The Lived Experience of
Women with Recurrent Ovarian Cancer

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Submitted in partial fulfillment of the requirements for the degree of Master of Education

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© August, 2000
Abstract

The purpose of this study was to understand the lived experience of 6 women with recurrent ovarian cancer. Six women were interviewed 2-20 weeks after the recurrence of their ovarian cancer. Interview questions focused on the meaning of the recurrence and their communication with others. Women were asked about the information and support that they felt they needed at that time. van Manen’s method of reflection and writing guided the inquiry. Analysis of the data revealed the themes of: my cancer is back; it means that I will die; talking about it; we are people, we are not a disease; information; and life has changed/life hasn’t changed. This study revealed the perspectives of these 6 women with recurrent ovarian cancer. It provided an understanding and knowledge about the lives of these women. Future research should explore the experiences of a larger group of women with recurrent ovarian cancer in order to address their unique needs.
Acknowledgements

This thesis is dedicated to the 6 women who were my co-researchers. To Anna, Ellen, Mary, Joan, Debbie, and Alice. It is also dedicated in memory of my friend and colleague, Dr. Greg O’Connell, who taught me the value of listening to the concerns of others.

I give thanks to the Hamilton Regional Cancer Centre Foundation for funding this project. I would like to thank my thesis committee for their advice, direction, and encouragement. My heartfelt thanks to Dr. Susan Drake, Dr. Michael Manley-Casimir, and to my mentor, Dr. Dauna Crooks. I would also like to thank my external examiner, Dr. Margaret Fitch for her knowledge and insight regarding research and ovarian cancer. I would also like to thank my colleagues for their support: Dr. John Mazurka, Dr. François Moens, Dr. Hal Hirte, and Dr. Mary Waddell, Kathy Smith, Kim Pirie, Betty Ann Lane, Tracey Mullen and Heather Harris for their courage to do what they do each day. I would also like to thank the women in gynecologic oncology: Dr. Laurie Elit for her advice and wisdom, and Joanne Ricciardone for her superb skill in listening to and transcribing my tapes. I would like to thank Kelly Tenbrinke for her typing skills.

I am grateful for my wonderful husband, Randy Brown, my family, and my friends. I would like to thank them for their belief in my cause and their continuous support throughout this project. One final thanks to my friend and colleague, Marilyn McInnes, for her helpful advice, editing, and willingness to go the last mile.
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CHAPTER ONE: THE PROBLEM

Introduction

This study examined the phenomenon of the lived experience of 6 women with recurrent or persistent ovarian cancer. This study has led to a deeper knowledge and understanding of the experiences of these women. It has helped focus and refine discussions, counselling, and education for these women. The educational changes are on a personal and professional level.

Background of the Problem

I have worked as a gynecologic oncology nurse clinician at the Hamilton Regional Cancer Centre for the past 8 years. I work with three physicians and their primary care nurses. I have a unique shared position between our host hospital and the Cancer Centre. My working day tends to be quite flexible. My position between the two facilities enables me to follow women from the time of their diagnosis through their entire illness.

A large proportion of my working day is spent focused on patient teaching and counselling related to surgery and/or chemotherapy. I have been in a privileged position to speak with women about their ovarian cancer. My concern has been that women who have recurrent ovarian cancer receive much less teaching and counselling than they did when they were originally diagnosed. This concept of not spending time has been a concern for me. I feel that these women deserve to have their problems discussed openly. I have always felt that there must be more that we can do for these women at this difficult time. As a nurse, I have felt powerless to help these women because I really did not know what they knew about their illness or if they really understood that their time was limited. Without a qualitative study, there was a limited understanding about their problems and
their wishes. The purpose of this study was to develop an understanding about the experiences of these women. I hope that this project will help to focus and refine discussions about the concerns of these women.

I listened to patients' stories about their cancer journey. Ovarian cancer patients struggle with multiple side effects of chemotherapy and undergo many physical changes related to their disease. These women experience great emotional turmoil within a short time. As the cancer progresses, their stories change immensely. As a nurse, I find their struggle awe inspiring; however, I feel powerless in helping them with their problems. It is important to understand the experiences of these women in order to make sense of their world and my own.

**Scope of the Problem**

Ovarian cancer is known as a silent and insidious disease. It is the leading cause of death in women with gynecologic cancer. The majority of women (63%) are diagnosed with advanced disease (Stage 3 and 4 ovarian cancer). The symptoms of ovarian cancer are quite vague, such as bloating, back pain, and changes in their bowel function. Usually, their disease is detected through physical examination rather than x-rays. Unfortunately, the disease is usually widespread before it can be seen on a standard x-ray. Sensitive screening tests, such as blood tests and radiological testing, have not been developed to date.

The estimated number of Canadian women who will develop ovarian cancer, this year, 2000 is 2,400. The estimated deaths from this disease will be 1,500 women (National Cancer Institute of Canada, 2000). The 5 year survival rate for all women with ovarian cancer is 35% (NIH, 1995). The overall survival rate for women with advanced
ovarian cancer is 15%. This survival rate means that the majority of women will die of this disease within a period of 5 years. Although ovarian cancer can occur in any age group, the average age of diagnosis is 61 years (NIH, 1995).

The standard treatment for ovarian cancer consists of a complete hysterectomy (removal of the uterus, fallopian tubes, and ovaries), surgical staging, and tumour debulking (removal of disease to less than 1 cm in size). Chemotherapy is then given over a period of 18 weeks. Approximately 75% of ovarian cancer patients have a complete response to their chemotherapy. A complete response means that their disease is not visible on CT scan. This response may last for a number of months to several years. The remaining 25% of patients have disease that becomes resistant to chemotherapy and is called “persistent disease.” (Refer to Appendix F for detailed explanation of terms).

Women may have a recurrence within 6 months to a year after chemotherapy. These two groups of women: women with persistent disease and women with a recurrence soon after their initial treatment will die within a short period of time (Berek & Hacker, 1994). This time frame may be anywhere from 2-12 months. The highest risk of recurrence is within the first 3 years after chemotherapy (Berek & Hacker, 1994). This recurrence may occur within the lining of the lung or the abdominal cavity. The recurrence of the tumour is generally found on physical examination or through routine x-rays (ultrasound or CT scan).

At the time of their recurrence, women are offered the choice of having chemotherapy immediately or waiting until they develop symptoms. No matter which choice they make there is no difference in their survival. The chances of responding to
this chemotherapy is 10-30% (American College of Obstetricians and Gynecologists Education Bulletin [NIH], 1998). Women with symptoms are offered chemotherapy for palliation of symptoms such as ascites (build-up of fluid within the abdomen), episodes of bowel obstruction, nausea, vomiting, and dehydration. They may have a response to chemotherapy and be free of symptoms for several months.

Often, out of perceived necessity, health care professionals focus on the treatment of the disease, while little attention is paid to the experiences of these women. Qualitative research provides a means to understand the experiences of women with recurrent ovarian cancer.

**Rationale**

The current literature available about ovarian cancer patients is limited. A review of the literature gives us little information about the personal meaning of recurrent ovarian cancer. Patients with recurrent cancer have high levels of distress related to their symptoms (Cella, Mahon, & Donovan, 1990; Guidozzi, 1990; Kornblith et al., 1995). This finding is not surprising. Patients with symptoms would be highly anxious if they have little control over the symptoms of their disease.

Several authors suggested that the present model of health care was not meeting patients' needs. They claimed that professionals needed to focus on caring when a cure was no longer possible (Bowes, Tamlyn, & Butler, 1999; Howell, 1999; LeShan, 1990; Spiegel et al., 1989). The literature underscored the importance of effective communication with patients confronting recurrent cancer (Northouse & Northouse, 1988). The communication issues and concerns important to patients, their families, and their health care providers are different (Mahon & Casperson, 1997; Northouse &
Northouse, 1988). Northouse and Northouse (1988) reviewed over 200 clinical papers and research studies published between 1966 and 1986. The communication issues identified by patients were information-seeking, disclosure of feelings, searching for meaning, and maintaining a sense of control over their lives. The communication issues for health care professionals centered around giving information, communication of hope, and the shared decision-making process. The issues for family members were quite different. Family issues focused on issues such as concealing their feelings, coping with feelings of helplessness, and seeking information from professionals.

The psychosocial issues of gynecologic cancer patients have been compared to women with benign gynecologic problems (Anderson, Anderson & deProsse, 1989; Gotay, 1984). Women with ovarian cancer have different concerns compared to healthy women. Recent studies described the devastating effect that ovarian cancer has on women’s lives (Fitch, Gray, DePetrillo, Franssen, & Howell, 1999). Research has identified the existential issues of women with other illnesses such as breast cancer (Campbell, 1986; Carter, 1993; Nelson, 1996) and HIV (Nicholas & Schilder, 1997). Qualitative studies of ovarian cancer patients provided an understanding about issues that were important to them. These studies did not focus on the concerns of recurrent ovarian cancer patients (Bowes et al., 1999; Howell, 1999).

Several studies addressed the importance of information sharing following a cancer diagnosis. There are no research studies that explore the educational needs of recurrent ovarian cancer patients. Information-seeking has been identified as a coping strategy that enhanced the patients’ sense of control (Adams, 1991; Derdiarian, 1987a, 1987b; Volker, 1991). Several studies identified incongruencies between the
informational needs perceived by the nurses and the patients (Griffiths & Leek, 1995; Lauer, Murphy, & Powers, 1982). The discrepancies between the communication issues of patients and the learning needs of patients represented gaps in the literature which could be addressed with this study. It is imperative to explore the thoughts, feelings, and beliefs of women with recurrent ovarian cancer in order to meet their unique needs.

Benner (1984) described the helping role of the nurse during the illness trajectory. The author stated that nurses needed to create a climate for a healing relationship. The steps needed to create that relationship were:

1. Mobilizing hope for the nurse as well as for the patient.
2. Finding an acceptable interpretation or understanding of the illness, pain, fear, anxiety, or other stressful emotion.
3. Assisting the patient to use social, emotional or spiritual support. (Benner, 1984, p. 49)

**Purpose of the Study**

The purpose of this study was to explore and describe the lived experience of women with recurrent ovarian cancer. It is important to understand and know the experiences of these women in order to provide adequate counseling and education. The current research about recurrent ovarian cancer patients' issues is limited (Brown, Roberts, Elkins, Larson, & Hopkins, 1994; Fitch et al., 1999; Guidozzi, 1990). Questions about what information that women felt they needed to know were incorporated into this study (Adams, 1991; Derdiarian, 1987a, 1987b; Volker, 1991). Phenomenological research technique explored the ovarian cancer patients' stories. Phenomenology provided an understanding about the lives of women with ovarian cancer (Howell, 1998;
In May 1999, I attended the First International Ovarian Cancer Forum. The goal of the conference was to develop an action plan against ovarian cancer with prevention, early detection, education, treatment, and research. Medical professionals, Ministry officials, and ovarian cancer survivors met to discuss the challenges in the diagnosis and treatment of ovarian cancer. A national survey of ovarian cancer patients was completed and results were presented at the symposium. The results of this survey provided quantitative data about the educational, research, and supportive care needs for these women.

Qualitative research projects were presented at the symposium. The two research projects will be discussed in Chapter Two. The information from the two qualitative studies provided rich descriptions of ovarian cancer patients’ lives and the issues that are important to them (Bowes et al., 1999; Howell, 1999).

This study is exploratory and may lay groundwork for future research. Information gleaned from this study will provide a greater knowledge of the experiences of women with recurrent ovarian cancer. The issues raised from this nursing research will identify information that will enhance my knowledge and my skill as a coach (Benner, 1984).

**Research Questions**

1. What is the lived experience of women with recurrent ovarian cancer?
2. What are the informational needs of women with recurrent ovarian cancer?

**Assumptions and Limitations**

The limitations of the study are associated with the descriptions of the women
who participated in the research study. Most of the women were middle aged and had similar social and economic backgrounds. This study reflected one point in time. Their responses reflected how they felt on the day of the interviews.

I had established relationships with most of the potential sample of women for this study. This relationship facilitated an honest, direct, and deeper description since rapport and empathy had already been established with them. The potential problem would have been the women's difficulty disclosing information because of fear of reprisals. Nurses often have dual roles in the research process (Raundonis, 1992). Cartwright and Limandri (1997) describe the challenges of the multiple roles in qualitative research. There is an official relationship called the researcher-participant relationship. The nurse-client relationship also existed. It was important to identify my role as a researcher during the interviews. Women interviewed during this study are known as co-researchers because of their intense involvement in the research process.

**Possible Implications for Practice or Research**

Phenomenological study allows the reader to understand the experiences of these 6 women with recurrent ovarian cancer. The lived experience of women with recurrent ovarian cancer cannot be addressed through interviews with 6 women. The research identified issues that were important to these women and provided basic information for future study.

Education took place on different levels. This study has changed my relationship with ovarian cancer patients. I have learned a great deal about myself through the shared experiences of these women. This research has provided information that can be shared with my colleagues and my patients. Information from this study will be shared with my
colleagues at the Hamilton Regional Cancer Centre through our Gynecologic Oncology team meetings and educational rounds. I am also a sessional instructor for Mohawk College in the Oncology Nursing Certificate Course. This new information will also be shared with my students and the hospital staff who care for these women.

Outline of Subsequent Chapters

Chapter Two summarizes the literature review. The review focused on the issues relevant to meaning and cancer. Information related to communication patterns with spouses and the role of the health care professional were included. Studies related to gynecologic cancer and ovarian cancer were included in the literature review. The literature review described research pertinent to learning needs of cancer patients.

Chapter Three describes the method of phenomenology. This chapter discusses the emerging design of the study as it relates to ovarian cancer patients and includes a description of data collection, analysis, and the reporting process.

Chapter Four describes the phenomenon of the lived experience of women with recurrent ovarian cancer. Analysis of the transcripts revealed five essential themes. These themes are supported by quotes from the Co-researchers.

Chapter Five presents a discussion of the findings. There is also a description of my perceptions of the research process and how the research affected me. Implications and recommendations for future research are discussed.
CHAPTER TWO: LITERATURE REVIEW

The literature review included journal information about the meaning of cancer, a cancer recurrence, and the communication patterns of cancer patients with family members and health care professionals. Research about meaning of a cancer diagnosis and recurrence was incorporated into the literature review because in phenomenology it is important to understand the meaning of the experience. There was no Canadian research about the meaning of ovarian cancer. For that reason, research about the meaning of cancer has previously focused on other disease sites, such as breast cancer.

The studies about gynecologic cancer provided an overview of work that has been done in this area. Few studies focused on ovarian cancer. There were a number of quantitative studies that focused on issues such as quality of life, coping styles, and the impact of illness. At the time of the literature review, there weren’t any published qualitative studies about the experiences of women with ovarian cancer.

To date, there is one quantitative study that focused on ovarian cancer. The recent study, the national survey of women with ovarian cancer, provided groundwork for future research, education, and identified the supportive care needs of these women (Fitch et al., 1999). Women stated that they wanted more information about all aspects of their care. In the journal article, the information needs of these women were discussed. A further review of the literature showed gaps in what information patients wanted and what information their nurses felt that they needed. This gap led me to include a question about information in the study guide.

The literature review described studies that pertain to patients’ informational needs at the time of diagnosis. There were discrepancies between the perceived needs of
patients compared to their nurses (Griffiths & Leek, 1995; Lauer et al., 1982). The qualitative nursing research studies presented at the Ovarian Cancer Forum provided a different type of information (Bowes et al.; Howell, 1999). The qualitative studies provided an understanding about the life experiences of ovarian cancer patients (Dawson, 1993; Howell, 1999; LoBiondo-Wood & Haber, 1994; Schaefer, Ladd, Lammers, & Echenberg, 1999).

Several studies described narratives or stories about the struggle with a cancer recurrence. The narratives described different types of information about the cancer journey. These narrative studies focused on issues that I felt were more close to my own sense of what this study should be about. The stories were rich with detail, and it is important that we listen to these stories, to value them and to celebrate the lives of these very ill women.

**Historical Perspective: Meaning of Illness**

It is important to define meaning. Yalom (1980) stated that meaning referred to sense of coherence. Taylor (1995) defines the search for meaning as an effort by an individual to understand the event. The individual seeks to understand the event by asking why it happened to them. The individual may look for a cause of the illness. There may also be an attempt to understand the significance of the illness.

Psychiatrist and holocaust survivor, Victor Frankl (1959), saw the search for meaning as a basic human need. Frankl and his relatives were taken to concentration camps. All his family was executed except him. In his situation, he saw himself and others in terrible conditions. They had no control over their situation. Frankl still felt that they had choices: there was a choice of their attitude toward their situation and their
captors. He described the search for meaning as an essential part of life.

In an early clinical paper, Schmale (1976) described the physician’s role in assisting patients with a cancer recurrence. The author stated that patients’ reactions to bad news depended upon their life experiences, their age, their role in the family and support systems. Schmale stated that physicians needed to be aware of the anxiety of their patients. He expressed the need for physicians to become more comfortable with their role in order to respond to the needs of their patients. This paper reflected the perceptions of a physician who cared for cancer patients.

In 1988, Arthur Kleinman, a psychiatrist and anthropologist wrote a book that propelled the patient’s experience of illness into a whole new world. He called for a change in the old medical model of health care to one that provided humane medicine. Kleinman stated that the medical system had failed patients by not listening to their stories and therefore devalued their illness experience. The rationale for studying the meaning of illness was to help the patient, family and health care professional enough to make a difference.

According to Kleinman (1988), illness had meaning in four unique aspects of a person’s life. These areas were personal, interpersonal, cultural, and social meanings. The illness had layers of meanings for each person. The personal meaning included explanations for the illness, the ramifications of the illness such as side effects of drugs, and the consequences of that illness. Social and interpersonal meaning of illness might include the toll that the illness had on their family, their work life, and financial constraints. Cultural meanings referred to the significance of the illness that is ascribed by the specific culture of the individual. Kleinman described a model for health care that
focused on the individual. His model used empathetic listening, and interpretation of the meaning of the illness to that individual.

Steeves and Kahn (1987) described meaning as an experience that was felt by an individual. The stories and experiences recounted by hospice patients were a mechanism for experiencing meaning in their lives. The authors described critical incidents given by hospice patients. These patients described their experiences. Through the descriptions, the patients felt that they made contact with forces greater than themselves. This process of describing experiences helped them with their struggle.

The authors stated that there was a connection between the search for meaning and coping. The authors identified a series of assumptions about the concept of meaning. The assumptions were: (a) meaning was an individual experience; (b) experience of meaning was often a positive one; and (c) experiences of meaning were often tied closely to suffering. The authors stipulated that certain conditions were necessary for this search for meaning. Patients must have adequate time, must be free of pain and they must be capable of perceiving experiences in their lives.

Weisman and Worden (1989) referred to the period of 100 days following a cancer diagnosis in which patients reviewed their lives, their illness, and their possible death. The researchers found that once patients overcame the shock of their initial diagnosis, most coped surprisingly well. In an earlier study, Weisman and Worden (1985/1986) assessed the emotional and psychosocial status of 102 recurrent cancer patients with six different types of cancer. The disease sites were breast (39), colon (12), Hodgkin’s disease (10), lung (6), malignant melanoma (19), and gynecologic cancer (14). Subjects were asked to compare the impact of their cancer diagnosis to their recurrent
cancer problem. The researchers used clinical findings such as symptoms, test scores from the Profile of Mood States, the Index of Vulnerability, and the Inventory of Current Concerns. Subjects felt that they were not more distressed at the time of recurrence than they were at the time of their cancer diagnosis. Thirty percent of the subjects reported lower levels of distress. The authors described two factors that affected emotional distress. These factors were symptoms and the degree of disability at the time of recurrence. These subjects reported that they received little support from their physicians and were more pessimistic about the future. The exact number of this distressed group was not given in the study report.

Subjects who were surprised by their diagnosis (61%) were highly distressed. The subjects with symptoms expressed feelings of anxiety and depression. This study provided valuable information about patient distress and their cancer recurrence. This study identified the important role that the health care provider had when discussing problems with cancer patients. The majority of ovarian cancer patients have symptoms, and so it gives credence for further study.

Lewis, Haberman, and Wallhagen (1986) described the search for meaning as means of obtaining control over what otherwise might be an overwhelming situation. This qualitative study described the experiences of 57 adults with late stage cancer. Content analysis of the interviews yielded four themes or categories that characterized their struggle with cancer. These themes were (a) monitoring progress of the cancer, (b) waiting it out, (c) refocusing control and (d) turning it over. Cancer patients sought to understand the impact of the cancer on their lives. The theme monitoring progress described the impact of the disease, and treatment on the individual, the status of their
illness, and concerns about their social support system. The theme waiting it out referred to how patients managed their lives around their illness. Refocusing control described properties whereby patients searched to understand their illness, fighting against illness, and searching for meaning. Turning it over referred to relinquishing control to others, philosophizing, and wishing for a change in their health status. This study described how patients managed and structured their lives despite having a late stage cancer. They structured their lives by trying to keep their lives normal. They made ongoing attempts to have routines in their lives and therefore control specific aspects of their illness. This study also described the importance of listening to patients’ stories about the effect that cancer has on their lives.

Descriptive research projects provided us with a greater understanding of the patients’ perception of illness. Mahon, Cella, and Donovan (1990) explored the psychosocial meaning of recurrent cancer using Lazarus and Folkman’s model of stress, appraisal, and coping. This theory proposed that cognitive appraisal and coping were critical factors during the time of stress. Primary appraisal was described as the process whereby patients evaluated the stressful event. After this initial encounter, the individual evaluated whether they would be able to do anything to overcome the event (secondary appraisal). The authors found that the meaning of recurrent cancer was influenced by past experiences with cancer and focused on death-related concerns.

The authors explored the patients’ distress at the time of diagnosis and recurrence with the use of retrospective recall. Recurrent cancer patients stated that they were more aware of the significance of their illness once the cancer had returned. The subjects stated
that their cancer recurrence caused fear of pain and death. They stated that the treatment decisions were more difficult because of the serious nature of their recurrent cancer.

Subjects described the importance of quality of life issues. They were more reluctant to accept side effects of treatment and fatigue for little gain in their overall survival. This study provided a great deal of information about how patients felt when faced with recurrent cancer.

The study had several confounding issues. The sample size was small (40 patients). Data were obtained at one point in time. Subjects included in the sample were about 30 days from their cancer recurrence. This time period may not have been long enough to obtain any meaningful data. Subjects with several recurrences were also included in the study. This notion of multiple recurrences seemed to muddy the waters of the study. Patients with several recurrences may have different issues from those who had one recurrence.

The conceptual framework used in the study was not described well. The qualitative portion of the study had data that was more meaningful and provided questions for future study. The majority of subjects reported that their caregivers assumed that they had more support than they actually had. Some of the subjects (45%) believed that their physician was no longer interested in them now that they had a recurrence of their cancer (Weisman & Worden, 1986). This statement alone calls for further study.

Taylor (1993) used a correlational, cross-sectional study to determine the factors associated with psychosocial meaning among recurrent cancer patients. This type of
research design was used to assess the relationships between certain factors and the meaning of the recurrence. The author sampled 74 subjects using six different survey instruments and assessed their search for meaning of their illness. Subjects who were highly distressed did not adjust well to their illness. Subjects who perceived a difficulty with the health care system had a poor sense of meaning of illness. The best predictors for a sense of meaning were marital status and adjustment to disease. The author suggested that the young, elderly or single subjects did not have adequate social support and therefore could not assess the meaning of their illness. Subjects who had symptoms or were dependent on others had not developed a sense of meaning of illness (Weisman & Worden, 1985/1986; Worden, 1989).

This study identified factors that affected the search for meaning. Certain factors such as symptoms, past experiences with cancer therapies, and quality of life affected the person's emotional response to a cancer recurrence. These factors do not tell us anything about the person who had a recurrence of their cancer. The authors suggested that nurses devise strategies to help patients adjust to their illness, encouraging patients to tell their life story, to create legacies, and to use social support resources available to them. In order to understand the patient's struggle, it is important to understand the communication with their spouses and families.

**Spousal Communication Patterns**

Early studies of spousal communication patterns identified problems with decreased family support and lack of communication. The patients did not discuss their illness with family members, yet they often found solace in speaking with others
(Chekryn, 1984; Gotay, 1984; Mahon et al, 1990; Weisman & Worden, 1985/1986; Worden, 1989). Mahon, Cella, and Donovan (1990) found that many subjects believed that their family members became less supportive over time. The subjects felt that they could not burden their families with discussions about illness and death.

The concept of caregiver burden is described in the literature. Zachlis and Shands (1991) reported that providing emotional support was one of the most difficult tasks for spouses. Spouses reported that they felt inadequate when dealing with feelings of depression and anxiety. Patients and their spouses were reticent to discuss emotional issues in each other’s presence for fear of causing mutual pain and anxiety (Northouse & Northouse, 1988).

Couples did not share the same meaning of the cancer recurrence. Chekryn (1984) found that communication about a cancer recurrence focused on the concerns about children and role disruption within the household. The researcher studied the psychosocial meaning of recurrence to the marital dyad. The sample consisted of women from a gynecologic oncology and radiation oncology clinic. There were 22 subjects involved in the study. Twelve women and 10 spouses were interviewed separately. They also completed a standardized measure of marital adjustment. Several themes were identified. These themes were: (a) difficulty with closure; (b) uncertainty about the future; (c) feelings of grief; (d) feelings of anger; (e) existential concerns; (f) expression of coping; (g) the impact of their disease on their family; and (h) the lack of shared meaning with their spouses.

Patients and their spouses experienced great difficulties with closure about the cancer. They described concerns about the uncertainty of their illness. They also
[Natural text goes here]
described feelings of being assaulted by their disease. Couples who scored high on the Dyad Adjustment Scale were divided into two groups: those who did and those who did not talk about their illness. Forty percent of the subjects stated that they did not talk about their recurrence with their spouse. Those subjects that did talk about their illness qualified the response by saying that they talked about it, but to a limited degree. Three spouses and three patients stated that the recurrence had caused a strain on their relationship. There were problems with role strain, psychological and physical separation caused by hospitalization, and financial hardships. Two spouses and 6 patients reported that they had had an improvement in their relationship since their cancer recurrence. Five couples reported that they had to change their priorities because of their children.

Couples were very concerned about the emotional stress of the illness on their children. The roles of the children also changed in the household because of the illness. These findings described many of the concerns that couples have about a cancer recurrence. It was difficult to interpret the study results. The description of lack of communication and the marital dyad were confusing. It seemed difficult to understand how their marriage was not affected by their lack of communication about the cancer.

Communication with Professional Staff

Mahon and Casperson (1997) discussed the perceptions and the needs of patients with recurrent cancer. This descriptive study identified several patient concerns. Staff presumed that patients would have knowledge of their disease and its treatment because of their previous cancer experiences. The majority of subjects (75%) felt that their health care providers assumed that they were coping better than they actually were (Weisman & Worden 1985/1986). They were perceived to have better support systems than they
actually had during this time. Cella et al. (1990) reported similar findings. The majority of subjects (90%) felt that staff paid less attention to them once their cancer recurred. A majority of subjects felt that their hope for recovery was strongly affected by their physicians. A majority of subjects (88%) were concerned about the burden their illness caused on their family, and 18% of the subjects felt that their families would be less supportive over time. This sense that patients with recurrence perceived that they received less attention and support was vital information for me to know as a nurse.

Worden (1989) found that familiarity with the health care system, cancer treatments and side effects caused less distress for patients with recurrence. Recurrent cancer patients were more focused on health problems and not issues related to family, social, or financial concerns. Patients with advanced disease were less likely to seek counseling or use problem-solving interventions. Priorities of patients with advanced disease may be related to their current health status and symptom control. Patients who have symptoms related to their disease are often not well enough to deal with extraneous issues.

**Studies Related to Gynecologic Cancer**

The body of available research on gynecologic cancer was limited. There was an abundance of research articles on the sexual implications of gynecologic malignancies but very little on the psychosocial issues of this same group. Anderson, Anderson, and deProsse (1989) studied the psychological outcomes of women with gynecologic cancer using a controlled prospective longitudinal study. The variables were emotional distress, employment difficulties, and marital and social adjustments. Subjects had early stage cervix cancer. Women in the control group were either healthy or had benign
gynecologic problems. Anxiety and adjustment in the disease group were high. Researchers identified that a cancer diagnosis caused an emotional crisis that was time limited and decreased with recovery. However, this study cannot be generalized to women with advanced or recurrent disease. Women with ovarian cancer often have little time to adjust to their illness. Powel and Midler (1998) stated that the concerns of ovarian cancer patients were likely similar to patients with other types of cancers. Ovarian cancer patients dealt with their problems over a short period. This compressed time frame caused a great deal of emotional distress for these patients.

A descriptive study addressed the psychosocial impact of gynecologic cancer. Roberts, Rossetti, Cone, and Cavanagh (1992) found a strong negative correlation between age and psychological distress. Younger patients were identified as high risk for psychological problems. The number of younger women or the age of these women was not identified in the study report. This finding was not surprising because younger patients do not have the life experiences to cope with a life-threatening illness. They also have losses associated with infertility, illness, marriage, and hopes for the future.

A large mixed study addressed the quality of life (QOL) of ovarian cancer patients. The researchers used qualitative and quantitative data analysis during the study process. Subjects were members of The National Coalition of Cancer Survivorship (NCCS). The group provided education and lobbied for the rights of cancer survivors. The organization has voluntary membership. Quantitative data were collected using a demographic tool and the QOL-Cancer Survivors Tool (Ersek, Ferrell, Dow, & Melancon, 1997). Qualitative data were collected. Subjects were asked to define the meaning of QOL and their experiences since their cancer diagnosis.
The study findings reviewed a moderately high QOL for long-term ovarian cancer survivors. Fatigue was a major issue for these women. Fatigue prevented them from performing tasks that they normally would have done. The negative impact of fatigue on QOL has been identified in earlier studies (Guidozzi, 1990; Kornblith et al., 1995).

Women reported several changes in their lives since their ovarian cancer diagnosis. Women experienced changes in sexual function, their self-concept, and feelings of attractiveness. Women experienced feelings of anxiety and depression. Fear of recurrence, death, and uncertainty for the future were difficult issues for these women.

Women described positive changes in their lifestyle after their cancer diagnosis and treatment. These women stated that they spent more time with their families and had changed their priorities at work. Women experienced negative changes of their illness, such as pain and fatigue. These women described feelings of guilt because their illness had caused emotional pain and anxiety for their families.

The authors described the limitations of the study. The women who participated in the study were not representative of all women with ovarian cancer. The findings were reflective of a population of women who were well educated and who belonged to support groups. The study also evaluated women at one point during their disease trajectory.

A large quantitative study of Canadian women with ovarian cancer has just been published (Fitch et al., 1999). The purpose of the study was to describe the perspectives of Canadian women with ovarian cancer. The researchers used a cross-sectional survey of a convenience sample. Surveys were sent to all of the Cancer Centres in Canada. The surveys were then distributed by the physicians or nurses.
The sample consisted of 315 women with ovarian cancer. The majority of women (97%) received this survey from their physicians, while 3% received the survey from a support group. The sample consisted of women who had received their primary treatment (37%), 30% had a recurrence, and 12% were unaware of their disease status.

Survey questions focused on issues such as: (a) diagnosis and the treatment; (b) impact of their illness on their quality of life; (c) communication issues; and (d) satisfaction with information. Several open-ended questions were included at the end of the questionnaire.

The majority of women (80%) reported that they had sufficient information about their treatment and its consequences. Only half of the women (55%) reported that they knew the stage of their disease. The remaining women (45%) knew little about the stage or nature of their illness. Issues that women identified as being important were information about their cancer, its treatment, side effects, and control of symptoms.

The majority of women (62%) felt that they needed someone to talk to about their cancer. The majority of women with recurrent disease (78%) reported that they needed to talk to someone about their experiences. The subjects identified those with whom they would discuss issues were a family member (45%), a friend (32%), and a mental health professional (29%).

Women reported both a positive and a negative impact on their lifestyle because of their illness. The majority of women (62%) reported positive changes in their lifestyle because of their cancer diagnosis. The positive changes were noticed in their relationships with others. A negative impact score was identified in their work life and financial status (Ersek et al., 1997).
The subjects identified specific problems related to their illness. These problems were side effects caused by their treatment (58%), sleeping difficulties (46%), difficulty concentrating (32%), fears of dying (36%), and fear of recurrence (54%). All of these problems were identified despite the fact that they reported a positive impact of their illness on their lives. The patients reported that they did not receive adequate help for these problems.

The informational needs of this group were quite high. Women felt that they had not received adequate help for their emotional reactions, counselling, and supportive care needs. The women with recurrent ovarian cancer were likely under represented in this study. The authors identified two areas that could have affected accrual of patients. A mechanism was not put into place to identify how many surveys were given out. A mechanism for follow-up of the survey was also not established. These two mechanisms would have increased the accrual of subjects and perhaps given a more representative sample.

Information gleaned from a qualitative study of ovarian cancer patients provided valuable information. Doris Howell (1999), a nurse researcher, presented the information at the recent Ovarian Cancer Forum. Eighteen women with ovarian cancer were interviewed and asked to describe how their illness had affected their lives.

Ovarian cancer was felt to be different from other cancers because the potential for death is so high (Powel & Midler, 1998). Women stated that the thoughts of death were always with them. They described the overwhelming impact of the cancer on their family and the ever-present fear of recurrence. There seemed to be a blending of the diagnosis of cancer with advanced disease. Women concluded that ovarian cancer was
terrifying and had changed their lives forever. The author concluded that women needed to feel in control of their lives. They needed to have access to information and needed help to understand that information. There was a need for access to supportive care. Women needed peer support, support groups, and access to health care professionals. This study not only allowed us to hear the women’s voice but also put a face to this disease.

Another study explored the psychological adjustment to the diagnosis of ovarian cancer and the emotion of anger (Bowes et al., 1999). This research project was presented in a poster at the Ovarian Cancer Forum. The authors interviewed 9 women with ovarian cancer. The data were analyzed using Glaser and Strauss’s grounded theory methodology. The researchers originally wished to explore the emotion of anger. The emotion of anger was not identified as a core category. Women were concerned about their early or impending death. Women used several coping strategies to search for meaning of their illness and to cope with their early death. These strategies were sharing experiences with other ovarian cancer patients, seeking information, seeking solace through religion, and relying on family for support. Women who had found meaning in their illness described feelings of being satisfied with life. Women who had not found meaning in their illness described feelings of despair. The concept of meaning was felt to be constantly changing. Women’s feelings of well-being depended upon their physical health. The authors concluded that an emphasis needed to be placed on caring when a cure is not possible.

Dawson (1993) interviewed 20 women to identify the experiences of women who underwent treatment for ovarian cancer. The study focused on these women 4 months
after their surgery and chemotherapy. These women were asked to complete three standardized measuring tools: the Beck Depression Inventory, a Mood adjustment checklist, and a symptom distress scale. They were then interviewed using a structured interview guide.

The majority of women talked about the symptoms that they had before their cancer diagnosis. They remembered vividly being informed about their cancer diagnosis but remembered very little after that period. Half of the patients remembered being given information about their restrictions and activities after discharge from the hospital. They stated that they wanted more information and time spent talking with them about their disease.

The author reported that a small number of women were depressed, but the overall mood of the women was positive. Women expressed confusion about their recovery and the statistics that they were given to them. Some women interpreted the statistics of survival as potential for cure. Patients stated that they wanted to be optimistic about the future but felt that they needed to know the truth about their illness.

The majority of women in the study found that they had the inner resources to envision their future optimistically. The author felt that the implications for nursing staff would be to be honest with the patients without destroying all hope for them.

**Informational Needs**

The informational needs of recurrent ovarian cancer patients have not been addressed in other studies. Adams (1991) stated that the content of patient education changed as their cancer progressed. The author identified patient learning needs throughout the cancer trajectory. This article described the patient education needs
during the five phases of illness. These phases were (a) diagnosis, (b) treatment, (c) rehabilitation/cancer survivorship, (d) remission, and (e) recurrence. Information-seeking was seen as a way to gain control over their serious illness (Lewis et al., 1986). Patients who were actively involved in their health care required specific information in order to make appropriate treatment decisions. The author described the educational process of the cancer patient as a multidisciplinary process consisting of social workers, physicians, nurses, and occupational and physiotherapists.

Derdiarian (1987a, 1987b) assessed the informational needs of newly diagnosed cancer patients. The information needs were identified in the areas of disease, personal, family, and social relationship. Information specific to the cancer included information about diagnosis, treatment, and disease prognosis. There were few differences noted despite gender, age and stage of cancer. These results were difficult to interpret because of a small sample size.

Lauer, Murphy, and Powers (1982) examined the learning needs of cancer patients by comparing the perceptions of the patient and the nurse about those needs. The subjects were nurses who provided patient education compared to the patients who received the education. There were discrepancies between the two groups. Nurses identified the learning needs of the patients as financial information, strategies for self-care, and communication skills when discussing their cancer with family and friends. Patients described their most important learning needs as receiving information about their cancer, its treatment, strategies for personal or self-care, and preparation for diagnostic tests. Patients felt that their most problematic area was controlling their side effects from treatment. In contrast, the nurses felt that patients' most problematic area
was the emotional aspect of their illness. The explanation for these discrepancies was likely related to lack of a learning needs assessment. Provision of information that patients want to know should be a priority.

Griffiths and Leek (1995) used a combined research technique to identify education issues from the nurses’ and patients’ perspectives. Questionnaires were sent out to members of the Oncology Nursing Society (ONS). Nurses were asked to give the questionnaires to two patients for completion. The nursing questionnaires contained questions about the use of patient materials, the availability of materials, and the timing of their use. An open-ended question asked how the ONS could improve patient education. The patient questionnaires asked information about the adequacy of patient education materials, timing of education, and the important questions that patients had about their cancer.

The questionnaires were completed and returned by 141 oncology nurses and 76 patients with cancer. The majority of nurses that responded worked in large metropolitan areas. The majority of patients had been diagnosed with cancer within the last 2 years. Breast cancer was the most frequently reported cancer type (37%). The majority of patients were receiving treatment in the forms of chemotherapy (65%) and radiation therapy (37%).

Both groups confirmed that there was a need for education materials. These materials came from a variety of sources. Some nurses used literature from the National Institute of Health and the American Cancer Society. Patients did not rate the information used from these sources. In addition to receiving information from health care professionals, patients received information from family/friends, the media, and
other patients with cancer. They reported that they infrequently used information from seminars, books, libraries, and support groups. Both nurse, and patients stated that the most valuable information was given during one-on-one discussions. They identified that written information was not always available following those discussions.

Nurses identified that a high priority was given to education about treatments. Both groups rated information about treatment side effects, treatment options, chemotherapy, and radiation therapy as being most important. Nurses identified that there were gaps in the available information about the impact of the cancer on patients' lives, life expectancy, and success rates of treatment.

The nurses and patients were asked to identify their most important questions related to cancer. Questions identified by nurses were the effectiveness of treatment and the side effects of that treatment. Questions identified by patients were related to success rates of treatment, information about what the future would hold for them, and how long they would live. It was obvious that the patients' concerns were related to the effectiveness of treatment and future plans. Nurses were more focused on problems that arose at the time of treatment.

There were some discrepancies between the opinions of the nurses and their patients. This study was not generalizable because the sample size was small. The subjects came from a large metropolitan area. Their issues of access to information were different from a rural population.

The information obtained from the study was used to explore the feasibility of creating a central clearinghouse for education materials. The ONS contacted the education departments at the Cancer Centres in order to provide a comprehensive list of
resources available to patients and staff.

So far, the literature review described the differences between the perceptions of patients and nurses about patient education (Griffiths & Leek, 1995; Lauer et al., 1982). Recent studies have identified that ovarian cancer patients needed more information (Fitch et al., 1999; Howell, 1999). Learning needs were individual. It would be timely to explore specific details of the type of information patients wished to receive and from whom.

Use of Narrative

Halldórsdóttir and Hamrin (1996) interviewed 9 subjects who were in remission or recovery phase of their cancer. The participants had breast cancer, cancer of the ovary, cervix, prostate cancer, skin cancer, and cancer of the colon. Two of the participants were in the terminal phase of their illness and the remainder were in remission. This phenomenological study explored the lived experience of having cancer. The most common theme identified by researchers was existential issues. The authors identified five basic subthemes: uncertainty, vulnerability, isolation, discomfort, and redefinition. Participants felt uncertainty throughout their cancer journey. Most of the participants described feelings of isolation and vulnerability at some point during their illness trajectory. Discomfort was expressed because of physical pain and/or symptoms. They stated that health care professionals had a profound effect on their emotional status. Medical appointments were emotionally charged but the staff helped them to sort through their problems. All the participants felt that their cancer experience had changed their lives (Howell, 1999). The participants had changed their goals in life and roles within their family. They described this redefinition in both a positive and negative way.
Summary of the Chapter

In summary, this chapter reviewed the literature about the meaning of an illness (Frankl, 1959; Kleinman, 1988). Throughout the literature, there was a description of the meaning of illness as an individual experience. This same illness affected the family and that person's social structure (Kleinman, 1988; Steeves & Kahn, 1987; Taylor, 1993). Certain factors such as symptoms, past experiences with cancer therapy, and quality of life affected the person's emotional response to a cancer recurrence.

Studies of spousal communication patterns identified problems with decreased family support and lack of communication related to mutual concern for causing distress (Chekryn, 1984; Gotay, 1984; Mahon et al., 1990; Weisman & Worden, 1985/1986; Worden, 1989). Subjects felt that they could not burden their family with discussions (Mahon et al., 1990; Northouse & Northouse, 1988; Zachlis & Shands, 1991).

Ovarian cancer patients had increased levels of distress because of the magnitude of their illness (Howell, 1999; Powel & Midler, 1998). Several studies addressed the impact of ovarian cancer on the women's lives (Fitch et al., 1999). Subjects reported changes in their lifestyle, family, and work life. Illness caused changes in their role and financial hardships. The large quantitative study (Fitch et al., 1999) likely underrepresented women with recurrent disease. Qualitative studies (Bowes et al., 1999; Howell, 1999) provided information about the emotional status of these ill women. These studies provided groundwork for future research.

A recurring theme that arose from the literature review was the need for information. Patients used information-seeking to control anxiety, sought control over their illness, and used this information for treatment decision making (Fitch et al., 1999;
Griffiths & Leek, 1995; Howell, 1999). Patients received information from different sources which included their families, friends, and peers with cancer (Griffiths & Leek, 1995). Since the publication of this study, the information sources available to patients have changed immensely. Patients and their families download information about cancer and its treatment from the Internet.

Phenomenological studies give us a glimpse into the world of cancer patients. The literature review leaves us with many questions about how patients cope with their cancer recurrence. It is important to address the concerns of women with recurrent ovarian cancer using qualitative research techniques.

Chapter Three describes the method of phenomenology and its use to explore the experiences of women with recurrent ovarian cancer. The data collection and analysis are discussed. The assumptions and the limitations of the study are reviewed.
CHAPTER THREE: METHODOLOGY

In this chapter, the description and rationale for the selection of qualitative research are discussed. There is a description of the women who participated in the study. They were referred to as co-researchers during this process. Data collection and analysis are discussed. Methodological assumptions and limitations are provided.

Description of the Methodology

Qualitative research methods were used in this study. Phenomenological research methods were chosen because there was little known about the lived experience of women with recurrent ovarian cancer (Merriam, 1988; van Manen, 1990). Phenomenology can be described as a philosophy, an approach, and a method (Oiler, 1982). Phenomenology is the study of the lived experience. The lived experience of a phenomenon focuses on what it is like to be living with the experience from the subject’s perspective. During the process of the research, inner meanings of that lived experience are uncovered as thick descriptions. Phenomenological reflection requires reflection about something that has been experienced by that individual. The phenomenological research method uses systematic questioning or dialogue with the subject in order to understand the individual’s experience.

Early works of the philosopher, Edmund H. Husserl (1859-1938) described phenomenology as a means of understanding the lived experience. Two concepts emerged from the work of Husserl: intersubjectivity and life-world. The term intersubjectivity refers to the belief in the existence of others who share a common world. Life-world referred to the study of the phenomenon as it was experienced. Other important influences in the field of phenomenology have been Maurice Merleau-Ponty
(1962), Martin Heidegger (1889-1976), and others. The work of Husserl and Heidegger developed out of a concern for the experiences of others and their meaning rather than through quantitative measurements. In later years, phenomenology has had a great impact on the world of psychotherapy (Colaizzi 1978; Moustakas, 1988).

van Manen (1990) described hermeneutic phenomenology as a human science that studies individuals. van Manen described the characteristics of phenomenological research. He described a dynamic interaction among six research activities:

1. Turning to a phenomenon of interest;
2. Investigating the experience as we live it rather than as we conceptualize it;
3. Reflecting on the essential themes which characterize the phenomenon;
4. Describing the phenomenon through writing and rewriting examples of the lived experience;
5. Maintaining a strong and pedagogical relation to the phenomenon;
6. Balancing the research context by considering the parts and the whole of the experience. (pp. 91-93)

van Manen (1990) referred to the subject as a co-investigator or co-researcher. The rationale for this title was that they had a personal stake in the study. They became involved in the research process and were concerned about the results. For the purposes of this study, the 6 women are referred to as co-researchers.

Co-researchers

Six women with recurrent ovarian cancer were interviewed about their experiences. Women with recurrent ovarian cancer were identified through the four-
physician/nurse teams (four physicians and their primary care nurses) at the Hamilton Regional Cancer Centre. Two women, Ellen and Anna, were chosen by me to take part in the pilot study. These women were asked to participate in the study because they had always been vocal about their needs. The remaining 4 women were approached to participate in the study by a nurse or physician within our department. Women were interviewed within a period of 2-20 weeks after their recurrence.

**Description of the Co-researchers**

Pseudonyms were used to identify participants in order to ensure anonymity.

Anna is 59 years old. She was born in Europe and immigrated to Canada 34 years ago. She has two sons aged 34 and 38. Anna lives in a suburban community. Her husband died in a car accident 7 months before her ovarian cancer was diagnosed.

Anna was diagnosed with breast cancer 17 years ago and she was one of the founding members of a breast cancer support group. In 1996, Anna was diagnosed with ovarian cancer. She was treated with surgery followed by chemotherapy. Her ovarian cancer recurred 3 years later. She has received palliative chemotherapy. Her disease is causing problems, but she continues to travel, ski, and garden.

Ellen is 57 years old. She lives in a suburban community with her husband. She has a son and daughter. Her daughter lives in another province. Her son and daughter-in-law live nearby, and the couple has one grandchild. She was diagnosed with ovarian cancer in 1995. She was treated with surgery followed by chemotherapy. Her cancer recurred 4 years later. She was receiving palliative chemotherapy and her tumors have failed to respond to the drugs. She now has a bowel obstruction and has decided to stop further treatment. (Ellen passed away in June of this year.)
Mary is 49 years old. She is married and has four adult children. She was diagnosed with ovarian cancer in November 1998. She was treated with surgery followed by chemotherapy. The ovarian cancer recurred in July 1999. Her cancer has failed to respond to chemotherapy. Mary has several medical problems because of her cancer. Her physical condition deteriorated since the study began. She enjoyed life and had close ties to her local community. She belonged to a religious organization. (Mary passed away in March of this year.)

Joan is 54 years old. She is married and has two adult children. She lives in a small community. She belongs to a religious organization. She worked out of the home, and her husband recently retired. She was diagnosed with ovarian cancer in July 1998. She underwent surgery and chemotherapy. Her cancer returned in April 1999. She is currently receiving chemotherapy.

Alice is 67 years old. She is married and has six adult children. She and her husband had a small business and have recently retired. She was diagnosed with ovarian cancer in January 1997. She received surgery and chemotherapy. The ovarian cancer recurred in November 1999. She is currently receiving chemotherapy.

Debbie is 55 years old. She is married and has two adult children. She worked as a travel agent and is now retired. Her husband is self-employed. The couple has two grandchildren.

Debbie was diagnosed with ovarian cancer in December 1998. She underwent surgery and chemotherapy. Her cancer returned in October 1999. Her cancer has failed to respond to chemotherapy. She is currently receiving palliative chemotherapy.

Initially, two interviews were planned with each woman in order to establish a
perception of the ovarian cancer patients’ world. The purpose of the second interview was to ask questions about remarks made by the women in the first interview. During the first interview, I had forgotten to ask Anna one of the questions, so it was a matter of asking her that question. She took that opportunity to add comments about her ovarian cancer. Ellen described her relationship with her physicians during the second interview. Debbie was asked about a comment she made on during the initial interview. Her response was that there must have been a transcription error. Joan had very little to add to our discussion. Each of the above second interviews were audiotaped and transcribed. These transcriptions were added to data. Mary and Alice were not interviewed the second time because they had given full descriptions of their experiences. I had discussed this issue with Dauna Crooks, and we agreed that their descriptions were complete.

The patients met the following inclusion criteria in order to participate in the study:

1. A diagnosis of recurrent ovarian or primary peritoneal cancer
2. Ability to speak English
3. Ability to give informed consent
4. Physical ability to tolerate one or two interviews.
5. Patients with a life expectancy of at least 3 months (identified by their physicians)
6. Patients who do not have a history of mental illness or cognitive impairment.

The majority of patients were known to me. I have established relationships with most of the ovarian cancer patients. Several of these women have been treated with surgery and/or chemotherapy under the care of the staff physicians on our team. My
relationship with these women enhanced the interviews because of an established trusting relationship. Women were allowed the freedom to choose whether they wanted to participate in the research project. After the pilot study, the next 4 women were approached by another nurse to decrease the possibility of coercion. The women involved in the pilot study were Anna and Ellen. Those interviews allowed me time to become comfortable with the equipment. There were some problems with the tape recorder. It was voice activated, and my voice did not pick up well during questioning. This problem was sorted out after the first interview by changing the tape recorder over to the normal function of recording.

The women were allowed time to decide whether they wished to participate in the study. I was aware of the power of subtle coercion and ensured that women felt free to participate or leave the study at any time (Lo-Biondo-Wood & Haber, 1994). All women approached agreed to be interviewed. Each woman was given a copy of the consent form and the interview questions before the interviews were scheduled. A copy of the consent was placed in their Cancer Centre chart. (Refer to Appendix A)

Interviews took place at a mutually agreeable location. The women were interviewed alone with the exception of one woman, Alice. She asked that her husband, Al, be present at the interview because they were fighting the disease together. He did not speak during the interview. The co-researchers were given the choice to be interviewed in their homes or at the Cancer Centre. An interview room was used at the Cancer Centre. They were assured anonymity throughout the study. Their names did not appear on any document. They were given pseudonyms.
Role of the Researcher

Before the interviews, I took some measures to enhance my skill as a researcher (Swenson, 1996). I have had several discussions with a trained research assistant regarding the interview process. I had done extensive reading about the interview process. The pilot study was done with two women. Dr. Dauna Crooks, an expert nurse researcher, reviewed the transcripts with me to identify changes to the interview style. She assisted me with the data analysis. This process helped to give consensual validation. This process decreased the likelihood of importing meanings which are not in the transcripts as described by (Benner, 1985). We reviewed the first two interviews. I had highlighted specific words and sentences on the original transcripts. Words from the highlighted area was written in the margin and entered into my field notes.

Over the past several years, my relationship with these women has changed because of restructuring in the hospital. Ovarian cancer patients now receive their chemotherapy at the Cancer Centre. Before this change, I would interview and examine these women in a small outpatient area of the hospital. Often, the physician would not see these patients during their chemotherapy appointments. I spent a great deal of time talking to them and would not be concerned about the length of time that I spent with them. This outpatient area has now closed, and my exposure to these women has changed immensely. This change meant that my relationship with women likely did not influence my research as I had previously thought that it might.

The study proposal was submitted and approved by Brock University Ethics Committee and the Research Ethics Board for Hamilton Health Sciences Corporation/McMaster University. A grant was awarded by the Hamilton Regional
Cancer Centre Foundation for payment of transcription costs, equipment, and parking reimbursement for the co-researchers.

The research proposal was presented at our Gynecologic Oncology team meeting. Several issues arose from this meeting related to the interviewing process and ethical issues. Suggestions from this meeting were incorporated into the research proposal. Discussion at the meeting centered around my relationship with the women and a concern whether they would be honest with me during the interview. The questions that arose from the meeting were kept in the field notes. Wording of one of the questions was changed to provide a more neutral tone. The question regarding how their cancer would affect their plans was restated as how their cancer would change their hopes for the future.

There was also a discussion about the introduction of the research project to women before the initial interview. Women were informed that I was the primary researcher. They were informed that I would not answer questions that arose during the interview. They were told that concerns or questions would be dealt after the interview. Additional information was added to the interview introduction about my role as the researcher.

During this research process, the rights of the co-researchers were of the utmost importance. Munhall (1994) stated that the therapeutic mandate of nursing advocacy took precedence over the research mandate of advancing knowledge if a conflict developed. Ethically, if a patient becomes distressed during the interview, the patient’s rights take precedence over any research project. I have worked for many years as a nurse and I have counselled patients about their problems and needs. The need for patient advocacy was
of the utmost importance.

It was recognized that the participant might become emotionally distressed at the time of the interview. I was prepared to stop the interview until the participant became composed and consented to continue with the interview. Morse (1995) stated that the majority of subjects found the interview process cathartic. Participants expressed an appreciation because someone had asked them about information that they would gladly share with others. It was possible that new issues would surface for the women after the interview. Subjects would be referred to a social worker, supportive care nurse, or psychiatrist if they required psychological assistance. Joan and Mary became tearful during the interview. The tape was shut off until they became composed. The interviews proceeded within a matter of minutes. Both women stated that they were emotional because of the nature of the interview.

Data Collection

Copies of the proposal were distributed to the nurse/physician teams responsible for accrual of patients.

The first set of interviews began in August 1999 and was completed in November 1999. Two women were approached to participate in the pilot study. The purpose of the pilot study was to identify problems with interview questions, equipment, and procedures for data analysis.

A semi-structured interview guide was used during the study. This type of interview allowed the women to identify issues of concern to them and to elaborate on them. The interview questions were broad and open ended. Once an element of rapport was established, the research questions began (Morse, 1995). Examples of the questions
were: Your physician recently told you that your cancer is back: What does that mean to you? How does this information change how you approach the day? What are your dreams or desires now? How has this cancer recurrence affected your hopes for the future? If you met a woman with ovarian cancer, what advice would you give her? (Refer to Appendix C and Appendix B for the introduction to the study and the interview questions.)

All interviews were audiotaped and transcribed verbatim. Our department secretary transcribed the tapes. I then listened to the tapes and compared them to the transcripts for any errors or omissions. Changes were made to the transcripts. I also kept field notes to record thoughts and reflections for future reference. Field notes were kept as a supplement to the transcripts. My field notes contained personal impressions, any nonverbal communication notes, and an account of what occurred in the setting during each interview. Data analysis began after the first transcript was completed. The process of data analysis is described below.

Data Analysis

van Manen (1990) described three approaches to identification of themes. They were the holistic; selective or the highlighting approach; and the line-by-line approach. These approaches were used and described in the text of this document. The transcripts were read initially to get a sense of the whole document. The process involved reading the document over many times. Significant words, sentences, or groups of sentences were highlighted in the original transcripts. Notations were made in the margins regarding statements that stood out. These statements were recorded in the field notes and dated.
I met with Dauna Crooks after the interviews with the first 2 interviews. I described my original impressions and we compared our perceptions of the transcripts. After the 4th co-researcher interview, the data were sorted into themes. I sent a letter out to the women describing the themes that emerged from the analysis (see Appendix E). I spoke to each woman regarding the letter. They agreed with the themes and the study continued. The interviews were completed by early December 1999.

The mechanism for working with the data was similar to the “cut up and put into folder” approach that was described by Bogdan and Biklen (1992). The data were sorted using two documents. Each paragraph was numbered before it was sorted. Data from the original transcripts were cut and pasted under the themes. When a paragraph was moved, it was underlined and identified with the initials on the intact copy. The data were sorted using this technique and by reading back and forth through the documents. Each paragraph within the transcripts was accounted for in the data analysis. Several portions of the data were not included in the data analysis. Anna’s description of her breast cancer diagnosis and Mary’s descriptions and quotes from the scriptures were not included because they were not relevant to this study. Anna’s description of her breast cancer diagnosis dated back to over 10 years ago. She had described her relationships with physicians at that time and therefore this description was not included in the data.

The original themes identified in December 1999 changed over time. The original themes were content categories related to the questions from the interview guide. An example of an original theme was the response to recurrence or relationships with others. The data analysis phase took many months to complete. (Refer to Table 1 for additional information regarding data analysis).
### Table 1
Data Analysis

<table>
<thead>
<tr>
<th>Content Categories related to questions</th>
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<tbody>
<tr>
<td>Emotional impact</td>
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<tr>
<td>Relationships with others</td>
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<tr>
<td>Uncertainty about the future</td>
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<tr>
<td>Information</td>
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<tr>
<td>Advice to other women</td>
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<tr>
<td>Spiritual issues</td>
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<td>Relationships with health care professionals</td>
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<th>Initial themes woven through the data</th>
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<td>Being aware of the recurrence</td>
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<td>Talking about dying</td>
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<td>Hope and hopelessness</td>
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<td>Being listened to</td>
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<td>Personal struggle</td>
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<th>Final themes collapsed from initial themes</th>
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<td>My cancer is back</td>
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<td>It means that I will die</td>
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<td>We are people; we are not a disease</td>
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<td>Information</td>
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<td>Life has changed/life hasn’t changed</td>
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The themes identified in January were: (a) being aware of the recurrence, (b) talking about dying, (c) hope and hopelessness, (d) being listened to, (e) personal struggle and (f) isolation, (g) normalizing life, (h) spirituality, (i) social support, (j) seeking information, and (k) personal transcendence. The data were cut up and pasted into these themes. The same data were placed into several different themes and lost its meaning. In February, I met with my thesis committee regarding the data analysis. It was decided that I didn’t need to discuss the initial themes with my co-researchers. I had agreement with the original content categories. I did meet with my co-researchers during their clinic appointments in February and March, 2000. The above themes were not the words of my co-researchers and did not represent their voices. The women did not talk about their transcendent moments. This process of moving back and forth through the data took time to accomplish.

I became totally overwhelmed by the data. I was able to go back to the data analysis once I reflected on my personal journey during this research project. I then was able to see the data more clearly and was able to collapse the themes. The initial themes were collapsed into the final themes, which represented the lived experience of women with recurrent ovarian cancer. The examples describe the original coding and the change to the experiences of the women. The italics indicate the co-researcher’s verbatim comments from the transcripts. This example also shows the technique that I used when moving data from the intact transcript to another document and coding of that data.

Joan

Paragraph 291-Now I know that I do selective things. I choose, if I feel like going someplace, I go. I have not committed myself to some of the organizations that I
did, because I don't want to feel the pressure of having to find somebody to fill the
spot if I can't make it to the meeting...Now I do things that I want to do.  N

Normalize Life

This term of normalizing life was my theme. After reflection, this quote was
moved to the theme, life has changed/life hasn't changed.

Debbie

Paragraph 418-No, no one talks to me about it. They all take care of me but... and
I think that they are protecting themselves too.  I-Isolation

This initial theme of isolation was not large enough to stand on its own. Again, it
was my theme and did not reflect the women's theme. It was then moved to talking about
it.

These two examples show how the themes changed over time into the final
themes. Again, each line was accounted for in the data analysis using the numbering
system and entry into my journal.

Triangulation of data was achieved through the variety of data sources (Creswell,
1994; Morse, 1995). The transcripts were the main source of data. Field notes were
reviewed during the data analysis. The field notes helped to capture the progression of
themes in the data analysis phase. The second interview served as a dialogue for
interpretation of meaning during the study.

Several issues related to rigor arise in the use of qualitative research. van Manen
(1990) discussed issues of credibility, transferability, and dependability. Credibility can
be described as the measurement of trust within the findings. Credibility is the
description of how vivid or faithful the description of the phenomenon is (Beck, 1993;
Guba & Lincoln, 1988). The data analysis provided a thick description of the research finding. Credibility of the research was maintained by keeping in-depth field notes. Dr. Crooks has extensive experience in qualitative research. She assisted me throughout the research process. Although I was the primary researcher, I worked collaboratively with individuals with qualitative expertise: Dr. Susan Drake, Dr. Michael Manley-Casimir, and Dr. Dauna Crooks, for validation of data (Benner, 1985). I also met with my research committee following the data analysis in February of this year.

**Methodological Assumptions**

Assumptions of the study were that the participants were open and honest. No one refused to participate in the study. Since the study has closed, I have had several women call me because they wanted to participate in the study.

**Limitations**

One limitation may have been the possible loss of women while on the study. Two women, Mary and Ellen, have passed away this year. Despite the fact that they did not live to see the results, the findings will be shared with their families. Mary wanted a copy of her transcript for her family. Ellen's family will receive a copy of the findings. No one withdrew from the study because of rapid progression of their disease. The remaining women will receive a copy of the findings. These women were highly involved in the research process. Following the interviews, they all expressed their wish to be updated about the study. They will receive a report.

The findings of this study reflected the experiences of these 6 women at one point in time. The ages of the women at the time of the interviews were 49-65. Women in
different age groups, culture, and sexual identity may have different issues. These study findings are not generalizable to other women with ovarian cancer.

Summary of Chapter Three

This chapter provided a description and rationale for the phenomenological research design. The role of the researcher and the relationship with the co-researchers were discussed. A description of the 6 co-researchers was given. Permission for research and the consent process were described within the chapter. Data collection and analysis were described. The assumptions and limitations of the study were reviewed.

Chapter Four discusses the findings of the study.
CHAPTER FOUR: RESEARCH FINDINGS

Interviews with Anna, Ellen, Mary, Joan, Alice, and Debbie provided rich accounts of their experiences with recurrent ovarian cancer. Phenomenological research uncovered the meaning of their illness and its recurrence. The findings of the study revealed an intertwining or weaving of themes related to their recurrence. Some women talked about their original cancer diagnosis. Some women felt the need to talk about their diagnosis before giving their descriptions about their present state of health. They described the perceptions of their illness at the time of recurrence. They discussed their feelings and the effect that ovarian cancer had on their lives.

Six themes emerged from the data analysis. These themes were: my cancer is back; it means that I will die; we are people, we are not a disease; talking about it; information; and life has changed. These themes are not separate but are like layers that interconnect.

**My cancer is back**

My cancer is back referred to the women’s responses at the time of hearing the news of the recurrence. Five of the 6 women described their recurrence as inevitable. The range of their responses was from shock and disbelief to disappointment and relief. Each woman dealt with the recurrence in her unique manner.

Anna talked about her initial appointment with the gynecologic oncologist 3 years ago. Her husband had died in a car crash 7 months before her cancer diagnosis. Her son flew in from Japan to be with her during the appointment. He pressed the doctor about his mother’s survival chances. Anna felt that she wouldn’t have asked that question because she was a person and not a statistic. Her son was given the information, as Anna
stated:

But anyway, he got the answer: 2 to 4 years. So toward the end of the third year I kind of felt a little bit smug thinking okay I have done it...so it was just more less a surprise.

She described her recurrence 3 years later as a fluke thing. She had been feeling well. She had an onset of abdominal pain. She went to her local hospital and saw the surgeon. She had an ultrasound scan. The doctor saw gallstones. She described what the surgeon found at the time of her operation. The young lady surgeon...had seen some more cancer in that area...so she just closed me up. She was given an appointment to see the gynecologic oncologist for discussion regarding further treatment. She decided to have chemotherapy because she felt that her children needed her. She couldn’t die yet because her husband had died recently.

Ellen described her recurrence in different terms. Ellen had been having pain for some time before hearing about her recurrence. She suspected that she had a problem. Ellen described her sense of relief with the news that her cancer was back.

In a way, it was a relief because I knew from what he had told me before that it would be back. And waiting for a recurrence was actually worse for me than having the cancer because I find that I can deal with things that are real.

Ellen described her feelings of sadness when the doctor talked to her and her husband. She described their reaction as being grief stricken.

Mary had symptoms of bloating before finding out about the recurrence. She had similar symptoms at the time of her cancer diagnosis. She suspected that something was wrong. When she heard the news of the recurrence, she walked out of the clinic and felt
that she would be dead in a matter of weeks. She then went to her family doctor and talked to him. She asked him if she should move up her daughter’s wedding date. He told her that it wouldn’t be necessary because she had months to live, not weeks.

For Mary and Joan, there was a short period from completing chemotherapy to having a recurrence. Joan described her feelings of shock and disbelief.

*That news was pretty devastating, especially since it had been 7 months since I finished the last round of chemo... I was totally shocked in finding out that the tumors were there again.*

Joan described herself as being very sad when she heard the news. After hearing about the recurrence, she became depressed. She described her feelings as: *I was feeling down... I wasn’t sleeping... I was feeling weepy.*

Her feelings of sadness went on for several weeks. She finally went to her family doctor who prescribed an antidepressant for her. She stopped the medication because of the side effects and she felt that she could deal with the problem herself.

Debbie had made an appointment with her physician because she was having problems. She was scheduled for an ultrasound. She had driven herself to the hospital that day because she was only having a test. Her husband normally came with her for discussions with the doctor. She described the events of the day she heard about the recurrence:

*She [the radiologist] told me that she did see a mass on the ultrasound... I guess my thoughts driving home were more about my family. There probably is a good possibility that in the future I will die.*
Alice talked about her feelings of disappointment. She was on a study drug for 2 years. She didn’t know whether she was receiving the experimental antibody or the placebo. Alice’s attitude was much different from the other women in that she was optimistic about the future. She stated, I figure I beat it once. I can do it again.

She had been in the hospital several times recently. She felt that her heart problems affected her more than her ovarian cancer.

Each woman talked about how they had heard about their recurrence. They described their feelings and their thoughts at that time.

It means that I will die

All of the women except Alice talked openly about their death and the losses that they would face in the future. The majority of women talked about their fears. Anna and Mary stated that they did not fear death. Anna stated, If you get that fear of death out of the way. Then life is so much simpler.

Mary described her discussion with her surgeon about ovarian cancer. She stated: Someone [the gynecologist] thought that I was in denial...I do know what the end results are going to be and, but I also know where I am headed. So there is no fear involved there.

During the interview, I asked Mary if she meant that she wasn’t afraid to die. I found it difficult to understand Mary during the interview. Mary talked about the bible and used quotes from the bible. It was difficult at times to sort out what she was saying to me. She was very clear in her answer. Death doesn’t frighten me. I think it’s more the way in which we die that we are afraid of than death itself.
Mary talked about her youngest daughter and her husband. Her daughter lived at home. She cared for her mother’s needs. She stated that her husband and daughter didn’t want to lose her, but the reality was that she was going to die soon.

Ellen talked about her fears and the losses that she faced in the future. She stated: Scary because I’ve seen in 4 years, I’ve seen six people die of cancer. So I pretty well know what’s ahead. And it’s scary...from the suffering point of view.

Ellen talked about her feelings of loss in regards to her children and her husband. One thing that talking about how you feel, is how devastating to think that you are going to leave your children behind...you’re always a mother and it’s bothering me so much that my children are going to grow up without me...I suppose my husband will meet somebody else. He’s a very nice man. So she’s got to be good to him. I’ll have to tell him all of that.

Joan wanted her grandchildren to remember her. She described her difficulties with thinking about death because she feels well. Most days I am really upbeat. I don’t get up every morning thinking I’m dying of cancer. I don’t feel like I’m dying. The fear is there. The fear of what’s ahead but I think that was ahead even when I had been diagnosed the first time. Just no one knows what’s ahead and the fear of the unknown is always great,

Alice did not talk about death or any fears that she had during the interview. She described her positive attitude. She stated, I think I have a better chance of survival and getting better and all the rest of it if I have a positive attitude.

Debbie described her perspective.
I am not preparing for death…my will is in order and I have a list…of family
items that I wanted to give to someone.

We are people, we are not a disease

The women expressed a need to be treated as individuals by their health care
professionals. Anna described her feelings.

There are a few things that I wish the professionals could give, and it has already
become so much better about the more compassionate way in which doctors and
nurses treat the people. I know they see only gloom and doom all day long and
you know if you go in and make a joke, you know they look at you.

Ellen described her relationships with health care professionals and provided
advice. She described her appointments as being impersonal or technical.
I really think that doctors and nurses should sit down, touch your hand, and treat
you as a person with an illness. They are more concerned with the illness than
they are with the person. Not all doctors are like that. I have been to some
doctors who are not, who listen and who don’t make you feel like you don’t know
too much.

She talked about how she knows or was aware of her body. She compared being
sick to knowing that your children are sick.

A person with cancer, for the first time or recurrent cancer is the same way. They
know if there’s something wrong and lots of times the doctors won’t act on those.
They just act on pure science and that’s it.

Ellen described her frustration about health care treatment.
We are not a disease, we are people. And we have to be treated like people. Doctors have to start listening to us. Not all doctors are like that but most of them I find are. My friend was at a country fair the other day. Her doctor didn’t recognize her. It’s like we leave our faces at the door.

Ellen talked about her relationship with her gynecologic oncologist. She had found it difficult to talk to him. This description was given during the second interview. She described her anger that she felt toward her gynecologic oncologist:

It’s been 5 years now and I think I have finally realized that the reason I didn’t like him was because I thought...we look up to our doctors, and especially this doctor, I think he is very knowledgeable and I think if anybody could cure me, he could and he obviously didn’t. So I was very angry with him and of course I wouldn’t tell him that...But now that I realize that’s what it was, I actually feel like I can talk to him sometimes because if the doctor can’t cure me, then who can?

Mary described an appointment at the ultrasound department. She had been examined by three different people and had to wait for hours during that appointment.

Well other than I think I’d like to see the hospital staff be a little more sensitive. I think it becomes such a mundane thing or an everyday thing with them and you are having this experience for the very first time of your life.

Joan described her feelings about visits to the Cancer Center.

It gets more and more difficult to come into the clinic for treatment as time goes on and it’s really necessary that everyone learns patience. Each time I come in, I find I have to track down labels...We sign in and we wait our turn at the lab.
Then you sign in and wait your turn at the clinic and I feel well, I just can't imagine if I was not feeling well or doing well, how horrible an ordeal it all would be.

When it's time to get that life-saving cell destroyer, it's so nice to have the nurse offer you a toast warm blanket, and tuck you in for the duration of your drip and I've had that every time.

Debbie and Alice felt that they had received the best care from home care staff to hospital staff.

The majority of women talked about their need to be listened to and treated as individuals. Some women talked about their perceptions of visits to the hospital and Cancer Center. They also described what changes needed to take place within the health care system. Their descriptions showed examples of examinations and discussions that are an everyday occurrence. These examples clearly identify situations which health care professionals take for granted but patients do not.

Talking about it

The women talked about discussions with others. The 6 women talked about the advice that they would give other women with ovarian cancer.

Anna felt that although she had difficulty giving advice, she supported other women by talking to them. She spoke about the individual's response to information, and advice.

It's so difficult because everyone is different. There are some people who just don't want to talk about it...other women think because this was your experience; it does not compare with yours.
Anna described her experiences with the breast cancer support group.

Women can help each other just by talking about it, by sharing and as you become a more long-term survivor, the newly diagnosed see that you have made it, maybe there's a chance for me to make it.

Both Ellen and Debbie talked about keeping the news of the recurrence to themselves for a while. Ellen underwent months of chemotherapy treatments before she told her family and friends. Ellen and her husband Bill shared the news about the recurrence with others when her hair fell out from her chemotherapy. She stated:

*I find a lot of times with cancer; you can’t be premature with it. It's sort of like announcing that you're pregnant. It's a long time before the actual event.*

Debbie and her husband told three people about her cancer recurrence.

*I found before...word does get around and I found one of the hardest things was people look at you like you have the plague...but when you have cancer, they just don't talk to you about it.*

During the interview, Debbie was surprised that I hadn't heard this kind of description from other patients. She compared having cancer with something benign like breaking your leg. She said at least with a broken leg, the cast would come off and people would remark about it. With ovarian cancer, there wasn't a positive outcome.

Alice described how it was difficult for her husband to understand what she was going through.

*Just like anything else, you can’t describe it to people. I mean they can only understand if they have felt it themselves. I used to get terrible migraine headaches. And Al was always very sympathetic and he would say I’m sorry, I*
can't do nothing. I don't know how you feel and this is true with anything whether it's emotional or physical unless you have had it yourself. You don't...no you can't describe it.

Ellen and Joan belonged to support groups in their local community. Joan found the support groups quite helpful. She talked about her feeling of comfort within the group. She didn’t have to worry about upsetting her family with discussions about her illness.

These people, you knew you could say anything to them. It would be kept in confidentiality. It was a place to vent, a place that you weren't afraid of upsetting family members or saying something that would cause some sadness. Actually, it was a good place to find out information

Ellen had a friend with ovarian cancer. She described her relationship with her. Her friend used the Web and helped Ellen find information about drugs. She and her friend joined a support group. The members of the support group had different kinds of cancer. She joked about the discussions in the support group.

We get jealous of each other's cancers...Well they get so much attention.

Everything is breast cancer. Whereas people with ovarian cancer, you very seldom hear about it. They have a dragon boat racing for breast cancer. The funds are always for breast cancer, you know. It seems ridiculous but I know this one friend of mine and myself, we look at each other and we roll our eyes and say here we go again-breast cancer.
Ellen felt that women with ovarian cancer should have their own support group. Her rationale was that ovarian cancer was so different from other types of cancer because of the poor prognosis.

Ellen discussed her relationship with her children.

Actually, I’ve talked to her [my daughter] because I had genetic testing done, BRCA test done, so you know we talked about it and they watch her closely. So we can talk about me getting back on chemo. My daughter-in-law asks me about my cancer. My son doesn’t talk about it. I guess maybe my son gets it through her [information about her illness]...I don’t even know if he asks her because she never says anything about that part. I doubt that he would ask me how I am feeling. She works at the hospital so she also knows when I’m in and when I’m out of there. It’s hard to keep a secret from her.

Debbie spoke to a woman on the telephone about the PICC (peripheral intravenous catheter) catheter. The woman did not want to ask about the PICC, she wanted to know how her family was doing:

She was looking for...she was asking more about the pump and how that affected my day-to-day living and she told me how she had had her recurrence and we actually weren’t looking for advice, we were talking more about our families and how it seems to affect everyone around us.

Alice and Debbie talked about their families’ difficulty understanding about their illness.

Alice described how her husband had difficulty understanding her problems:
Well, I think that Al [her husband] worries more about me than I do. I don’t know if it’s because first of all our different attitudes in faith and secondly I have always told him it’s easier to be the sick person than it is to be the person worrying about the sick person and he worries a lot more than I do. My children, they don’t say much but I know from their attitudes that they’re very concerned. And again I think it goes back to its harder to worry about somebody than to be the person that they are worrying about.

Debbie described how her family dealt with her ovarian cancer.

Well, you know, I have thought a lot about it and I don’t know whether they think they are protecting me and I know people have trouble talking about cancer and, like our son came home at Christmas and other than acknowledging that he now realized how sick I really am. That was all that was ever mentioned from the time he arrived until the time that he left. And, but basically how the rest of them are.

Each woman talked about the effect that ovarian cancer had on their lives. They described their need to talk about their illness. Despite the fact that ovarian cancer is rare, the majority of women connected with others with the same disease. Several women talked about their families’ difficulty with the illness.

**Information**

Some women sought out information from various sources. Information was gleaned from magazine and newspaper articles, health care providers, peers, and support groups. Some women used their information-seeking as a means to control their lives. Others found the information unhelpful, negative, and unavailable. Two women received
information solely from their physicians. They felt that other information was not important to them.

Anna described the information that was available to her at the time of her original cancer diagnosis. Anna did intense reading at the time of her breast cancer diagnosis. She felt that she already knew a lot about cancer in general.

*When I was diagnosed with ovarian cancer...I went to the library, opened the book and the first thing I read was survival chances are 43%. I looked at the date. It was 1983 so it was way out of date. So I closed the book and I said forget it.*

Ellen wanted specific information from her doctor about her ovarian cancer. She came to her doctor’s appointments with a list of questions. She also had her husband present during the majority of visits.

*Where the tumors were, the size of the tumors, how long the chemo would take, how effective it was? And we also talked about different kinds of chemo...that’s the only way probably I am in charge by getting all this information.*

Like Ellen, Joan felt that she wanted to be in control by getting information about her disease. Joan talked about the information that she wanted to know and how she gets that information.

*Today, I got a number to call, but just didn’t know where to look to find somebody that...everything is kept so confidential unless people are out there on the bandwagon promoting people to look for their symptoms and really out making a stand, you don’t find a lot. You have to really start asking a bunch of questions*
and digging yourself to find somebody that is still in existence after being diagnosed with ovarian cancer.

Mary did not want any information about her recurrence. She had not sought out information at the time of her original diagnosis. She did ask the physician if she could look at her CT scan at the time of recurrence. She said that it was her body and she wanted to see the film.

*It's funny, nothing. I really did not want to know what the symptoms were for this progression of this disease because I thought my mind might play tricks on me and make me think that I was having more symptoms than what I was.*

Joan was very precise about what type of advice she would give to a woman with ovarian cancer.

*I would tell her to ask questions and be persistent. If you don't get answers, keep asking. Find everything out you can about the illness. Make the most informed decisions you can when it comes to how you wish to be treated. Be as much in control as possible. It gives you just a feeling still of well being if you are making the decisions, it's your body, your illness, your future is really important too.*

Joan reflected that patients should be given more information about supportive therapy. She felt that patients weren't being told enough about the psychiatrists and nurses that are available for counselling. She would encourage women to bring family members because you don't always remember what has been said during the appointment with the doctor.

*Alice and her husband felt that they wanted information from the doctor.*
I really don’t believe in self-doctoring unless you are a doctor. I mean you know sometimes you go out and get other information, it can be very misleading if you can’t interpret it properly, so I figured I’m better off getting my information straight from the doctor.

Debbie felt that unless you ask the question you are not going to get the information.

What I found is that I am sure that there is knowledge about my disease that hasn’t been passed on to me and I guess I would just appreciate someone sitting down and saying how much do you want to know? What would you like to know?

Debbie went to the library at the time of her original cancer diagnosis. She read about ovarian cancer, diet, and treatment. She also went on the Internet and found information.

She also talked about the limited information about ovarian cancer, but she has made her friends aware of the information on ovarian cancer.

I don’t think women are that knowledgeable about ovarian cancer. I mean there is so much done for breast cancer and lung cancer and all the other cancers. But I had never heard anything about ovarian cancer but maybe it’s where I live.

Information was not available at the time of recurrence or their original cancer diagnosis. The information resources were not available to the women. They described the information as unhelpful, not accessible, or not reliable. Some of the women talked about their need to advocate for themselves. Finding information was important to them. Some women felt that the information was negative and there wasn’t a need to pursue it.
Life has changed/life hasn’t changed

Life has changed/hasn’t changed were paradoxical themes for the women since their diagnosis with cancer. Some women described a change in their perception of life because of their cancer recurrence, or an event in their lives or their beliefs. This feeling ranged from seeing things more vividly, prioritizing tasks, and doing enjoyable things.

Some women felt that their lives hadn’t changed. The majority of women talked about trying to keep their lives as normal as possible.

Anna felt that her outlook on life had changed some time ago. She was diagnosed with breast cancer 17 years ago. Anna described her viewpoint:

*I think that the hardest time was right after breast cancer... I have kind of gone through all the emotional part 17 years ago. I always say that I have died my deaths then. And... take every day as it comes, as it came, and I still do that.*

Anna’s husband and son were involved in a car accident 7 months before her ovarian cancer diagnosis. Her husband died in the accident. She talked about how her husband’s death had affected her. Anna described her death as being inevitable. She felt that it was important to do something nice for herself every day.

Ellen talked about her feelings about recurrent cancer. She talked about her change in attitude since her original cancer diagnosis. She described how the cancer recurrence had helped her to help others. Physically, Ellen had been feeling more tired and needed to nap during the day.

*Having cancer, having a recurrent cancer is not all bad. I’ve learned a lot of things because you can sort of feel the closeness of death. Um, I think I’m happier in some ways. I get a lot more out of life. I’ve learned how to tell people*
that I love them and I see a lot of beauty that I didn’t see before... You see things
that some people who are never sick will never see. They maybe don’t want to.
I’ve had the time and the opportunity to have those feelings.

She described how her recurrence has given her a freedom of speech.

I’m becoming very outspoken. Not rude... I feel like somebody is being hurt by
someone else... I feel like I can get away with it; even though they don’t know that I
am sick. I know that I’m sick so I’m going to stick up for somebody.

Ellen described her role as a mentor for others.

I help a lot of people who have cancer, who are diagnosed with cancer. A lot of
people say that I am a very good mentor for them because I listen to them and I
tell them the facts... I just try and help people the best way I know how. Just
supporting people.

Mary talked about the positive effect that having cancer had on her life. She felt
that her beliefs had helped her cope with her disease.

It’s not a nice place to be but then again it sounds stupid to say, it’s an interesting
experience. It’s been a growing experience for me... nothing has changed other
than the fact that you know that, I know my death is closer than what I’d thought
it was.

Joan felt that her life had not changed since she was aware of the recurrence.

I think I approach most days the same now as I did before, BC, before cancer.

I’ve always tried to do accomplishments... Now I know that I do selective things.

Debbie felt that her cancer recurrence had given her time to do things that are
important to her.
null
I can write little letters to my grandchildren, do all kinds of things that those people never had an opportunity to do.

Debbie described how she tried to have a normal life.

I think that for the most part, my life is pretty normal... I don't push myself any longer... I think especially keeping it from people has made it easier for me to be seen more normal and lead a more normal life.

The recurrence caused some women to change their lives. They felt that their lives were not the same as before the cancer diagnosis. Some changes were because of their physical symptoms. Some women felt that they needed to keep life as normal as possible.

The majority of women talked about the importance of their beliefs. Some women talked about the strength that they gained from their religious beliefs. Ellen felt that she was not spiritually happy.

Anna felt that she received a lot of love and energy from others. She described her beliefs.

I don't belong to any denominations but I believe that there is somebody/something that watches over us and we just have to come to that conclusion that if the time is over, the time is over.

Ellen described her personal beliefs.

I do have a desire in that I am not spiritually happy yet. That is one desire that I'd love to have fulfilled. I've started taking some courses on basic Christianity and I talk to people. It's either going to come or it's not going to come.

Mary described how she would share her faith with others. She described:
Well, I think basically it would be sharing my faith and sharing the experiences with, of the family and what I've seen and just to live each day to its absolute fullest because the person who told you have ovarian cancer could walk out and get hit by a bus and be gone and you'd still be here. No one is promised tomorrow.

Joan found that her beliefs were a source of comfort and support.

I don't want to die yet but when I do, I believe I am going to heaven and so that is comforting. I think that God is in control...Sometimes I feel a little hypocritical because I think, if I thought heaven was so wonderful, why do I want to stay here so much longer? Which I do.

Alice felt that her faith was very important to her.

I know that there is somebody up there that's got stronger powers than I have and I put my faith in Him to help me through and when it comes down to the bottom line, I think He'll do what's best for me.

Debbie also had strong religious beliefs.

I'm okay and I think it's my belief in God and health because...it's the Lord's time for Debbie to be with the Lord, so I can accept that.

It [her faith] has calmed me into believing in the big picture and not just the small picture of my life...it's everyone else's.

The women's personal beliefs gave them a sense of comfort, belonging, and strength. Ellen found that she was not spiritually happy. All of the other women talked about their beliefs quite openly.
Women talked about their hopes for the future. Hope held different meanings. The majority of women talked about their need to remain hopeful. The range of hope varied from not seeing a future to being completely optimistic.

Anna talked openly about her plans. She bought a condominium the day before the interview. She wanted to close her cottage up north and move to a smaller unit. She wanted to be closer to her friends. She talked about her hopes:

*The dream is always a wish to be around for a little while longer to enjoy it, life.*

Ellen didn’t see a future with her in it. She described her feelings:

*I have no hopes for the future. One of the dreams that I had has been fulfilled. I wanted my daughter to get married. She was just married in February. Besides that, I don’t really have any dreams anymore. I can’t see any future.*

Mary talked about her hopes in terms of her religious faith.

*I’d talk about hope. I guess I’d have to share my faith. That’s the only thing that I can do because to me that’s where, that’s what sustained me and kept me right through everything.*

Alice talked about her hopes in short and long terms. She spoke of wanting to go to Florida in the short-term. Long term she wanted to see her grandchildren finish school.

Joan described her feelings of hopelessness.

*My hopes are still there for the future but in reality, I think the future just got shorter...But I do want more time.*

These 6 women talked about their lives with ovarian cancer. They described their hopes, beliefs, and the effect that their cancer recurrence had for them and their families. The themes described the meaning of the recurrence of ovarian cancer for these women.
The theme *my cancer is back* referred to the women’s response at the time of hearing the news about the recurrence. The recurrence meant that they would die. *It means that I will die* referred to the discussions about death and the fear of death. Women talked about their personal losses and its effect on their family.

The theme *we are people, we are not a disease* referred to the women’s need to be treated as individuals by their health care professionals. They talked about issues or events which health care professionals take for granted as commonplace. They described their need to be listened to as individuals, as women with cancer.

*Talking about it* referred to women’s discussions with others regarding their cancer. Some women felt that they could not discuss their cancer with their families. Women felt comfortable sharing information about their disease in support groups. The majority of women had talked to other women with ovarian cancer. The theme, *information* referred to information that was given or requested by women. The information which women acquired came from a variety of sources. Some used the Internet, while others felt uncomfortable using the computer system. Some women wanted to receive information from their physicians. These women did talk about their need to have information at the time of decision-making regarding their treatments. Women also gave specific advice for others with ovarian cancer.

The theme, *Life has changed/life hasn’t changed* referred to the women’s statement that their life was different since their cancer diagnosis or recurrence. Some women felt that their lives had changed immensely. They felt that there were things that they needed to accomplish before their death. Because of their faith, some women felt that they had the courage to move on and be spiritually content with life and death. Some
women became mentors for others. The majority of women talked about their need to keep their lives normal. For the majority of women, this meant that they lived each day to its fullest potential, whether that meant having little accomplishments or large ones.

Summary of Chapter Four

Chapter Four described the findings of the interviews with the 6 women. Women talked about their experiences with health care professionals. They described their relationships with others. They described how their lives had changed since their cancer recurred. Some women felt that the cancer had not affected their lives.

Chapter Five describes my personal journey with these women. I describe how the study has affected my life and my perceptions of women with ovarian cancer. This chapter also includes a discussion of the findings, with particular mention of some differences in the interviews. Implications for future study and the limitations of the study are discussed in Chapter Five.
...
CHAPTER FIVE: SUMMARY, RECOMMENDATIONS, AND CONCLUSIONS

This study described the lived experience of women with recurrent ovarian cancer. With the work of van Manen (1990) as a focus point, the study focused on the experiences of 6 women. The findings identified 6 themes related to the recurrence of ovarian cancer. These themes reflected the women’s’ feelings related to the recurrence of their ovarian cancer. The themes were: (1) my cancer is back; (2) it means that I will die; (3) we are people, we are not a disease; (4) talking about it; (5) information; and (6) life has changed.

Personal Journey

Reflecting over the last year, I realized that I have traveled a great journey with 6 courageous, genuine, and sometimes, fragile women. This research project became my focus and my challenge. Previously, I thought that this study would not affect me in my personal or professional life. I was mistaken. I realized that these women talked about things that we took for granted, such as talking about their lives, their health, and their death. I also realized that this project belonged to the women who were deeply involved in the study. As they moved from months after their recurrence to the changes in their overall health, I moved with them. Initially, I was shocked by some of their descriptions, yet I was deeply affected by their ability to be open and honest. I became aware of their personal struggle and feelings of isolation. I began to understand what their lives were like living with recurrent ovarian cancer.

As the year progressed, I became increasingly aware of my own feelings of uneasiness. This sense of uneasiness accompanied my feelings of inadequacy in my role
as a nurse caring for these women. Over the years, I had become disillusioned with my job because of the work load and changes in support staff. I realized that I had been distancing myself from my patients and my own feelings. It was easier not to become too involved, and in retrospect I was “burned out.”

My feelings and reflections have led to a new energy, a feeling of what it means to be a nurse caring for women with recurrent ovarian cancer. This awareness led to a way of knowing the women. I had thought that I knew my patients before this study; however my perceptions were not realistic. My perception was based on the appearance of women at their clinic appointments. The majority of women or patients come to their clinic appointments usually wearing a brave face. The conversations that I would normally have in an examination room at the Cancer Centre were hurried at best due to time constraints and concerns about holding up the room for the next person.

This sense of not taking up time or room space becomes part of our life in a busy clinic and interferes with meaningful interactions with patients. While doing the study, I became aware of a new meaning. After the initial interviews, I met with several women to clarify issues and discuss reflections. Ellen stated that she had been reflecting on certain aspects of the interview. She stated that she had moved on to other issues and no longer felt that way. It became apparent to me that the interviews reflected one moment in time. These women had a message that they wanted to pass on, but their feelings were not static.

The research with these women has enriched my life. I continued with the research process paying particular attention to every detail of the study. I went through experiences over the past several months where I became overwhelmed by the data. It
took me a long time to sift through the data, reading the transcripts repeatedly. As I read over the transcripts, sorting the data, I could hear their voices. Reading them over led me into their world: their lifeworld. The problem was that I needed to deal with my own feelings. I became so concerned about leaving the data intact, not wanting to leave anything out for fear that it would not have the same meaning. I wanted to be true to the study and to the women.

After my interview with Ellen, I was shocked by her statements about the health care system. I had thought that her perceptions would not be like the other women. I found it difficult to believe that women could be treated in such a manner. Then I heard similar descriptions from others. These women needed to be listened to and treated as individuals.

I had made comments in my journal after the interviews, reflections about further discussions and my feelings. Initially I was saddened by the women’s feelings about their treatment. I became disheartened. I now feel saddened for my colleagues because they have not come to know these women as I have over the past 10 months.

Ellen had shared a book with me that she was reading called: Close to the Bone: Life-Threatening Illness and the Search for Meaning. She told me that I needed to read this book in order to understand how she felt when she came for her clinic appointments. Ellen compared her experience of coming to the Cancer Centre as feeling like a piece of meat hanging on a hook. I went out and bought the book. It is not a book to read in one sitting. One night while reading it, I sat up in bed and thought, “my God I know what she’s talking about.”
The author, Jean Shinoda Bolen, described the myth of Inanna who was the Queen of Heaven and Earth. Inanna went to the underworld to visit her sick sister, Ereskigal, who was the Queen of the Underworld. Inanna gave up a series of belongings when she entered the underworld. The author described how a person with an illness underwent the same process when entering the hospital. A person gives up several layers of things. These layers meant authority, responsibility, and dignity.

During the interview, Mary had described an event that took place in the ultrasound department of the hospital. She had been in the ultrasound department for hours and had been examined by three different people. The radiologist wanted to perform a procedure. She refused and stated that it was not necessary. She stated, “I have ovarian cancer that’s what’s causing the blockage [from her kidney]). There isn’t any big mystery here.” She was tired, hungry, and wanted to go home. The radiologist took the towel off her abdomen, wiped his hands off and then threw the towel in the laundry bin. He walked out of the room and left her lying there. Mary was covered with gel and had difficulties getting up. Mary stated that she had been treated in an inhumane manner. She felt that staff should be more empathetic. They should understand that patients with cancer are ill and cannot tolerate long waiting times and unfair treatment.

After that interview, our service had admitted a very ill, elderly women to the hospital. One day she had to go to radiology for a series of tests. Her family had not come in that day and she was very anxious about going by herself. I did something that I had not done for a long time. I asked her if she wanted me to accompany her. I thought, well what would I do if she was my mother. She was alone and frightened. The experience was overwhelming.
We waited in the hospital corridor. She was shuffled from one room to another. The nurse tried to put a tube down her throat and into her stomach. She coughed and gagged during the procedure. She had aspirated her stomach contents into her lungs. When she finally got into the procedure area, I became alarmed because her condition had deteriorated. I called her physician. I told him that she would be unable to tolerate the procedure. She then had a smaller procedure. She went back to the ward. She was in the radiology department for over 3 hours.

After that experience, I began to think that these women were right. They were being treated in a manner that I wouldn’t like. I now have an increased sense of awareness about my role as an advocate for these women.

I have developed an understanding and knowledge about the lives of these 6 women. My feelings about women with recurrent ovarian cancer have now changed. I now can see a new hope. I found that there are things that nurses and physicians can do to enrich the lives of these women. I can listen to them. My ears are now open and my eyes are open to the reality of living with recurrent ovarian cancer. The discussions with these women have helped me focus the discussions with other women and their families.

My relationship with Ellen evolved over time. Ellen completed her chemotherapy. She became ill again. She was hospitalized with a bowel obstruction. She had a tube placed in her stomach to drain the gastric juices. She decided not to have further treatment including chemotherapy that would make her feel sick. She wanted to spend her remaining time feeling well and with her family. She stated that she felt that she could not have made this decision without the study. She told me that the study made her look at things that were important, and she had decided to die with dignity. Her
daughter, Cathy, stated that her mother’s perspective on life and death has affected them greatly. Cathy also sees things differently because of her mother. She stated that she is now more aware of things such as the sunrise and being happy to be alive. Ellen continues to give me comments about the study and encouragement to finish my thesis. In retrospect, I could not have gone through this research project without her strength, courage, and insight.

I have learned that my most prized possession is my ears. These women expected to be listened to and to be respected as individuals. I also learned a valuable lesson from these women. They described their cancer as being life altering. Several women described the positive aspects of ovarian cancer. They saw their cancer as a challenge: to live each day to the fullest, and to help others. These women reached out to others, and provided hope for them. They sought information from a variety of sources. They advocated for others. We have learned much from each other during the study.

I cannot talk to women with ovarian cancer as I had before the study. My initial intention was to interview these women and then continue my job as I had in the past. This concept has been scattered to the winds. My feelings and reflections have led to a new energy, a feeling of what it means to be a nurse caring for women with ovarian cancer.

The research with these women has enriched my life. As a nurse, I thought that I knew my patients well, but that perception was not true. The most empowering part of the research has been the development of relationships with these women. I see myself as an instrument, like a camera. This metaphor of the camera reflects that my eyes are like a
camera, with a wide-angle lens. This lens allows me to bear witness to the story of these 6 women.

**Discussion of Findings**

There were themes of the lived experience of women with recurrent ovarian cancer. Some issues were not brought out in the analysis because they could not stand on their own. Ellen described the sexual changes she had experienced since her cancer diagnosis. The other women did not talk about their sexuality. Alice did not talk about her death, while the other women referred to their death quite freely. Probably the most remarkable moments during the interviews were several women’s descriptions about their relationships and communication with others. Several women described their families’ inability to talk about their illness. Their personal struggle seemed to be quite isolating at times.

During the interviews, Alice did not talk about death. She remained positive about her prognosis and the future. As I worked through the data analysis, I was concerned that she had not spoken about death and wondered if I should ask her about it. After speaking with my thesis committee, it was decided that I should not ask her whether she had thought about her dying. This issue was probably more of an anxiety of my own. She had probably thought about dying. She had recently been discharged from the hospital because of her heart condition. Her personal belief was that she must remain positive. She felt that her positive outlook led to a positive overall outcome. In the end, I continue to respect her story rather than trying to fit discussions into categories or themes.

Ellen talked about her lack of sexual desire. She expressed her sadness over her loss of sexual desire. She described her feelings of guilt. She stated, "It’s sad because
with my husband I know how much he loves me...I have no sexual desire, to have sexual relations. He respects that but it’s not fair so you feel a little guilty about that.”

In a discussion later, she asked if any of the other women talk about changes in sexual function. She felt that it had not been addressed. During that discussion, I offered her sexual counselling, but her husband refused because he felt that people would be looking into his head. Her husband reflected that he was comfortable with their relationship without intercourse. He just wanted her to be alive.

Communication issues addressed in my study were not found in other studies. Bowes, Tamlyn & Butler (1999) identified that family members provided support for the women with ovarian cancer. In my study, women talked about the difficulties that their family had in talking about their illness. Spouses or children did not understand the emotions that the person was going through once their cancer recurred. It should not be an expectation that families provide emotional support. There is a supportive care clinic available at the Cancer Centre that could be a resource for women and their families.

Another emerging theme was how others do not talk about the cancer. Ellen stated that people ask how you are but really don’t want to know the details. She stated if she told people how she really felt that they would cry, feel guilty. It was easier just to say that she was fine.

Ellen talked about her feelings of loneliness. She described her feelings:

The best thing that I...I’ve thought about this and the best word that I can use to make you understand is that I feel lonely. I have all kinds of friends and supporters but I still feel that I am by myself...Every once in a while I get teary eyed and I go to bed and always cry to myself.
Debbie gave specific examples of how her family and friends are not helpful. She and her husband kept the news of her recurrence to themselves. She stated, "I found one of the hardest things was people look at you like you have the plague." She told me that she wouldn’t put herself through that experience again. She talked about how her family believed in "keeping a stiff upper lip." The above examples of the women’s experiences were overwhelming to me. I was surprised by their feelings of loneliness and isolation. There were several other instances through the transcripts where women described how others did not talk about their illness. The families didn’t talk about their illness because it was too upsetting for others. Although in my heart I had always known that these issues were a problem, I was not prepared for their descriptions.

Ellen described unhelpful comments that people made, "People tell you to live one day at a time; people saying 'you look so well' and 'I could step in front of a bus today and be killed.'" She reflected that people didn’t know what to say to you. Unfortunately, that concept has not changed over time. Most people don’t know what to say to people who are very ill.

Many issues such as talking to family, talking about their illness, and dealing with the physical changes in their health are issues which we take for granted in life.

Reflection of the study revealed many personal meanings to me. The reflections allowed me to go outside of the data and reflect on changes over the time of the study. Once outside the data, I gained an understanding of what it was like to have recurrent ovarian cancer. I was also able to reflect on the personal changes that I underwent during the study. I am now better able to identify what issues were important for these women.

After doing the data analysis, I came across an article entitled, "In your skin you
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are different: Women living with ovarian cancer during childbearing years.” This recent study by Schaefer, Ladd, Lammers, and Echenberg (1999) examined the experiences of 5 young women living with ovarian cancer 1 year after their cancer diagnosis. These women had early stage disease and were in their childbearing years. Four of the women had been undergoing infertility treatments or had problems with painful periods. The women were interviewed several times throughout the study. After the interviews, the analysis of data revealed the themes of: serendipitous diagnosis, managing treatment, the horrible hair experience, hysterectomy, unfairness of menopause, body changes, intimate dreaming, being with others, being normal/different, being vigilant, being heard, and trying to make sense of it. This study explored the meaning of an ovarian cancer diagnosis to young women.

The findings had similarities and differences to this study. The study findings reflected the aspects of the ovarian cancer diagnosis and treatment. The themes being with others, being normal/being different, being vigilant and being heard were issues that were described by the women in my study. Being vigilant described how the women were aware of their bodily functions and changes that they had from day to day. In my study, women described an awareness of their bodies. They described how they became aware of changes and that they knew about their bodies better than the nurses or physicians did. The theme being heard resembles the theme: we are people; we are not a disease. The difference between the two studies was that the women in my study were older. They were mothers and grandmothers. They were older also in the sense that they may have been in the health care system longer. They voiced their concerns and they learned how to advocate for themselves.
In retrospect, I am glad that I read this article after I had done the analysis. While doing the analysis, I read far too many articles, and this research may have made the analysis more difficult for me.

The findings from my study complemented many of the findings from the study by Fitch et al. (1999). Fitch et al. described the benefits of belonging to a support group. These benefits were encouragement from others, reinforcement, and an opportunity to speak with others and a way to find out information from fellow cancer patients. In my study, Anna, Ellen and Joan talked about the benefits of belonging to a support group. Ellen described how she wanted to belong to a support group for ovarian cancer, not a general support group.

Fitch et al. found that the women felt that they had not received adequate help for their psychosocial problems. The authors suggested that the women receive help for emotional reactions, counselling and supportive care. Again, the women from my study discussed their reactions to their recurrence. Several women described their need for additional support and counselling. Unfortunately, some women did not know how to access the health care system and ask for help.

The issue of sexuality was similar to the larger study done by Fitch et al. (1999). Women's sexuality was not identified as a problem in this large study. This finding might reflect our way of thinking about sexuality as the act of intercourse. Intimacy issues need to be addressed as part of holistic health care. Unfortunately, unless the professional asks the appropriate questions then this aspect of sexual health is seldom introduced into the conversation by the patient.

Fitch et al. (1999) found that women had positive and negative aspects of their
illness. This finding was reflective of the findings from my study. Women described how life had changed or not changed. It is interesting to note that women described their need to prioritize their activities. This theme is paradoxical as these women stated that their lives hadn’t changed but then proceeded to describe how they only did things that were important to them. The time of recurrence is a time to take stock of what is important to them.

Dawson (1993) found that the majority of women had inner resources to envision their future optimistically. Dawson (1993) stated that the implications for nursing staff would be to be honest with patients without destroying hope.

Women in my study had paradoxical feelings of hope and hopelessness. They too wished to have open and honest discussions with health care professionals however they found that the nature of these discussions were negative. The differences between the two groups were: women in the Dawson (1993) study had recently undergone their initial chemotherapy while the women in my study were aware of their recurrence. They described hopes as well but their hopes were for more time.

**Conclusions**

The purpose of this study was to explore and describe the lived experience of women with ovarian cancer. The focus of the study was to understand women’s experience in order to help them through their illness trajectory. Information from previous quantitative studies failed to reveal the unique issues raised by these women. It was felt that the women’s voices were not heard.

The literature review covered a number of issues related to meaning and cancer. The literature review also focused on issues related to communication and information
pertinent to cancer patients. Several studies focused on issues of quality of life using symptom distress scales. Nursing research on ovarian cancer is in its infancy state. Ovarian cancer is a disease with a poor prognosis. It is difficult to generalize the findings of qualitative studies from other cancer disease sites, such as breast or lung cancer.

The information from this study can be used to help others understand the meaning of recurrent ovarian cancer. Informational needs of this group ranged from requiring no information to wanting to know specific disease-related information. It is important to identify the unique learning needs of the individual on an ongoing basis. The most valued aspect of the illness trajectory is the relationship that the women had with their health care providers. It was important for these women to have their stories heard, their lives valued, and their issues validated by others.

There have been major changes in information that is now available for newly diagnosed women with ovarian cancer. There are pamphlets available, web sites, and library resources. Women need to be able to access information. I hope that in the future the health care system in general will become more focused on issues that are important to women with ovarian cancer. Women need to be provided meaningful support. Peer support has been available through the Canadian Cancer Society and the Wellwood Resource Center. Women need to be given the above resources and support in order to empower them to live meaningful lives with ovarian cancer.

Howell (1998) states that nurses can act as a catalyst when helping patients search for meaning of cancer. Nurses have a privileged relationship with cancer patients. We can listen to the patients and strive to develop an understanding of their illness, establish a means of knowing that patient, and allowing them to share their stories with us.
According to Howell, nurses are in a position to bring compassion and support to patients with cancer. The support that nurses can offer transcends the level of caring for people with illnesses. Nurses can become involved in patients' lives, not just their disease. The environment of caring can be created through listening to stories that patients have to tell. Patients should be supported through discussion, reflections about their life, and the meaning of their illness. As nurses, we need to provide a presence to help patients with active listening, assistance with discovery of meaning, and bearing witness to their illness.

**Implications for Education, Health Care and Future Research**

The implications for future education and research are challenging. There is a need to look beyond this research project. This study provided groundwork information about the experiences of these 6 women with recurrent ovarian cancer. This study could be used as a pilot study for a larger group of women (20), which would further explore the lived experience of women with recurrent ovarian cancer. This research project would be obviously much larger, using a research team with a research assistant to interview women and analyze the data.

Another study question might focus on the decision-making process for second line chemotherapy or chemotherapy after a recurrence. Further questions might focus on the quality of life issues of women with recurrent ovarian cancer.

As a nurse clinician, I can and have changed the way that I interact with women with ovarian cancer. My initial response would be to act as a resource for other nurses regarding the issues of women with ovarian cancer.
As an educator, I can share the findings of this study with my colleagues at the Cancer Centre through our regional oncology rounds. I will also be able to share this information with my nursing colleagues at our national cancer conference.

Women with ovarian cancer could benefit from a patient and family support and education program. The education may be provided by a physician and/or nurse. Additional education may also be provided using a video, pamphlets or books with personal testimonials. A questionnaire could be sent out to ovarian cancer patients regarding the need for this type of program. A focus group would be used to identify specific needs or issues which women would like to have included in the program.

During the study, women talked about their fears of dying and difficulties with communication with others. Most women stated that they could not talk to their family about their disease and their prognosis. They described their feelings of isolation. At the time of recurrence, women should be offered a referral to our supportive care department. It would be beneficial to facilitate open communication of the feelings of family member. These discussions might help reduce the sense of isolation and depression associated with recurrent cancer. It is my hope that a peer support program could be established for ovarian cancer patients. Some women are too ill to take part in a support group. They could be offered a telephone buddy system whereby a woman with ovarian cancer is matched with an ovarian cancer survivor. A research project could be address the use of such a system using a standardized survey instrument. The survey instrument could be used at several times during the trajectory of illness along with interviews. The goal of such a project would be to help decrease the sense of isolation by providing support from another cancer patient.
The number of studies that could develop from my study is endless. My main concern is that the women’s voices be heard and that they have the appropriate counselling, education and access to resources. The major hurdle to providing support for these women is the discussions that they have with their health care providers. During this project, I have been quite aware of the amount of time that I spend with patients. One suggestion that can go forward immediately is that we spend our time wisely with women with ovarian cancer. If the women with recurrent ovarian cancer have little time to live, then we need to provide the tools to improve their lives and that of their families.
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Appendix A

Consent Form

Hamilton Regional Cancer Centre
Centre Régional de Cancérologie de Hamilton
Division of Gynecologic Oncology
699 Concession Street, Hamilton, ON, L8V 5C2
Tel: (905) 389-5688 Fax: (905) 575-6317

Hamilton Regional Cancer Centre
Brock University
Department of Graduate Studies in Education

Title of Study: The Lived Experience of Women with Recurrent Ovarian Cancer

Researchers: Martha Finn, Reg. N., B.Sc.N., Dr. Susan Drake, Dr. Dauna Crooks & Dr. Michael Manley-Casimir (905) 389-5688

Name of Participant: (Please print)

I understand that this study will involve identifying my personal responses to a recurrence of ovarian cancer. The purpose of this research study is to describe the thoughts, feelings and beliefs of women with recurrent ovarian cancer. About 6 women with ovarian cancer will take part in the study. This study will take 3 months to complete. The researcher will spend about one hour discussing my experiences with ovarian cancer. It is likely that a second interview may be necessary to clarify issues that were discussed at the time of the first interview. In total, this study will require approximately two hours of my time. The interview will be audiotaped. A written account of the interview will be produced. I may be asked to review this document and clarify some issues. An abbreviated report will be given to me at the completion of the study.

The process of remembering my experiences with recurrent ovarian cancer can be difficult. Sharing information can help the health care team to understand problems or issues. This process will be helpful in working with me and future ovarian cancer patients and their families.

I understand that my participation in this study is voluntary. I may withdraw from this study at any time and for any reason without penalty. There is no obligation to answer any question that I may find upsetting.

I understand that all personal data will be kept strictly confidential. The information will be coded so that my name is not associated with my answers. I understand that only the researchers named above will have access to the data.
If you have any questions or concerns about your participation in the study, you can contact Martha Finn at (905) 389-5688 or Dr. Susan Drake (Advisor) at (905) 688-5550, ext. 3931.

Thank you for your help. Please take one copy of this form with you for further reference.
I have fully explained the procedures of this study to the above volunteer.

Participant Signature ___________________________ Date ____________________

Researcher Signature ___________________________ Date ____________________
Appendix B

**Interview Introduction for Patients**

I understand that you recently have learned that your cancer has recurred. I would like to interview you because I want to learn how women like yourself cope with a recurrence of their ovarian cancer. The interview is really about your experiences with recurrent ovarian cancer and your thoughts about that experience. I would also like to ask you about the types of information that you would like to know about your cancer and its treatment.

The answers from all of the women that are interviewed will be combined for my report. All of the information given today will be confidential. The information that you provide during the interview will not interfere with your care in any way. Your name will not appear on any document. Dr. Dauna Crooks, a nurse researcher will be assisting with analysis of information. I would like to tape the interview so that I will be a concentrate on what you are saying rather than taking notes. The tapes will be destroyed once the interview is transcribed. All of the study information will be kept in a locked filing cabinet in the department of Gynecologic Oncology. What you tell me today may benefit health care professionals and other women with ovarian cancer. Is it all right with you if I tape the interview? Do you have any questions?
Appendix C

Interview Questions

1. Your physician recently told you that your cancer is back: what does that mean to you? What was it like for you at that time?

2. Can you describe the events and feelings that you experienced at the time of the cancer recurrence?

3. Can you help me to understand what it is like to be in your place?

4. How does this information change how you approach the day?

5. What are your dreams, or desires at the present time?

6. How has this cancer recurrence affected your hopes for the future?

7. Can you describe what information was important for you to know at the time of the recurrence? At the time of recurrence, what information would have been important for you to know?

8. How did you receive this information?

9. Did you look for more information? If so, where did you find the information?

10. If you met a woman with ovarian cancer, what advice would you give her?

11. Is there anything that I should have asked you? Are there things that other physicians, nurses or women should know about?
Appendix D

Letter of Introduction of the Study

Letter to Co-Researchers

I am currently enrolled in the Master of Education program at Brock University. My exit project focuses on the experiences of women with recurrent ovarian cancer under the supervision of Dr. Susan Drake. Enclosed are the consent form and a copy of the interview questions.

A copy of the consent form will be filed on your chart. Information that is shared during the interview will be confidential.

Thank you for considering participating in my study. You may decline to answer any questions during the interview. Participation in the study will not interfere with your care. You may withdraw from the study at any time. An abbreviated copy of the research findings will be sent to you at the end of the study.

Thank you

Martha Finn
(905) 389-5688
Appendix E

Letter Regarding Analysis of Themes

Hamilton Regional Cancer Centre
Centre Régional de Cancérologie de Hamilton
Division of Gynecologic Oncology
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22 November, 1999
Dear Co-Researchers,

As co-researchers, each woman needs to decide whether she agrees with the themes. There were a number of common themes among the four women. This summary is not meant to be inclusive.

The main themes that arose were:

• Each woman described the emotional impact of their cancer recurrence. Each woman discussed their unique or individual ways of coping with day to day life.

• There was a description of their relationships with others. Women received support from their families, friends, and other cancer patients. Despite the fact that there are no support groups available for ovarian cancer patients, most women sought information and support from others with the same problem.

• Both positive and negative encounters with health care professionals were discussed.

• A common theme throughout all the interviews was the uncertainty about the future versus the prospect of death. Spiritual issues were discussed. The importance of spirituality varied greatly.

• Some women wanted specific information about their cancer recurrence and treatment while others felt that this information was not important to them.

• Each woman gave specific information about advice that they would give to women with ovarian cancer. Each woman discussed the need to be listened to and to be treated as an individual rather than a disease.

Any comments would be appreciated. I will call you within the next week or so. Thank you.

Martha Finn
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Appendix F

Definition of Terms

**Ascites:** is a build up of fluid within the abdominal cavity.

**Bowel obstruction:** is a blockage occurring anywhere along the bowel. It may occur suddenly over a period of days or weeks. During that time, bowel activity slows affecting the passage of gas or bowels movements. Sometimes, all activity stops. Bowel obstruction may occur because of presence of tumour spread in women that have advanced or recurrent ovarian cancer *(Hamilton Regional Cancer Centre, 1992).*

**Cancer:** is a general term for more than 100 diseases characterized by uncontrolled, abnormal growth of cells in humans *(Mosby’s Medical, 1998).*

**Debulking:** refers to the surgical removal of visible tumour.

**Gynecologic oncologist:** is a physician with advanced training in caring for women with gynecologic malignancies. The advanced training consists of a two-year training program involving surgery, chemotherapy and treatment.

**Health care professional:** refers to any registered/licensed professional who participates in the delivery of health care such as physician, social worker, dietitian, and registered nurse.

**PICC catheter:** refers to a permanent catheter that is inserted into the arm for purposes of blood work and chemotherapy.

**Primary care nurse:** is a Registered Nurse who practices within a primary nursing model. He/she has expert knowledge in oncology and is responsible and accountable for provision as well as management of patient/family-centered care. Care is delivered on a continuum throughout the cancer experience during: diagnosis, staging, treatment...
planning, treatment, follow-up and discharge within the ambulatory, hospital and community settings (Hamilton Regional Cancer Centre, 1998).

**Primary peritoneal cancer:** is a cancer that simulates cancer of the ovary. The disease arises from the lining of the abdominal cavity. Women may have had their ovaries removed in previous operations. If their ovaries are in place, they usually are normal in appearance. The disease is normally widespread in the abdominal cavity (Berek & Hacker, 1994).

**Medical oncologist:** is a physician with advanced education in the field of cancer care and who specializes in the delivery and care of patients receiving chemotherapy.

**Quality of life:** is affected by the impact of disease on one’s life. Quality of life is described using four dimensions: (a) physical well-being, (b) psychological well-being, (c) social concerns, and (d) spiritual well-being (Ferrell, Grant, Rhiner, & Padilla, 1992).

**Persistent disease:** refers to the status of ovarian cancer patients when their disease is no longer affected by the chemotherapy.

**Recurrence:** is the reoccurrence of cancer anywhere in the body after their primary treatment of surgery and chemotherapy.

**Staging:** refers to description of the spread of cancer in the body. Ovarian cancer is staged using surgery before chemotherapy. This surgery usually consists of a hysterectomy, removal of the fallopian tubes and ovaries and a layer of fat called the omentum. Some women may not be able to have this procedure done because their disease is widespread throughout the abdomen.
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