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No More Sticky Notes: The Early Implementation of an Ovarian Cancer Survivorship Care Plan

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NO MORE STICKY NOTES:
THE EARLY IMPLEMENTATION OF AN OVARIAN CANCER SURVIVORSHIP CARE PLAN

by

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NO MORE STICKY NOTES: THE EARLY IMPLEMENTATION OF AN OVARIAN CANCER SURVIVORSHIP CARE PLAN

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ABSTRACT

Background: Over the past 10 years, the number of people diagnosed and living with cancer has increased exponentially. In 2006, the Institute of Medicine (IOM) released a report targeting survivorship care as an area that was not being appropriately addressed. Since then, the majority of research has focused on breast, colon, and prostate cancers, the three most common cancer types. Historically, survivorship care plans (SCPs) have been identified as important tools that can aid a patient's transition from acute survivorship to extended and permanent survivorship and from oncologist to primary care provider.

Purpose: The purpose of this descriptive qualitative pilot study was to focus on the cancer survivorship of women with ovarian cancer. In attempt to meet the specific needs of this population, this study implemented an ovarian cancer specific SCP (O-SCP) with women who have been newly diagnosed. The O-SCP was implemented at the beginning of treatment rather than at completion in order to address survivorship needs at the onset of patients' survivorship journey, rather than at the completion of treatment. Because uncertainty begins at diagnosis, the O-SCP may be a tool to address this state from the onset of diagnosis and during and after treatment.

Methods: Purposive sampling was used to recruit seven women newly diagnosed with ovarian cancer. Data were collected at two different meetings with the participant: first, when the O-SCP was implemented, and second, approximately six weeks later, when an open-ended, semi-structured interview was conducted with each patient. Thematic analysis was carried out on the seven digitally-recorded interviews.

Results: Three categories of themes emerged during analysis: resource, communication, and negative emotional response. Themes were interrelated with each other.

Discussion: New information was identified regarding the usefulness of a disease-specific SCP for women diagnosed with ovarian cancer when the O-SCP was implemented at the beginning of chemotherapy treatment. While this study was small is size, it produced positive preliminary findings that the early implementation of an O-SCP provides a benefit to patients and may reduce uncertainty. Notably the early implementation of the O-SCP provided patients with a good resource and facilitated improved communication with outside providers.

Future Research: Further research is necessary to explore if the early implementation of an O-SCP can reduce specific negative emotional responses (such as fear, anxiety, and anger) exhibited by women with ovarian cancer. In addition, to distinguish the needs of women newly diagnosed with ovarian cancer and those whose cancer reoccurs and whether O-SCP should exist specific to each population. Finally, further content analysis of the O-SCP would also be worthwhile to determine usability in the target population, including cultural acceptability, visual appeal, and ease of understanding.

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Chapter 1: Introduction

Survivorship: Prevalence and Definition

In 2006, it was estimated that 11.4 million cancer survivors lived in the United States, a rate that has tripled over the previous 30 years (National Cancer Institute, 2009). From 1976 to 2006, the number of women living with ovarian cancer for longer than five years increased from 37% to 45% (American Cancer Society, 2006). It was estimated that 21,880 women would be diagnosed with ovarian cancer in 2010, representing nine percent of the total number of cancer diagnoses in the United States (Altekruse, et al., 2009; Howlander, et al., 2010). Within the state of New Mexico, the projected number of new ovarian cancer diagnoses per year is 125 per 100,000 (New Mexico Tumor Registry, 2009), with an overall five-year survival of 53% (New Mexico Facts and Figures, 2007). Unfortunately, the majority of ovarian cancer diagnoses in New Mexico are made in the advanced stage, which has a five-year survival rate of 27% (New Mexico Facts and Figures, 2007).

Cancer survivorship has been defined in two ways: 1) the period of time that follows primary treatment (Hewitt, Greenfield, & Stovall, 2006); and 2) the process from diagnosis through treatment, and beyond cancer (National Cancer Institute [NCI], 2010). The latter definition, that cancer survivorship begins at the time of diagnosis, is the basis for the survivorship statistics provided by the NCI and the definition on which this thesis is based.

Specific periods of survivorship are further defined in three ways. Acute survivorship is the time from diagnosis through treatment. Extended survivorship is the time immediately after treatment is completed. Permanent survivorship is a longer-term period, often meaning that the passage of time since treatment is measured in years (Mullan, 1985).

Survivorship Care Plans

In response to the increasing number and needs of cancer survivors, the Institute of Medicine (IOM) published the report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, in 2006. This report defined the post-treatment period as a distinct phase of the cancer experience that required an individualized plan of care. IOM identified four essential components of survivorship care: 1) prevention of recurrent and new cancers and other late effects; 2) surveillance for cancer and assessment of medical and psychosocial late effects; 3) intervention for consequences of cancer and its treatment; and 4) coordination between specialists and primary care providers to ensure all the survivor's health needs are met (Hewitt, et al., 2006).

One of the ten recommendations made by the report was that all cancer patients should be given a survivorship care plan (SCP) at the end of treatment that outlines the patient's diagnosis and treatments, what the patient will need as she moves forward, and who will provide this care. The primary goal of the SCP is to bridge the gap in communication between oncologists and primary care physicians and to decrease the confusion survivors often face once they are cancer free (Gilbert, Miller, Hollenbeck, Montie, & Wei, 2008).

Organizations such as National Comprehensive Cancer Network (NCCN), American Society of Clinical Oncologists (ASCO), Lance Armstrong Foundation (LAF), and the IOM have developed recommendations related to treatment and survivorship care. The potential of the SCP is not fully understood. While current research has indicated that both clinicians and patients recognize the need for a disease specific survivorship care (Gage, et al, 2011), as well as the need for providers to communicate more information early in the treatment course (Hewitt & Ganz, 2007), no study has specifically researched the early implementation of a disease specific SCP.

Uncertainty in Illness

In 1990, Merle Mishel developed the Reconceptualized Uncertainty in Illness Theory (RUIT) that defined uncertainty as it relates to chronic illnesses, such as cancer. Within the context of illness, the concept of uncertainty refers to the cognitive state that occurs when the patient does not know or understand the meaning of illness-related events or when the individual cannot adequately categorize the illness event because of insufficient cues (Mishel, 1988). Uncertainty influences how the patient perceives and eventually adapts to illness and the ensuing treatments (Corbiel, Laizner, Hunter & Hutchinson, 2009; Garofalo, Choppala, Hamann & Gjerde, 2009; Lockwood-Rayermann, 2006; Yu Ko & Degner, 2008). Recognizing this concept may be a necessary element to successfully addressing survivorship care for ovarian cancer patients. Mishel's RUIT is the conceptual framework of this study because of its interconnectedness to the difficult challenges that arise with a cancer diagnosis.

Ovarian Cancer

Women diagnosed with advanced stage ovarian cancer face a unique survivorship course. Similar to other cancer diagnoses at the onset of diagnosis, the patients are confronted with uncertainty about the healthcare providers treating them, the treatments, and the effects of cancer on their lives and the lives of their families. Most of all, patients are confronted with the uncertainty of their own mortality. What distinguishes the survivorship of ovarian cancer patients from the survivorship of other cancers is the extensiveness of their treatment and the lower rate of survival (Ferrell, Smith, Juarez, & Melancon, 2003). Because ovarian cancer survivors represent a small portion of the overall cancer survivor population, they receive less attention in survivorship care literature when compared to other more common cancers.

This qualitative pilot study explores the early implementation of a disease-specific SCP at the beginning of chemotherapy treatment for women newly diagnosed with ovarian cancer. The uncertainty that accompanies a cancer diagnosis is a challenge to care that must be recognized and addressed. The early implementation of the SCP may be an effective way in which to address uncertainty. Very little research exists, however, to support methodology, timing, useful content, and long-term effectiveness of any one method of SCP implementation. Therefore, this author designed a qualitative research study using an ovarian cancer-specific SCP (O-SCP) and interviews to address the issue of uncertainty in ovarian cancer survivorship.

Chapter 2: Review of Literature

Survivorship

In 1976, a seminal study found that the 100-day period post-diagnosis was a period of "existential plight," a critical time of physical and psychosocial distress that was not being addressed (Weisman and Worden, 1976). More than two decades ago, a Swiss oncology nurse, Rosette Poletti, made the statement that, "the goal of cancer nursing should be to help the patient be a fully functioning person first, and a cancer patient second" (Poletti, 1985). Yet today, despite all of the treatment advances, increase in survival rates, and known needs of survivors, the integration of survivorship care with treatment is still lacking (Beesley, Eakin, Steginga, Aitken, Dunn, & Battistutta, 2008; Hill-Kayser, Vachani, Hampshire, Jacobs & Metz, 2009; Lockwood-Rayermann, 2006; Miller, 2008; Morgan, 2009; Oeffinger & McCabe, 2006).

Since the IOM report (2006), research has focused on the long-term issues that confront cancer survivors. General survivorship concerns include late physical effects, lack of consistent long-term medical follow-up, psychosocial concerns, employment and insurance issues, and discrimination. Multiple studies have found that most survivors, in general, feel unprepared for the long-term physical and psychological effects of their treatment and do not believe their survivorship needs have been addressed (Ganz, Casillas, & Hahn, 2008; Hewit, Bamando, Day, & Harvey, 2007).

The survivorship issues for women with ovarian cancer have another level of complexity – their treatment is aggressive and carries significant psychosocial and physical effects (Ferrell, et al., 2005; Lockwood-Rayermann, 2006). Few studies focus on their specific or long-term needs.

The initial treatment of ovarian cancer patients usually includes an aggressive pelvic debulking surgery with lymph node removal (Liu, Ercolano, Siefert, & McCorkle, 2010; Lockwood-Rayermann, 2006; Martin, 2007). If optimal debulking is achieved (meaning no residual disease in pelvis), then intraperitoneal and intravenous chemotherapy with platinum and taxane medications are recommended (National Comprehensive Cancer Network [NCCN] Practice Guidelines in Oncology, 2010). Alternatively, the adjuvant therapy of six to eight cycles of intravenous platinum and taxane chemotherapy every three weeks is the standard of care (Martin, 2007).

The prominent symptoms reported by women with gynecologic cancers are pain, fatigue, bowel dysfunction (both constipation and diarrhea), depression, anxiety, disturbed sleep, hair loss, peripheral neuropathy, nausea, lack of appetite, lymphedema, weight gain, decreased sexual activity and fertility issues (Ferrell, et al., 2003; Ferrell, et al., 2005; Fox & Lyon, 2007; Hodgkinson et al., 2007; Lakusta et al., 2001; Liu, et al., 2010; Lockwood-Rayermann, 2006).

The psychosocial impact of an incurable cancer is significant (Lockwood-Rayermann, 2006; Mirabeau-Beale et al., 2009). A qualitative study by Ferrell et al. (2005) found that the top ten concerns for women are: 1) distress of initial diagnosis; 2) distress of treatment; 3) family distress; 4) fear of recurrence; 5) uncertainty; 6) concern that relatives will be diagnosed with cancer; 7) fear of a second cancer; 8) fear of future diagnostic tests; 9) sexuality; and 10) fear of dying. Their study surveyed a total of 1,383 women with ovarian cancer. However, it was limited by sample bias for two reasons: first, 95% of their participants were Caucasian. Second, 72% of the women had a college or graduate education.

In addition, Lockwood-Rayermann (2006) conducted a metanalysis of 28 articles exploring the psychological issues of patients with gynecologic cancers. She found that the long-term needs of women with ovarian cancer have not been explored and are not addressed. She concluded that psychosocial distress correlates with the number of physical symptoms. Intervention studies that focus on psychological needs of cancer patients are needed to compliment the care of their physical needs, (Mirabeau-Beale et al, 2009) as they often have an additive effect (Fox & Lyon, 2007; Lockwood-Rayermann, 2006).

Two studies looked at long-term needs of gynecological cancer survivors (Beesley, et al., 2008; Hodgkinson et al., 2006). These studies were not specific to ovarian cancer and included women with cervical and endometrial cancer. All three diseases have very different treatment regimens, survivorship trajectories, and long-term survivorship needs. Beesley, et al. (2008) conducted a population-based survey in 802 women with gynecological cancers. The highest five needs identified by Beesley were: 1) fear about cancer spreading; 2) concerns about the worries of those close to them; 3) uncertainty about the future; 4) lack of energy/tiredness; and 5) not being able to do things they used to. Their findings demonstrated that 43% of women had at least one unmet need. The findings that women experienced unmet needs was consistent with Hodgkinson et al. (2006), who found 52% reported unmet needs.

The body of survivorship research employs a wide variety of methodologies (quantitative, qualitative, randomized trials, case studies, literature reviews, grounded theory, and ethnography studies) to explore the physical and psychological issues ovarian cancer patients confront. However, all of these methodologies have commonalities in their findings: survivorship needs are extensive, but are not being addressed appropriately or at all (Lockwood-Rayermann, 2006; Mishel, et al., 2003; Morgan, 2009; Yu Ko & Degner, 2008).

Advances in cancer treatments and early detection increase the number of cancer survivors living beyond initial diagnosis and treatments (Miller, 2008). The goal of survivorship care is to increase the length and quality of life for those diagnosed with cancer. As a result of the research, which identified the high percentage of women with unmet needs, oncology teams need to focus not only on the quantifiable disease and treatments, but also the preparation of cancer patients for the immeasurable uncertainty of survivorship (Corbeil, et al., 2009; Garofalo, et al., 2009; Yu Ko & Degner, 2006).

Prior to this study, no research has addressed survival and long-term side effects during ovarian cancer survivorship. No studies have explored the use of a disease-specific SCP on the physical and psychosocial well-being of ovarian cancer patients, leaving this population very much “lost in transition.”

Uncertainty in Illness

The ovarian cancer experience is one with tremendous uncertainty, resulting from a typically poor prognosis, aggressive treatments and resulting side effects, impact on family, and an often, new awareness of mortality. Within the context of illness, uncertainty occurs when the patient does not know or understand the meaning of the illness-related events or when the individual cannot adequately categorize the illness event because of insufficient cues (Mishel, 1988). Furthermore, uncertainty is a cognitive state of “not knowing” that prevails in all cancer survivors and is apparent in both the acute and chronic stages of a cancer diagnosis (Corbeil, et al., 2009; Mishel,1988;

Mishel, et al., 2003; Yu Ko & Degner, 2006). In 1990, Merle Mishel developed the Reconceptualized Uncertainty in Illness Theory (RUIT) that was an extension of her original Uncertainty in Illness theory. The RUIT is based on the principles of the chaos theory and its depiction of the imbalance in chronic illness (Bailey & Stewart, 2006; Yu Ko & Degner, 2008). Mishel identified four elements of uncertainty in illness: 1) ambiguity about the illness state; 2) lack of information about illness, treatment, treatment effects, and side effect management; 3) complexity of available information, the system of care, and relationships with providers; and 4) unpredictability of an individual's illness course, prognosis, future, quality of life, and level of function (Bailey & Stewart, 2006). All of these elements are applicable to the cancer survivor's experience and can be addressed by SCPs.

When a person is initially diagnosed with cancer, the period of acute uncertainty begins. Using the NCI's definition of survivorship, this is the point from which a patient begins their journey as a cancer survivor (NCI, 2010). During this journey, they must undergo and complete a variety of difficult treatments, only to enter into the period of chronic uncertainty (Yu Ko & Degner, 2008). Treatment completion does not signal the end of the cancer experience (Miller, 2008). Many individuals and families continue to face complicated care issues related to the cancer diagnosis and side effects related to treatments (Lockwood-Rayermann, 2006). Within this context, the concept of uncertainty accurately reflects the threat to one's previous view of life and explains that, with the removal of control and predictability, the stability of a patient's system is challenged. Ultimately, the patient's view of life must change or adapt for survival (Yu Ko & Degner, 2008).

While uncertainty is inherently neutral, how one chooses to handle it creates either a positive or negative adaptation (Mishel, 1988). The positive effects that may occur when uncertainty is addressed are a greater appreciation of life, improved interpersonal relationships, enhanced spirituality, and a healthier lifestyle. Conversely, when uncertainty is not recognized and addressed, the patient has an exaggerated fear of the future, recurrence, and lingering long-term side effects (Ferrell et al., 2003).

Survivorship Care Plans

A SCP is an instrument that is used to provide a survivor with the information about the cancer treatments, as well as information about her oncologic follow-up appointments, psychosocial concerns, health maintenance behaviors, possible long-term side effects of the disease and/or treatments, and information to guide her in the event that she experiences employment or insurance discrimination (Hewitt et al., 2006; Miller, 2008). Specifically, the IOM recommends the following key elements be added to the SCP (Hewitt, et al, 2006, p.8):

- “Specific tissue diagnosis and stage;
- Initial treatment plan and dates of treatment;
- Toxicities during treatment;
- Expected short-and long-term effects of therapy;
- Late toxicity monitoring needed;
- Surveillance for recurrence or second cancer;
- Who will take responsibility for survivorship care;
- Psychosocial and vocational needs; and
- Recommended preventative behaviors/interventions.”

Providing this type of information in one document may provide a significant interface between survivorship and uncertainty (Hill-Kayser et al., 2009; Miller, 2008; Morgan, 2009). The purpose of the SCPs that have been researched is to do the following: 1) facilitate communication about the patient’s care after active treatment; 2) bridge the gap in communication between the patient's primary care provider and oncologist; 3) teach the patient about the possible late side effects of cancer treatment and where to seek help in those situations, and, most of all; 4) empower the patient in her care. Developing this information at the time of diagnosis helps enhance quality of life and decrease uncertainty (Hewitt et al., 2006; Miller 2008; Morgan, 2009). The sharing of information may address directly the ambiguity of the illness state, future consequences and provide the patient with an increased feeling of control and involvement (Baravelli et al., 2009; Ganz et al., 2008). Hoffman and Stovall (2006) found that survivors perceived a higher quality of life when they felt they were informed of their options and had control over decision making. Use of the SCP puts health care providers in a unique position to positively influence the patients' entire cancer experience.

The following organizations lead the development of SCPs: the American Society of Clinical Oncologists (ASCO), NCI, the LIVESTRONG Survivorship Center of Excellence, the University of Pennsylvania Abramson Cancer Center, Memorial Sloan-Kettering Cancer Center, IOM, the City of Hope, and a collaboration between National Coalition for Cancer Survivorship (NCCS), the University of California Los Angeles (UCLA) Cancer Survivorship Center, WellPoint, and Genentech's program, Journey Forward.

There are a number of templates for SCPs accessible to providers and patients online. ASCO has two templates, one to be used as a treatment summary and another that is a combined treatment plan and summary. The later is the only template that includes space for the treatment plan, which implies use early in the treatment period. The

University of Pennsylvania Abramson Cancer Center has implemented, and now maintains, a survivorship care planning tool designed by nurse and physician input for Oncolink. The American Journal of Nursing has developed “A Prescription for Living” treatment summary and care plan. Journey Forward has developed a general SCP template that also includes a detailed patient and provider resources list at the end.

The Oncolife generic template created by Oncolink, was tested with 33,343 individuals. Ninety percent of these users rated satisfaction levels with this tool as “good” to “excellent.” The limitations of this template and study is that 82% of the population are college-educated and 87% are Caucasian, opening the door to bias. The transferability of this study is decreased because it does not reflect the population within the United States (Hill-Kayser et al., 2009).

Miller (2008) conducted a small pilot study that implemented a breast cancer specific care plan in five women. She found that all components of the SCP were beneficial to the survivors. Specifically, the women found the SCP useful in clarifying information about their cancer history and treatment and that the written information was especially useful. She also found that oncology nurses played a critical role in the actual implementation of SCPs and were able to facilitate a multidisciplinary approach that was necessary to the implementation. The implementation of SCPs is a proactive means of assisting the survivor’s transition between care levels empowering the cancer survivor and maximizing beneficial health outcomes. The limitations of Miller’s study were a small sample size and that it was specific to only women with breast cancer. It was a pilot case study that utilized interviews prior to and after the implementation of the SCP. No form of measurement was discussed.

While the SCP created by Miller (2008) was concise, it was only a treatment summary. Its purpose was not to be an interactive tool for the patient to use throughout treatment, but rather a brief synopsis of the care provided. Information about the experienced side effects during treatment and the potential long-term side effects after treatment were not included.

In 2009, Baravelli, et al. provided a sample bowel cancer specific SCP to oncologists, primary care providers, nurses and patients and recorded their impressions of the SCP. They found that most of their patient participants felt a degree of uncertainty about the future once treatment was completed. The majority of patients responded that the components of the SCP provided useful information that would help decrease uncertainty, but this information had not been provided to them until the completion of therapy. This study had a small sample size with limited representation. However, its strength was that a broad spectrum of stakeholders were surveyed.

In general, SCPs have primarily been studied in breast, colon, prostate cancers and Hodgkins lymphoma (Baravelli et al., 2009; Hewitt et al., 2006). No research has examined the utility of SCPs within gynecology oncology. Furthermore, a variety of methods have been employed to implement SCPs. Such methods include implementation by the healthcare team during a designated office visit, use of internet SCPs designed for the patient to create (separate from the healthcare team), and healthcare based models of care provided by both the oncologist and the patient's primary care provider that would better aid survival care (PCP) (i.e., Community-Based Shared-Care Model, Disease-Specific Cancer Survivor Programs, and Comprehensive Survivor Programs) (Hill-

Kayser et al., 2009; McCorkle, et al., 2009; Miller, 2008; Morgan, 2009; Oeffinger & McCabe, 2006).

Timing of Implementation. The SCPs provide a means for health care providers (HCPs) to increase the quality of life for patients in the oncology setting by providing them with a process for active involvement (Cox & Wilson, 2003; Miller, 2008). Despite the known benefit and enthusiasm for SCPs, the research regarding the most acceptable format, content, and even how the information should be delivered is underdeveloped (Baravelli et al., 2009). Up to this point, all of the SCPs within the literature have been implemented at the end of treatment. Early implementation of the SCP is unexplored and could be a more holistic solution that addresses the four elements of Mishel's Reconceptualized Uncertainty in Illness Theory. Furthermore, early implementation of the SCP is more congruent with the definition of survivorship. When the SCP is implemented at the beginning of treatment, uncertainty may be addressed and the patient may be empowered by increased information and more dynamic patient-provider communication.

In a single-blinded, randomized and longitudinal quantitative study by McCorkle et al. (2009), early intervention for patients recovering from surgery and undergoing chemotherapy resulted in an increased quality of life when both psychological and physical impacts were addressed early in their course of treatment and survivorship. The strength of this study was its large number of participants. They used multiple *a priori* linear regression models, as well as mixed effect regression models for measurement. Additionally, they used a self-report questionnaire at 1, 3, and 6 months post-surgery, the Epidemiological Studies-Depression Scale, the ambiguity subscale of Mishel's

Uncertainty in Illness Scale, the Symptom Distress Scale, and the Short-Form Health Survey (SF-12).

Marbach and Grifie (2011) conducted a qualitative research study using focus groups to examine patient preferences for content and methods of delivery, educational information and SCPs. They found that it was essential to approach each survivor with individualized educational information, an initial treatment plan, a SCP at the end of treatment, and emotional support. Specifically, "participants reported they needed information at all phases of treatment" (p. 338). In addition, they identified themes of confusion and anger among the survivors. The treatment plan and educational tools provided during treatment addressed the overwhelming anger and confusion of the patients and family members.

Hewitt et al. (2007) conducted a qualitative study using focus groups and interviews with cancer survivors, nurses, PCPs, and oncologists to explore the current survivorship care and the feasibility of incorporating the SCP into their practice. They conclude that both doctors and nurses found the SCPs beneficial. However, only the nurses believed that the actual implementation was feasible. Physicians believed that the SCP was too burdensome to their already busy schedules.

Challenges. The challenges to the implementation of SCPs are: lack of institutional support; access to information from numerous providers; time constraints related to completing the SCP; debate as to who should complete the plan; and absence of evidence-based guidelines dictating essential components of surveillance and intervention (Earle, 2006; Ganz et al., 2008). In addition, the needs and responses to interventions among the survivors are as diverse as the population and, therefore, difficult to determine where to focus the limited resources (Hewitt, et al., 2006).

In sum, the literature reviewed provides evidence that cancer survivors experience significant uncertainty in survivorship and SCPs are beneficial means of addressing uncertainty. At the time of this study, no research addresses specifically 1) implementation of a SCP at the beginning of treatment, 2) implementation of a SCP in women with ovarian cancer, or 3) implementation of an ovarian cancer SCP (O-SCP). This study seeks to address this gap of knowledge by implementing an O-SCP at the beginning of chemotherapy treatment.

Chapter 3: Methodology

Overview

As identified in the previous chapter, many questions about the use of SCPs still exist, supporting the need for continued research. The original intention of a SCP was to address the transitional needs of cancer patients once active treatment is complete; however, the potential of this tool is much greater. There is a scarcity of research analyzing the survivorship needs of women with ovarian cancer. This may be attributed to the high risk of disease recurrence and overall low rates of survival. Unlike other, more curative cancers, women with ovarian cancer usually do not have a clear transition of care from oncologist to primary care physician. In order to meet the specific needs of this population, this study implemented the O-SCP at the beginning phase of the patient's diagnosis to address survivorship needs at the onset of their journey, rather than at the completion of treatment.

The IOM report (2006) endorsed both quantitative and qualitative research methodologies to assess outcomes associated with the use of treatment summaries and SCPs. A qualitative, descriptive research design was used in this pilot study in order to best describe the experience related to the early implementation of an O-SCP in a population of newly diagnosed ovarian cancer survivors. The interpretive nature of this thesis is grounded in the field of qualitative research and seeks to better understand the experience of the ovarian cancer patient's survivorship.

In general, qualitative methodology allows for a deeper exploration of the richness and complexity (Burns & Grove, 2008) inherent to ovarian cancer patient's survivorship experience. There are three primary components of qualitative research: data collection, analytic and interpretive procedures, and written and verbal reports (Strauss & Corbin, 1990). The process of data collection and analysis will be discussed in this chapter.

Conceptual Framework

Few comprehensive models or conceptual frameworks exist in the research of cancer survivorship. Because of this, it is difficult to define the conceptual framework for this thesis. Most appropriate for the content of this study; however, is Mishel's RUIT (*Appendix A*). It provides a framework for the assessment of uncertainty, which supports the use of a SCP as an early intervention tool, with the intent to decrease uncertainty. Mishel's RUIT has been well validated in the literature over the years.

Aims

The specific aims of this pilot study were to:

1. Develop an O-SCP for ovarian cancer survivors to be implemented at the beginning of chemotherapy treatment,
2. Test the O-SCP in ovarian cancer survivors, and
3. Determine the usefulness of the O-SCP in this population.

Methodological Approach

Because of the scarcity of published research examining the efficacy of implementing SCPs in the ovarian cancer population, this study examined the use and acceptability of a SCP in a sample of women newly diagnosed with ovarian cancer. The O-SCP was implemented during the participant's second cycle of chemotherapy and data were collected using open-ended, semi-structured interviews during their fourth cycle of chemotherapy. Interviews were conducted as the O-SCP was being tested, which aided the investigator in understanding how people perceive and interpret language and their own experiences with the O-SCP (Burns & Grove, 2008). Field notes also were recorded throughout the data collection period. According to Corbin & Strauss (2008), “field notes are data that may contain some conceptualization and analytic remark” (p. 123). They are important during data collection in order to capture theoretical ideas stimulated by the data that might otherwise be lost.

Thematic analysis was used to examine themes both within each interview transcript and across participants. Themes represented a pattern of response among participants and allowed for exploration of underlying ideas that shaped the content of the data described (Fereday & Eimear, 2006). The nurse researcher sought to identify recurrent patterns from participants’ comments to illuminate the meaning behind the transcripts and understand the interconnected themes in the data.

Setting

Research was conducted at two different outpatient cancer clinics: 1) the University of New Mexico Cancer Center (UNMCC) and 2) Southwest Gynecologic Oncologists (SGO). UNMCC is a National Cancer Institute-designated cancer center in an academic medical center. SGO is a private cancer clinic that specializes in gynecologic cancers. Both clinics are located in an urban city in the southwestern region of the United States. Utilization of both centers for recruitment provided a maximally diverse setting and population. In addition, the two centers staff four of the five gynecology oncologists in the state.

Sample

The sample size of this study was based on the availability of the target population during the time frame allowed for this thesis project. In 2009, 81 women were treated by UNMCC for ovarian cancer (C. Muller, personal communication, March 12, 2010) and approximately 50 are diagnosed per year at SGO (F. Ampuero, personal communication, June 18, 2011). Based on the time limitations of this study and the availability of the target population, the aim was to recruit 10 participants using purposive sampling. This method of sampling is useful to gain insight into a new area of study and to obtain in-depth understanding of a complex experience within a relatively short period of time (Burns and Grove, 2008).

Specific inclusion criteria were set so that quality data could be gained by a very narrow focus. Eligible participants were women, newly diagnosed with either early stage clear cell ovarian cancer, advanced stage epithelial ovarian cancer, primary peritoneal cancer, or cancer of the fallopian tube. Women with these diseases are offered surgery and chemotherapy as the standard of care. Depending on the characteristics of the disease, either surgery or chemotherapy will be offered first, but the standard of care is treatment with both modalities. Early stage clear cell ovarian cancer is included because it is a highly aggressive cell type that requires the same treatment as more advanced epithelial cell of the ovary, peritoneum, or fallopian tube (NCCN Practice Guidelines in Oncology, 2010). Participants were excluded from the study if they had borderline ovarian cancer or early stage adenocarcinoma of the ovary or fallopian tube because the standard of care is surgery only. The criteria for inclusion in the pilot study were as follows:

1. Diagnosed with advanced stage epithelial ovarian cancer (stage II, III, or IV), cancer of the peritoneum or fallopian tube, or early stage ovarian cancer with clear cell pathology.
2. Undergoing adjuvant or neoadjuvant chemotherapy
3. Age over 18 years.
4. Ability to read and speak English.
5. Consent to participate.

Instruments

Ovarian Cancer Survivorship Care Plan. The O-SCP (*Appendix B)* developed for this study is based on observations from the nurse researcher's clinical practice, and encompasses both original ideas, as well as elements from the care plans, designed by Journey Forward and ASCO (ASCO, 2011; Journey Forward, 2011). Both of these organizations have generic care plans as well as targeted care plans for a few disease sites. At this time, there are no targeted care plans published for gynecological cancers. In addition, this O-SCP template adheres to the IOM's recommendation of content for SCP development (Hewitt, et al., 2006).

This O-SCP is a document that permits an ongoing interaction between the patient and the treatment plan and summary, allowing for early implementation and continuous development of the plan throughout the course of treatment and after. The O-SCP has been reviewed by clinical experts in gynecology oncology care at UNMCC (two physicians, one nurse practitioner, one physician assistant, and numerous nurses), clinical oncology nurses and an oncology nurse practitioner who practices outside of the institutions of research, the thesis committee members, and two ovarian cancer survivors.

Demographic Questionnaire. The demographic questionnaire provided to patients requested the following information from participants: name, date of birth, address, home telephone number, cell phone number, primary and secondary language, race/ethnicity, level of education, and family income level (*Appendix C*).

Data Collection

Data collection occurred over a period of four months. Staff (nurses, medical assistants, nurse practitioners, physician assistants, and physicians) working at the outpatient cancer centers identified all new patients, screened them for eligibility by using a screening questionnaire (*Appendix D*) and contacted the nurse researcher regarding potential participants. The nurse researcher then approached the potential participants in one of two ways: 1) if the patients were at the outpatient cancer center for their first or second cycle of chemotherapy, they were asked by the chemotherapy nurse if they would be willing to talk to the nurse researcher about the study; 2) if they were not physically at UNMCC or SGO for treatment, and were between cycles one and two, they were called and asked if information could be mailed to them about the study (*Appendix E*). If amenable, they were approached by the nurse researcher and asked to participate in the study when they came back to the outpatient cancer center for the next treatment. Once verbal agreement was given by the eligible patient, the nurse researcher discussed the purpose of the study. If the patient was interested in participating, an informed consent was obtained. No incentives were given for participation in this study. All patients approached chose to participate.

O-SCP Implementation. The information for the O-SCP was retrieved by the nurse researcher from the participants' medical record and entered into their O-SCP. The

O-SCP was then implemented during the participants' second cycle of chemotherapy. The implementation process took approximately one hour. Approximately three weeks later, the participant was called prior to cycle three and reminded to bring her SCP to her next appointment.

Interview. Open-ended, semi-structured interview techniques were utilized for data collection during the participants' fourth cycle of treatment. The questions (*Appendix F)* explored the content of the O-SCP template, the effect of early implementation, and appropriateness of the O-SCP within this population of survivors. Each interview took approximately one hour. Data collection was achieved through the interview when the individuals disclosed their personal histories, perspectives, and experiences, particularly when sensitive topics were being explored. The interviews explored the participants' cognitive and emotional experiences and provided an in-depth discussion beyond what ordinary conversational conventions permit (Britten, 1995). All data collection took place during the participant's scheduled appointments to limit any inconvenience to the patient. The interview was conducted in the outpatient chemotherapy suite, in a private room, with the door closed to ensure privacy and confidentiality.

After two interviews were conducted, the nurse researcher consulted with an expert qualitative researcher regarding the interview technique. Interviewing techniques were refined and additional follow-up questions (i.e., "can you tell me more?") for clarifications were inserted. The addition of the clarification questions improved the flexibility of the interview and allowed for new follow-up questions to permit greater exploration of the various themes that emerged throughout the study.

In sum, ten participants consented to be participants for the study. O-SCPs were implemented with all of them. Interviews were conducted and demographic information was collected on only seven of the 10 participants as a result of delays in chemotherapy caused by neutropenia (one participant) and hospitalizations (two participants). For these three participants, their fourth cycle of chemotherapy was delayed until after the deadline for data collection. Final analysis was completed on seven participants.

Human Subject Protection and Ethical Considerations

Permission to conduct this research was sought from the University of New Mexico's Health and Science Center Human Subject Protection board through their standard application process. All data gathered from participant resources were collected with explicit permission from the participants and in full compliance with the Human Subject Protection guidelines.

Only the nurse researcher and the thesis committee had access to the data. The individualized O-SCPs and follow-up interview data were kept in a locked file cabinet at the University of New Mexico Cancer Center. The O-SCPs and all data on the computer were password protected. Once this information is no longer needed for the study, all of these materials will be destroyed, or at two years following the close of the study, whichever occurs first.

Digital audio-recording occurred with permission from the participants only during the interview to assist with data collection and analysis. After completion of this thesis, all recordings will be erased. During the interviews, caution was taken not to disclose any of the names or private, individual health information. A transcriptionist was used to transcribe the interviews. The Human Subjects Protection board did not require a confidentiality agreement to be executed by the transcriptionist.

Data Analysis

Descriptive statistics were used for the analysis of demographics, while descriptive qualitative analysis, using thematic analysis, were used for the qualitative data. All interviews were digitally recorded and transcribed.

Thematic analysis is identification of themes that emerge from data collection, such as interviews and field notes. It is a form of pattern recognition within the data, where emerging themes become categories of themes (Fereday & Muir-Cochrane, 2006) by "careful reading and re-reading of the data" (Rice & Ezzy, 1999, p. 258).

In this pilot study, qualitative analysis of the interview data and field notes proceeded inductively while engaged in data collection through constant comparison. Constant comparison is an analytical process that involves continuously relating what was heard previously to what is being heard presently (Strauss & Corbin, 2008).

Thematic analysis of the data occurred in two phases: an exploratory phase and a confirmatory phase. In the exploratory phase, the transcripts were thoroughly reviewed and the nurse researcher conducted a preliminary coding of themes. The transcripts and identified themes then were reviewed by the thesis committee, which included three expert qualitative researchers, and the themes were further developed and analyzed. Finally, the transcripts were reviewed by an oncology nurse practitioner, who practices outside of the institutions of research, to yield a clinical perspective.

In the confirmatory phase, the nurse researcher and thesis committee members independently categorized the themes in order to yield the major themes in the data. Once themes emerged, they were categorized and further analyzed and cross-referenced with the demographic data. The three major themes identified were agreed upon by the nurse researcher and thesis committee members.

Methodological Rigor

In qualitative research, the aim of the study's trustworthiness is to support the argument that the findings are worthwhile. There are four components of trustworthiness: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). The in-depth thematic and interpretive coding analysis increased the reliability and validity of the analysis. Furthermore, the collective data analysis by the group promoted inter-rater reliability and addressed confirmability by assessing for potential bias or distortion. Fabrication of evidence, while not intentional, can be a problem in the process of interpreting data (Fereday & Muir-Cochrane, 2006). The team worked independently, as well as collaboratively, to corroborate and legitimize the identified themes and prevent fabrication of evidence.

Careful description of the setting and sample population assist with transferability, allowing the reader with a similar patient population to apply the findings to his or her clinical practice setting. Dependability was addressed by first recognizing that context is ever-changing. Knowing this, the changes that occurred in the setting and how the changes affected the research

Chapter 4: Results

Participant Demographics

The ages of the seven women who participated in the study ranged from 42 to 72 years old, with an average age of 60. The majority of participants had advanced stage ovarian cancer (57.1% were stage III and 14.3% were stage IV). One participant was receiving neoadjuvant chemotherapy while the rest (85.7%) had surgery first followed by chemotherapy. The majority of participants were Non-Hispanic White (N=5; 71.4%) and lived in New Mexico (N=6; 85.7%). The other participants were Hispanic (N=1; 14.3%) and Native American/Alaska Native (N=1; 14.3%). English was the primary language for 71.4% (N=5) of the participants. There was a variety of educational backgrounds: one participant finished graduate school, two participants finished college, one participant had some college, one participant finished high school, and two participants had some high school. Approximately 86% of the participants had a family income ranging from $35,000-$99,999. One participant had a family income level of $20,000. Table 1 below outlines the participant demographics in detail.

Table 1. Participant Demographics

	N=7
Age at Diagnosis	
Average Age (years)	60
Mean (range)	42-72
Stage of Cancer	
I	14.3%
II	0%
III	57.1%
IV	14.3%
Unstaged	14.3%
Treatment	
Hysterectomy followed by adjuvant chemotherapy	85.7%
Neoadjuvant chemotherapy followed by surgery	14.3%
Residence	
New Mexico	85.7%
Arizona	14.3%
Race	
Hispanic	14.3%
Native American or Alaska Native	14.3%
White	71.4%
Highest Level of Education	
Some elementary school	0%
Finished elementary school	0%
Some high school	28.6%
Finished high school	14.3%
Some college	14.3%
Finished college	28.6%
Graduate school	14.3%
Family Income Level	
Less than $20,000	14.3%
$20,000-$34,999	0%
$35,000-$49,999	28.6%
$50,000-$74,999	28.6%
$75,000-$99,999	28.6%
More than $100,000	0%
Primary Language	
English	71.4%
Spanish	0%
Native American/Alaska Native	14.3%
Northern European	14.3%

Three categories of themes emerged during analysis: resource, communication, and negative emotional response. Each of the major themes identified, while distinct in its’ own right, is not mutually exclusive of the others. Rather, the themes often show indications of interrelatedness with one another and involve sub-category themes. Each category will be discussed in detail. Table 2 below outlines the final themes identified by the team of researchers. It also conveys the many sub-categories that also emerged.

Table 2: Major Themes Identified from Interviews
Participants (N=7)

Resource	* For family * For patient * Rural state – resource to share with rural health providers * Present and future * When traveling * Memory tool * Concise * Side effects/ progress tracking/ emotional support * Tracking Ca125 * Learning aid * Educational
Communication	* With Family * With community * With rural health providers * With providers – needs to be updated more frequently * With providers – more details about their specific care. * Many had specific/detailed stories about their care or concerns. * Many did not understand the purpose of the O-SCP * Interactive tool
Negative Emotional Reaction	* Concerns about who will take care of them in the future * Who will check their Ca125 * MD did not have time to explain things and answer questions *Powerlessness *Anger *Overwhelmed by disease and care *Confusion regarding the purpose of O-SCP *O-SCP too complicated *Too Much * Anxiety * Fear

Resource

In general, participants indicated that the O-SCP is a good resource. However, participants' opinions differed in identifying when the O-SCP became useful for them. All participants indicated that the O-SCP is a good resource for future use and over half of the participants felt that the O-SCP is useful to have at the beginning of treatment. In particular, a few participants said that having the medical teams' contact information in the O-SCP was very useful.

Other participants indicated that the O-SCP is a good resource to share with their families, friends, and community. One participant identified the O-SCP as a good resource to share with third parties "because sometimes I forget. People ask questions about what drugs I'm going on in the treatment cycle and it's good that I can reference that."

A sub-category identified by the study participants is use of the O-SCP as a "memory tool" for participants who felt cognitive changes from their treatment. One participant said, "I would write side effects in there [on the O-SCP] so I could remember to tell the doctor." Another said:

> "It definitely writes down a lot of things that I have a tendency to forget." She continued: "It's informative for me and gives me a lot of info that when I first came, of course even though I heard, I didn't listen to it."

A third participant remarked: "My brain gets foggy from the chemo and it's helpful to have [the information] laid out and then if someone asks me I can show them."

Numerous participants remarked that the usefulness of the O-SCP resulted from having a comprehensive amount of information in one concise document. Having access to this information may empower patients to feel more involved or knowledgeable about the scope of their treatments. One participant said the O-SCP helped her feel more involved in her care, "just by providing me the ongoing knowledge and having a place to write it down. That's critical…yeah…other than putting it on a little sticky notepad and losing the little sticky note."

The majority of participants (N=5) reported being able to track the results of their Ca125 tests as a benefit (Table 3). One participant remarked that, "If I get my lab results, like my Ca125 was 10, I write that in there so that helps me, and, I feel better." Another said, "It's organized where I can put my Ca125 results."

Table 3.
Theme: Tracking Ca125's (N=5)

Demographic Category	***Response***	***Percentage***
Education Level	____ Some elementary school	**0%**
	____ Finished elementary school	**0%**
	____ Some high school	**0%**
	_1__ Finished high school	**20%**
	_1__ Some college	**20%**
	_2__ Finished college	**40%**
	_1__ Graduate school	**20%**
Primary Language	_4__ English	**80%**
	____ Spanish	**0%**
	____ Native American/Alaska Native	**0%**
	_1__ Northern European	**20%**
Race	____ Asian	**0%**
	____ Black or African-American	**0%**
	_1__ Hispanic	**20%**
	____ Native Hawaiian or other Pacific	**0%**
	Islander	**0%**
	____ Native American or Alaska Native	**80%**
	_4__ White	**0%**
	____ Other race	
Income Level	____ Less than $20,000	**0%**
	____ $20,000 - $34,999	**0%**
	_1__ $35,000 - $49,000	**20%**
	_2__ $50,000 - $74,999	**40%**
	_2__ $75,000 - $99,999	**40%**
	____ More than $100,000	**0%**

Not all of the participants felt that the O-SCP was a useful tool to use as a resource because it was contrary to their preferred method of recording information. One participant was critical of the O-SCP because she already, “had all this written down at home,” on her calendar. She felt that there was not enough space to write in all of the side effects she had experienced. She wanted a place to record her symptoms on a daily basis.

Another woman felt that she did not need the O-SCP during active treatment because she had been tolerating her treatments well. “I don’t dwell very much on it. So I have not taken this out and looked at it a whole lot. Maybe I’m doing too well.”

Timing of O-SCP Implementation. As a secondary theme within this category, this study explored the early implementation of the O-SCP at the beginning of chemotherapy treatment. Most participants felt that the information contained on the O-SCP would be very beneficial at the end of treatment. One participant felt that possibly it would have been better to have the information one year after treatment. However, most participants stated that the O-SCP was useful during treatment, as well. When specifically asked, “At what point in your care do you think this information is most helpful,” one participant simply responded “always.” Another said, “Most helpful throughout the whole treatment plan…I mean, very much at the beginning, definitely, but throughout, you know the whole treatment plan.”

The implementation of the O-SCP at the beginning of treatment provided the patients with an interactive tool. One participant remarked,

> “I found this [participant pointing to the place to record side effects after each cycle] that you wrote down very helpful…you know from each time to the next to see, to go back and see if uh, if there, if there is a difference or an improvement, because you know, I think…it’s great to keep track of.”

Another participant benefited from having all of her providers contact information displayed in one area. “What helped me so much is the patient care team [that was listed in the O-SCP]. I had a question and I got to call the nurse that works for my doctor. It was really helpful to have this.”

Communication

The theme of communication emerged strongly during the analysis of the interviews. The potential for the O-SCP to serve as a useful tool for communication with family, friends, community, and other medical providers was identified. The information within the O-SCP was especially useful if the patient required care at an institution different than where the patient was receiving cancer treatment.

One participant, who lives in Arizona (six hours away from UNMCC), became sick and was hospitalized closer to her home where no one was familiar with her cancer care. She took the O-SCP with her to the hospital. Her daughter reported back to their oncologist that, “one of the most helpful items was the booklet [O-SCP] that the research nurse put together for her. The doctors at the hospital were very impressed with this whole packet of info.” Another theme, related to travel or care in unfamiliar institutions, was identified by a participant who was leaving for a trip between treatments. She planned to take the O-SCP with her in case she had any health problems that required treatment. She stated, “I think it’s something that you can keep forever, and then like, I’ll be taking a trip in about 5 weeks, I’ll take this with me in case I have some problems.”

Many sub-categories of communication emerged during the analysis of the data. First, a few participants felt confused and frustrated with their care. Often during the interviews, the patients needed to talk more about the specific details of their care. One participant said, “A person that is just new to all this, I don’t think that they give you enough information to start with.” She was preparing to start a new chemotherapy. She was angry during the interview and remarked, “I don’t even know any side effects from this [new chemotherapy]…” The use of the O-SCP inherently requires additional time to discuss identified issues, including side effects, as well as a patient’s additional questions and concerns.

Another sub-category that emerged was the awareness of cultural assumptions. In response to being asked if the information contained on the O-SCP was helpful, one American Indian participant stated that, “We would just probably only expect to see them [records] at the doctor’s office, not really with us or on hand you know.” This theme is particularly relevant because of the percentage of American Indians in New Mexico. Providers must be aware of beliefs about the use and ownership of information by patients, especially by patients from different cultural backgrounds. Providers need to be aware of the cultural assumptions they place on their patients of different cultures.

Finally, a number of participants felt that the O-SCP would have been more useful had the medical team, or nurse researcher, written their Ca125 results in the O-SCP for the patient throughout the treatment course. Participants identified that they were not given their Ca125 test results to record and no one did it for them.

Negative Emotional Response

The final theme identified in this study was categorized as “negative emotional response.” Many of the following sub-categories were embedded: powerlessness, anger, fear, anxiety, and confusion. However, because the themes were so enmeshed with one another and were limited to seven participants, it was difficult to accurately identify what specific emotions emerged from the data.

During the first phase of theme identification, the nurse researcher identified an anger theme. However, after further analysis with the expert qualitative researchers and the oncology nurse practitioner, this theme was identified as fear. After further discussion with a psychology clinical nurse specialist, this theme was identified as anxiety because the participants were displaying a fear of the unknown (S. Davidson, personal communication, June 20, 2011). Because the purpose of this study was not to identify specific emotional responses, this theme has been more appropriately identified as negative emotional response.

Participants had a negative emotional response about their treatments, their providers, and their future. The previously mentioned participant who appeared angry during the interview continued to say, "I really love Dr. [name removed] but I know, I know she's really busy. It's just that a person--a person that this is being done to doesn't know what's going on."

The negative emotional responses that the patients expressed for the future were concerns about who will take care of them if their doctor leaves, who will follow their Ca125s, and the possibility of secondary cancers. For example, when one participant was asked if she had any further questions or concerns she remarked, "let's say I'm 15 years out and I get a different kind of cancer, would my doctor still be here?"

Another emotional sub-category that emerged was that of "too much." At times the participants were confused about the purpose of the O-SCP despite the education provided about its purpose prior to its implementation. One participant remarked, "At first it's a little overwhelming, yeah, it's a little overwhelming and I think basically because I didn't take the time to read it, to read the instructions."

A cross-referencing of themes to the participant demographics (Table 4) showed that 100% of the participants who were confused by the purpose of the O-SCP and who expressed the theme "too much" were not college educated. Of those participants, 50% displayed anger during their interview.

Table 4.
Theme: "Too Much" (N=4)

Demographic Category	***Response***	***Percentages***
Education Level	____ Some elementary school	**0%**
	____ Finished elementary school	**0%**
	_2__ Some high school	**50%**
	_1__ Finished high school	**25%**
	_1__ Some college	**25%**
	____ Finished college	**100% are not college graduates**
	____ Graduate school	
Primary Language	_3__ English	**75%**
	____ Spanish	**0%**
	_1__ American Indian/Alaska Native language	**25%**
	____ Danish	**0%**
Race	____ Asian	**0%**
	____ Black or African-American	**0%**
	_1__ Hispanic	**25%**
	____ Native Hawaiian or other Pacific Islander	**0%**
	_1__ Native American or Alaska Native	**25%**
	_2__ White	**50%**
	____ Other race	**0%**
Income Level	_1__ Less than $20,000	**25%**
	____ $20,000 - $34,999	**0%**
	_1__ $35,000 - $49,000	**25%**
	_2__ $50,000 - $74,999	**50%**
	____ $75,000 - $99,999	**0%**
	____ More than $100,000	**0%**

Changes to the O-SCP

Changes that may be made to the O-SCP include the addition of more space to write side effects after each cycle of chemotherapy, simplification of the language to a sixth grade reading level, and confirmation that all components and language within the O-SCP are targeted to the patient. For example, one participant did not understand the term, “interventional radiology,” even though she had visited the radiology department for her port placement. This language could be simplified to “where your port was placed.”

Evaluation of Interview Questions

The participants were asked interview questions that had not been tested prior to their use in this study. Evaluation of the questions suggests that some are direct and easy to understand by patients. However, other questions use language or concepts that are difficult to understand. For example, the word “helpful” is used in many questions; yet, it is also a word used in many responses. It is difficult to identify the particular meaning that patients ascribe to that term and develop a deeper understanding of the patient’s explanation. Conceptually, participants appeared to struggle with questions that involve future care. Their focus, at the time of the interview, was on the events happening to them at that moment and surviving the present. It appeared that patients felt overwhelmed by thinking about the future. In response to a question about whether the information helped to reduce anxiety regarding future health care needs, one patient said, “Umm, I don’t – I don’t have an answer for that.”

The question, “How was your understanding of your treatment plan different than what was provided to you with the survivorship care plan?” also seemed to be a difficult question for most participants to understand. Patients appeared to have a difficult time distinguishing between the meaning of "treatment plan" and "survivorship care plan," because the two terms sound similar.

The question, "What parts of this care plan didn't make sense to you?" seemed to be a difficult question for patients to answer. Research suggests that there is a gap in communication between providers and patients (Davis, Kennen, & Marion, 2007). This interview question highlights this point. Many participants exhibited confusion about the O-SCP during the interviews; yet, when asked directly, all but one participant said the O-SCP made sense. For example, one participant remarked, "They [sections of the O-SCP] all made sense. They were all here for a reason."

Observation of the participants provided valuable information about comprehension levels of participants. Through observation of the participants, it appeared that they wanted to make the impression to the provider that they understood everything said to them or provided on the O-SCP. In other words, they wanted to be "good patients." In addition, it was discovered through observation that one participant did not read or write English. When she was asked the question if any of the content didn't make sense to her, she answered: "I thought it was nice to have."

Another question that received unexpected responses was: "Does any of the SCP content scare you?" Most participants did not answer this question directly. Rather, participants often spoke about their cancer experience. One participant remarked that she was scared when she was first diagnosed. Another said, "We just leave that at the doctor's office and don't worry about it or don't even talk about it. It's just over there." One patient stated that it was scary to see her diagnosis in "black and white." A few times, participants simply stated a fast, one word answer, “no.” The two participants who seemed to express more fear, were emphatic in their responses to this question, and that, “No,” nothing scared them, “Nothing at all.”

Chapter 5: Discussion

This pilot study utilized qualitative methods to explore and analyze the effects of early implementation of a disease-specific SCP for women with ovarian cancer. The ovarian cancer experience is one with tremendous uncertainty, resulting from a typically poor prognosis, aggressive treatments and resulting side effects, impact on family, and an often, new awareness of one's own mortality. Uncertainty begins at diagnosis, and the O-SCP is a tool that may be used to address this state during and after treatment.

The specific aims of this pilot study were to: 1) develop an O-SCP for ovarian cancer survivors to be implemented at the beginning of adjuvant chemotherapy treatment; 2) test the O-SCP in ovarian cancer survivors; and 3) determine the usefulness of the O-SCP in this population. All of the aims of this study were met and participants determined the O-SCP to be useful.

The major themes that emerged from the data were resource, communication, and negative emotional response. All three themes were interrelated with one another. For example, the theme of communication exists in conjunction with the resource theme because a good resource promotes better communication. Further, improved communication helps to decrease uncertainty, and may decrease negative emotional responses.

This study provided evidence to support the early implementation of the O-SCP. The majority of participants found the O-SCP to be a good resource during active treatment. Some used it for tracking their Ca125s and their side effects after each treatment, while others identified the potential for that use. Participants found that being able to track this information was encouraging because they were able to see objective evidence of improvement. Furthermore, it also helped them to feel more involved in their care.

Many of the women commented that they were having memory problems because of treatment and that the written O-SCP helped keep track of information to refer back to as needed. McCorkle et al., (2009) found that interventions implemented immediately after surgery for gynecological cancer and before chemotherapy significantly decreased uncertainty and distress and increased quality of life. The sharing of information and improved communication between providers and patients required when implementing a SCP may address the ambiguity of the illness state, future consequences, and provide patients with an increased feeling of control and involvement (Baravelli, et al., 2009; Ganz et al., 2008).

The early implementation of the O-SCP provided patients with essential information about how to contact their providers, and it also became a resource that provided immediate communication to outside health facilities and providers regarding the patient's diagnosis and treatment if care was required between chemotherapy treatments. The O-SCP proved to be a beneficial resource that acted as an extended form of communication for patients who live in rural communities, away from their oncologist and treatment facility. Further, the O-SCP was identified as a resource to take when travelling in the event that health problems arise.

As an interactive resource, the early implementation of the O-SCP may help facilitate improved communication between providers and patients. There is a gap in communication between providers and patients when communication exists only in a verbal format (Davis, Kennen, & Marion, 2007; Santoso, Engle, Schaffer, & Wan, 2006).

It is not uncommon for providers to talk, while patients nod their heads in response, allowing the providers to assume that the patient understands the information. Use of the O-SCP may help the practitioner identify whether the patient comprehends the information being conveyed during appointments. Verbal-only communication renders itself to increased miscommunication and misunderstanding (Davis, Kennen, & Marion, 2007). Incorporating a written format for communication during appointments enhances communication, such as sharing results (Ca125) to patients. The written document also may facilitate improved communication because it provides a guide by which the patient engages with the provider. The patient may simply identify areas on the O-SCP that she would like the provider to address or on which greater elaboration is required. This allows a provider to better identify patient comprehension. In addition, it empowers the patient to engage with the provider and address questions or concerns the patient may not raise in the absence of the O-SCP. Not only can the O-SCP empower the patient to further engage with the provider, but the patient can return home with the documentation to which she can refer after the appointment or share with family members if desired.

As a resource and tool to facilitate communication between providers and patients, the O-SCP also may help patients become active participants in they health care. Grunfeld, et al., (2011) found that implementation of a SCP at the end of treatment did not have a positive impact on patient outcomes or adherence to follow-up guidelines. Early implementation of a disease-specific SCP, however, may result in "personalized, preventative, and participatory care" (Jacobs, et al., 2009, p. 400).

If the SCP is implemented early, during her treatment period, providers can play an instrumental role in guiding the patient in how to participate in her treatment and care.

Patients may be taught how to use the O-SCP so that, when treatment is completed, they fully understand the potential of the resource and how to become an active participant in their health care. This teaching process also facilitates improved communication between the providers and patients. One researcher found that nearly 40% of patients do not follow their oncologist's advice about follow-up care regarding their general health needs with a PCP (Snyder, et al., 2008). Use of this interactive tool may teach the patient how to be more involved in and engaged with her care after the immediate treatment phase is complete.

Coordination of care is complicated with a cancer diagnosis. At some point, the patient may no longer need to contact the oncologist in a primary capacity. Follow up care, in some cases, may be more appropriate to address with the PCP. The O-SCP may be used to bridge the gap in communication that currently exists through phases of survivorship. In addition to existing as a resource to track Ca125 results and side effects during treatment, the O-SCP outlines the follow-up care conducted by the oncologist once treatment ends versus the follow-up care that will be necessary to direct to the PCP. The O-SCP can help consolidate all of the information that is necessary to know about appointments, when it is appropriate to see an oncologist rather than a PCP, and the contact information for all providers.

The negative emotional response theme is also interwoven into the themes of resource and communication. The concerns that indicated patients were experiencing negative emotional responses were: (1) the concern of upsetting their doctor by needing more from them; (2) the concern of not being a good patient, (3) the concern of not knowing what to expect each day from the treatments, and (4) the concern of the future.

It was difficult to untangle the negative emotional themes that emerged into specific categories partly because of the small sample size. The themes anxiety, fear, confusion, and anger are well reported in the literature (Beesley et al., 2008; Cox et al., 2008, Ferrell et al., 2003; Hodgkinson et al., 2007; Liu et al., 2010; Marbach & Griffie, 2011; Mirabeau-Beale et al., 2009) and present in a dynamic relationship. In this study it was difficult to understand if specific negative emotional responses, such as fear and anxiety, made the O-SCP more confusing; if everything related to the cancer diagnosis and treatment, including the O-SCP, was too much for the participant to handle at once; or if the O-SCP, itself, was too complicated. If the latter is true, then use of the O-SCP could have caused more confusion, fear, anxiety, and/or anger.

It is potential that the O-SCP was too complicated for some participants, and this could have contributed to the negative emotional responses. Sammarco and Konecny (2010) and Ko & Hsu (2005) both found that lower educational levels among women in their studies correlated with higher levels of uncertainty and distress. This study is consistent with those findings.

Mishel’s RUIT was an appropriate conceptual framework to support the early implementation of the O-SCP in women diagnosed with ovarian cancer. Mishel identified four elements of uncertainty in illness: 1) ambiguity about the illness state; 2) lack of information about illness, treatment, treatment effects, and side effect management; 3) complexity of available information, the system of care, and relationships with providers; and 4) unpredictability of an individual’s illness course, prognosis, future, quality of life, and level of function (Bailey & Stewart, 2006).

All of these elements are applicable to the ovarian cancer survivor's experience. Implementing the O-SCP early in treatment provides an improved opportunity to share information, lessoning the ambiguity of patient's current state and providing knowledge about specific details of the patient's cancer, treatment, and potential side effects. In addition, the O-SCP provides an interactive tool for the patient to record her experiences and share it with her provider that, in turn, creates a more dynamic relationship with the patient's health care team. Finally, the presence of negative emotional responses among some participants of this study suggests that the early implementation of the O-SCP may be the instrument that can continue to address uncertainty.

Challenges of the Study

Participants appeared confused by the purpose of the O-SCP. This confusion may be attributed to many causes. First, in order to decrease the burden of this study on the patient and on the health care team, participants were contacted when it was convenient for all of them. The nurse researcher met the patient at their scheduled chemotherapy visit and after the nurse was done starting their IV and initiating their pre-meds to that they would not experience any delays as a result of the study. Unfortunately, the education about the study occurred after the Benadryl pre-medication was given. Often, the participant was starting to get tired during the interview.

Participant confusion about the O-SCP also appears to have resulted from the fact that the implementation of the O-SCP did not have the support of the patient's medical team. The idea of the study was supported. However, because it was "just a study," the medical team did not incorporate its use into the standard of care for their practice. Therefore, the O-SCP was not addressed by the providers during the appointments with the patients. In order for this plan to be understood and embraced as an interactive tool, it needs to be used and reinforced with the patient by the entire medical team. A suggestion to address this problem would be to design the study to better emulate the interaction desired by the medical team.

The design of this study challenged some participants' comprehension. Consenting patients at cycle one for a study on survivorship care is difficult because patients were scared and overwhelmed during their first cycle of treatment. The concept of survivorship was potentially outside of their comprehension at this point in time. Furthermore, there was a risk of reacting to the taxane chemotherapy during the first and second infusions and patients may have been preoccupied by this risk. Education about the O-SCP was provided to one participant immediately after recovering from a reaction to the chemotherapy. It was seemingly therapeutic for her to have another person to process the events of the reaction; however, it was not a good time to talk to the patient about the purpose of the study and talk about her care after treatment.

Barriers to Implementation

Part of the success to implementing a SCP depends on the medical team's commitment to the process. It is a commitment to quality care, which requires an investment of time, energy, and resources. It is a real-time document that takes time to complete and maintain. The team must have time for the tool. However, the tool must not be too time intensive. Other barriers to implementing SCPs are lack of institutional support, reimbursement for survivorship care, and deciding whose role it is to implement and update the information on the SCP. Furthermore, if it is not the provider filling out the SCP, deciphering providers' notes in patients charts in order to fill out the SCP may be challenging and time consuming.

Limitations

The primary limitation of this study is the sample size. While the themes that emerged were repetitive, saturation was not achieved. There is potential that more themes may emerge with more participants. The sample was strengthened, however, because participants were recruited from two very different cancer centers, providing a more diverse population. While these limitations can decrease the generalizability of the study, it is not the main intent of this qualitative study. In qualitative research, the focus is on the quality of information obtained from the person, situation, event, or documents sampled versus the size of the sample (Burns & Grove, 2009).

The use of purposive sampling also limits this study because it decreases transferability. There are no controls for the effect culture plays in the needs of the survivor. Since this study was conducted within the framework of a master's degree curriculum, time limitations were also limiting factors. More data could have been collected and analyzed, from which potentially more themes may have emerged, if more time would have been available to the nurse researcher.

Despite the stated limitations of this study, the early implementation of an O-SCP template for ovarian cancer patients is novel and, at the time of this research, appears to be the first to be developed. The goal was to ascertain whether the O-SCP and its implementation strategies met the needs of this group of survivors. This pilot study was especially important because of the lack of understanding of the needs of this particular survivor population.

Chapter 6: Implications for Future Research and Practice

While this pilot study identifies the benefit of early implementation of a disease-specific SCP for women diagnosed with ovarian caner, it also identifies a number of concerns, which require further research and analysis. Further research is necessary to identify specific negative emotional responses exhibited by ovarian cancer survivors and how the O-SCP may be revised or better implemented in order to help alleviate these negative emotional responses. In addition, future research should compare the implementation of the O-SCP for women receiving adjuvant or neoadjuvant chemotherapy with women who are being treated for recurrent ovarian cancer. A difference may exist between these two populations regarding the usefulness of the O-SCP or the uncertainty experienced by them, especially since recurrent ovarian cancer patients may be more familiar with certain aspects of care and may have specific ideas for how the O-SCP could be better utilized. Consequently, the content of the O-SCP template may need to contain different information depending on whether a patient has a new diagnosis or recurrent cancer.

Third, further study is required to identify the time commitment necessary for effective implementation and utilization of the O-SCP. Implementing the O-SCP requires additional time by the oncologist and cancer care team. If implementation of the O-SCP requires too much time, it is unlikely to be utilized by the care team.

Fourth, it is unclear whether the O-SCP was too complex or whether more involvement by the medical team was required to educate the patients about the use of the O-SCP as a resource or how to be more actively involved in their care. Initial data indicates that the O-SCP used during this study was too complex for some patients or that additional education was necessary to achieve patient comprehension. Two participants who did not use the O-SCP to track their CA125 levels and did not find it to be a useful tool had “some high school” for education, suggesting patient educational level is an important factor to consider when implementing the O-SCP. Further research and analysis should address demographic variables and utility of SCPs.

Fifth, further research is required to identify whether the O-SCP can be adapted to meet different cultural needs. An interesting cultural nuance identified during this study was that an American Indian participant believed the cancer information and records did not belong to her, and she did not want the information in her home. This may be a cultural nuance that needs to be better understood and respected.

Finally, content analysis of the O-SCP for usability in the target population, including cultural acceptability, visual appeal, and ease of understanding would be worthwhile.

Conclusion

While this study was small is size, it produced positive preliminary findings that the early implementation of an O-SCP provides a benefit to patients and may reduce uncertainty. Such positive findings warrant future research to explore the foregoing areas identified and to develop the most effective method of implementation.

Appendix A: Mishel's Reconceptualized Uncertainty in Illness Theory

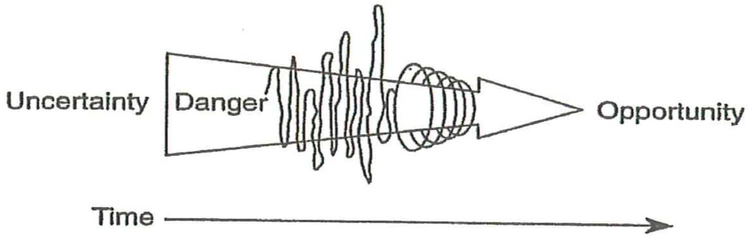

Figure 28-2 **Reconceptualized model of uncertainty in chronic illness.** (Copyright Merle Mishel, 1990.)

Appendix B: Ovarian Cancer Survivorship Care Plan (O-SCP)

Preparation Date:____________

General Information

Patient Name:__________________ DOB: ____/____/____ MRN: ______________________

Home phone #: Work Phone #: Cell Phone #:

Support Contact Name: - ____________________________________ Relationship________________

Support Contact Phone #: (H)__________________ (W)___________________ (C) ____________________

Patient Care Team

Specialty	**Name**	**Contact Information**
Gynecology Oncologist		
Medical Oncologist		
Primary Care Provider		
Nurse Practitioner		
Physician Assistant		
Nurse		
Mental Health Provider		
Clinical Trial Nurse		

Background Information

Family Cancer History:

Genetic Testing:

Major Comorbid Conditions:

Tobacco use: [ ] No [ ] Yes, past [ ] Yes, current If yes, has cessation counseling been provided ______

Surgical History

Age at Diagnosis: _________

Surgery Date: Surgical Procedure:

Tumor Type and Stage: Pathologic Stage:

Is this cancer diagnosis new or a recurrence? [ ] New [ ] Recurrence

Vascular Access Device (VAD): [ ] Yes [ ] No Type of VAD:__________________ Date: ___________

Surgeon: ______________________________ Facility: ____

Intra-Peritoneal Port : [ ] Yes [ ] No Surgeon: _____________________________ Date: ___________

Facility:____________________

Appendix B: Ovarian Cancer Survivorship Care Plan (O-SCP), cont.

Treatment Plan	**Treatment Summary**
Ca125 Pre-Surgery ________ **Date:** ____/____/____	Ca125 Post-Treatment _______ Date: ____/____/____
Height: _________in/cm	
Pre-treatment weight: __________lb/kg	Post-treatment weight: _________lb/kg
Pre-treatment BSA: ____________	
Pre-treatment ECOG status: _______	Post-treatment ECOG status:_______
Treatment Recommendation (medication, frequency, and number of cycles):	Blood Transfusions: [ ] Yes [ ] No Dates:
Treatment on Clinical Trial? [ ] Yes [ ] No Trial Name:________________________________	

Treatments and Dates	**Note side effects, delays, or dose reductions**
Cycle 1 ____/____/____	
Anxiety [ ] Depression [ ] Trouble sleeping [ ]	**Neulasta [ ] Neupogen [ ] Aranesp [ ]**
Cycle 2 ____/____/____	
Anxiety [ ] Depression [ ] Trouble sleeping [ ]	**Neulasta [ ] Neupogen [ ] Aranesp [ ]**
Cycle 3 ____/____/____	
Anxiety [ ] Depression [ ] Trouble sleeping [ ]	**Neulasta [ ] Neupogen [ ] Aranesp [ ]**
Cycle 4 ____/____/____	
Anxiety [ ] Depression [ ] Trouble sleeping [ ]	**Neulasta [ ] Neupogen [ ] Aranesp [ ]**
Cycle 5 ____/____/____	
Anxiety [ ] Depression [ ] Trouble sleeping [ ]	**Neulasta [ ] Neupogen [ ] Aranesp [ ]**
Cycle 6 ____/____/____	
Anxiety [ ] Depression [ ] Trouble sleeping [ ]	**Neulasta [ ] Neupogen [ ] Aranesp [ ]**
Cycle 7 ____/____/____	
Anxiety [ ] Depression [ ] Troubles sleeping [ ]	**Neulasta [ ] Neupogen [ ] Aranesp [ ]**
Cycle 8 ____/____/____	
Anxiety [ ] Depression [ ] Trouble sleeping [ ]	**Neulasta [ ] Neupogen [ ] Aranesp [ ]**

Major side effects of treatment: [ ] Hair loss [ ] Nausea/Vomiting [ ] Neuropathy [ ] Low blood count
[ ] Fatigue [ ] Menopause symptoms [ ] Bone pain

Appendix B: Ovarian Cancer Survivorship Care Plan (O-SCP), cont.

Symptom Management Medications

Anti-nausea	**Dose**	**Pain**	**Dose**	**Constipation/Diarrhea**	**Dose**
[ ]Reglan	________	[ ]Morphine	________	[ ]Stool Softener	________
[ ]Compazine	________	[ ]Oxycodone	________	[ ]Laxative	________
[ ]Phenergan	________	[ ]Vicoden	________	[ ]Anti-diarrheal	________
[ ]Zofran	________	[ ]Percocet	________	[ ]Other	________
[ ]Lorazepam	________	[ ]Ibuprofen	________	[ ]Other	________
[ ]Decadron	________	[ ]Other	________		
[ ]Other	________	[ ]Other	________		
[ ]Other	________				

End of Treatment Summary

Reason for stopping treatment: [ ] Completion [ ] Toxicity [ ] Progression [ ] Other

Response to treatment: [ ] Complete [ ] Partial [ ] No response [ ] Progression [ ] Not measurable

Date of Response: ________________

Treatment-related hospitalization required: [ ] Yes [ ] No

Dates: _________ _________ _________

Serious toxicities during treatment (list all):

Ongoing toxicity at completion of treatment:

Additional Therapies Planned

Drug Name	**Comments**	**Date started**
		____/____/____
		____/____/____
		____/____/____
		____/____/____

Oncology Follow-Up Recommendations

Follow-up Appointments and Tests	**Year 1**	**Year 2**	**Year 3**	**Years 4 & 5***
Oncologists Appointment with Pelvic Exam	Every 3 months	Every 3-6 months	Every 6 months	Every 6 months
Ca125 Test (if it was a good indicator in your disease)	Every 3 months	Every 3-6 months	Every 6 months	Every 6 months
CT Scan	Once (or if symptoms are present)			
Genetic Screening	If it has not already been done.			

*** After 5 years, the need for future tests and visits are decided by the patient and doctor.**

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Appendix B: Ovarian Cancer Survivorship Care Plan (O-SCP), cont.

Primary Care Follow-Up Recommendations

Mammogram: every 1-2 years starting at age 40.
Blood pressure: your PCP should manage your blood pressure medications if you are taking them.
Diabetes: If you have diabetes, this should be managed by your PCP.

Cholesterol: check every year starting at age 45. Your PCP will manage the medications if you need them.
Bone density: In general, screening should begin at age 65 and should be done every two years. Talk to your oncologist, as he/she may want to order this test.

Signs and Symptoms to Report to you Oncology Team

* Abdominal pain
* Feeling of fullness of inability to eat a full meal
* Swelling or pain in one or both legs
* Abdominal bloating
* Shortness of breath of difficulty breathing

Ovarian Cancer Follow-up Sheet

Date	Ca125 Result	CT Scan/Type/Facility
____/_____/_____	__________	____________________________
____/_____/_____	__________	____________________________
____/_____/_____	__________	____________________________
____/_____/_____	__________	____________________________
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____/_____/_____	__________	____________________________
____/_____/_____	__________	____________________________

Health Maintenance Behaviors

Exercise: CDC recommends a minimum of 30 minutes of "moderate-intensity physical activity" 5 days a week, or at least 20 minutes of "vigorous-intensity activity" on 3 days a week. Muscle strength is also recommended (i.e. lifting weights, using resistance bands, yoga).

Nutrition: Eat a minimum of 5 servings of fruits and vegetables a day; eat whole grains; choose lean protein; and keep dairy to low fat. Aim for a variety of foods. Limit alcohol consumption to one drink a day for women and two drinks a day for men. Eat foods high in vitamin D as food, not supplements, is the best source of vitamins and minerals.

Nutrition in combination with exercise is the best prevention of cancer recurrence.

Appendix B: Ovarian Cancer Survivorship Care Plan (O-SCP), cont.

Referrals Provided	Name	Institution	Contact Information
[ ] Dietician:	________________	________________	________________
[ ] Genetic counselor:	________________	________________	________________
[ ] Psychiatrist:	________________	________________	________________
[ ] Psychologist:	________________	________________	________________
[ ] Physical therapist:	________________	________________	________________
[ ] Social Worker:	________________	________________	________________
[ ] Smoking cessation counselor:	________________	________________	________________

	Resources for Patients	
American Cancer Society (ACS) Guidelines on Nutrition and Physical Activity for Cancer Prevention	Short version of the ACS Nutrition and Physical Activity Guidelines, that includes how to maintain a healthy weight and how to stay active.	Website: www.cancer.org Phone #: 1-800-227-2345
CancerCare	CancerCare is a national nonprofit group that gives free support services to those affected by cancer: people with cancer, caregivers, children, loved ones and those who have lost loved ones. These programs include counseling, education, financial, and practical help. No cost.	Website: www.cancercare.org Phone #: 1-800-813-HOPE
Cancer.Net	Award-winning patient information website that provides oncologist-approved information to help patients and families make informed health-care decisions.	Website: www.cancer.net
Employee Assistance Program (EAP)	This service is offered, for the most part, through large employer groups. EAPs help employees and their families deal with issues such as: • Short and long-term disability • Personal and emotional concerns • Legal and financial advice This service is confidential. To learn more, ask your employer about your company's EAP.	

Appendix B: Ovarian Cancer Survivorship Care Plan (O-SCP), cont.

Facing Forward: Life After Cancer Treatment	Feelings and feedback from cancer survivors. This book is written by the National Cancer Institute and offers tips to help people get through this time.	Website: www.cancer.gov Phone #: 1-800-4-CANCER
From Cancer Patient to Cancer Survivor: Lost in Transition - video	This short film by the Institute of Medicine features the stories of cancer survivors and supports the need for a Survivorship Care Plan.	Website: www.IOM.edu Phone #: (202) 334-2352
National Ovarian Cancer Coalition (NOCC)	The mission of the NOCC is to raise awareness and promote education about ovarian cancer. The Coalition is committed to improving the survival rate and quality of life for women with ovarian cancer. Through national programs and local Chapter initiatives, the NOCC's goal is to make more people aware of the early symptoms of ovarian cancer. In addition, the NOCC provides information to assist the newly diagnosed patient, to provide hope to survivors, and to support caregivers.	Website: www.ovarian.org Phone #: 1-888-OVARIAN
Women's Cancer Network (WCN)	WCN provides different tools and information about gynecologic cancers. You can read about ovarian cancer survivor stories, find information about how to manage your side effects, gather additional information on cancer statistics, find available clinical trials, and learn about new cancer treating drugs.	Website: www.wcn.org Phone #: 312.578.1439

Patient Signature____Date____________

Oncologist Signature______________________________________Date____________

Nurse Coordinator Signature_________________________________Date____________

Appendix C: Demographic Questionnaire

DEMOGRAPHIC QUESTIONNARIE

Name:__________________________________**Date of Birth:**____________________

Address:____

City:__________________ **State:** _________________ **Zip Code:** ________________

Home Phone Number:_________________ **Cell Phone Number:** ________________

Primary Language:__________________ **Secondary Language:** _________________

Race:

____ Asian
____ Black or African-American
____ Hispanic
____ Native Hawaiian or other Pacific Islander
____ Native American or Alaska Native
____ White
____ Other race

Highest Level of Education:

____ Some elementary school
____ Finished elementary school
____ Some high school
____ Finished high school
____ Some college
____ Finished college
____ Graduate school

Family Income Level:

____ Less than $20,000
____ $20,000 - $34,999
____ $35,000 - $49,000
____ $50,000 - $74,999
____ $75,000 - $99,999
____ More than $100,000

Appendix D: Screening Questionnaire

OVARIAN CANCER SURVIVORSHIP CARE PLAN SCREENING QUESTIONNAIRE

Inclusion Criteria		
1. Diagnosed with advanced stage ovarian cancer (stage II, III, or IV), cancer of the peritoneum or fallopian tube, or early stage ovarian cancer with clear cell pathology	YES	NO
2. Undergoing adjuvant of neoadjuvant chemotherapy	YES	NO
3. Greater than 18 years of age	YES	NO
4. Able to read and speak English	YES	NO
5. Female	YES	NO

Exclusion Criteria		
1. Diagnosed with borderline ovarian cancer, or stage I adenocarcinoma of the ovary or fallopian tube	YES	NO
2. Does not require chemotherapy treatment for diagnosis	YES	NO
3. Under 18 years of age	YES	NO
4. Unable to read or speak English	YES	NO
5. Prefers not to have chemotherapy treatment	YES	NO

Appendix E: Letter to Potential Participants

January 30, 2011

Dear _______________,

My name is Carolyn Phillips and I'm an oncology nurse at UNM Cancer Center. I also am in school studying to become a Nurse Practitioner. As part of my program, I am doing a study to evaluate the use of a Survivorship Care Plan (SCP) for women newly diagnosed with ovarian cancer. I am writing you to ask you to consider participation in this study.

A SCP is a tool that has been used at the end of cancer treatment to summarize the treatments received and to outline information about the oncology follow-up appointments, psychosocial concerns, health maintenance behaviors, and possible long-term side effects from treatment. I believe the potential for this tool is much greater. In this study, I am evaluating the utility of implementing the SCP *during* treatment instead of at the end.

To date, there is no research examining the use of SCPs in women with ovarian cancer. In general, there is a lack of research analyzing the survivorship needs of women with ovarian cancer. This study will introduce a new concept by implementing the SCP at the beginning phase of treatment, thereby addressing the survivorship needs at the onset rather than waiting until the completion of treatment.

How does participation in this study affect you?

If you decide to participate in this study the following will be asked of you:

1. When you arrive in the chemotherapy suite for your second treatment, I will meet with you for about an hour. During this time I will discuss the SCP that has been specifically targeted to your treatment plan.

2. I will call you before your scheduled third cycle of chemotherapy to remind you to take your SCP to your doctor's appointment.

3. During your fourth chemotherapy treatment, I will again meet with you during your treatment and ask you a few questions about your opinion of the SCP.

We will take extra measures to ensure that your privacy is protected. Each time I meet with you, we will talk in a private room to ensure you privacy and confidentiality.

Participation in this study is completely up to you. When you come for your next treatment on (date), we can discuss the study further and you can let me know if you are interested in participating.

Appendix F: Interview Questions

1. What is your overall impression of the SCP?

2. How is the SCP helpful? What kind of information is most helpful to you?

3. Of the information provided in the SCP, what did you already know?

4. Is it helpful to see your treatment plan in writing? If so, why? If not, why?

5. How was your understanding of your treatment plan different then what was provided to you with the SCP?

6. At what point in your care do you think this information is most helpful?

7. What parts of this care plan didn't make sense to you?

8. Does the SCP make you feel more involved in your care? If so, how? If not, why?

9. Does any of the SCP contents scare you?

10. Did the information help to reduce any anxieties that you had regarding your future healthcare needs? How did it help?

11. Do you think there was enough information on the SCP? Was there too much? What would you add or remove?

12. What further concerns/questions do you have about your treatment and follow-up care that were not answered by the SCP?

References

Altekruse SF, Kosary CL, Krapcho M, Neyman N, Aminou R, Waldron W…Edwards BK (eds). *SEER Cancer Statistics Review, 1975-2007*, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2007/, based on November 2009 SEER data submission, posted to the SEER web site, 2010.

American Cancer Society. Cancer facts and figures 2006. Retrieved on November 27, 2009 from http://www.cancer.org/downloads/STT/CAFF2006PWSecured.pdf.

American Society of Clinical Oncology. (2011). *ASCO Cancer Treatment Summaries.* Retrieved from http://www.cancer.net/patient/Survivorship/ASCO+ Cancer+ Treatment+ Summaries.

Ayanian, J.Z. & Jacobsen, P.B. (2006). Enhancing research on cancer survivors. *The Journal of Clinical Oncology, 24* (32), 5149-5153.

Bailey, D.E., & Stewart, J.L. (2006). Uncertainty in illness theory. In A.M. Tomey & M.R. Alligood (Eds.), *Nursing Theorists and Their Work* (pp. 623-642). St. Louis, MO: Mosby.

Baravelli, C., Krishnasamy, M., Pezaro, C., Schofield, P., Lotfi-Jam, K., Rogers, M…Jefford, M. (2009). The views of bowel cancer survivorships and health care professionals regarding survivorship care plans and post treatment follow-up. *The Journal of Cancer Survivorship*, 3: 99-108. Doi: 10.1007/s11764-009-0086-1.

Beesley, V., Eakin, E., Steginga, S., Aitken, J., Dunn, J., & Battistutta, D. (2008). Unmet needs of gynaecological cancer survivors: Implications for developing community support services. *Psycho-Oncology*, 17, 392-400.

Britten, N. (1995). Qualitative research: qualitative interviews in medical research, *British Journal of Medicine*, 311(6999): 251-253.

Corbeil, A., Laizner, A.M., Hunter, P., & Hutchison, N. (2009). The experience of uncertainty in young adults with cancer. *Cancer Nursing*, 32(5), E17-E27.

Corbin, J. & Strauss, A. (2008). *Basics of Qualitative Research,* 3rd ed. Thousand Oaks, CA: SAGE Publications.

Cox, A., Bull, E., Cockle-Hearne, J., Knibb, W., Potter, C., & Faithfull, S. (2008). Nurse led telephone follow up in ovarian cancer: A psychosocial perspective. *European Journal of Oncology Nursing,* 12, 412-417.

Cox, K. & Wilson, E. (2003). Follow-up for people with cancer: Nurse-led services and telephone interventions. *The Journal of Advanced Nursing, 43* (1), 51-61.

Davis, T.C., Kennen, E.M., & Marion, J. (2007). Clearing the way: Practical strategies for improving health literacy and cancer communication. *Oncology Issues.* Retrieved from http://accc-cancer.org/oncology_issues/articles/sepoc07/davis.pdf.

Earle, C.C. (2006). Failing to plan is planning to fail: Improving the quality of care with survivorship care plans. *The Journal of Clinical Oncology, 24* (32), 5112-5116.

Fereday, J. & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Jouranl of Qualitative Methods, 5* (1), 1-11.

Ferrell, B.R., Cullinane, C.A., Ervin, K., Melancon, C., Uman, G.C., & Juarez, G. (2005). Perspectives on the impact of ovarian cancer: Women's views of quality of life. *Oncology Nursing Forum, 32* (6), 1143-1149.

Ferrell, B.R., Smith, S.L., Juarez, G., & Melancon, C. (2003). Meaning of illness and spirituality in ovarian cancer survivors. *Oncology Nursing Forum, 30* (2), 249-257.

Fox, S.W. & Lyon, D. (2007). Symptom clusters and quality of life in survivors of ovarian cancer. *Cancer Nursing, 30* (5), 354-361.

Gage, E.A., Pailler, M., Zevon, M.A., Ch'ng, J., Groman, A., Kelly, M…Gruber, M. (2011). Structuring survivorship care: discipline-specific clinician perspectives. *The Journal of Cancer Survivorship.* DOI: 10.1007/s11764-011-0174-x.

Ganz, P.A., Casillas, J., & Hahn, E.E. (2008). Ensuring quality care for cancer survivors: Implemening the survivorship care plan, *Seminars in Oncology Nursing, 24* (3), 208-217.

Garofalo, J.P., Choppala, S., Hamann, H.A., & Gjerde, J. (2009). Uncertainty during the transition from cancer patient to survivor. *Cancer Nursing,* 32(4), E8-E14.

Gil, K.M., Mishel, M.H., Belyea, M., Germino, B., Porter, L.S., LaNey, I.C… Stewart, J. (2004). Triggers of uncertainty about recurrence and long-term treatment side effects in older African American and Caucasian breast cancer survivors. *Oncology Nursing Forum, 31*(3), 633-639.

Gilbert, S.M., Miller, D.C., Hollenbeck, B.K, Montie, J.E., & Wei, J.T. (2008). Cancer survivorship – Challenges and changing paradigms. *Journal of Urology, 179*(2), 431-438. Doi: 10.1016/j.juro.2007.09.029.

Grunfeld, E., Levine, M. N. , Julian, J. A., Pond, G. R., Maunsell, E., Folkes, A…Sisle, J.J. (2011) Results of a multicenter randomized trial to evaluate a survivorship care plan for breast cancer survivors. Paper presented at the American Society of

Clinical Oncology (ASCO), Alexandria, VA. Abstract retrieved from http://www.asco.org/ascov2/Meetings/Abstracts?&vmview=abst_detail_view&confID=102&abstracted=79733.

Hewitt, M.E., Bamundo, A., Day, R., & Harvey, C. (2007). Perspectives on post-treatment cancer care: Qualitative research with survivors, nurses, and physicians. *Journal of Clinical Oncology*, 25, 2270–2273. doi: 10.1200/JCO.2006.10.0826

Hewitt, M.E. & Ganz, P.A. (eds). (2005). Implementing cancer survivorship care planning: Workshop summary. Institute of Medicine of the National Academies. Washington, D.C.: The National Academy Press.

Hewitt, M.E., Greenfield, S., & Stovall, E. (2006). *From cancer patient to cancer survivor: Lost in transition.* Washington, D.C., National Academies Press.

Hill-Kayser, C.E., Vachani, C., Hampshire, M.K., Jacobs, L.A., & Metz, J.M. (2009). An internet tool for creation of cancer survivorship care plans for survivors and health care providers: Design, implementation, use and user satisfaction. *The Journal of Medical Internet Resources, (11)*3. 749-755. doi: 10.2196/jmir.1223.

Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G.E., Stenlake, A., Hobbs, K.M…Wain, G. (2007). Long-term survival from gynecologic caner: Psychosocial outcomes, supportive care needs, and positive outcomes. *Gynecologic Oncology*, 104, 381-389.

Hoffman, B. & Stovall, E. (2006). Survivorship perspectives and advocacy. *The Journal of Clinical Oncology*, 24: 5154-5159.

Howlader, N., Noone, A.M., Krapcho, M., Neyman, N., Aminou, R., Waldron, W…Edwards, B.K. (eds). *SEER Cancer Statistics Review*, 1975-2008, National

Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2008/, based on November 2010 SEER data submission, posted to the SEER website, 2011.

Jacobs, L.A., Palmer, S.C., Schwartz, L.A., DeMichelle, A., Mao, J.J., Carver, J.,…Meadows, A.T. (2009). Adult cancer survivorship: Evolution, research, and planning care. *CA: A Cancer Journal for Clinicians, 59,* 391-410.

Journey Forward. (2011). *Journey Forward: Guiding Survivors As They Move Ahead.* Retrieved from http://journeyforward.org/about-journey-forward.

Ko, N. & Hsu, S. (2005). Informational needs, health locus of control and uncertainty among women hospitalized with gynecological diseases. *Chang Gung Medical Journal*, 28(8), 559-565.

Lakusta C.M., Atkinson M.J., Robinson J.W., Nation J., Taenzer P.A. & Campo M.G. (2001). Quality of life in ovarian cancer patients receiving chemotherapy. *Gynecology Oncology,* 81, 490–495

Lincoln, Y. & Guba, E. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Liu, S., Ercolano, E., Siefert, M.L., & McCorkle, R. (2010). Patterns of symptoms in woman after gynecologic surgery. *Oncology Nursing Forum, 37* (2), E133-E140.

Lockwood-Rayermann, S. (2006). Survivorship issues in ovarian cancer: A review. *Oncology Nursing Forum*, 33(3), 553-562.

Marbach, T.J. & Griffie, J. (2011) .Patient preferences concerning treatment plans, survivorship care plans, education, and support services. *Oncology Nursing Forum, 38* (3), 335-342.

Martin, V.R. (2007). Ovarian cancer: An overview of treatment options. *Clinical Journal of Oncology Nursing, 11,*201-207. doi: 10.1188/07.CJON.201-207.

McCorkle, R., Dowd, M., Erolano, E, Schulman-Green, D., Williams, A., Siefert, M…Schwartz, P. (2009). Effects of nursing intervention on quality of life outcomes in post-surgical women with gynecological cancers. *Psycho-Oncology*, 18, 62-70.

Miller, R. (2008). Implementing a survivorship care plan for patients with breast cancer. *Clinical Journal of Oncology Nursing*, 12(3), 479-487.

Mirabeau-Beale, K.L., Kornblith, A.B., Penson, R.T., Lee, H., Goodman, A., Campos, S.M…Matulonis, U.A. (2009). Comparison of the quality of life of early and advanced stage ovarian cancer survivors. *Gynecologic Oncology*, 114, 353-359.

Mishel, M.H. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship*, 20, 225-231.

Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship, 22*, 256-262.

Mishel, M., Germino, B.B., Belyea, M., Stewart, J., Baily, D.E., Mohler, J.…Robertson, C. (2003). Moderators of an uncertainty management intervention for men with localized prostate cancer. *Nursing Research, 52*(2), 89-97.

Morgan, M.A. (2009). Cancer survivorship: History, quality-of-life issues, and the evolving multidisciplinary approach to implementation of cancer survivorship care plans. *Oncology Nursing Forum,* 36(4), 429-436. doi: 10.1188/09.ONF.429-436.

Mullan F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine* 313(4):270–273.

National Cancer Institute- "Estimated US cancer prevalence counts: Who are our cancer survivors in the U.S.?" Retrieved on November 27, 2009 from www.cancercontrol.cancer.gov/OCS/prevalence/index.html/OfficeofCancerSurvivorship.

National Comprehensive Cancer Network Practice Guidelines in Oncology. (2010). Epithelial ovarian cancer/fallopian tube cancer/primary peritoneal cancer. Retrieved on June 22, 2011 from http://www.nccn.org/professionals/physician_gls/pdf/ovarian.pdf.

New Mexico Facts & Figures, 2007. New Mexico Department of Health, 2007. Retrieved on June 6, 2011 from http://www.cancernm.org/cancercouncil/pdf/NMCFF_FINAL_8-28-07_reduced%20size.pdf.

New Mexico Tumor Registry (2011). Age-adjusted invasive cancer incidence rates in New Mexico, ovary, 2007. Retrieved on June 21, 2011 from http://cancer-rates.info/nm/.

Oeffinger, K.C. & McCabe, M.S. (2006). Models for delivering survivorship care. *Journal of Clinical Oncology, 24* (32), 5117-5124. doi: 10.1200/JCO.2006.07.0474.

Poletti, R.A. (1985). Ethics of death and dying. *International Journal of Nursing Study, 22*(4), 329-334.

Rice, P.L. & Ezzy, D. (1999). *Qualitative Research Methods: A Health Focus.* New York, NY: Oxford University Press.

Sammarco, A. & Konecny, L.M. (2010). Quality of life, social support, and uncertainty among Latina and Caucasian breast cancer survivors: A comparative study. *Oncology Nursing Forum, 37* (1), 93-99.

Santoso, J.T., Engle, D.B., Schaffer, L., Wan, J.Y. (2006). Cancer diagnosis and treatment: communication accuracy between patients and their physicians. *The Cancer Journal, 12* (1), 73-76.

Snyder, C.F., Earle, C.C., Herbert, R.J., Neville, B.A., Blackford, A.L. & Frick, K. (2011). Preventative care for colorectal cancer survivors: A 5 year longitudinal study. *Journal of Oncology Practice, 26,* 1073-1079.

Strauss, A. & Corbin, J. (1990). *Basics of Qualitative Research.* Newburry Park, CA: SAGE Publications.

Weisman, A.D. & Worden, J.W. (1976). The existential plight in cancer: significance of the first 100 days. *International Journal of Psychiatry Medicine, 7*(1), 1-15.

Yu Ko, W.F. & Degner, L.F. (2008). Uncertainty after treatment for prostate cancer: Definition, assessment, and management. *Clinical Journal of Oncology Nursing, 12* (5):749-55