthcare Directive form was also provided in the website within a topic and on the navigation bar for women to complete and bring to their oncologist.

Each topic in the *Learning Library* was written at three levels of increasing information. The three levels were designed to require the user to agree to more in-depth information before clicking the next tab, serving as a juncture where a patient might choose to stop reading if the content was causing stress. Information was written for easy understanding and a glossary of medical terms was provided on the navigation bar. A screenshot is below highlighting the tabs of increasing information.

Figure 2.1.1 Screenshot: Intervention Website
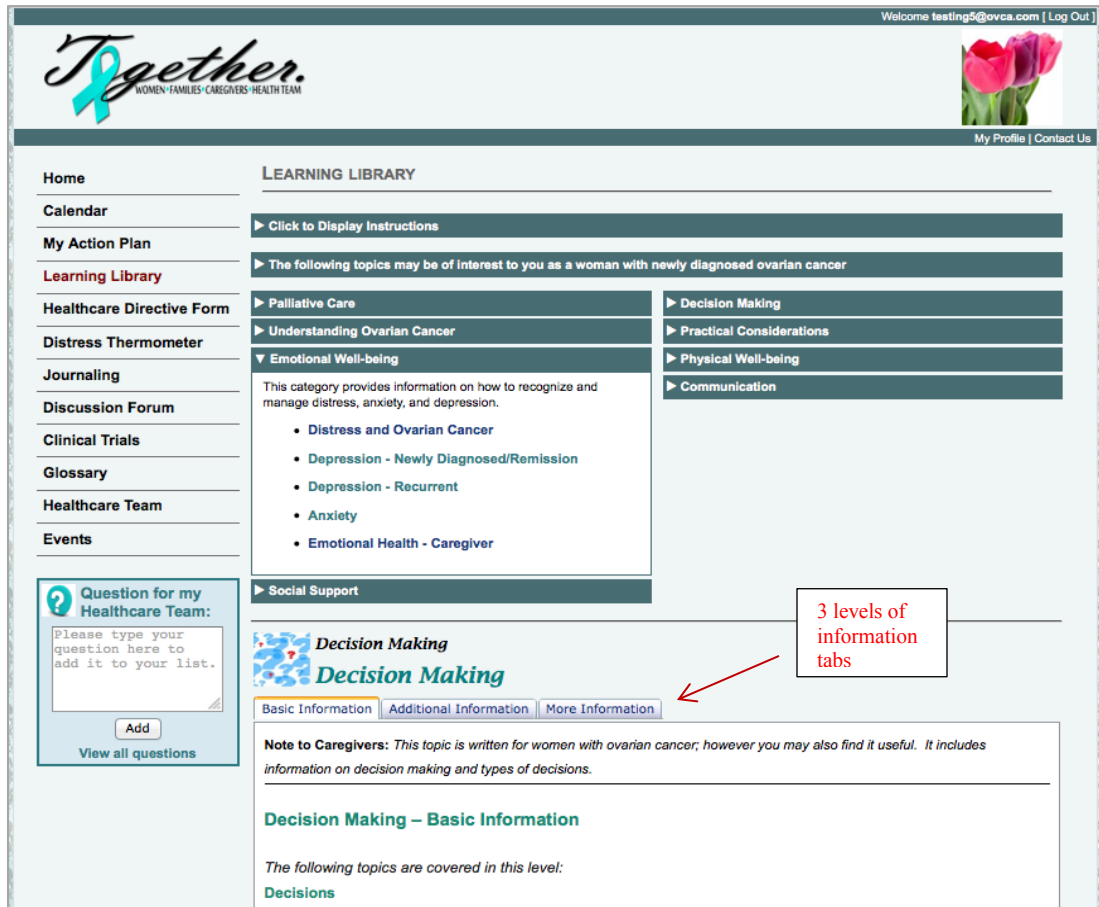
The full library of topics included Understanding Ovarian Cancer, Palliative Care, Communication, Decision-making, Emotional Well-being, Physical Well-being, Practical Considerations (legal and financial), and Social Support. Social network features allowed users to create their own profile, share a journal with others, and post to discussion forums.

The navigation bar on the left side contained links to activities and resources. The center of the webpage displayed links to topics in the *Learning Library*, organized by theme. Research and writing for the topics *Palliative Care*, *Advance Healthcare Directive*,

Communicating with Your Provider, and *Practical Considerations* (legal and financial) was the responsibility of this researcher, with final approval by the principal investigators. Final responsibilities shared with other team members included usability testing, editing and revising all topics before uploading to the final version website, testing of all functionality, and validating for correct performance immediately prior to the launch of *Together*.

The control website was created using the background design of the intervention site, but including only links, organized by topic, to PDFs of documents provided by the clinic in paper form, as part of usual care. Clicking on a dark teal topic opened the educational forms for reading. There were no other functions available to users on this site

Figure 2.1.2 Screenshot: Control Website
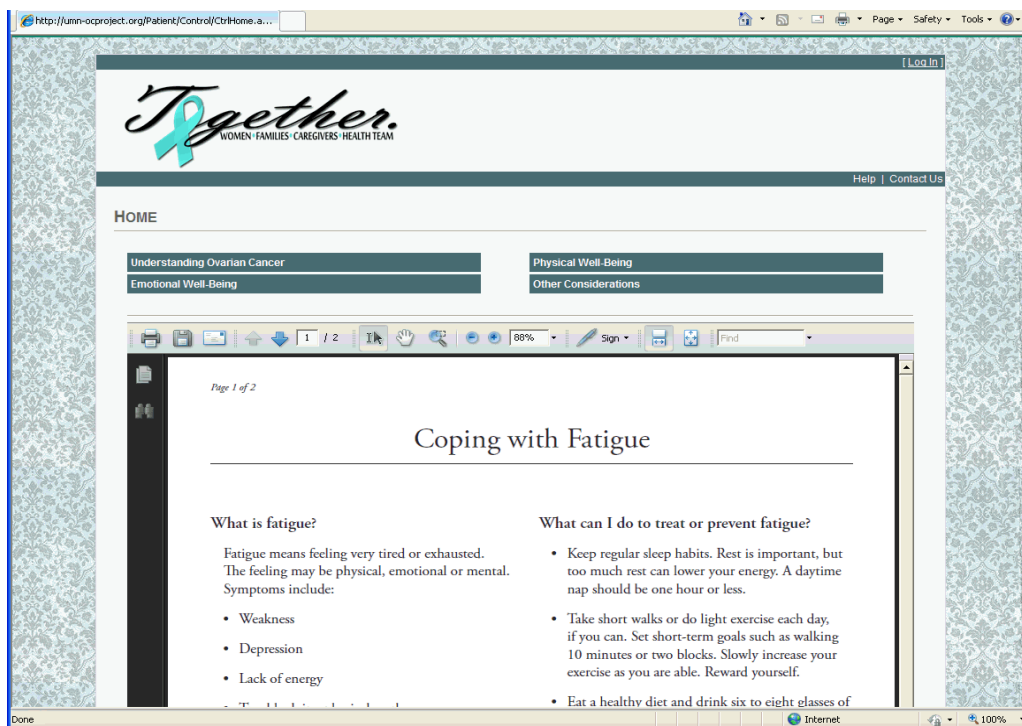
2.2 *Questions for My Healthcare* Team

The tool to assist in improving communication was designed concurrently with the intervention website. Information from the literature review and informal interviews with clinicians at the Gynecological Oncology Clinic informed its design. The clinicians expressed 2 primary concerns:

1. Ovarian cancer patients repeat the same questions at different appointments.

2. Time for clinic visits is often less than desired, due to surgeries performed earlier in the day that took longer than originally anticipated.

Memory issues associated with chemo-brain, fatigue, and stress make retaining important information during appointments difficult for women with ovarian cancer. When patient waiting times are longer, patients become more fatigued and clinicians are stressed.

Because of these issues, the *Questions* box was designed for a patient to enter questions between appointments. Answers could be added in the text box by a provider or patient for reference at any future time. It was hypothesized that the *Questions* box would increase the quality and efficiency of the clinical encounter - specifically by resulting in a patient-created list of concerns and questions to be retrieved and answered from the "white" time between clinic visits. It would also result in a historical list of questions and answers for patient review at any time.

By design, it was visible to the women in the intervention group while browsing on every page of the website. Directions for use were found within the box itself and introduced formally in the topic *Communicating with Your Provider*. The *Questions* box was also suggested for use within 6 other learning topics, with instructions repeated. Each question
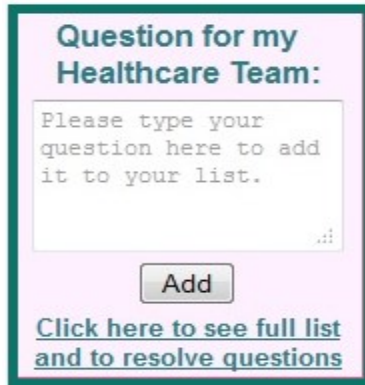
entered would be automatically saved and time-stamped. The list was printable by the patient for bringing to the clinic and accessible for direct viewing on computers and iPads with internet access provided in the clinic. Implementation of the *Questions* box could therefore make appointments more efficient, change the dialog during a clinical encounter, and increase new information exchange between patient and provider.

Figure 2.2.1 Screenshot: *Together* **- Question for my Healthcare Team text box**
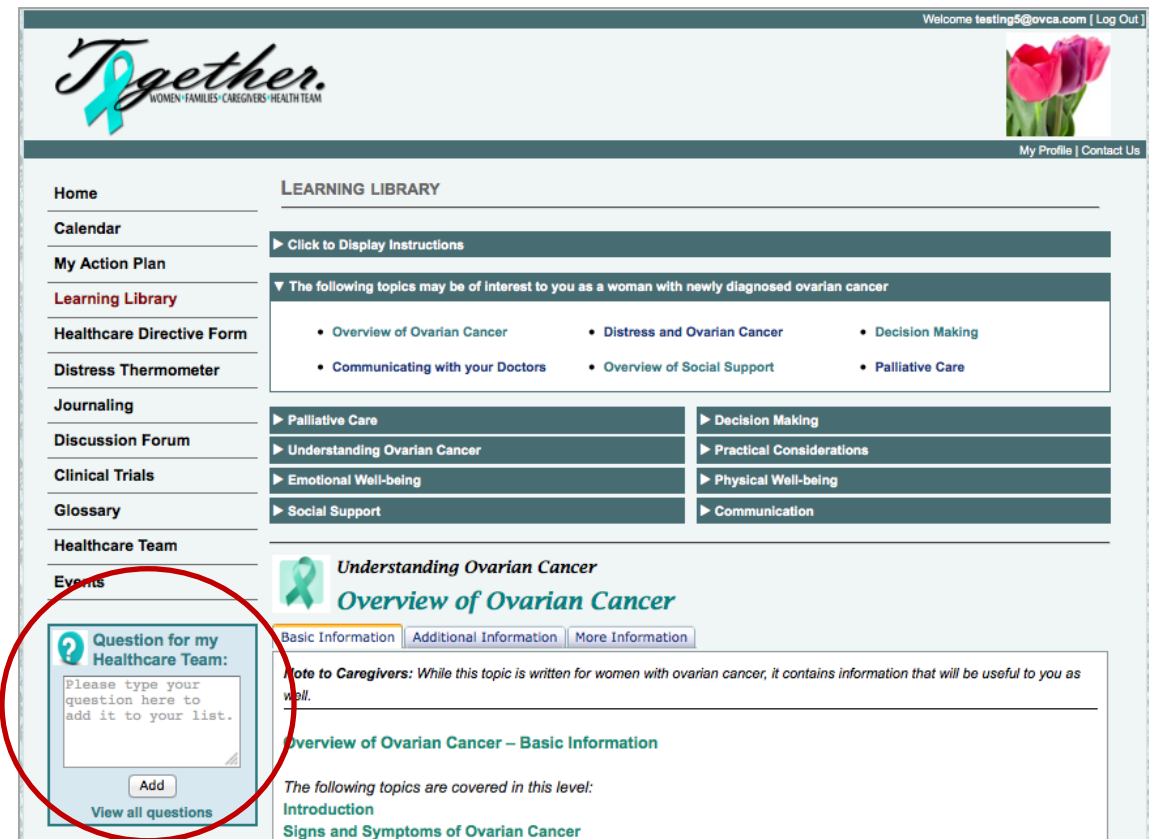
Clicking on the box allowed for immediate and continuous text entry in the small box while browsing all topics, using tools like the distress thermometer, the calendar or writing in their journal.

Figure 2.2.2 Questions Box - approximate laptop screen display size

Clicking on a link at the bottom of the *Questions* box opened up a full screen display with a complete history of questions and answers entered and stamped by date, with a printer icon to click for printing a paper copy. Patients were able to enter a category type for the question, enter answers if found on their own, and indicate with a check mark whether the concern or question was resolved. A screenshot of this page is with testing data is below.

Figure 2.2.3 Screenshot: Full page display of Questions for My Healthcare Team

Additional documented barriers to good communication during clinic visits for women with ovarian cancer were also taken into account:

- The majority of initial diagnoses are made at Stage III-IV (advanced) disease, correlating with high patient distress (Geller, et al 2010)

- Treatment and disease side effects include pain, nausea, anxiety, depression, and extreme fatigue (Donovan, 2005)

- Most patients have misinformation and limited knowledge about their disease, treatment options and trade-offs, and the management of side effects (Lewin, 2005)

The net effect of disease and symptom burden for women with ovarian cancer - combined with less than optimal communication with their oncologist - is that these factors likely lead to poorer outcomes in most measures of QOL (Keyser, 2010) than are possible.

2.3 Usability Testing

In April of 2012, usability tests were performed over 2 days on both the intervention and control websites. Two clinicians, a woman newly diagnosed with stage 3 ovarian cancer, her caretaker, and a user experience expert performed tasks from scripts created to include testing of the most important features of the website, including the *Questions* box. Using talk-aloud methodology, notes were taken and analyzed to identify issues with usability and revisions needed. The communication tool was rated high on usability by all testers. No changes were made to the *Questions* box which remained visible at all times in the navigation bar while browsing *Together*. Comments from the testers included that it was usable for short interactions with the website, and the display with directions for use was easily understood by them. The woman with ovarian cancer said she "would definitely use it" if it was available to her. A clinician said "it was a great idea" and had positive comments about "how helpful it could be for the patient to use".

Feedback for the full website from the testers fell under 4 main categories – task orientation, navigation, time to refresh, and page layout and visual design. During the

test, 3 of the 4 users said the "obvious path" to use on the site was not clear and that they were overwhelmed with text. When new pages did not load in the expected time, 2 testers commented that they "thought they had done something wrong". These items and other improvements were made in the next iteration of development using a formal list created by the usability expert.

A new home page clarifying how to use the site and the path back to this page was added, as was additional white space. Text sizes were standardized, all hyperlinks were abbreviated and made to look and act the same as any other website, and changes to the server by the IT team reduced time to refresh.

A second expert review was conducted after the updates were made, and the resulting website was evaluated using commercial software based on Nielsen's 10 usability heuristics, the Chisnell & Reddish 20 heuristics for older adults, and the website usability guidelines of David Travis. The software report is below. Each row represents 10 different worksheet pages that rate the following areas: 1) Home Page, 2) Task Orientation, 3) Navigation and Information Architecture , 4) Forms & Data Entry, 5) Trust & Credibility, 6) Writing and Content Quality, 7) Page Layout and Visual Design, 8) Search, 9) Help, Feedback & Error Tolerance and 10) Overall Score. The first column, or raw score, is scored with a -1 (website feature doesn't comply with standards), 0 (somewhat complies, is not present, or not applicable), or a 1 (feature complies with standards).

Table 2.3.1: Final Expert Usability Review

Summary				
	Raw score	**# Questions**	**Answers**	**Score**
Home Page	13	20	19	84%
Task Orientation	20	44	32	81%
Navigation & Information Architecture	14	29	23	80%
Forms & Data Entry	3	23	16	59%
Trust & Credibility	7	13	10	85%
Writing & Content Quality	15	23	21	86%
Page Layout & Visual Design	11	38	35	66%
Search	0	20	0	
Help, Feedback & Error Tolerance	-1	37	9	44%
Overall score		247	165	73%

The Questions column represents the total number of questions that could be answered about the website for each category. The Answers column reflects the score received from the questions if they applied. The software uses a complex algorithm to compute the final overall score from all data. The site as launched received a 73% overall score.

While significant improvements were made to increase usability, issues remained. Navigation was more difficult than a usual website, required extra scrolling, and a few links required a user to leave the website. *Together* was created using pre-coded templates, which restricted the flexibility of the coding and navigation, and resulted in less than the usual "look and feel" of other standard internet sites; the front end had been developed using Microsoft .NET framework with Ajax used 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. Due to restricted time and money, navigation remained a challenge, requiring extra time by a user. While time to refresh was still not optimal, it was improved. The new home page with instructions for use was displayed immediately after first login, and could also be accessed at any time on the navigation bar under the *Home* tab. After the usability report was delivered, all functionality was tested again by the project team members, and the website was approved for future deployment.

3. PROVIDER ENGAGEMENT

3.1 Engagement Events

There were 2 phases of clinician engagement for the website project. The first occurred in the spring of 2010 where patients, providers, and administrators met to discuss ways to create more patient-centric care in the University Clinic. The following comments were offered by clinicians:

- There is a chasm between a doctor's values and abilities and patient expectations.

- In order to have patient-centered care you have to have good communication.

- Physicians are not always good communicators and they do not have good role models when they are taught.

- Patients expect their providers to lead decision-making. 90% of patients want full information and physicians are not always capable of providing that.

- Time is a challenge.

- The new model of care is shared decision-making. The old model was paternalism.

- Physicians need to work with the patient and the entire health care team.

Similarly, the focus group of ovarian cancer patients at the same meetings led to comments such as the following:

- Patients don't want to "bother" the physician with their needs.

- They would like to feel more in control and competent in managing their disease.

- They want to be more pro-active in their care and be their own informed advocate.

- They do not always understand the medical terminology used by providers.

- When they are stressed at appointments, it is difficult to remember what was said.

- Patients cannot process and remember a lot of medical information at once

Both groups identified common barriers to good patient-provider communication and the resulting frustration. Clinicians actively engaged in this initial meeting which included a C-level health system executive who facilitated the event.

The second phase occurred in late June of 2012, when the *Together* website was formally presented by Dr. Melissa Geller to providers and staff of the Gynecological Cancer Clinic during their monthly research meeting. The website was projected and manipulated to display content and features. Project members were introduced and the process of recruiting patients in the clinic was explained. Providers were reminded that some patients would be receiving the control website, randomized by computer. The clinicians would know which patients were participating in the study only by actively asking the research coordinator. The targeted launch date of September 1, 2012 was announced.

3.2 Workflow Analysis

A workflow analysis was completed to determine where data entered by a patient on the *Together* website could be used during a clinic exam. With both the resident and the primary provider clinical workflow, the site could be used at the first patient encounter to facilitate information exchange on patient health status, concerns and questions. The clinic administrator fully supported this use in workflow and was an advisor to the project team when time allowed.

A primary concern with implementation of *Together's* tools for patients, such as sharing entries on the distress thermometer and the *Questions* box with a provider, was that this process required patient initiation. In order to facilitate communication on specific topics

of concern, women in the intervention group would have to access and use the site - most

likely at home - and then access the site electronically in clinic or bring in print-outs.

Figure 3.2.1: Gynecological Cancer Clinic Workflow
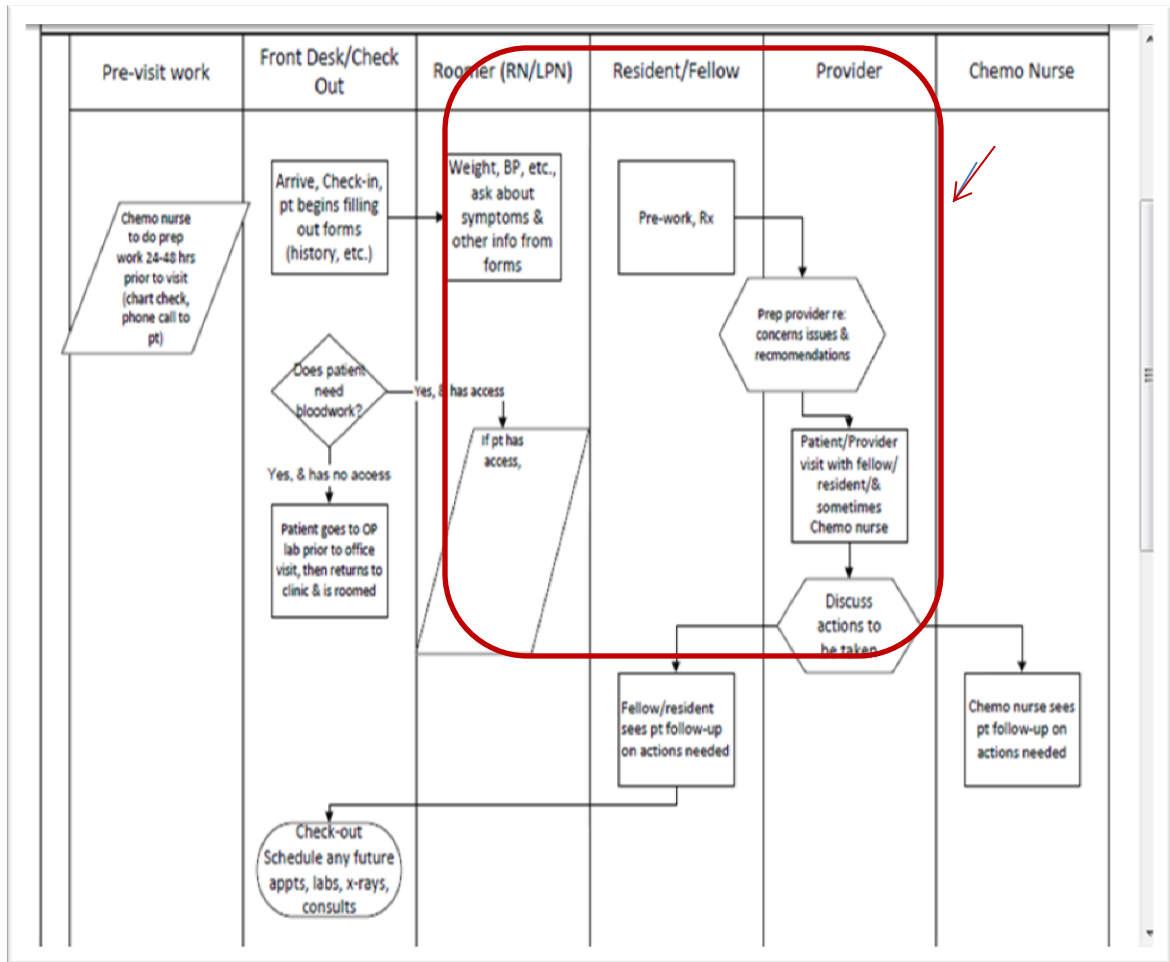
All three tasks in the provider workflow column below could include its use, and assist in

the process of communication. The study coordinator could also assist with its use in

clinic, but did not have designated time for this facilitation. He primarily consented

patients and provided a means to access the pre-study survey, which most women

completed at home electronically. This researcher was also in the clinic when notified by the study coordinator, to assist study participants who had requested help with using the websites (intervention and control) and were in the clinic or infusion (chemotherapy) center.

4. METHODOLGY

4.1 Specific Aims and Hypotheses

The communication tool on *Together*, created for individual patients to enter their questions, concerns, and symptoms (PROs) on a real-time basis (as they occur) in a free text box was deployed and tested for multiple outcomes.

The specific aims of this study were to:

- Conduct a pre/post experimental study with two arms (intervention and control) to evaluate the impact of the *Questions for My Healthcare Team* text box on patient/provider communication, and selected patient outcomes.

- Run reports, post-study, of the tool use by patient ID, date and time; including clicks on it, text entered and saved, and answers entered and saved to identify item type and any patterns or correlations of use.

4.2 Conceptual Framework

Expanding on the oncologist-patient relational communication involvement (RCI) conceptual model (Step, 2009) and Epstein's model (2005) of factors influencing patient-centered communication, the following framework guided this research:
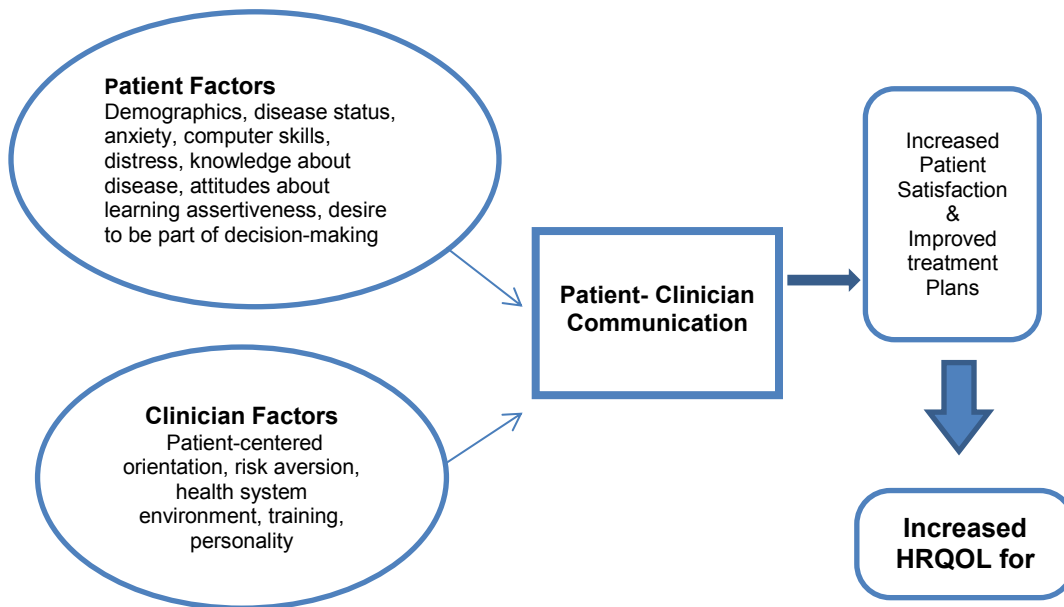
Figure 4.2.1: Conceptual Framework

The tool for PRO collection was implemented to elicit and understand patients' concerns and needs for information alongside the dynamic factors in the diagram which interact to influence patient-centered communication. Patient reports can bring an opportunity for patients and clinicians to reach a shared understanding of problems and treatments, as well as help patients be involved in their care to the degree that they wish. Patient factors, including current disease status and physical symptoms, as well as psychological distress and anxiety, often overwhelm women during clinic visits. Clinicians have varying degrees of comfort in addressing the disease trajectory of ovarian cancer, especially near end-stage, and have little training on how to discuss QOL issues and patient preferences. There can also be an unconscious collusion between patient and oncologist to avoid speaking about death and dying (Back, 2010). The clinical encounter, however, is primary to patient-centered care and identifying patient's information needs, preferences

for treatments, and ensuring better outcomes including how to maintain the best QOL during and after treatments, and when to stop actively treating cancer. For this population of oncology patients, diagnosed at Stages 3 and 4, good communication with their provider is extremely important.

4.3. Hypotheses

The 2 main hypotheses for this research were:

H1. There will be a difference in reported satisfaction with communication by patients between the intervention and control groups.

> H1a.) Patients in the intervention group will report greater improvements in satisfaction with communication than patients in the control group.

> H1b.) Patients in the intervention group who use the *Questions Box* more will report greater satisfaction with communication than patients who use it less.

H2. Patients who use the *Questions* box will change their reported anxiety from time 1 (baseline) to time 2 (60 days post baseline).

> H2a.) Patients in the intervention group will report a greater decrease in anxiety than those in the control group.

> H2b) Patients in the intervention group who use the *Questions* box more will report a greater reduction in anxiety levels about communicating with their providers than patients who use it less.

4.4 Experimental Design and Data Collection

Design: The study was a randomized controlled trial with pre- and post-study surveys for the control and intervention groups, designed to test the communication tool. The

particular goals were to determine the frequency and type of health care issues reported on the *Questions* box, and to obtain preliminary information on acceptability, ease of use, and measured changes in perceptions of improved communication and anxiety.

Study Population: Participants were women with advanced stage (III/IV) or recurrent ovarian cancer, primary peritoneal, or fallopian tube cancer who were at least 18 years old, with at minimum a fifth grade education. Participants were also required to be able to read and write in English, have access to a computer and the internet, and have no documented history of psychiatric issues other than depression. All participants provided voluntary written informed consent prior to study entry.

Recruitment: To examine the short-term efficacy of the PROs tool, 53 women fitting the eligibility criteria were recruited from the Gynecological Oncology Clinic beginning in early September, 2012. Participants were recruited in the clinic by the study coordinator. Those who agreed to participate were consented and immediately registered into the study using the website page below, creating a new user account. Registration information included their first and last name and email address. The disease status - newly diagnosed, first recurrence, multiply recurrent, remission - was also recorded. They were assigned a patient ID number immediately upon completion of registration. The registration screen is displayed below.

Figure 4.4.1 Registration Website Screenshot
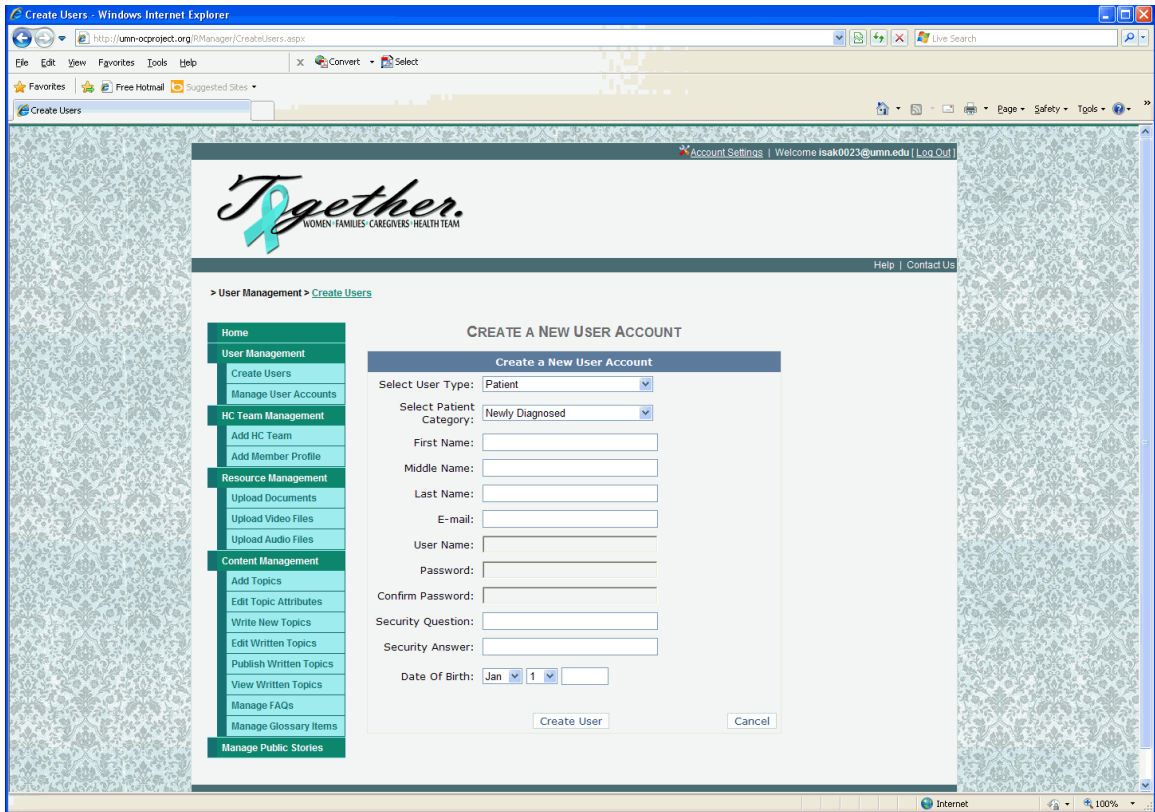
It was important to collect participants' disease stage because it was used in the intervention group for recommending topics from the *Learning Library* that would be most relevant to the women as determined by their disease progression. Thus, subjects at the same stage received the same reading recommendations, which had been pre-programmed into the website.

Measures: Measures were collected at baseline and 60 days post-baseline. Demographics collected included age, race/ethnicity, income, education, religion, and relationship status. Disease information collected included years since ovarian cancer diagnosis, current stage, and whether or not they were receiving chemotherapy during the 60 day

trial period. Psychological measures included perceived seriousness of disease threat, style of coping with threatening situations, and anxiety and depression measures. Frequency and confidence with computer use were also collected. This data, as well as validated survey questions about patient-provider communication and satisfaction, and two new questions original to the study were collected pre- and post-study for assessing the *Questions Box*.

Procedures: The study was conducted in accordance with the International Conference on Harmonisation (ICH) for Good Clinical Practice (GCP), the Declaration of Helsinki, and the appropriate regulatory requirement(s). The University Of Minnesota IRB reviewed and approved all appropriate study documentation in order to safeguard the rights, safety and well-being of the patients.

Following registration, enrolled women completed a baseline survey for the larger study, which imbedded the survey questions to evaluate the usefulness of the *Questions Box*. Upon completion of the pre-survey, participants were immediately randomized into the intervention or control group. Participants randomized to each website had open access for a minimum of 60 days. During enrollment, all participants agreed to access the website at least 2-3 times per week.

Patients logged into the website each time they accessed it. "Access" was defined as any activity on the website. At 60 days post-baseline measures, all participants received an e-mail informing them they were eligible to complete the post-study survey. If not completed within 2 weeks, a follow-up phone call by the study coordinator was initiated. Upon completion of the study, a $50 gift card was mailed to each patient.

The intervention website included instructions regarding how to use the *Questions for My Healthcare Team* text box, and a notification (repeated throughout the website) that their provider would not answer or see questions entered unless they were printed or accessed electronically during an appointment. Directions for use suggested printing out their questions at home, using an electronic device of their own and bringing it to the clinic, or accessing the site through one of the iPads purchased for the study in the clinic. In addition, there was a secure computer off of the clinic lobby with a printer that patients could use while waiting for a clinic visit.

5. DATA ANALYSIS

5.1 Introduction

The *overall* goal of PROs at the clinical level of care is to improve QOL for patients by providing a means to aid and supplement their communication with providers and improve health care outcomes. Due to the short length of this intervention--60 days of access/usage by each patient--this study did not attempt to measure improvements in those long-term goals (healthcare outcomes), but rather to create a user-friendly tool that had perceived value by users and to forward a process of improved patient-provider communication. Statistical analyses were conducted using an intention-to-treat analysis, with all participants being analyzed regardless of the number of times they logged into their respective website during the 60 day trial.

5.2 Study Population

Of the 53 women with ovarian cancer recruited, 35 finished the pre-study survey and 29 finished the post-study survey. Eighteen subjects dropped out after recruitment, prior to

taking the survey and randomization; reflecting a high drop-out rate. A total number of

20 women were randomized into the intervention group, and 15 into the control group.

One subject was dropped as she was out of state, and recruited initially in error.

Figure 5.2.1 Enrollment and Randomization of Women with Ovarian Cancer
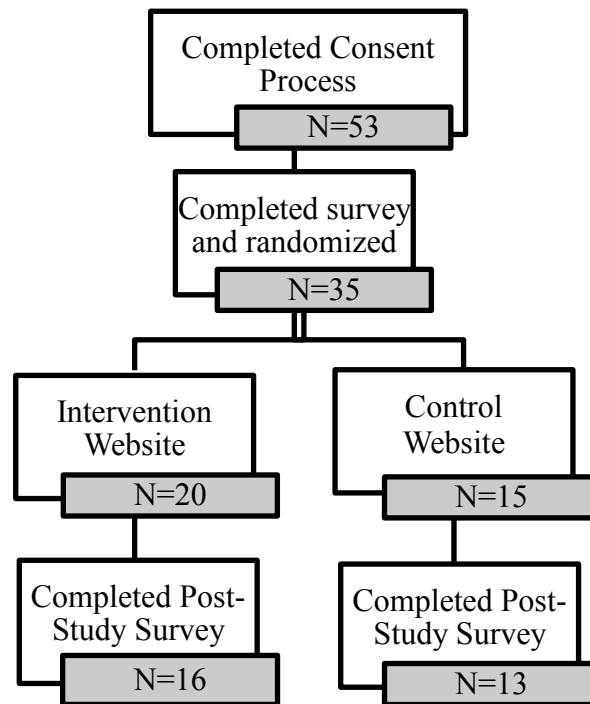
Six women did not complete the post-survey. A table of comparison of women who

consented and then dropped out verses those who completed follows. Patients who

completed the study did not appear to differ statistically by whether or not they were in

chemotherapy treatment, p-value 0.77, but were more likely to complete the study if they

were younger (mean age 57.9 v. 63.3), p-value 0.05.

Further analysis of participation by disease stage required using an adjusted p-value.

Adjusted p-value means adjusted for multiple comparisons; technically the correct p-

value to use. Using the adjusted p-value of 1.00, disease stage was significant. In this

case, it seems that the significant p-value is driven by the difference in participation between those with first recurrence and multiply recurrent and possibly the difference between those with first recurrence and remission.

Table 5.2.2. Comparison of Women who Consented by Participation in Study

| Variable | Dropped out after recruitment | | Completed Study | | |
	N	%	N	%	p-value
Disease Status					0.094
Newly Diagnosed	5	27.8	11	31.4	
Remission	6	33.3	8	22.9	
First Recurrence	1	5.6	11	31.4	
Multiply Recurrent	6	33.3	5	14.3	
In Chemotherapy					0.777
No	8	44.4	14	40.0	
Yes	10	55.6	21	60.0	
	N	Mean (SD)	N	Mean (SD)	
Age at Study Entry	18	63.3 (9.2)	35	57.9 (9.5)	0.052

	Unadjusted p-value	**Adjusted p-value**
Newly diagnosed vs. Remission:	p=0.707	p=1.00
Newly diagnosed vs. First Recurrence:	p=0.197	p=1.00
Newly diagnosed vs. Multiply Recurrent:	p=0.264	p=1.00
Remission vs. First Recurrence:	p=0.081	p=0.486
Remission vs. Multiply Recurrent:	p=0.695	p=1.00
First Recurrence vs. Multiply Recurrent:	p=0.027	p=0.162

Demographic and clinical data collected on women who completed the study is detailed below. The women were mostly white, highly educated, worked outside of the home, and were married or partnered. More than a fifth of the women who completed the study had a low household income level (< $25,000).

Table 5.2.3 Demographic and Clinical Data – Women with Ovarian Cancer (N=35)

Variable	N	%
Race/Ethnicity		
White, Non-Hispanic	30	90.9
Other	3	9.1
Missing	*2*	
Highest Education		
Did Not Graduate High School	1	2.9
High School Graduate	6	17.7
Some College	15	44.1
College Graduate	11	32.4
Professional School	1	2.9
Missing	*1*	
Work Outside of Home		
Yes	23	32.4
No	11	67.7
Missing	*1*	
Annual Household Income		
<$25,000	8	22.9
$25,000-$49,999	7	20.0
$50,000-$74,999	11	31.4
$75,000-$99,999	2	5.7
>$100,000	7	20.0
Marital Status		
Single	4	11.8
Married/Partnered	22	64.7
Divorced	6	17.7
Widowed	2	5.9
Missing	*1*	
Living Arrangement		
I live with someone.	25	73.5
I live alone.	9	26.5
Missing	*1*	
ChemoTreatment During Study		
Yes	21	60.0
No	14	40.0
History of Other Cancer*		
No	28	80.0
Yes	7	20.0

Survey reports of computer skills were slightly higher than expected at "good" (43.6%) to "very good" (15%). Over half indicated that they used a computer several times and more than 80% of the subjects felt confident using the internet. (See Appendix Table 2A for detail.)

5.3 Communication Survey Results

Primary analyses focused on comparing the changes from baseline to post-study (60 days) by intervention group among the women on questions related to communication with their oncologist. The differences in change in proportions between randomized groups were performed using Fisher's Exact tests (SAS 9.3,Cary, NC). Results of the questions to evaluate outcomes on communication and satisfaction with communication with their oncologist follow.

Table 5.3.1. Communication with Provider – by Study Group

| | Pre-Study N=35 | | | | Post-Study N=29 | | | | |
| | Control | | Intervention | | Control | | Intervention | | P* |
Question	N	%	N	%	N	%	N	%	
I bring a prepared list of questions to my clinic appointments .[1]									0.42
Always	3	20.0	5	25.0	5	38.5	3	18.8	
Sometimes	12	80.0	14	70.0	8	61.5	13	81.3	
Never	0	0.0	1	5.0	0	0.0	0	0.0	
Overall Satisfaction with relationship with oncologist:									0.80
Very Satisfied	14	93.3	18	90.0	10	76.9	13	81.3	
Somewhat Satisfied	1	6.7	2	10.0	2	15.4	3	18.8	
A Little Satisfied	0	0.0	0	0.0	1	7.7	0	0.0	
Not Satisfied	0	0.0	0	0.0	0	0.0	0	0.0	
After leaving my appointment, I am frustrated when I realize I forgot to ask my doctor something important to me. [1]									0.95
Strongly Agree	1	6.7	1	5.0	3	23.1	3	18.8	
Agree	5	33.3	5	25.0	3	23.1	4	25.0	
Disagree	8	53.3	13	65.0	5	38.5	8	50.0	
Strongly Disagree	1	6.7	1	5.0	2	15.4	1	6.3	

Question	Pre-Study N=35 Control		Intervent.		Post-Study N=29 Control		Intervent.		P*
	N	%	N	%	N	%	N	%	P*
I don't feel comfortable asking comfortable of my doctor. [2]									1.00
Strongly Agree	0	0.0	0	0.0	0	0.0	0	0.0	
Agree	1	6.7	0	0.0	1	7.7	2	12.5	
Disagree	4	26.7	13	65.0	5	38.5	6	37.5	
Strongly Disagree	10	66.7	7	35.0	7	53.9	8	50.0	
My doctor explains things to my satisfaction. [3]									0.58
Strongly Agree	9	60.0	9	45.0	7	53.9	8	50.0	
Agree	5	33.3	11	55.0	5	38.5	8	50.0	
Disagree	1	6.7	0	0.0	1	7.7	0	0.0	
Strongly Disagree	0	0.0	0	0.0	0	0.0	0	0.0	
My doctor asks me about my symptoms and questions. [4]									0.84
Strongly Agree	12	80.0	12	60.0	6	46.2	8	50.0	
Agree	3	20.0	8	40.0	7	53.9	8	50.0	
Disagree	0	0.0	0	0.0	0	0.0	0	0.0	
Strongly Disagree	0	0.0	0	0.0	0	0.0	0	0.0	
My doctor is interested in my worries about my illness. [5]									0.20
Strongly Agree	8	53.3	9	45.0	5	38.5	8	50.0	
Agree	6	40.0	8	40.0	8	61.5	5	31.3	
Disagree	1	6.7	2	10.0	0	0.0	3	18.8	
Strongly Disagree	0	0.0	1	5.0	0	0.0	0	0.0	
My doctor explains things clearly to me. [6]									0.45
Strongly Agree	10	66.7	10	50.0	8	61.5	8	50.0	
Agree	4	26.7	9	45.0	4	30.8	8	50.0	
Disagree	1	6.7	1	5.0	1	7.7	0	0.0	
Strongly Disagree	0	0.0	0	0.0	0	0.0	0	0.0	
Sometimes my doctor does not listen to me. [3]									1.00
Strongly Agree	0	0.0	0	0.0	0	0.0	0	0.0	
Agree	2	13.3	0	0.0	1	7.7	2	12.5	
Disagree	4	26.7	11	55.0	5	38.5	5	31.3	
Strongly Disagree	9	60.0	9	45.0	7	53.9	9	56.3	
I often leave my doctor's office with unanswered questions. [7]									0.84
Strongly Agree	0	0.0	0	0.0	0	0.0	0	0.0	
Agree	2	13.3	2	10.0	1	7.7	1	6.3	
Disagree	5	33.3	10	50.0	9	69.2	9	56.3	
Strongly Disagree	8	53.3	8	40.0	3	23.1	6	37.5	

* Compare post-study proportions between treatment groups

[1] Original to study
[2] Galassi, Patient Communication, 2003
[5] Flocke, Satisfaction with Interpersonal Communication, 1998
[3] Stewart, Patient Solicitation, 2000
[4] Little, Communication and Partnership, 2001
[6] Little, Clear Communication and Patient Reaction, 2001
[7] Ramsay, Clinician-Patient Communication, 2000

There were no statistically significant differences between those with access to the *Questions* box on the *Together* website and the control group on measures of self-reported satisfaction with communication with their provider, satisfaction with explanations, or satisfaction with physician solicitation of symptoms and questions. Other findings (although not statistically significant) pointed to a slight increase in feeling that their doctor is interested in their worries about their illness.

Post-study free text comments from participants expressed appreciation for the website, reflecting understanding of a "desire to help" and the provider wanting to share information.

5.4 Questions Box Usage: Results

The intervention group of 20 women with ovarian cancer had access to the *Questions* box for a minimum of 60 days. Due to the small study sample, no statistically significant results could be drawn from its use. Final data reports showed the following regarding the 16 (of the original 20) who completed the post-survey:

- 2 women entered questions in the box and saved them (12.5%)

- 4 patients total (25%) clicked on it a total of 14 times

- 5 questions (total) were entered and saved by 2 patients

For those who used the *Questions for My Healthcare Team* box, specific questions related to its use were programmed to appear in the post-study. While only two users noted using the *Questions* box, responses suggested that the text box was easy to use, that one patient did view the *Questions* box content with her provider, and that it was helpful in tracking symptoms. One woman agreed that it helped her communicate with her doctor, and the other reported it did not. One user was in active chemo treatment and the second was not. There was insufficient participation to test whether patients who used the *Questions* box more frequently than others resulted in greater satisfaction with communication with their provider (H1B). Low rates of use also prevented the testing of rates of usage of the Questions box and reductions in anxiety about communicating with their oncologist (H2b).

Table 5.4.1 Intervention Only - Question for my Healthcare Team

Question	N	%
Did you use the Question for my Healthcare Team box on your webpage?		
No	14	87.5
Yes	2	12.5
Did your doctor(s) view Question for my Healthcare Team and talk about your listed concerns with you during your appointments?		
Yes		
No	0	0.0
Missing	1	50.0
	1	50.0
Recording my questions/concerns was easy and convenient.		
Strongly Agree	0	0.0
Agree	2	100.0
Disagree	0	0.0
Strongly Disagree	0	0.0
Recording my questions helped me reduce my feelings of anxiety about communication with my doctors.		
Strongly Agree	0	0.0
Agree	1	50.0
Disagree	1	50.0
Strongly Disagree	0	0.0

Question	N	%
It improved my communication with my doctor(s).		
Strongly Agree	0	0.0
Agree	1	50.0
Disagree	1	50.0
Strongly Disagree	0	0.0
It helped me track my health status and symptoms.		
Strongly Agree	0	0.0
Agree	2	100.0
Disagree	0	0.0
Strongly Disagree	0	0.0

A table of the questions entered was accessible from a de-identified report generated at the close of the study. Questions/concerns entered related to disease information and symptom management:

Table 5.4.2 Questions/Concerns entered in to Text box

- Ask my doctor about recurrence.

- What exactly is known about Psammocarcinoma?

- Can I eat soy nuts? I have read a lot of articles linking soy to cancer and was wondering if I could resume eating soynuts?

- What can I do about the leg cramps I am experiencing? I get them almost nightly and it has been for almost over two weeks.

- I have having severe cramping in my lower abdomen into the lower part of my back on the left side

The database administrator ran final post-study reports required by investigators and programmed prior to the website launch, including all usage data of the intervention

website's tools. The final report is below and shows that the *Question for My Healthcare Team* box fell in the mid- range of being accessed (defined as clicking on it) compared with the other tools; but by just 4 patients total - low in comparison to the other tools.

Table 5.4.3 Together Patient Tools Usage

Item	# Times Accessed*	# Users Accessed
Distress Thermometer	33	11
Action Plan	31	15
Discussion Forum	26	11
Calendar	21	12
Healthcare Team	19	10
Clinical Trials	16	11
Questions for Healthcare Team	**14**	**4**
Journaling	12	9
Events	11	8
Glossary	11	7
Healthcare Directive Form Page	10	8
Healthcare Directive PDF	2	2

*Clicked on

Post-study, the intervention patients were asked to rate their satisfaction with the individual website features and tools. Five patients or 1/3 of the women reported being somewhat satisfied or very satisfied with the *Questions for My Healthcare* box. The majority reported that they did not use the tool or did not remember if they did. The following table details survey results and analyses of all of the interactive tools on *Together*. One subject did not complete this section of the post-survey, leaving 15 responders from the intervention group.

Table 5.4.4 Intervention Only - Satisfaction with Tools/Features.

	Don't Remember /Did Not Use		Very Dissatisfied		Somewhat Dissatisfied		Somewhat Satisfied		Very Satisfied	
Feature	N	%	N	%	N	%	N	%	N	%
Calendar	9	60.0	0	0.0	0	0.0	4	26.7	2	13.3
My Action Plan	8	53.3	0	0.0	0	0.0	5	33.3	2	13.3
Learning Library/Topics	6	40.0	0	0.0	0	0.0	5	33.3	4	26.7
Healthcare Directive Form	9	60.0	0	0.0	0	0.0	1	6.7	5	33.3
Distress Thermometer	8	53.3	0	0.0	0	0.0	3	20.0	4	26.7
Journaling	10	66.7	0	0.0	0	0.0	3	20.0	2	13.3
Discussion Forum	7	46.7	0	0.0	2	13.3	4	26.7	2	13.3
Clinical Trials	8	53.3	0	0.0	0	0.0	6	40.0	1	6.7
Glossary	8	53.3	0	0.0	0	0.0	4	26.7	3	20.0
Healthcare Team	7	46.7	0	0.0	1	6.7	3	20.0	4	26.7
Question for My Healthcare	9	60.0	0	0.0	1	6.7	4	26.7	1	6.7
Amount of Information shared with my caregiver	8	57.1	0	0.0	0	0.0	4	28.6	2	14.3

6. CONCLUSIONS

6.1 Website Use

At the close of the study, database reports were run on all activity on Together by patient ID numbers: every log in, time active for that log in, topics accessed from the *Learning Library*, as well as tools clicked on (accessed) and tools actually used. Overall use of *Together* was lower than expected, and is detailed below:

Table 6.1 Actual Use Data

Control Website:
Number of Users beyond the survey: 14 (out of 15 who completed pre-survey)
Numbers of Log-ins: 62
Number of Log-ins per person: Median (Range) = 4.5 (2-8) times
Time per Session: Mean (SD) = 15.9 (8.7) minutes*

Intervention Website:
Number of Users beyond the survey: 20 (out of 20 who completed pre-survey)
Numbers of Log-ins: 100
Number of Log-ins per person: Median (Range) = 4.5 (1-13) times
Time per Session: Mean (SD) = 19.9 (14.6) minutes*
        *Those in the intervention group spent significantly longer on the website (p=0.049).

Item	# Times Accessed*	# Users Accessed
Learning Library		
Living with Ovarian Cancer Video	3	3
Advance Health Directive	2	2
Anxiety	1	1
Being a Caregiver	1	1
Clinical Trials	4	4
Communicating with Family	1	1
Communicating with Providers	2	2
Decision Making	9	5
Distress and Ovarian Cancer	1	1
Emotional Health	1	1
Genetic Testing	1	1
Health Insurance	2	1
Nutrition and Exercise	4	3
Overview of Ovarian Cancer	22	12
Palliative Care	6	6
Recurrence	4	4
Action Plan	31	15
Calendar	21	12
Clinical Trials	16	11
Discussion Forum	26	11
Distress Thermometer	33	11
Events	11	8
Glossary	11	7
Healthcare Directive Form Page	10	8
Healthcare Directive PDF	2	2
Healthcare Team	19	10
Journaling	12	9
Questions for Healthcare Team	15	4

Although subjects had initially agreed to log in at least twice a week for an 8 week period at a minimum during recruitment (16 times total), the mean log-ins per patient was only 4.5 for the 60 day trial period.   Low usage was a confounding factor to use of the *Questions* box. Other studies have found that frequently eHealth applications are not used as intended and they have high attrition rates (Borosund, 2013). 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 (Ruhland, 2013).

Comments from *Together's* intervention group post-trial during informal interviews highlighted difficulties with using the *Together* intervention website and attributed their low usage to:

- Health status (fatigue, difficulty concentrating)

- Problems with access (forgetting their username or password, internet connectivity)

- Difficulty navigating the website

- Too much information displayed on a screen – "overwhelming"

- Overall stress – "not a priority"

6.2 Barriers to Questions Box Use

Patient Initiative

Due to the documented communication needs of women with ovarian cancer and the constant visibility of the *Questions for Your Healthcare Team* text box, it was hypothesized that a majority of patients in the intervention group would make use of this tool. A known concern was that use of the *Questions* box in clinic depended upon patient

initiative and planning. Disease burden was observed and noted by this researcher when assisting during recruitment and also noted in post-study comments by study participants; primarily extreme fatigue and difficulty concentrating due to active chemotherapy treatment. Learning how to navigate and use new website with these side effects was a challenge, and for a few women, not possible during the 60 day trial period.

No real-time connectivity

Patients who did access the intervention site with the *Questions* box were told within the website that their questions could not be answered on a real-time basis, as through email. If the questions *could* have been answered by a nurse/clinician via email or phone in a timely manner, the tool may have had greater *perceived* value and therefore increased usage. Literature reviews reveal that physicians perceive the agreement to answer email from patients as an extra *liability* as well as time consuming (Epstein, 2005). The oncologists at this clinic currently do not accept any electronic communications from patients (including through MyChart) and similarly, cite time shortage, liability, and lack of funding for a designated clinician for monitoring and responding. There was not funding from the study itself for a nurse to review and answer items from the website. Post-study, 4 participants were interviewed about the *Questions* box using open-ended questions to solicit feedback. Three reported viewing it on *Together*, and thought it was a "good idea". Two of these women said they would have used it if it had real-time connectivity to their provider for answers; a third suggested that it be changed for response by email through the University/ Fairview system's MyChart. The fourth woman with ovarian cancer was in chemotherapy treatment and reported viewing the

website very few times and not using any of the tools, due to side effects. They all expressed an appreciation for access to the website as a whole, regardless of usage.

Lack of Clinician Solicitation

The Gynecologic Oncology Clinic is more protocol-driven than other specialty clinics, with significant patient variation and appointment delays due to morning surgeries of unpredictable length. Introducing a new technology into a clinical encounter is challenging in general; introducing a tool like the *Questions* box into this complex healthcare clinic with competing priorities and time constraints was expected to be more difficult. As studies have shown that nurses are more likely to review patients' reports of QOL issues than doctors (Hilarius, 2008), it was a possibility that the questions entered by patients may have been discussed when first seen by a nurse during rooming, when solicitation of symptoms and vital statistics are taken. In addition, an ovarian cancer patient has every other clinic visit with a nurse practitioner instead of her oncologist during treatment, and opportunities to speak with each type of provider took place during the trial period. The communication tool, however, was reported as used just once during a clinic visit.

Interventions like this tool have been identified to be complex and challenging as they aim to change both clinician and patient behavior with a number of shorter term outcomes needing to be achieved before the longer term desired improvements in patient outcomes and QOL can be achieved (Greenhalgh, 2008). They work best with strong clinician engagement, high level administration involvement, and adequate time to become accepted as a standard part of workflow (Hilarius, 2008).

Health Status, Stress, and Short Time Frame

The study period was just 60 days reflecting its purpose to pilot and test a prototype to inform future research. This time frame, if complicated by chemotherapy or poor health state, did not allow for use while feeling better. One user commented that it "was not a priority". With such a short time frame and the study protocol requiring that a participant be in active treatment during the trial period, use was likely affected by health status.   A large percentage - 60% - of the study participants were in chemotherapy during the 60 day trail period, randomized approximately equally into both arms. The side effects of chemotherapy can cause extreme fatigue and memory loss or foggy thinking (chemo-brain). Some patients were recruited on infusion days and had difficulty remembering how to access the site at a later time. When they could log on, users commented to the study coordinator that the website had "too much information" to navigate or that they were "too tired". As part of the trial was designed to measure the effect of education on specific patient outcomes, providing a lot of education topics and information was deemed a requirement, but was reported by users as overwhelming, thus deterring use. In addition, as shown in the demographics data, 22% were financially stressed (household income < $25,000) while burdened with additional costs related to their disease. The social networking feature also did not work as planned. Recruitment took place over a 6 month time period, so while early users were told there may not be enough participants to communicate with initially, that this might change with time. Participants who attempted to post to the social forum stopped when there was no response from others. This part of *Together* was designed both for social support and as a feature that was likely to increase

47

logins to the site and more use overall. If this feature had worked, there may have been more activity and overall access of *Together* and its tools.

Coping Styles

Pre and post surveys from the larger study included validated measures for Emotional and Social Health among patients. Pre-study survey data showed an equal balance between styles of coping with distressing medical information. Approximately half of the participants were information seekers; the other half avoided or "blunted" distressing medical information. Not every patient wants to ask questions about their disease. Some prefer to have the doctor manage knowledge-sharing and make decisions ("blunters"). It seems likely that the women with ovarian cancer who were not information seekers (50%) would then be less likely to use the *Questions* box, as they avoid new information in order to avoid increased anxiety (Petzel, 2010). Coping and styles of information-seeking determine whether patients will take the initiative to ask questions. In this case, 50% fell into the group that would be considered less likely to use a text box listing questions for their oncologist This finding emphasizes the importance of using a larger sample size to test a communication feature like this for meaningful, statistical significance.

Disease Stage

Two patients commented that they would have used this website earlier in the course of their disease, when they first needed information. Because they had had ovarian cancer for some time, they already had disease, symptom management, and coping information.

The Questions box was less likely to be used by this type of patient, who was already well-informed.

6.3   Summary of Findings: Overcoming Identified Barriers

This study had numerous limitations, many due to the communication tool being dependent upon the *Together* website – a pilot website with limited funding and documented usability issues. In addition, *Together*'s protocol required that participants be in active treatment with access to both sites for only 60 days. The study was also vulnerable to selection bias - it was conducted at a single academic gynecological oncology clinic which sees predominately educated, white, insured women. It also required access to a computer with internet connectivity, in an era where access to mobile phones is more prevalent, especially in rural areas (Hesse, 2010). However, the study identified problems to avoid and provided insights for future research. In particular, recommendations for designing and testing a new intervention to assist with ovarian cancer patient-provider communication between clinic appointments are the following:

- Develop a secure, mobile app - with high ratings for design and usability - for free text questions that connects to the patient EHR with a dedicated clinician for response within 24 hours, meeting CMS Meaningful Use criteria
- Make it available to a larger number of ovarian cancer patients (other studies have used 300+), at all stages of disease and across multiple health systems, allowing for more power for statistical analysis
- Keep the app simple; maintain cancer education and other tools separately

- Require clinician education on the app and review of entries sent to the EHR during a clinic appointment

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In the *WebChoice* study, the highest rated component was receiving an answer from a nurse by a phone call back. Good response time and feeling supported are extremely important to the communication process and patient-centered care, especially in complex healthcare domains like ovarian cancer. A communication tool must provide real-time connectivity and reasonable response time to be perceived as useful and to be used by patients to improve the communication process.

7. FUTURE DIRECTIONS

Recent, similar studies have found that frequently eHealth websites are not used as intended and that they have high attrition rates (Borosund, 2013). As presented earlier, despite a number of potential benefits to both the clinician and the patient, patient-reported measures of health have not been commonly or systematically used within routine practice by clinicians in the care of individual patients. There are a number of practical, methodological and attitudinal barriers which have so far limited the use of PROs within routine practice. The extent to which these barriers are overcome is likely to influence the effectiveness of such instruments in improving the process and outcomes of patient care. There is a strong need for research on the use of patient-reports of health moving forward. Currently, there is great variety across health care environments in the type of instrument used - paper, website, mobile application - as well as how, when and where the patient uses it, when the clinician views it, whether training is provided, as well

as the nature of the PRO data itself (Greenhalgh, 2008). With a new emphasis on patient-centered care and a need to prove cost-effectiveness, the inclusion of patient entered data into the clinic appointment of the chronically ill seems inevitable.

Creating a PRO tool designed for ease of use on a mobile device and providing training for both patients and clinicians on how and when to use it is in the planning stages for a future research study. Healthcare is rapidly moving to the mobile platform, which allows for easy access and the creation of tools for patients to assist them in managing chronic disease. Other cancer clinics, such as Johns Hopkins, are using nurse 'navigators' to facilitate patient care and to answer questions by phone or email as they arise. This type of intervention and extra guidance has been proven successful in research studies at other institutions as well (Ruhland, 2012).

A study conducted on 325 breast and prostate cancer patients in Norway for a period of one year and published recently (Børøsund, 2013), found statistical evidence that different user characteristics are associated with different use patterns of e-messages to doctors. Latent class and latent transition analysis (LCA) where a cluster of psychosocial variables was tested with single user variables was applied to this study's results to target future web-based support. The LCA revealed that lower levels of social support, higher levels of symptom distress, and higher depression were associated with higher use of messages to oncology nurses. The relevance of these findings is that there are many cancer patients in need of additional supportive care, between clinic visits, and patients do reach out for help when it is provided in a timely, efficient manner. E-messaging

should be a part of patient-centered care to answer these needs and to augment the communication process.

In October of 2012, CMS issued final Stage 2 Meaningful Use eligible professional core objectives. One of these 17 items was "Use secure electronic messaging to communicate with patients on relevant health information". A recent informal review of ovarian cancer centers across the country found that e-messages from patients are slowly becoming an added feature on patient portals, usually responded to by the next working day. Disease education is provided in a non-interactive website. With financial incentive from CMS to use secure e-messaging to communicate, this model of patient-provider communication will likely become more common over time.

The ovarian cancer patient population is unique, with complex symptom clusters. Oncologists at the University clinic have recognized a need for more patient-centric care, coordination, and communication. After the results of the larger study are published, it is expected that the system will evolve into a mobile application with less "education" but more practical tools. An automated system of information exchange between patient and provider has been proposed, whether through the adoption of e-mail alerts, automatic feeds into the EHR, or a combination of both.

For providers, the goal of viewing PROs and communicating more completely with patients is to affect their management and treatment plans in a positive manner. For their part, patients will also have to participate in the discussion of how they want to work together with clinicians. Patient-centered care is premised on the idea that clinicians and patients share a common human experience, even though their roles may exaggerate the

distance in their positions (Step, 2009), and is relationship-based. Mastering communication with very ill patients is a skill that can be taught to providers and requires active listening, appropriate emotional response, and an ongoing commitment to the patient's care (Back, 2010).

At the spring event of 2010, ovarian cancer patients identified the following desires for their care from providers:

- Respect of patient goals

- Listening to the needs of the patient and caring about what she says

- Help in understanding medical "jargon" in order to learn to communicate concerns and needs best

- Caring response to patient needs and wants

- A team who is available 24/7

- A "planful" approach – help in knowing what to expect and how decisions will impact day-to-day function/life

- Allowing the patient to drive their care and having their "team" support them

- Open communication options and honesty to help make decisions

- Recognizing the uniqueness of each patient

These elements are a reflection of a desire for patient-centered care, and state clearly what they want from their oncologists: compassion, respect, accessibility, and improved communication on many issues from a "team" of providers. Supportive communication tools that technology has made possible can assist in helping to meet these wishes. Previously published research has indicated that cancer patients have extensive

informational needs about the disease process, likelihood of cure, and treatment options. Patients have also reported a desire to know what they will experience during treatment and ways to decrease treatment-related adverse effects. The current supportive climate for patient involvement at the University of Minnesota Gynecological Clinic has the potential to overcome likely short-term challenges to an electronic messaging system with timely provider response by a dedicated nurse coordinator such as been proposed moving forward. As CMS has recently added incentive, the clinician-patient relationship can be changed across healthcare domains. Good communication can minimize the emotional distance between providers and their patients and result in greater satisfaction for both parties. Future studies will evaluate the outcomes of e-messaging to learn:

- How to best encourage patient participation

- What differences result between prompted and self-initiated patient reports (e-messages)

- How best to leverage the PROs for use in the electronic health record

Longitudinal studies linking better patient outcomes to better communication are especially needed. Conceptual models are still in their infancy. This research study was a small step in learning how to provide tools to patients that will be used and assist in the process of improving communication for a patient group that is faced with many complex health issues.

Human Subjects Protection

The study was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects. All

patient data was de-identified using the safe-harbor method. Approval for this study was obtained from the University of Minnesota Institutional Review Board (Study Number: 1201S09521).

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Conflicts of Interest

The author declares that she has no conflicts of interest in this research.

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Table A.1. Health and Ovarian Cancer Knowledge – by Study Group (among completers)

	Pre-Study		Post-Study				
			Control		Intervention		
Measure	**N**	**Mean (SD)**	**N**	**Mean Change (SD)**	**N**	**Mean Change (SD)**	**P-value**
Health Literacy[1]	35	66.4 (2.7)					
Ovarian Cancer Quiz[2]	35	8.3 (1.6)	13	-0.1 (1.0)	16	0.4 (1.2)	0.209
Attitudes about Learning[3]	35	63.2 (7.1)	13	-2.2 (3.0)	16	-0.9 (4.8)	0.431

[1] Ranges from 0-70, higher is better
[2] 10 True/False items, Score range 0-10
[3] 21 items related to learning about cancer, Score range 21-84, higher is better

Table A.2. Computer Experience: Pre-study

	Patients (N=35)	
Question	**N**	**%**
How Often Use Computer		
First Time	3	8.6
A few times a month or less	3	8.6
Once a week	3	8.6
Every day or two	7	20.0
Several times a day	19	54.3
Rating of computer skills		
Poor	3	9.4
Fair	10	31.3
Good	14	43.8
Very Good	5	15.6
I am confident in my computer skills.		
Strongly Disagree	1	2.9
Disagree	4	11.8
Agree	22	64.7
Strongly Agree	7	20.6
I am confident using the Internet.		
Strongly Disagree	0	0.0
Disagree	6	17.7
Agree	17	50.0
Strongly Agree	11	32.4
I am confident in searching the Internet for health information.		
Strongly Disagree	0	0.0
Disagree	5	14.3
Agree	17	48.6
Strongly Agree	13	37.1
I am confident about the accuracy of health information I find on the Internet.		
Strongly Disagree	0	0.0
Disagree	12	35.3
Agree	19	55.9
Strongly Agree	3	8.8
I am confident in my abilities to use e-mail.		
Strongly Disagree	1	2.9
Disagree	1	2.9
Agree	13	38.2
Strongly Agree	19	55.9

Table A.3 Use and Satisfaction with the Website – by Study Group

		Post-Study			
		Control		**Intervention**	
Question	**N**	**%**	**N**	**%**	**P-value***
Information provided was relevant to me.					0.721
Strongly Agree	4	30.8	3	20.0	
Agree	5	38.5	6	40.0	
Neither Agree nor Disagree	2	15.4	5	33.3	
Disagree	2	15.4	1	6.7	
Strongly Disagree	0	0.0	0	0.0	
The website was interactive.					0.616
Strongly Agree	2	15.4	2	13.33	
Agree	4	30.8	6	40.0	
Neither Agree nor Disagree	7	53.9	5	33.3	
Disagree	0	0.0	2	13.3	
Strongly Disagree	0	0.0	0	0.0	
The website was at the 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	
Strongly Disagree	0	0.0	0	0.0	
It was easy to find the information important to me.					0.269
Strongly Agree	1	7.7	4	26.7	
Agree	8	61.5	4	26.7	
Neither Agree nor Disagree	3	23.1	6	40.0	
Disagree	1	7.7	1	6.7	
Strongly Disagree	0	0.0	0	0.0	

Table A.4 Post-Study Free Text Comments "Is there anything else you would like to share with us regarding the website?"

INTERVENTION

• nope
• I sent you a long note on this question. Did you receive it? I was booted back to a previous page of the survey when I hit the proceed button. In essence, I said that I regret how little I took advantage of this site and that I would like to start over! My lax minimally used computer skills and the bubble of good health that I have been in since joining Dr. Geller in June of
• I wish I would have had this info when I was first diagnosed. It was very informative.
• Very nicely done. Easy to find things.
• very poor communication between health care providers and myself. I asked several questions on the website and never received a response.
• I wish there would have been more participants to chat with about ovarian cancer.
• Had a hard time logging in and finding website. So I feel I did not use it properly. Some reasons are my lack of computer knowledge and an overall feeling of fatigue that kept me from exploring the website. I believe it would have been more useful had I applied myself. Overwhelmed with on well feelings kept me from a lot of my normal activities. I apologize for my lack of help.
• I am not good yet with laptop and I never see any movies of this.

Table A.5 Post-Study Free Text Comments "Is there anything else you would like to share with us regarding the website?"

CONTROL

• Haven't checked it out all that much yet, but I will.
• No
• Some information about ratings for Cancer or CA 125, what do these test results mean could be included. Also more information for follow ups. I have been done with treatment for 3 years. Most questions you are asking are for those within treatment. You need to provide more information for those that have completed.
• No
• I had already found much of the information on the website elsewhere. It's nice to have it all available in one place. I have not been in need of pallative care and responses of "Not Applicable"
• A lot of repetition and hard to understand what was being said at times
• I feel I have good communication with caregiver, etc. I didn't like going to a page that was photocopied. Some may think someone was rushed to put info on there and info isn't that important.
• I came to the Website after dealing with ovarian cancer for six years...so, most of what is there I had already seen or researched. BUT...if I were a new patient to cancer, the site is very helpful.
• Some questions were a little hard to answer ie. Pallative care. I am not familiar with the info for that care.

APPENDIX B

B.1 Website Page Content Sample

Topic in Learning Library: *Communicating with your Providers*

Communication with Your Provider - Basic Information

The following topics are covered in this level:
Challenges
Ways to Prepare for Your Appointment
At the Clinic Appointment
Self-Check

Challenges

Communicating with your physician can be difficult and frustrating. You may be anxious and have many questions. While they do have your best interests in mind, doctors may have limited time to dedicate to you during your visit. Good communication is the most important part of the doctor-patient relationship.

The most common obstacles on the part of both the physician and the patient that prevent proper communication are:

- **Time**
  o Physician appointments are usually only 15-20 minutes long.
- **Communication Styles**
  o Can differ significantly between patients and their oncologists as well.
- **Emotions**
  o Fear, anger, or frustration can be present in the room.
- **Language Barriers**
  o Doctors may use medical terms that are unfamiliar to patients.
- **Fatigue**
  o Both patients and physicians may be fatigued.
  o This may cause irritability, confusion, and forgetfulness.

Ways to Prepare for Your Appointment

Being prepared will go a long way in making sure that you come out of every appointment feeling like you got your questions answered and that you understand what is going on regarding your healthcare. The following information will help to make the most of your time with your physician so appointments are more informative, efficient, and satisfying for everyone involved.

Before Your Visit: Organize Questions and Concerns using the *Together* **Questions Box**

Use the teal box on this website (pictured above) - available on **every page** below the navigation bar on the left hand side of the page - to keep a list of questions and

concerning symptoms as they come up. Type in your questions and the website will save them for you by date. A day or two prior to your visit, go through this list by clicking on the "full screen" view. You may want to add notes or additional questions. This page is also a good place to list medical terms you do not understand, or articles you have read and have questions about. It can be printed out from your computer.

You may also print this page out and bring it to your visit. It will save a lot of time during your visit by allowing you and your physician to talk about the topics that are the most important to you. If you prefer, your oncologist and nurse will be able to view your questions and concerns on their computer during an appointment to discuss them with you. They may even choose **to enter answers for you on your list** so you can refer to them later.

Identify Your Goals
In addition to your list of medical questions, identify your goals for your upcoming visit. Write down what you would like to have accomplished. You may want to share this with your caregiver. Prioritize these goals in order of importance. These may include:

- Forms that need to be completed:
  health insurance documents, leave of absence forms, disability insurance forms,
- Recent tests results to give your doctor that he may not have access to
  For example, test and imaging results from a different healthcare system.
- Providing your completed Advance Healthcare Directive

    o You can access the **Advance Healthcare Directive Form** by clicking on it from the navigation bar.

Lists to bring

- Current Medication List:
    o Prescriptions, over-the-counter, herbal supplements, vitamins, topical medications, alternative medications and treatments; allergies and previous adverse reactions; prior medications and why they didn't work.
- Medication Refills Needed
- Medical History: (if the doctor does not have this already)
    o A complete but concise summary of your medical history and all previous treatment you have received for ovarian cancer.

At the Clinic Appointment
Speak Up: Clear and open communication is a must when you are part of a team. Be straightforward even if it is embarrassing.

- Give your doctor your lists so they know what you want to discuss.
- Studies have proven that the use of lists created by patients make for better communication and outcomes.
- Keep your goals in mind.

- Ask questions as they come up.
- Don't be afraid to voice your ideas and concerns

Tips and Advice

Clarify: Use words such as "exactly" or "specifically"
Ask: How will this help me?"

What will happen if I don't do this?

When you say to increase activity, exactly what kind and how often?

Does exercise mean weights or walking?

What do you mean by "come back if not better"? When and how much better?

Negotiate: If a suggestion is unrealistic for you, say so - don't leave discouraged because you can't do it all. Doctors can simplify or adjust treatments so you can live with the recommendations.

- Request a cheaper drug or one with fewer side effects and less risk.
- Ask for an easier regimen or a less painful procedure.
- Remember: it's okay to think about your decision or change your mind.
- Never be pressured or scared into an action.

Short of a life-threatening emergency, there is always time to think things through.

Streamline your visit: Physicians today are busier than ever. Use your time with your physician wisely.

- When discussing your concerns, leave out unnecessary details.
- Studies have shown that physicians interrupt patients after about 23 seconds so use this time carefully.
- Focus on specifics.

If there isn't enough time to address all of your concerns request handouts or brochures or review this website for that information. Schedule another appointment to discuss the concerns more in depth.

Before you leave the office

- Ask the doctor for written instructions.
- Summarize and make sure to clarify anything you aren't familiar with.
- Don't leave without fully understanding your diagnosis and treatment.
  - If the doctor has left the room, ask a nurse

Self-Check

Answer the questions below to see how well you have understood the material you have read in this section. This is not a quiz and your answers will not be saved. You can return and re-check your knowledge as many times as you want.

1. Do you feel self-conscious or embarrassed when talking about your symptoms with your doctor?

Yes - This is very common. Remember that doctors are fully aware of the side effects of ovarian cancer and chemo treatment. These include sexual issues, constipation and pain. You should enter items that you find embarrassing to talk about in the pink box, so your doctor will know your problems without your having to say them. You may ask him/her to view your webpage or hand over a paper copy or list.

No - Very good. You should be open and unafraid to talk about symptoms that are troubling you.

2. Do you forget to ask important questions you have during your clinic visit?

Yes - Keeping a running list of questions for your health care provider is helpful. If you learn to use the **Questions for My Healthcare Team Box** pictured above that is on every page of this website, your doctor will have a record of your questions and concerns ready to refer to during your appointment time.

No - Good news! You for some reason you do have difficulty in the future or want the nurse or doctor to already have your list of questions and concerns, use the pink box pictured above to list them. It has been designed for your convenience and your provider can look at it during your clinic visit.

Below is a link to a brochure given out at the Gynecological Cancer Clinic. It covers many topics including those you may need to communicate with your doctor about.   <PDF Link>

For additional details, click on the next tab

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Communicating with Your Provider – Additional Details

The following topics are covered in this level:
Communicating Outside the Office
Using the Internet
Methods
Rights and Responsibilities
Video: Asking Your Doctor Questions
Suggested Action Plan

Communicating Outside the Office

I forgot to ask…Commonly, questions come to mind outside of the office. If your problem is urgent, call the office right away. Otherwise, check first to see if your question can be answered in this website. Consult your pharmacist for medication questions.

Using the Internet

The Internet is a great place for researching information to discuss with your doctor, but relying on online information for medical answers can be dangerous. There are some excellent sources of information on the internet, as well as good support sites and discussion forums. It is important to educate yourself on how to discern legitimate websites and resources from those that are scams, or full of misinformation.

Remember to look carefully at a website to see who is providing the information- is it a vendor trying to sell a product, or is there an advisory board made up of clinicians who approve all site content? Another important tip is to protect your privacy. All websites should have a privacy policy, and you should read it before using their site. Be wary of website registration forms that ask too much private information. Is there a reason they need your date of birth or credit card number for you to post in a discussion forum? Will they sell your information to other companies? These things should be explained in a privacy policy. The best advice is common sense- if they ask too much information, or it seems inappropriate trust your instincts.

The National Library of Medicine provides some great tips for using the internet to find reliable health information. Begin on their web page called Evaluating Health Information. From there you can find links to tips on Health Web Surfing, how to evaluate health information on the web, health literacy and even health related scams.

*Note: C*licking *on the link below will* **open** *a new window. Remember: if you open a new window, you need to return to the Together website to securely log out. You can securely log out by* selecting **Log Out** *from the toolbar on the upper right hand corner of the screen.*

National Library of Medicine Evaluating Health Information Website:
http://www.nlm.nih.gov/medlineplus/evaluatinghealthinformation.html

If you want to educate yourself further on how to surf the web safely, the National Library of Medicine also offers a tutorial through Medline. Their tutorial takes about 16 minutes to complete. Clicking *on the link below will* **open** *a new window. Remember to return to this website to securely log out of your session.*

Medline Plus Web Tutorial:
http://www.nlm.nih.gov/medlineplus/webeval/webeval.html

Although there is a lot of reliable informtion available for you on the internet, there is also an abundance of health related scams and "quackery." A physician, Stephen Barrett, M.D. has created a website called "*Quackwatch- Your Guide to Quackery, Health Fraud, and Intelligent Decisions*." He works closely with the National Council Against Health Fraud to help guide and protect consumers. Below are two links, the first takes you to

the main page of his website and the second will take you directly to the Quackwatch page on questionable cancer treatments. While there are many resources and people that truly want to help cancer patients, there are also people looking to take advantage of the critically ill. This website is a good resource for fake and faulty cancer claims and cures.

Before trying any alternative treatment, you should check this webpage. If you cannot find any information about it on Quackwatch, or have any questions about other information you find on the internet, you should discuss it with your healthcare team. Do not try any new medication or treatment (even if it claims to be all natural or herbal) without first consulting your healthcare team. As you will read on the Quackwatch site, a lot of these natural treatments can cause you serious harm.

Remember that clicking *on either of the links below will* **open** *a new window. Remember to return to this website to securely log out of your session.*

Quackwatch Website: http://www.quackwatch.org/index.html

Quackwatch Questionable Cancer Treatments:
http://www.quackwatch.org/00AboutQuackwatch/altseek.html

Methods

Communicating by telephone

The office nurse can handle most questions. Call early in the day, but be aware that your call may not be returned until the end of the day. Before you call:

- Try to compose a one sentence description of the problem, including symptoms and dates.
- Have medication bottles handy as well as your pharmacy phone number.
- Write down your questions and have a paper and pencil handy to record instructions.
- Inform the office if family members may receive information.

Communicating by e-mail

The majority of families with computer access want to communicate with physicians via email. Physicians generally are less comfortable with that route. Both sides have concerns about confidentiality. Currently, most doctors at the University clinic do **not** offer personal email communication. While it has benefits like ending telephone tag, speed, and cutting costs, there are risks. These include privacy and security, as well as physician concerns of staff workload and malpractice liability.

Instead of using personal, non-secure email communications, many clinics and hospitals offer patient portals where secured message communication is possible. For example, Fairview Health Services offers MyChart (http://www.fairview.org/MyChart/index.htm). At your next clinic visit, ask your provider if they offer a patient portal such as MyChart, and how to sign up for it.

Fairview's MyChart Services allow the patient to:

- Schedule appointments with a provider of your choice as well as lab work, mammograms and DEXA bone density screenings.
- Review normal test results and email your care team with any questions.
- Submit a prescription renewal request to your care team.
- Send messages and ask questions of your health care team at any time.
- View and print medical information such as visit summaries, health history, medication lists and immunization schedules.

Rights and Responsibilities

Remember, communication is a two-way street and it starts with you. Speak up!

- You have the right to understand:

o your diagnosis

  - o your symptoms
  - o tests and procedures
  - o all the risks and options.

- Your doctor has the responsibility of:

  - o treating you with respect,
  - o listening and addressing embarrassing questions,
  - o educating and informing
  - o considering your opinions and concerns.

- You are responsible for:

  - o coming to scheduled appointments
  - o taking your medication as prescribed
  - o reporting adverse effects
  - o becoming knowledgeable about your cancer diagnosis
  - o informing your doctor about your symptoms, progress, questions and concerns.

Make every word count!

Video: Asking Your Doctor Questions

Below you will find a link to a video from the American Healthcare Research and Quality Institute about asking your doctor questions.

*To **start** the video*, click *on the arrow. You may **pause** it by* clicking *on the "||" (pause bars) and later **continue** to view by* clicking *on the arrow again.*

<link to video>

Suggested Action Plan:

○　　　I will try to rest before a clinic appointment. I will be better able to cope with any wait time, and perhaps feel less stressed.

○　　　I will use the website's thermometer to enter how I am feeling and check the boxes of items that are causing me distress. (I will view this with my doctor or nurse at an appointment.)

○　　　As I think of questions or experience symptoms that are difficult to manage, I will type them in the teal Questions box. A record of my entries will be maintained. I will also use it for questions about articles I have read, medical terms I do not understand, and about research studies I am interested in.

For additional details, click on the next tab

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Communicating with Your Provider - More Information

The following topics are covered in this level:
Specific Strategies
What is Patient-Centric Care?
Video: How to Communicate Effectively with your Doctor
Suggested Action Plan

Specific Strategies

Pain
Describe it:

- Mention where it hurts
- How much (use a scale of 1-100)
- What makes it better or worse
- Describe it (tingly, achy, knife-like)
- List medications used
- Communicate the impact on your daily functioning

Decide on your pain management goals. "I need better pain control" could mean completely pain-free (but possibly sleepy) **or** it could mean enough pain control to be able to play with your grandchildren, work 20 hours a week, or sleep comfortably. You and your doctor need to be working towards the same goals.

Talking about tests
Discuss:

- The reason for the test (Diagnosis? Change in treatment?),
- Method
- Accuracy

- Preparation
- Pain involved,
- When to expect results
- Insurance coverage.

Test results are written in medical language that can be misinterpreted by non-medical people and well-trained medically knowledgeable friends. **Ask your doctor to explain the wording in simple terms**. Do not settle for a glossing over such as "that's nothing to worry about".

Talking about Medication
You should know or learn**:**

- Medication's purpose,
- How to take it (with food, time of day, when to stop)
- Adverse effects
- Interactions with other medications
- When it should take effect
- Cost

Make sure you can read the prescription if it is not sent electronically to the pharmacy. If you can't, the pharmacist might not be able to either. To minimize errors and complications, it's a good idea to have one doctor prescribe all of your prescriptions, even specialty medications.

Talking about alternative/complementary therapies (ACTs)
Discuss the pros and cons, of ACT's such as vitamin supplements and others, and determine if there may be any interaction with your medications. Understandably, doctors may be hesitant to advocate ACTs without scientific testing, however, your doctor or another provider may be able to give you further information on a specific ACT that you are researching.

What is Patient-Centric Care?

Definition
The needs and wishes of the patient should be at the center of the care process and plan. In the last decade, medicine has shifted to this type of more "patient-centric" care. Your needs or desires for information and control over your care plan are very important to this process.

You will be making choices from options provided by your oncologist, and can do this best when provided with the information you want.

Below is a link to a journal article that describes one clinic's attempt to improve the process of communication with a written take home plan. If you are interested in research on patient-physician communication, click on the article link.

Clicking *on the link below will* **open** *an electronic document called a PDF. You must have a PDF reader installed, such as Adobe Reader (available for free at* http://get.adobe.com/reader/*). This will enable to you open the document, print it, or save it for viewing later. Some PDF forms are also fillable, meaning you can type data directly into the form. When you are finished with the document, simply* **close** *it to return to the Together website*

<Journal Article PDF link>

Video: How to Communicate Effectively with your Doctor

The video below was created by a doctor who has worked in cancer care and examined the challenges faced by patients during appointments in clinic and in the hospital. It is 40 minutes long, so you may want to skip over parts of it or pause it and watch it over a few days. It is very insightful and may help you to know that research and work like this is being done to improve the delivery of healthcare.

To **start** *the video,* click *on the arrow. You may* **pause** *it by* clicking *on the "||" (pause bars) and later* **continue** *to view by* clicking *on the arrow again.*

<link to video>

Suggested Action Plan:

Make a log of all of my medications (including over-the-counter), how I take them, dosage, and why I am taking that medication. Bring this log to my next doctor's appointment.

I will track my pain on a scale from 1-10 on a daily basis. I will make a list of my goals regarding pain relief and share this with my doctor. (Ex.: What number on a scale from 1-10 do I want my pain to be at?)

Ask my caregiver to accompany me to appointments to help me in communicating and remembering information exchanged.

****

The information provided in this topic includes content from:

Teutsch, C. 2003. "Patient-Doctor Communication". *Med Clin N Am,* Vol 87, 1115-1145.

Arnold, Robert. Video: "How to Communicate Effectively with Your Doctor". University of Pittsburgh School of Medicine.

Websites:
www.ahrq.gov
www.cancer.net
www.nlm.nih.gov/medlineplus
www.nocc.org
www.quackwatch.org