MOTHERS WITH CANCER: A PHENOMENOLOGICAL STUDY

By

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To the Faculty of Washington State University:

The members of the Committee appointed to examine the thesis of MICHELLE R. BARTHOLET find it satisfactory and recommend that it be accepted.

Chair

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I would also like to thank the participants for their dedication in helping other mothers with cancer and their willingness to share their life experiences. I hope this study and article reflect their aspirations. My desire is that this article reveals the importance of nurses coming to understand that these women are much more than cancer patients. Each of these women taught me how strong they are in their lives, especially in their battle against cancer. Thanking them will never be enough for the learning experience I was able to achieve.

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Abstract

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The diagnosis of cancer alters the course of life by impacting relationships, daily activities, work, and roles of affected individuals. This qualitative phenomenological pilot study explored the lives of 5 women, and their changing roles as mothers diagnosed with cancer. The study looked at nursing practice and the need to develop additional nursing diagnoses, assessment tools, and interventions to better address the needs of this population. Mothers who are diagnosed with cancer have multiple roles and face unique challenges in taking care of their children and themselves while undergoing treatment. Several common concepts that emerged during the data analysis were communication, being cared for, self-esteem, and coping skills. This study found that it was essential for nurses to be better equipped to facilitate, assess, and intervene with the adaptation process of this subculture of women.

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Dedication

This thesis is dedicated to all of the wonderful mothers that I had the privilege of caring for during my time as an oncology certified nurse. They were all an inspiration to me, which is why I decided to do this study and article. The fight, drive, and strength each one demonstrated during this time of grief was unbelievable. It is my hope to capture that essence in this thesis. Additionally, I want to provide nursing practice with the insight of how nurses can do a better job in assisting these women with this crisis. We are here to provide a better quality of life for our patients. Their journeys of ill health can be positive if they are given the correct guidance and support. Nursing practice must ensure this outcome.

CHAPTER ONE

Introduction

Background

The National Cancer Institute (2007) estimated that 679,510 women would be diagnosed with cancer in 2006. In the United States, the median age at diagnosis for all types of cancer was 67 years of age. However, 2.7% of those diagnosed were between ages 20 and 34, 6% between ages 35 and 44, and another 13.5% from ages 45-54 (National Cancer Institute). An estimated 31.2% of women diagnosed with cancer were of child-rearing age. Currently, malignancies and heart disease account for almost half of all deaths in young and middle adulthood for both genders (Valanis, 1999).

Healthy People 2010 goals and objectives for cancer are to reduce the overall cancer death rate (U.S. Department of Health and Human Services [DHHS], 2000). Presently, a relative 5-year survival rate of 60% is seen for all cancers. Cancer death rates for all sites combined decreased an average of 0.6% per year from 1990 to 1996 (DHHS). Cancer can dramatically change a person's life, particularly where treatments are often debilitating and the long term survival is increasing (Pilkington & Mitchell, 2004). Because long term survival is increasing, it is essential for cancer patients to learn how to live with the disease, which includes addressing quality of life issues.

A diagnosis of cancer is a stressful event that impacts people's lives by changing their family roles (Zabalegui, Sanchez, Sanchez, & Juando, 2005). It is associated with increased levels of stress and heightened levels of depression and anxiety among patients and relatives. Such a cancer diagnosis impacts the whole family (Edwards, & Clarke, 2004). In addition, children of parents with cancer show an increased level of anxiety compared to children whose parents are healthy (Elmberger, Bolund, & Lützén, 2000). It is essential for nurses to understand the experience of mothers with cancer so that mothers can successfully complete their treatment and continue to maintain their role in the family.

Problem Statement

The diagnosis of cancer alters the course of life by impacting relationships, daily activities, work, and roles of the individuals. Mothers diagnosed with cancer have multiple roles and face challenges in taking care of both their children and themselves while undergoing cancer treatment. There is a lack of research on this issue. Additionally, there is a lack of available resources in some communities to assist these women. Due to time restraints, it is difficult for nurses to fully assess and provide holistic care for these mothers.

Purpose Statement

The purpose of this qualitative phenomenological pilot study is to explore the lived experiences and changing roles of mothers diagnosed with cancer who have children ages 4-20 living at home. This study looked at nursing practice and the need to develop additional nursing diagnoses, assessment tools, and interventions to better address the needs of this population. It is vital for nurses to assist mothers with cancer in their changing roles during a cancer diagnosis. In order to do this, nurses must understand those changing roles and what these mothers live through. Ideally, knowledge gained in this study will direct further research into various aspects of the lived experience of mothers living with cancer.

This study is an attempt to illuminate this experience and equip the nursing profession with a holistic view of the mother's needs. The optimal application of this study will lead to an assessment tool for nursing practice. In turn, this may result in a more positive overall experience for these women and their families during this time of crisis.

Conceptual Framework

This pilot qualitative study used a phenomenological approach to inquiry, which describes the lived experiences of a certain phenomenon (in this case, mothers with cancer). The objective of phenomenology is to interpret the experience based on thought and dialogue with the purpose of promoting understanding of the concepts (Morse & Field, 1995). Qualitative research strives to uncover the understanding that already exists in people's experience (Smythe & Giddings, 2007). Comparable nursing research studies have been conducted using phenomenology as their framework. Hanks (2008) used phenomenology to reveal the participants' lived experiences with nursing advocacy. Another study using phenomenology looked at the lived experiences of pediatric cancer patients (Fochtman, 2008).

Phenomenology was chosen for this study in order for nurses to recognize the experiences and the essence of being a mother with cancer. Ideally, this knowledge will assist nurses in their appreciation and understanding of what these women live through during this crisis and how nurses can better care for them.

This study used both subjective and objective data to assess these women and gain knowledge on the meaning of what it is like to be a mother with cancer. The investigator watched and noted the body language of these women during the interviews, providing objective data. The interview of the participants was recorded and further analyzed to provide rich, explicit, narrative data. The data was then assimilated and evaluated to provide better insight of what these women lived through.

Literature Review

A literature review was performed, using the CINAHL database. This search included published studies during the years 2000-2008. Searching the database for the term “cancer” resulted in 69,317 cited studies. When the word “mother” was added to the literature search, the quantity of articles dropped down to 360. Adding the word “phenomenology” took that search down to three studies. Published research studies that focus on cancer are abundant. There are, however, limited studies that focus on the lived experiences of mothers with cancer.

One central concept noted throughout the various studies in the literature was communication and relationships within the family (Billhult & Segesten, 2003; Edwards & Clarke, 2004; Elmberger et al., 2000; Holmber, Scott, Alexy, & Fife, 2001; Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005; Shands, Lewis, & Zahlis, 2000; Svavarsdottir & Sigurdardottir, 2006; Visser et al., 2005; Walsh, Manuel, & Avis, 2005).   In a U.S. study by Walsh et al., the authors revealed how a diagnosis of cancer impacts family relationships. The four major themes that evolved were increased closeness and intimacy, communication avoidance, separation or termination of the relationship, and problems related to sexuality. Svavarsdottir and Sigurdardottir determined that it was feasible to offer a family level educational and support intervention. Edwards and Clarke established that good family functioning is associated with lower levels of distress, depression and anxiety. Those families that were perceived to have a lower level of family cohesion had higher levels of psychosocial distress and depression. These findings demonstrate the need for good family evaluations, communication, and support during cancer treatment.

Another established concept was child-centered parenting (Elmberger, Bolund, & Lützén, 2005; Helseth, & Ulfsaet, 2005; Kristjanson, Chalmers, & Woodgate, 2004; Saldinger, Porterfield, & Cain, 2004) The data revealed that mothers were more child-centered than fathers, that parents surviving sudden deaths were more child centered than those surviving anticipated deaths, and that lengthy illness was associated with less child-centered parenting (Saldinger et al.). Additionally, women with a cancer diagnosis dealt with the moral concerns of being a good parent and being a patient, revealing that the role of being a mother and being a good patient was a moral conflict in nature (Elmberger, et al., 2005). The findings demonstrate that these women felt that their children's needs were not taken care of during their cancer treatment and that this is an area that nursing practice should explore (Elmberger et al., 2005). Another important finding was that cancer consumed the parents' energy, both physically and emotionally, which forced a shift of priorities and change of values that usually brought the family members closer together (Helseth, & Ulfsaet, 2005). The study concluded that nurses need to directly approach parents with young children about these challenges and offer them assistance (Helseth, & Ulfsaet, 2005). Additionally, it is important for family, friends, and the school system to provide a sense of normalcy about the lives of adolescents to help them cope with their mother's diagnosis (Kristjanson et al.).

Other key concepts of the research were coping skills and role changes of the mother during a cancer diagnosis (Anagnostopoulos, Kolokotroni, Spanea, &

Chryssochoou, 2006; Avis, Crawford, & Manuel, 2004; Fitch, Bunston, & Elliot, 1999; Ohlen, & Holm, 2006). Roles are influenced by social factors. For example, when a mother is diagnosed with cancer, her role as a caretaker will be altered (Fitch et al.). A mother needs to balance the situation of being needed, not keeping up with demands, a will to be strong, and allowing herself to be sick (Ohlen & Holm). The physical impacts of cancer are particularly disruptive to mothering roles (Fitch et al.). One of the concerns of women under 50 is chemotherapy induced menopause and the side effects (Avis et al.). Therefore, nurses need to be proactive in planning, controlling, and assisting with the anticipated side effects of the cancer treatment.

Finally, one of the few studies looking at single women with breast cancer and their school-aged children found that there is a need for additional services and informational sources (Lewis, Zahlis, Shands, Sinsheimer, & Hammond, 1996). Single women with children require these services in order to deal with the pressures of breast cancer and the excessive levels of distress (Lewis et al.). Clearly, the research illustrates that nursing practice can improve in this area for mothers with cancer.

Other important concepts the research revealed are that anxiety and depression symptoms are found more often among adolescents than in preadolescent children with a parent with cancer (Helseth & Ulfsaet, 2003). Maintaining a stable family life becomes more difficult when cancer affects one of the parents (Elmberger et al., 2000). One of the interventions discussed in this article was that the role of a health care worker should be expanded to facilitate communication about cancer between family members and the patient.

The literature demonstrates that there has been significant research on the subject of how cancer affects families. There are, however, limited phenomenological data regarding mothers and their needs during a cancer diagnosis. This is evident from the results of the literature search. Additionally, the literature has established the need for nurses to be better equipped to facilitate, assess, and intervene with the adaptation process of mothers with cancer. This is also evident from the literature and the studies' findings. The strengths of the research were the documented concepts related to the family and women with cancer.

Studies have shown that the care provided for mothers with cancer is insufficient in the areas of family communication, better assessments of chemotherapy side effects, and good family evaluation. These deficits demonstrate that there is a need to appreciate the life experiences of mothers with cancer. Ideally, this understanding will change nursing practice to better assess and support the life that mothers with cancer face. The literature reviewed demonstrates that many women struggle in adapting to life with cancer. This study is an attempt to broaden the scope of nursing practice that deal with this population. In order to give mothers with cancer a voice in how their treatment is facilitated, further research and nursing interventions are necessary. The journey that these women and their families embark on by themselves is intense. Nurses need to develop an awareness of these women's perceptions in order to help prepare them for this journey.

Research Question

The purpose of this study was to address issues that mothers with cancer experience and to explore the adequacy of nursing care provided for mothers with cancer.

The research question of this study is: What are the lived experiences of mothers diagnosed with cancer who have children age 4-20 living at home?

Definition of Terms

Adaptation: A process of managing demands of stress through the use of coping and problem solving strategies (Friedman, Bowden, & Jones, 2003).

Cancer: Any malignant neoplasm that can invade other structures and has uncontrolled growth (Friedman et al., 2003).

Convenience sampling: The selection of the most readily available persons as participants in a study (Polit & Beck, 2004).

Dependency: Being reliant on someone or something else for help, support, favor and other needs (Friedman et al., 2003).

Neoplasm: Any abnormal growth of new tissue, benign or malignant (Friedman et al., 2003).

Role: Set of behaviors that are defined and expected of a person of a certain social position and culture (Friedman et al., 2003).

Saturation of the data: The collection of data in a qualitative study to the point where a sense of closure is attained because no new data emerge (Polit & Beck, 2004).

Snowball sampling: When a participant in the study gives the information to other possible participants, which intensifies people's awareness of the study and provides additional participants (Morse, 1989).

Significance to Nursing

To optimize patient care, nurses must understand the complex dynamics inherent in the roles of mothers with cancer. Comprehension of this subculture is necessary for nurses to fully facilitate the mothers' coping skills and subsequent recoveries. Ultimately, the goal of this study is to identify and address issues specific to mothers with cancer. Anticipated future research directions include the development of nursing assessment tools and interventions for the concepts that emerge from the data.

CHAPTER TWO

Method of Study

Design

This pilot qualitative study used the phenomenological approach to investigate the lived experiences of mothers with cancer. Phenomenologists believe that lived experiences give meaning to each person's perception of a particular phenomenon (Polit & Beck, 2004). The methodology has been used extensively by researchers in sociology, psychology, and nursing (Moustakas, 1994).

Open ended questions during the interview process provided the participants with the opportunity to express their experiences of living with a cancer diagnosis and managing their changing roles within the family. The investigator provided a time of silence after each question, allowing the participants to express themselves and tell their own story.

The concepts that emerged from the interviews illuminated a comprehensive understanding of the lived experiences of these women. Ultimately, the approach of phenomenology was used in this study so that nurses would better understand what it means to be a mother with cancer. This understanding might enable nurses to assist the mothers and their families through the difficult circumstances that arise during this time of crisis.

Setting

The researcher and participants decided on mutually agreeable locations which provided privacy to ask open-ended questions and allowed the participants to express their experiences. These interviews took place in the investigator's office, the participant's office or home, which provided a private relaxing atmosphere for the interview to be conducted. Two of the participants chose their offices, two participants selected their homes, and one agreed to meet at the investigator's office for the interview process.

Population and Sample

The initial plan for recruitment was to obtain referrals from a local cancer support facility and an oncology office. Convenience sampling was first chosen because Yakima is rural and the investigator wanted to capture outlying areas. In the end, however, the participants were word-of-mouth referrals from acquaintances of the investigator, and from some of the participants. The group of women represented a snowball sample consisting of five mothers with cancer. Inclusion criteria were: women who spoke English and had a cancer diagnosis of stage II-IV within the last 10 years, with children from the ages of 4-20 who were living at home during this diagnosis and treatment.

The sample consisted of five mothers with cancer, four with breast cancer and one with lymphoma. Two of the women were diagnosed with cancer nine years ago, and three of the participants were diagnosed 2-3 years ago. All of the participants had surgery, chemotherapy and radiation. In addition, one of the women had a stem-cell transplant. Four of the mothers were from Yakima and one was from Spokane, Washington. All of the participants were professional working Caucasian women: two were nurses, one was a medical professional, one was an instructor at a college, and one was a school counselor. Four participants worked throughout their treatment and one woman stopped working. The participants' age range was 38-55 years. Four of the women were married and one was divorced. The women had 2-4 children living at home during the diagnosis and treatment of their disease. There were a total of 13 children, 9 boys, and 4 girls. The children's ages ranged from 3-22 years old.

Rigor

Qualitative studies intend to describe the human experience as it is lived, through the collection and analysis of narrative, subjective material (Sharts-Hopko, 2002). Therefore, to assure reliability, phenomenological studies look at rigor, credibility and dependability. People shape their own experiences, and that truth is reflective of one's own socio-cultural context (Sharts-Hopko).

In this study, rigor, credibility, and dependability were established by the data being transcribed by the investigator. Field notes (observational data) were taken while the participants were interviewed and recorded. The data was then transcribed by the investigator. These field notes illuminated the emotions of the participants. They were assimilated into the transcription.

The investigator then gave the transcribed data back to the participants for review. This is called member checking and is a way to establish credibility and dependability of the transcribed data. It gives the participants the opportunity to provide more information or make corrections to wrong interpretations (Lincoln & Guba, 1985). The participants were asked if they had any additions or clarifications of the transcribed data or if the data demonstrated what they experienced. This data was then reviewed and analyzed by the investigator, looking for common themes and unique experiences of the participants (Sharts-Hopko, 2002). These concepts were flagged using different highlighters of a variety of colors. Notes were also taken by the investigator using different colored pens.

This data analysis was methodically reviewed and analyzed by the investigator over several months. Additionally, the investigator left an audit trail by taking notes of the analyzed data and listing the concepts that emerged from the data. The audit trail provided data that can be reviewed by other investigators and allows the reconstruction of the findings that were found in this study. The investigator also noted her biases and assumptions prior to analyzing the data to insure they would not be brought into the elucidation of the data.

The literature findings are similar to the findings of the women in this study. According to the literature, some of the areas of concern in the lives of cancer patients are communication between the families, child-centered parenting, coping skills, untreated side effects of chemotherapy, and role changes. The analysis of the data in this study revealed that the participants were concerned with communication, being cared for, self-esteem, and coping skills.

In phenomenology, it is important for the investigator to acknowledge and reflect on assumptions of potential biases. One assumption or bias of the investigator in this study regarding mothers with cancer was that the influence of being a mother will assist her in making decisions regarding her care. Moreover, the investigator felt that the mothers with multiple support systems to assist her in her changing roles would have better experiences and would adapt more easily than mothers without this support. It was the investigator’s belief that the mothers who communicate with their support systems and children would excel physically and mentally through their cancer diagnoses because they would be able to address their needs as individuals and mothers. The investigator had to set aside biases during the interview and data analysis to provide a clear interpretation of the data.

Data Collection

The data collection included demographic data, i.e., marital status, ethnicity, number of children, gender and age of children, type and stage of cancer, type of treatment, and the date the participant was diagnosed (see Appendix A). The data collection also consisted of semi-structured interviews, using open-ended questions, allowing the women to direct the flow of information. This resulted in the essence of their experiences being expressed. During the interview process, the investigator's observation of body language and affect were included in the field notes, alongside the information gathered from the discussion. This is an essential step in qualitative research (Marshall & Rossman, 1995).

The participants were interviewed for approximately one hour and the interviews were audio taped. These audio tapes were then transcribed by the investigator. To ensure trustworthiness, the investigator kept auditable research logs and journals providing an audit trail. After the data was transcribed, it was given to the participants to review for any discrepancies. A follow-up interview would have been conducted if results or transcribed data in the first interview did not reflect the participant's meaning or experience. The transcribed in-depth interviews provided data that was analyzed, which elucidated the concepts. The following are sample questions asked during the interview process:

1. What were your experiences when you were told you had cancer?
2. How did your family find out you had cancer? What were their reactions?

3. What were your experiences with your treatment for cancer?
4. How has being a mother with cancer affected your experiences of being a parent?
5. What were your experiences with the health care providers?
6. What were your experiences with community resources? Did you use any resources?
7. (If Married) How did your husband handle the news of the diagnosis and following treatment? Were there any changes in his role as a father during that time?
8. As a mother with cancer, what changes to the health care system would have helped you to be more successful through this experience? (see Appendix B)

After the interviews, field notes were completed by the investigator. The field notes were observations the investigator made during the interviews. These observations included the atmosphere in which the interviews were conducted, reactions and body language of the participants.

The investigator transcribed the audiotapes, assisting in the evaluation of the data and discovery of the concepts that emerged. Comparison between the field notes and interview data helped identify further concepts and inconsistencies of the diverse lived experiences of the participants. The committee and committee chair provided guidance with the assessment of the data.

Saturation of the data was questionable because of the low number of participants involved. The number of participants was limited because of the snowball sampling and time restraints for completing the thesis. Adding one or two more participants may have been beneficial to ensure data saturation and develop a broader view of the phenomenon.

Data Analysis

In phenomenology, the data analysis is a search for concepts that emerge from the data (Marshall, & Rossman, 1995). The investigator transcribed the audio taped interviews, which brought the investigator closer to the data. The investigator looked for statements in the interviews about how the participants experienced being a mother with cancer. Listing the significant statements, the investigator treated each statement as having equal worth, and developed a list of non-repetitive, non-overlapping statements (Creswell, 1998). The transcribed data went through an extensive, time-consuming evaluation process to identify emerging concepts. These concepts were flagged and further synthesized.

The data analysis was performed by the investigator. The committee and committee chair facilitated the investigator's data analysis by providing guidance in analyzing and coding. In this study, the investigator was required to be critically reflective on the way mothers with cancer reproduced their experiences. Interpreting the phenomena required rigorous reading and re-reading of the transcribed data, questioning, comparing, and dwelling on the mothers' experiences.

The data collected was analyzed by hand data method and color coding, which included different colors of highlighters and pens to flag and illuminate the concepts. These concepts lead to the essence of the phenomenon under investigation, which was being a mother with cancer (Streubert-Speziale & Carpenter, 2007). As the investigator interviewed and analyzed the data, common themes began to emerge. This analytical process required the investigator to focus on the data until clarification of the women's experiences were revealed.

Human Subject Considerations

To partially address ethical issues, this study was submitted and received prior certification of exemption from the Washington State University Institutional Review Board (WSU IRB). The IRB number assigned to this study was 10257-001. Qualitative phenomenological research is unpredictable and can have unanticipated ethical issues (Streubert-Speziale & Carpenter, 2007). It was essential to develop an informed consent. This study had an English-only informed consent that received prior approval from the WSU IRB (see Appendix C). The purpose of an informed consent is to give the information needed to help the participants to decide whether or not to participate in the study. After a verbal explanation of the study by the investigator, a written informed consent was signed prior to the interview of the participants.

The human subjects' considerations conformed to the mandates outlined in the Health Insurance Portability and Accountability Act (HIPPA) and the sharing of confidential material. The investigator has received a certification by the National Institutes of Health and Human Subjects Training to be able to participate in research studies (Appendix D).

Though there are inherent risks in any research study, the risks of this research study were believed to be minimal. The interviewer was exploring the lived experiences of mothers with cancer. There was emotional expression related to reflecting on the participants' experiences and there was potential for some stress for the participants.

The WSU IRB paperwork is attached (see Appendix E). The researcher, committee chair, and committee signed the forms prior to submission to ensure completeness of the application. This study had expedited IRB status because of the low risks to the subjects.

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CHAPTER 3

Mothers With Cancer: A Phenomenological Study

The results of this study will be submitted to the *Oncology Nursing Forum* for publication.

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The following manuscript utilizes APA using the *Publication Manual of the American Psychological Association* (APA), 5th edition (2001). As directed by the journal's editorial requirements and staff, the format of this manuscript adheres to the published articles and requirements listed in Appendix F.

Abstract

The diagnosis of cancer alters the course of life by impacting relationships, daily activities, work, and roles of affected individuals. This qualitative phenomenological pilot study explored the lives of 5 women, and their changing roles as mothers diagnosed with cancer. The study looked at nursing practice and the need to develop additional nursing diagnoses, assessment tools, and interventions to better address the needs of this population. Mothers who are diagnosed with cancer have multiple roles and face unique challenges in taking care of their children and themselves while undergoing treatment. Several common concepts that emerged during the data analysis were communication, being cared for, self-esteem, and coping skills. This study found that it was essential for nurses to be better equipped to facilitate, assess, and intervene with the adaptation process of this subculture of women.

Mothers With Cancer: A Phenomenological Study

The National Cancer Institute (2007) estimated that 679,510 women would be diagnosed with cancer in 2006. In the United States, the median age at diagnosis for all types of cancer was 67 years of age. However, 2.7% of those diagnosed were between ages 20 and 34, 6% between ages 35 and 44, and another 13.5% from ages 45-54 (National Cancer Institute). An estimated 31.2% of women diagnosed with cancer were of child-rearing age. Currently, malignancies and heart disease account for almost half of all deaths in young and middle adulthood for both genders (Valanis, 1999).

Healthy People 2010 goals and objectives for cancer are to reduce the overall cancer death rate (U.S. Department of Health and Human Services [DHHS], 2000). Presently, a relative 5-year survival rate of 60% is seen for all cancers. Cancer death rates for all sites combined decreased an average of 0.6% per year from 1990 to 1996 (DHHS). Cancer can dramatically change a person's life, particularly where treatments are often debilitating and the long term survival is increasing (Pilkington & Mitchell, 2004). Because long term survival is increasing, it is essential for cancer patients to learn how to live with the disease, which includes addressing quality of life issues.

A diagnosis of cancer is a stressful event that impacts people's lives by changing their family roles (Zabalegui, Sanchez, Sanchez, & Juando, 2005). It is associated with increased levels of stress and heightened levels of depression and anxiety among patients and relatives. Such a cancer diagnosis impacts the whole family (Edwards, & Clarke, 2004). In addition, children of parents with cancer show an increased level of anxiety compared to children whose parents are healthy (Elmberger, Bolund, & Lützén, 2000). It is essential for nurses to understand the experience of mothers with cancer so that mothers can successfully complete their treatment and continue to maintain their role in the family.

Literature Review

A literature review was performed, using the CINAHL database. This search included published studies during the years 2000-2008. Searching the database for the term “cancer” resulted in 69,317 cited studies. When the word “mother” was added to the literature search, the quantity of articles dropped down to 360. Adding the word “phenomenology” took that search down to three studies. Published research studies that focus on cancer are abundant. There are, however, limited studies that focus on the lived experiences of mothers with cancer.

One central concept noted throughout the various studies in the literature was communication and relationships within the family (Billhult & Segesten, 2003; Edwards & Clarke, 2004; Elmberger et al., 2000; Holmber, Scott, Alexy, & Fife, 2001; Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005; Shands, Lewis, & Zahlis, 2000; Svavarsdottir & Sigurdardottir, 2006; Visser et al., 2005; Walsh, Manuel, & Avis, 2005). In a U.S. study by Walsh et al., the authors revealed how a diagnosis of cancer impacts the family relationships. The four major themes that evolved were increased closeness and intimacy, communication avoidance, separation or termination of the relationship, and problems related to sexuality. Svavarsdottir and Sigurdardottir determined that it was feasible to offer a family level, educational and support intervention. These findings demonstrate the need for good family evaluations, communication, and support during cancer treatment.

Another established concept was child-centered parenting (Elmberger, Bolund, & Lützén, 2005; Helseth, & Ulfsaet, 2005; Kristjanson, Chalmers, & Woodgate, 2004; Saldinger, Porterfield, & Cain, 2004) The data revealed that mothers were more child-centered than fathers, that parents surviving sudden deaths were more child centered than those surviving anticipated deaths, and that lengthy illness was associated with less child-centered parenting (Saldinger et al.). Women with a cancer diagnosis dealt with the moral concerns of being a good parent and being a patient, revealing that the role of being a mother and being a good patient was a moral conflict in nature (Elmberger, et al., 2005). The findings demonstrate that these women felt that their children's needs were not taken care of during their cancer treatment and that this is an area that nursing practice should explore (Elmberger et al., 2005). Another significant finding was that cancer consumed the parents' energy, both physically and emotionally, which forced a shift of priorities and change of values that usually brought the family members closer together (Helseth, & Ulfsaet, 2005). The study concluded that nurses need to directly approach parents with young children about these challenges and offer them assistance (Helseth, & Ulfsaet, 2005). Additionally, it is important for family, friends, and the school system to provide a sense of normalcy about the lives of adolescents to help them cope with their mother's diagnosis (Kristjanson et al.).

Other key concepts of the research were coping skills and role changes of the mother during a cancer diagnosis (Anagnostopoulos, Kolokotroni, Spanea, & Chryssochoou, 2006; Avis, Crawford, & Manuel, 2004; Fitch, Bunston, & Elliot, 1999; Ohlen, & Holm, 2006). Roles are influenced by social factors. A mother needs to balance the situation of being needed, not keeping up with demands, a will to be strong, and allowing herself to be sick (Ohlen & Holm). The physical impacts of cancer are particularly disruptive to mothering roles (Fitch et al.). One of the concerns of women under 50 is chemotherapy induced menopause and the side effects (Avis et al.). Therefore, nurses need to be proactive in planning, controlling, and assisting with the anticipated side effects of the cancer treatment.

Finally, one of the few studies looking at single women with breast cancer and their school-aged children found that there is a need for additional services and informational sources (Lewis, Zahlis, Shands, Sinsheimer, & Hammond, 1996). Single women with children require these services in order to deal with the pressures of breast cancer and the excessive levels of distress (Lewis et al.). Clearly, the research illustrates that nursing practice can improve in the area of mothers with cancer.

There has been significant research on the subject of how cancer affects families. There are, however, limited phenomenological published studies regarding mothers and their needs during a cancer diagnosis. The literature has also established the need for nurses to be better equipped to facilitate, assess, and intervene with the adaptation process of mothers with cancer.

These studies cited in the literature review have shown that the care provided for mothers with cancer is insufficient in the areas of family communication, better assessments of chemotherapy side effects, and good family evaluation. These deficits demonstrate that there is a need to appreciate the life experiences of mothers with cancer.

Nursing practice should evolve to better assess and support the life that mothers with cancer face. The literature reviewed demonstrates that many women struggle in adapting to life with cancer. This study is an attempt to broaden the scope of nursing practice that deal with this population. In order to give mothers with cancer a voice in how their treatment is facilitated, further research and nursing interventions are necessary. The journey that these women and their families embark on by themselves is intense. Nurses need to develop an awareness of these women's perceptions in order to help prepare them for this journey.

Population and Sample

The initial plan for recruitment was to obtain referrals from a local cancer support facility and an oncology office. Convenience sampling was first chosen because Yakima is rural and the investigator wanted to capture outlying areas. In the end, however, the participants were word-of-mouth referrals from acquaintances of the investigator, and from some of the participants. The group of women represented a snowball sample consisting of five mothers with cancer. Inclusion criteria were: women who spoke English and had a cancer diagnosis of stage II-IV within the last 10 years, with children from the ages of 4-20 who were living at home during this diagnosis and treatment.

The sample consisted of five mothers with cancer, four with breast cancer and one with lymphoma. Two of the women were diagnosed with cancer nine years ago, and three of the participants were diagnosed 2-3 years ago. All of the participants had surgery, chemotherapy and radiation. In addition, one of the women had a stem-cell transplant. Four of the mothers were from Yakima and one was from Spokane, Washington. All of the participants were professional working Caucasian women: two were nurses, one was a medical professional, one was an instructor at a college, and one was a school counselor. Four participants worked throughout their treatment and one woman stopped working. The participants' age range was 38-55 years. Four of the women were married and one was divorced. The women had 2-4 children living at home during the diagnosis and treatment of their disease. There were a total of 13 children, 9 boys, and 4 girls. The children's ages ranged from 3-22 years old.

Research Design

This pilot qualitative study used a phenomenological approach to inquiry, which describes the lived experiences of a certain phenomenon (in this case, mothers with cancer). The objective of phenomenology is to interpret the experience based on thought and dialogue with the purpose of promoting understanding of the concepts (Morse & Field, 1995). Qualitative research strives to uncover the understanding that already exists in people's experience (Smythe & Giddings, 2007). Comparable nursing research studies have been conducted using phenomenology as their framework. Hanks (2008) used phenomenology to reveal the participants' lived experiences with nursing advocacy. Another study using phenomenology looked at the lived experiences of pediatric cancer patients (Fochtman, 2008).

This study used open ended questions during the interview process providing the participants with the opportunity to express their experiences of living with a cancer diagnosis and managing their changing roles within the family. The investigator provided a time of silence after each question, allowing the participants to express themselves and tell their own story.

This study used both subjective and objective data to assess these women and gain knowledge of what it is like to be a mother with cancer. The investigator watched and noted the body language of these women during the interviews and provided objective data. The interviews of the participants were recorded and further analyzed to provide rich, explicit, narrative data. The data were assimilated and examined, which provided insight into what these women lived through. The approach of phenomenology that was used in this study may provide nurses with a better understanding of what these mothers and their families go through during this difficult time.

Results

The results of this study represent the investigator’s interpretation of the data. This data illuminated the participants’ experiences. Several common concepts emerged during the data collection and analysis: communication, being cared for, self esteem, and coping skills. In addition, the participants made recommendations on how the medical profession could better care for mothers with cancer.

Communication

All of the women expressed that communication was difficult during this time of crisis. The most difficult communication was with their children. It was difficult for these mothers to tell their children that they had cancer, because they wanted to protect them. They did not want to “lie" to their children, yet they did not know how much, or how little to tell them. These mothers wanted their children to know that they were ill but that their death was not imminent.

The participants did not receive assistance on how to tell their children about their cancer. They expressed a need for someone in the medical profession to address this issue and assist mothers with cancer on how to communicate with their children. One participant stated, “It would be a huge thing to have help telling your child you have cancer. What do I say, how do I say it? I think it would be helpful with the terminology, how do you say cancer without it being so scary?” One mother said she did not want her children to think she would drop dead. All of the women wanted to protect their children from fear of the word, "cancer."

The women also stated it was difficult communicating with the rest of the family. Three of the five women told their families they had cancer during a major holiday because the participants wanted to inform all their family members on one occasion. They thought it best to do so on a significant holiday. The three participants all stated that their holiday was ruined because of the reactions of family members and the bad news. It was just too emotional for them.

Three of the participants stated that their husbands avoided communicating about their diagnoses and about what might happen if they died. One participant stated, "My husband picked up and did cleaning and he really stepped up to the plate. But, he did not want to talk about my cancer and if something were to happen to me." Another participant stated, "My husband is a very nice guy but he did not know what to do. I leaned on my friends more then him because I did not feel like he could face it." The third participant stated, "My husband was just closed down inside." This demonstrates the importance of assisting cancer patients with communication skills in talking about their disease.

Being Cared For

A significant concept of all five of the participants was the need for multiple support systems to assist them through their treatment. They also recognized that they had to let themselves be taken care of. Most of the participants in this study were women that took care of their families. It was difficult for these women to allow other people into their homes and help them with their "roles" within the family.

In all five cases, someone from the community made meals for the families. These people were co-workers, friends, family or members of social groups the participants knew. They also had people who took care of the children during the mother's sickest times. One of the participants lived with her parents during her treatment because she was divorced and her ex-husband passed away six months earlier. Two other participants had a sister come into her home and help with the laundry and housecleaning.

Significant others played a supportive role in their recovery. Usually, the significant other took on a caregiver role, took over some of the mothers' roles, and helped with house cleaning and cooking. This, however, caused some stress for some of the participants because they felt they could not perform their "roles" as mothers'. Elmberger, Bolund, and Lützén (2005) also found this in their published study.

One of the major concerns for several of the participants regarding their care was that medications were not being prescribed for the side effects of the chemotherapy. This led to one of the participants using marijuana to aid with her negative side effects. One participant "fired" her first oncologist because he would wait until she was extremely ill before intervening with necessary treatment. The participant that did not receive prescriptions necessary to sleep, eat, or function during her treatment reflected on this time, "The chemo made me feel like I had the flu for 9 months. The doctors were not giving me anything. The doctors never asked me if I needed anything and I felt awful." After trying the marijuana, she stated, "I could eat, I felt hungry and I could sleep and I think I was stoned for the rest of the nine months."

Another care issue for the participants was that their emotional needs were not being addressed. This is an area in which nurses could provide better assistance. Support for emotional needs during this crisis is imperative. One participant stated, "I think people need to know they need to ask for things, and the doctors and nurses need to do a better job on the assessment part. Especially the emotional part of it because it was never brought up to me. I was not ready to die and no one ever talked to me about it."

Self-Esteem and Guilt

The participants acknowledged that this was a time of decreased self-esteem and feelings of guilt. This was also a finding in Elmberger, Bolund, and Lützén (2005). Because these women went through physical and emotional changes during their treatment, one of the largest concerns was that they could not care for their children or families like they did before they had cancer. One participant stated she had feelings of guilt towards her youngest son because she was not there for him. She said, "There were so many things I would have liked to have done with him and just could not do it. I felt guilty." Another participant stated, "I had horrible guilt about not being there for my children. I would lay awake crying, not sleeping, and thinking about not being able to play with my kids."

Two of the participants had difficulty dealing with chemotherapy-induced menopause. The menopause caused physical and emotional changes, which in turn decreased their self-esteem. This was a concept also found in the published study of Avis, Crawford, & Manuel (2004). One of the participants that had chemotherapy-induced menopause had side effects that caused undue strain in her marriage. She stated that "Chemo put me into early menopause. I have no libido. Someone needs to address this. I was blessed to have a husband that can accept me, even though I am less than perfect. I think some people or not all marriages could go through this, and I think the medical people are missing the boat."

All of the participants in this study experienced the loss of their hair due to treatment. This hair loss caused anxiety and was a constant reminder of their cancer. Before their treatment, all of the participants had long hair. They all decided to cut it short and later decided to shave it off. This hair loss made them feel insecure which affected their self-esteem. One participant stated, "I did not sign up to have cancer and lose my hair. It was a reminder of how sick I was." The participants stated that their hair loss made them tell people they had cancer, even those people they would not have normally told.

Coping Skills

The participants in this study used different types of coping skills. The data revealed that the main coping skills were taking control, prayer, work and humor. These coping skills provided a means for them to deal with their cancer.

One of the coping skills was managing aspects of their lives they could have control over.   This gave the women empowerment in knowing they could exert some control. These women took control over how they lost their hair. For example, four of the five women shaved their hair before they lost it to chemo. One participant stated, "I wanted control of when my hair was going to fall out so I set up a hair-shaving party. I was going to choose when it was going to come out." Another participant stated, "My son helped me shave my head and I think it empowered him to know you can take your own fate into your own hands."

Two participants used prayer as a coping mechanism. Both of them relied on prayer to help relieve their fear. One participant stated, “I knew I was going to be alright, but then again, you are still scared. My friends would come by and pray with me. It seemed God would send them when I was down and I needed them most.”

Four of the five participants stated that they used humor as a coping skill to help them through this crisis. They used humor to replace the pain they were feeling. One participant stated, “My family handled it really well but they joke to take the pain away. That is the way we dealt with the cancer.” Another participant stated, “I think keeping a sense of humor is important and we really did not talk about what might happen if I died.”

Work was another coping skill for four of the five participants. Those that continued working during their treatment said that they gave all of their energy to work and would come home and need to sleep. Work gave them a purpose and helped them to persevere. One participant stated, “Work gave me something to look forward to and kept me going. I needed that. You look at yourself as the person who is going to school and is going to help the kids and do something with your life. If I could not have that, I would have done so much worse.”

It is not clear which of the four coping skills had the most positive impact on these women’s’ lives. The participants that used humor as a coping skill, however, seemed to perform better on a daily basis. They were the same four that kept working throughout their treatment.

The participants wanted to make their lives and the lives of their children as normal as possible. Three of the four concepts found in this study assisted the participants in dealing with their cancer. Accepting assistance from other people, having open communication, and relying on their coping skills provided them with a sense of normalcy and provide a better quality of life.

Interventions

The participants reflected on what they felt could be better addressed by the medical professionals. All of the participants felt an intervention was needed to assist their children through this difficult time. Several suggestions were made by the participants: age-appropriate pamphlets for different ages, something to help explain what cancer is, a support group for kids, and a daycare at the cancer center.

It is important for the nursing profession to do a quality assessment on the side effects of chemotherapy and address the needs of the patients. Patients should not have to go through chemotherapy without medication to alleviate these side effects. Some interventions suggested by the participants are:

1. A time-line for seeing doctors and knowing what to do by certain dates
2. Pamphlets for different technical support that show how to create personal blogs, group emails, and helpful websites about different cancers
3. Available activities to help pass the time while waiting for doctors
4. Group support for patients who have completed their chemotherapy
5. A celebratory retreat for patients that have completed their treatment

Discussion and Implications

These women were well educated and had support during their diagnosis and treatment of cancer. Yet, each woman had difficulties, and their needs were not completely met during this time of crisis. Not all patients have this support or intellectual knowledge. This is why it is important for nurses to understand the lived experiences of mothers with cancer. Addressing their needs and knowing what could be improved upon is imperative.

With the time restraints put on nursing practice during this shortage of nurses, it is important to find ways to assess patients using an efficient, yet holistic, approach. Besides assessing each patient for side effects of the chemotherapy, nurses need to address the areas of family roles, work, finances, support, children and significant others.

One outcome of this research could be to assist nurses with a better evaluation of the mother's needs. An initial form could be filled out by the mothers that asks about their support systems and needs see Appendix G for a suggested format. After the mother completes the form, the nurse would review the answers with the patient. For visual effect, a diagram of their needs would accompany the initial assessment form (see Appendix H). A plus or minus would be written on this form to represent strengths and areas of concern (see Appendix I). These forms would be placed in the mother's chart to remind nurses to assess the areas of concern during their treatment time. If there were a concern, the nurse, social worker, or physician would need to intervene. They would need to make a referral to community resources or give further assistance. This would provide holistic care and enhance the quality of life for the patients.

Another helpful intervention would be providing family conferences. The conferences could assist mothers with ways of telling their families, friends and children what to expect after their diagnosis and during their treatment. The physicians and staff would need to implement procedures particular to their cancer centers.

Limitations

The limitations of this pilot qualitative study were the low number of participants and the time restraints for completing the study. In addition, the newly designed assessment tools need to be studied further to discover whether or not these tools would assist nurses in aiding these mothers with cancer during their diagnosis and treatment. Ideally, this study will encourage more studies on the illuminated concepts.

Conclusions

The participants in this study wanted to share their personal experiences and make a difference in the quality of nursing care provided to mothers with cancer. Providing this insight may give nurses a better perspective of their patients. The assessment tools provided in this study are meant for nurses to review in order to enhance the assessment and care provided for these women. These tools are just a beginning to what can be done differently in assessments and interventions. Patients' journeys of ill health can be positive if they are given the correct guidance and support. Nursing practice must ensure this outcome.

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APPENDIXES

Appendix A

Mothers with Cancer Study: Demographic Data

Age:_____ Birth date: _________ Ethnicity:___________ Religion: ______________

Highest level of Education Completed: ____

Ever Married: ☐Yes How many times have you been married? ______________

☐No

If married how long have you been married? __________________

Are you divorced? ☐ Yes

☐ No

If yes, when were you divorced? ______________________

Length of marriage prior to divorce: ______________________

How many children do you have? _______

Age and Gender of children: ____

What kind of cancer do you have? ____

What stage is your cancer? ____

Year and month of your cancer diagnosis: _________________________

Are you currently being treated for your cancer? ☐ Yes ☐ No (See Follow up question Bellow)

If yes, what kind of treatment are you taking? ☐ Chemotherapy ☐ Radiation therapy

☐ Surgery

Explain: ____

Have you been treated for cancer in the past? ☐ Yes ☐ No

If yes, what was the type of treatment? ☐ Chemotherapy ☐ Radiation therapy

☐ Surgery

When were you treated? ____

Appendix B
Mothers with Cancer Study
Script for Interviews

Research Question: What are the lived experiences of mothers with cancer?

Primary Question: What were your experiences of being a mother with cancer?

Secondary Questions, or follow up questions may include but are not limited to:

1.) Tell me about what it was like when you were first told about your cancer?

2.) How did your family find out you have cancer? What were their reactions?

3.) Share your experiences you had with your cancer treatment?

4.) How has being a mother with cancer affected your experiences of being a parent?

5.) What were your experiences with the health care providers?

6.) Tell me about your experiences with community resources? (Did you use any?)

7.) (If you have a significant other) How did your significant other handle the new of the diagnosis and following treatment? Were there any changes to the significant other's role?

8.) As a mother with cancer, what changes to the health care system would have helped you to be more successful through this experience?

9.) Is there anything else you would like to add?

I would like to thank you for taking your time and answering these questions for me. I sincerely appreciate you participating in this study. When I have all of the data collected I will notify you and let you review the information, if you would like?

It was very nice meeting you and getting to know you.

Appendix C

WASHINGTON STATE UNIVERSITY
CONSENT FORM

Investigator:

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Participant Consent

Project Title: Mothers living with cancer.

Introduction

The purpose of the study is to look at the life experiences of mothers diagnosed with stage II-IV cancer within the past ten years and who have dependent children ages 4-20 living at home during the diagnosis and treatment phase.

Researcher’s statement

I am inviting you to be a part of a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what I will ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When I have answered all of your questions, you can decide if you want to be in the study or not. This process is called ‘informed consent.’ I will give you a copy of this form for your records.

PURPOSE AND BENEFITS

The purpose of this study is to explore the life experiences of mothers with cancer. This research will provide insight into the lives of mothers living with a cancer diagnosis and their changing roles. Knowledge gained in this study may assist other mothers facing cancer. The desired outcomes of this study are to enhance nursing practice, including the development of additional nursing diagnosis and interventions to better address the needs of mothers with cancer.

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PROCEDURES

This study consists of an initial interview lasting about an hour in length. After the interview notes are transcribed they will be given to you for review. If you feel any changes or clarifications are needed a second interview will be set up. These interviews will be scheduled within a 6 month period. The location of the interviews will be determined by you, the participant. The location needs to be confidential, allowing for questions and answers, without interruption. I have two different office locations available in Yakima, if you would like to use one of these locations. One is at Yakima Valley Community College, and the other is at a local doctor's office.

The research question of this study is: What are the lived experiences of mothers with cancer?

Initially, I will be interviewing you for approximately one hour. A follow up interview will be conducted if there is a need for clarification or changes. In the initial interview I will be using open ended questions to allow you to talk freely about your experiences of being a mother with cancer.

RISKS, STRESS, OR DISCOMFORT

Anticipated risks are minimal. This study consists of personal interviews with you the participant. I will ask you questions regarding your experiences being a mother with cancer and the impact it has on you and your family. Therefore, there may be some stress, and emotional expression related to reflecting about your experiences.

INJURY AND COMPENSATION

In the unlikely event of any emotional discomfort resulting from the questions asked in the study no reimbursement, compensation or free medical treatment is offered by Washington State University.

OTHER INFORMATION

Your identity will be kept confidential with respect by me the investigator. Data will be confidential and linked to identifiers and not linked to your name. The data will be held by me, the investigator but no other agencies will have access to identifiable data. The findings may be published in a nursing journal, presented at professional conferences, or be used as a part to future studies. At the conclusion of the study the audio tapes will be destroyed.

You may refuse to participate or may drop out from the study at any time. This study has no connection to you, your cancer treatment, or your provider. You will not receive any money by taking part in this study. You may have to bear some cost in gas-mileage by driving to a Yakima location for participation during the interview/s. No other costs are foreseeable. You may have intangible benefits in this study by the sharing of your story. The study benefit may assist other mothers with cancer.

MEDICAL RECORDS ACCESS

This study does not involve access to medical records or protected health information.

____

Printed name of researcher Signature of researcher/Interviewer

Date _______________________

Participant's statement

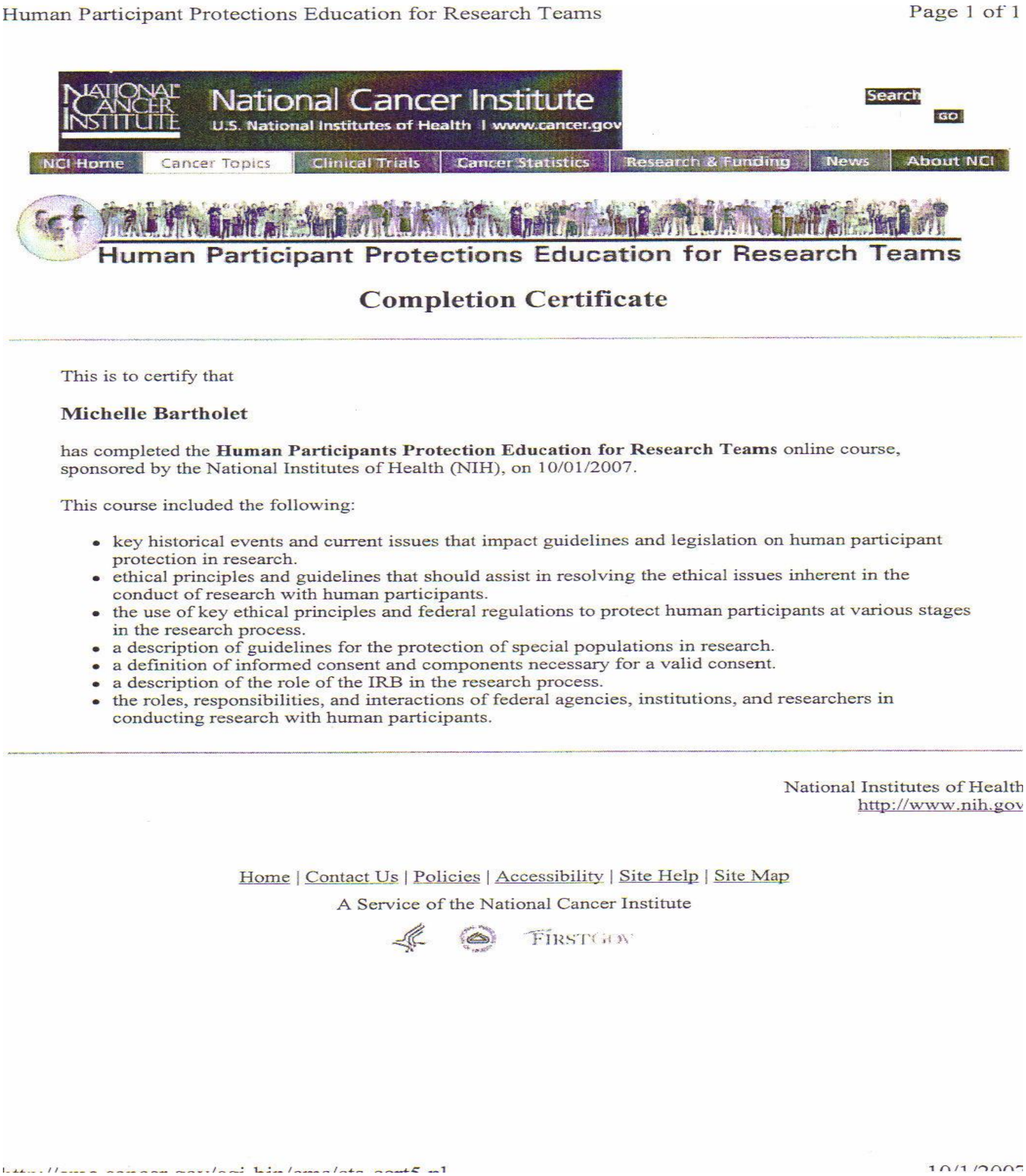
This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have general questions about the research, I can ask the researcher listed above. If I have questions regarding my rights as a participant, I can call the WSU Institutional Review Board at (509)335-9661. The WSU IRB has certified this study be exempt for human participation. I will receive a copy of this consent form.

____

Printed name of participant Signature of participant

Date _____________________

Appendix
D



Human Participant Protections Education for Research Teams   Page 1 of 1

Human Participant Protections Education for Research Teams

Completion Certificate

This is to certify that

Michelle Bartholet

has completed the **Human Participants Protection Education for Research Teams** online course, sponsored by the National Institutes of Health (NIH), on 10/01/2007.

This course included the following:

- key historical events and current issues that impact guidelines and legislation on human participant protection in research.
- ethical principles and guidelines that should assist in resolving the ethical issues inherent in the conduct of research with human participants.
- the use of key ethical principles and federal regulations to protect human participants at various stages in the research process.
- a description of guidelines for the protection of special populations in research.
- a definition of informed consent and components necessary for a valid consent.
- a description of the role of the IRB in the research process.
- the roles, responsibilities, and interactions of federal agencies, institutions, and researchers in conducting research with human participants.

National Institutes of Health
http://www.nih.gov

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FIRSTGOV

http://cme.cancer.gov/cgi-bin/cms/cts-cert5.pl   10/1/2007

Appendix E

WASHINGTON STATE UNIVERSITY HUMAN SUBJECTS FORM

To receive approval from the WSU Institutional Review Board (IRB) for the use of human subjects, submit the following packet of materials to your department for initial review and signatures. Your department will forward the packet to the IRB for final review and approval. When your packet has been received by the IRB it will be checked for completeness. If not complete, it will be returned with a request for additional materials necessary for the review. To determine the level of review needed for your protocol turn to Section 2, Page 6.

PACKET CHECKLIST

<u>EVERY PACKET MUST INCLUDE THE FOLLOWING MATERIALS</u>.

1. Completed and Signed WSU Human Subjects Forms _X_
2. Documentation of Consent Procedures (one or more of the following):
    a. Consent Form, _X_
    b. Verbal Consent Script,
    c. Cover letter.
    d. Wavier Request
3. Any survey instruments or questionnaires to be used. _X_
4. A list of interview questions or topics, in as much detail as possible. _X_
5. If you are accessing protected health information (PHI), complete and attach a completed HIPAA Authorization Form & HIPAA Appendix A _N/A_
6 Any advertisement or recruiting materials _X_
7. **Exempt protocols**: Signed original _X_
   Expedited Protocols: Signed original and two copies of items 1-5. ___
   Full Board Protocols: Signed original and 16 copies of items 1-5. ___
8. **Original** must be <u>single-sided</u> and <u>not stapled</u>. **Copies** may be <u>stapled</u> and <u>double-sided</u>.

AVOID THE TOP 5 MISTAKES PEOPLE MAKE WHEN SUBMITTING AN APPLICATION!

1. Stating that the data is anonymous when it is actually confidential (See Section 5, Definitions).
2. Not giving enough information as to who will have access to the data.
3. Stating there are no risks to a project. Even though the risks may be low, they need to be listed on the form.
4. The signature page does not have all the required signatures.
5. Consent forms and survey or interview instruments are not attached for review.

REVIEW TIMETABLE

Exempt reviews are reviewed as the packets are received and will take no more than 10 working days for approval once they have arrived at OGRD.
Expedited reviews are reviewed as the packets are received and will take about 12 working days for approval once they have arrived at OGRD.
Full Board reviews will be reviewed at the next monthly meeting of the IRB, <u>if and only if</u> the packets are received at OGRD at least 10 working days prior to the meeting date.

ELECTRONIC VERSIONS OF THIS FORM

Use contact number below to request copy.

<u>WORLD WIDE WEB SITE</u> at www**.research-compliance.wsu.edu** under **IRB**.

HOW TO CONTACT THE IRB

Phone:	(509) 335-9661, Research Compliance Office
Campus Mail:	campus zip 3140
Fax:	(509) 335-1676
Email:	irb@wsu.edu
Mail:	WSU IRB, PO Box 643140, Pullman, WA, 99164-3140

SECTION 1

PLEASE TYPE. If you use an electronic version of this form, use a different font for your responses. DO NOT leave a question blank. If a question does not apply to your protocol write "n/a."

Principal Investigator(s) (PI):____Dr. Phyllis Eide, Ph.D., RN, MS, MPH, APRN, BC,

Department:______*Nursing_*_______ Campus:___*WSU/ICN*_________ Campus Zip:______*99224*___ ____

Campus Building & Room #:__________WSU/ICN, Room # 367 *Spokane, Wa*___

Status: Faculty__X____Adjunct Faculty_______*Staff*_________Graduate Student _____ ___Undergraduate______

Contact Phone Number*: (509) 324-7246* Contact Email Address:____*eide@wsu.edu*____

Mail Correspondence To: *Dr. Phyllis Eide, WSU/ICN,* 2917 W Fort George Wright Drive, *Room # 367, Spokane, WA 99224*_

Project Title:_______ Mothers with Cancer: A Qualitative Study_____________________

TYPE OF REVIEW: EXEMPT_X__ EXPEDITED___ FULL BOARD___

Estimated project start date:__*February 10, 2008* Estimated data collection completion date:__*August 10, 2008*_

Is there, or will there be extramural funding that directly supports this research? YES ____ NO_X___

If yes, funding agency (s):_________________________________ PI on grant:______________________

OGRD# _________________

ABSTRACT: Describe the purpose, research design and procedures. Clearly specify **what the subjects will do**.

Overview: *The purpose of this study is to explore the lived experiences of mothers with cancer. This research will provide insight into the lives of mothers living with a cancer diagnosis and their changing roles. Knowledge gained in this study may provide guidance for other mothers facing cancer.*

This is a qualitative study using the phenomenological approach to explore the lived experience of mothers with cancer. The purpose of phenomenology is to examine the lived experiences of a certain phenomenon based on thought and dialogue with the purpose of promoting understanding of a concept.

The total number of participants in this study will be 4-8 and the inclusion criteria of the participants will be: to have any cancer diagnosis of stage II-IV, to have children living at home from the ages of 4-20, to be able to speak and read English and to have a cancer diagnosed within the last ten years. The participants will be interviewed initially for approximately one hour and these interviews will be taped. The taped interviews will be transcribed and the transcribed data will then be given to the participants. If the participants would like to clarify or add any information to the transcribed data than a follow up interview will be conducted. The data collection will be in-depth interviews, using open ended questions to allow the participants to talk freely about their lived experiences of being a mother with cancer. The interviews will be semi-structured allowing the patients to direct the flow of information. The in-depth interviews will yield data that will be analyzed in order to elucidate concepts.

The research question of this study is: what are the lived experiences of mothers with cancer?

I. DATA COLLECTION

A. Check the method(s) to be used **(underline all items in the columns on the right that apply)**:

___Survey: Administered by: investigator subject mail phone in person internet/email
__*X*_ Interview: one-on-one focus group oral history other

If you are using a survey or doing interviews, submit a copy of the survey items/ interview questions

__ Observation of Public Behavior: in classroom at public meetings other
___Examination of Archived Data or Records: academic medical legal other (briefly describ
____
___Taste/Sensory Evaluation: food tasting olfactory
___Examination of Pathological or Diagnostic Tissue Specimens
___Therapeutic: biomedical psychological physical therapy
___Experimental: biomedical psychological other
___Other: Briefly Describe ____

B. Data: Anonymous ___ Confidential __X_ Intentionally identified___ (**Please See Definitions, Section 5**).

C. What form of consent will be obtained? (**Please see Section 6 for sample consent and assent templates**)

a. Implied	___	(Please attach cover letter or describe terms.)
b. Verbal	___	(Please attach consent script.)
c. Written	_X__	(Please attach consent form.)
d. Seeking Waiver of Consent	___	(Contact the IRB for further information.)
e. Consent Not Applicable	___	(On a separate page explain why not.)

D. If anonymous or confidential, describe how anonymity or confidentiality will be maintained (e.g., coded to a master list and separated from data, locked cabinet, office, restricted computer, etc..).
E. List all sites where data might be stored.

Identifiers will be used for the participants and the coding system is alpha-numeric. The recordings, transcribed data, and the demographic form will be coded. The coded identifiers will be placed on a master list and stored separate from all other unidentified records and locked in a cabinet file and office. Furthermore, field notes and interviews will be transcribed and stored on a flash drive in a separate area under lock and key. The flash drive will not have any identifiers attached to it, only coded data will be placed on a dedicated flash drive.

Who will have access to the data? Please be specific.

1**.) Dr. Phyllis Eide**, Ph.D., RN, MS, MPH, APRN, BC, Assistant Professor, WSU/ICN, office phone: (509)324-7246, Fax: (509)324-7341, e-mail: eide@wsu.edu.

2.) **Dr. Janet A. Lohan**, Ph.D., RN, CPN, Senior Instructor, WSU/ICN, office phone: (509)324-7265, Fax: (509)324-7341, e-mail: lohan@wsu.edu.

3.) **Dr. Denise A. Smart**, RN, BSN, MPH, Dr.PH, Clinical Instructor, WSU/ICN, office phone: (509)324-7255, Fax: (509)324-7341, dsmart@wsu.edu.

4.) **Michelle R. Bartholet**, RN, BSN, OCN, Graduate Student, WSU/ICN, home phone: (509) 965-1723, cell phone: 509-969-1627, e-mail: nursembartholet@charter.net.

These are the four people that have access to the raw data and to the field notes. No other people will have access to the data.

F. Will video tapes ___ audio tapes _X__ photographs ___ be taken? YES __X__ NO____
If yes, where will tapes or photographs be stored?

The tapes will be stored in a locked file and office of Michelle R. Bartholet, RN, BSN, OCN, the investigator. The information will be held for 3 years under lock and key and then all tapes will be incinerated.

E. When will all research materials be destroyed?

Research transcription will be held 3 years, and computer files will be purged. Audio tapes will be incinerated after transcribed data has been verified.

II. DESCRIPTION OF THE POPULATION (See Definitions, Section 5, Page 9)

1. Approximate number: ___4-8 subjects_______ Age Range: *22-50*__
   How will subjects be selected or recruited and how will subjects be approached (or contacted)?

Participants will be recruited by a convenience/snowball sampling method which consists of word of mouth recruitment and flyers placed at such locations as the voluntary cancer support office, and doctor's office. These flyers will contain information regarding inclusion criteria, the investigator's number, and e-mail address. Inclusion criteria are: to have any cancer diagnosis of stage II-IV, to have children living at home from the ages 4-20, to be able to speak and read English, and to have a cancer diagnosed within the last ten years.

2. Will subjects be compensated* (include extra credit)? YES ____ NO_X___
   Must they complete the project to be paid? *N/A*

3. Are any subjects under 18 years of age? YES___ NO__X__

4. Are any subjects not legally competent to give consent? YES ____ NO__X__
   If yes, how will consent be obtained? From whom? Are there procedures for gaining assent?
   (Please attach assent form.)

5. Will any ethnic group or gender be excluded from the study pool? YES __X__ NO___
   If yes, please justify the exclusion.

This study will be looking at the lived experiences of mothers with cancer. Therefore, males will be excluded from the study. Additionally, the Principal Investigator only speaks English and will only be able to interview people who speak English.

6. Is this study likely to involve any subjects who are not fluent in English? YES ____ NO_X___
   If yes, please submit both the English and translated versions of consent forms and surveys, if applicable.

7. Does this study involve subjects located outside of the United States? YES ____ NO__X__
   If yes, on an attached page please explain exactly "who the subjects are," and the identities (if possible) and responsibilities of any additional investigators.

8. Does this study involve the use or creation of protected health information? YES ____ NO__X__

(See Section 5 for a definition of protected health information.) If yes, complete and submit Appendix A along with the completed human subjects application.

III. DECEPTION (See Definitions, Section 5, Page 9)

If any deception is required for the validity of this activity, explain why this is necessary. Please include a description of when and how subjects will be debriefed regarding the deception, and **attach a debriefing script**.

There is no deception needed in this study.

IV. RISKS AND BENEFITS (See Definitions, Section 5, Page 8)

A. Describe any potential risks to the subjects, and describe how you will minimize these risks. These include stress, discomfort, social risks (e.g., embarrassment), legal risks, invasion of privacy, and side effects.

Anticipated risks are minimal. This study consists of personal interviews of participants. The interviewer will ask questions regarding the lived experiences of mothers with cancer and the impact on the family. Therefore, there may be some stress, and emotional expression related to reflecting their experiences.

B. In the event that any of these potential risks occur, how will it be handled (e.g., compensation, counseling, etc.)?

The investigator will acknowledge the participants feelings and guide them back to their health care provider for follow-up.

C. Will this study interfere with any subjects' normal routine? YES___ NO__x_

Interviews can be made for times that will not interfere with participants' routine or appointments.

D. Describe the expected benefits to the individual subjects and those to society.

There are gaps in the research on mothers with cancer and how these women experience their cancer diagnosis and changing roles. Therefore, this study is intended to develop a better understanding of mothers with caner by having these women share their feelings and stories. The desired outcomes are to enhance nursing practice, including the development of additional nursing diagnosis, interventions to better address the needs of this population and assist or guide other mothers facing cancer.

E. If blood or other biological specimens will be taken please address the following. *N/A*

Brief Description of Sampled Tissue(s):______________________________

Describe the personnel involved and procedure(s) for obtaining the specimen(s). Note that the IRB requires that only trained certified or licensed persons may draw blood. Contact the IRB for more details on this topic.

V. USE OF DATA COLLECTED (Check all that apply)

1. __X__Thesis/Dissertation
2. __X_Journal Article/Publication/Presentation
3. __X_Grant Activities
4. ___ Other : Briefly Describe:____

VI. PROJECT CHECKLIST (Attach additional pages as necessary.)

A. Will any investigational new drug (IND) be used?
YES___ NO_X__

B. Will any other drugs be used?
YES___ NO__X_

If yes to A or B, on a separate page, list for each drug:

1. the name and manufacturer of the drug,
2. the IND number,
3. the dosage,
4. any side effects or toxicity, and
5. how and by whom it will be administered.

C. Will alcohol be ingested by the subjects?
YES___ NO_X__

If yes, on a separate page, describe what type and how will it be administered. Refer to the guidelines for administration of ethyl alcohol in human experimentation (OGRD Memo No. 18 available at OGRD).

VII. FINANCIAL CONFLICT OF INTEREST

Does the researcher or any other person responsible for the design, conduct, or reporting of this research have an economic interest in or act as an officer or director of any outside entity whose financial interest would reasonably appear to be affected by the research?
YES ___ NO_X__

If yes, please answer the following: *N/A*

If the economic interest involved is a "significant economic interest" as defined in WSU's Conflict of Interest Policy, has a plan for managing, reducing or eliminating any conflict been established by the Conflict of Interest committee? *N/A*

YES ___ NO ___

SECTION 2

Is your project EXEMPT?

Exempt Reviews

Federal regulations specify that certain types of research pose very low risks to subjects, and therefore requires minimal review from the IRB. To determine if your project is exempt, answer the following questions.

1. Will subjects be asked to report their own or others' sexual experiences, alcohol or drug use, and will their identities be known to you? YES__ NO_X_
2. Are the subjects' data directly or indirectly identifiable, and could these data place subjects at risk (criminal or civil liability), or might they be damaging to subjects' financial standing, employability or reputation? YES__ NO_X_
3. Are any subjects confined in a correctional or detention facility? YES__ NO_X_
4. Are subjects used who may not be legally competent? YES__ NO_X_
5. Are personal records (medical, academic, etc.) used with identifiers and without written consent? YES__ NO_X_
6. Will alcohol or drugs be administered? YES__ NO_X_
7. Will blood/body fluids be drawn? YES__ NO_X_
8. Will specimens obtained from an autopsy be used? YES__ NO_X_
9. Will you be using pregnant women by design? YES__ NO_X_
10. Are live fetuses subjects in this research? YES__ NO_X_

If you answered YES to any of the questions above, then your project is NOT exempt, but may still qualify for expedited review (see Section 3, Page 7).

If you answered NO to the questions, your research might be EXEMPT if it fits into one of the following categories.

(Circle or Underline all that apply)

1. **Educational Research:** Research conducted in established or commonly accepted educational settings, involving normal educational practices. This is for research that is concerned with improving educational practice.
2. [✓ **Surveys, Questionnaires, Interviews, or Observation of Public Behavior.**] To meet this exemption, the subject matter must not involve “sensitive” topics, such as criminal or sexual behavior, alcohol or drug use on the part of the subjects, unless they are conducted in a manner that guarantees anonymity for the subjects.
3. **Surveys, Questionnaires, Interviews or Observation of Public Behavior.** Surveys that involve sensitive information and subjects’ identities are known to the researcher may still be exempt if: (1) the subjects are elected to appointed public officials or candidates for public office; or (2) federal statute(s) specify without exception that confidentiality will be maintained throughout the research and thereafter.
4. **Archival Research.** Research involving the collection or study of existing data, documents, records, pathological or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. These data/samples must be preexisting, which means they were collected prior to the current project.
5. **Research Examining Public Benefit or Public Service Programs.** To qualify for this exemption, the research must also be conducted by or subject to review by an authorized representative of the program in question. Studies in this category are still exempt if they use pregnant women by design and their purpose is to examine benefit programs specifically for pregnant women.

6. **Taste Evaluation Research.** Studies of taste and food quality evaluation. Studies of taste evaluation qualify for this exemption <u>only if</u> (1) wholesome foods without additives are consumed; <u>or</u> (2) if a food is consumed that contains a food ingredient at or below the level of and for a use found to be safe.

FINAL QUESTION: Are any subjects under 18 years of age? YES__ NO_X_

<u>If</u> your study uses subjects under 18 years of age, <u>and</u> you plan to use surveys, questionnaires or do interviews, <u>then</u> your project is NOT exempt. All other exemptions apply even if subjects are under the age of 18.

<u>If</u> you answered NO to the questions and your study fits into one of the six categories, then your project <u>is</u> EXEMPT.

SECTION 3

<u>Does your study qualify for EXPEDITED review</u>?

Expedited Reviews

Expedited reviews are for studies involving no more than minimal risk or for minor changes in previously approved protocols. To meet expedited review criteria your protocol must meet the following conditions: no more than minimal risk to the subjects, subjects must not be confined in a correctional or detention facility, and one or more of the following types of participation on the part of subjects.

(Circle or Underline any that apply to your project)

1. **Collection of excreta and external secretions:** sweat, saliva, placenta, and/or amniotic fluid. None of these may be collected by "invasive" procedures, such as those that use cannulae or hypodermic needles, such as in amniocentesis.
2. **Recording of data using noninvasive procedures routinely employed in clinical practice.** This includes but is not limited to the use of "contact" recording electrodes, weighing, tests of sensory acuity, electrocardiography and electroencephalography, and measures of naturally occurring radioactivity.
   This does NOT include procedures which: a) impart matter or significant amounts of energy to the subjects, b) invade the subjects' privacy, or c) expose subjects to significant electromagnetic radiation outside the visible range (e.g. Ultraviolet light from tanning beds).
3. **Collection of hair or nail clippings**, **teeth from patients whose care requires the extraction or collection of plaque and/or calculus** using routine procedures for the cleaning of teeth.
4. **Voice recordings** made for research purposes such as investigations of speech defects and speech pathology.
5. **Moderate exercise** by healthy volunteers.
6. **Experimental research** on individual or group behavior or on the characteristics of individuals, such as studies of perception, cognition, game theory or test development.
   This does NOT include studies...
   ...that involve significant stress to the subjects.
   ...that are intended to produce a relatively lasting change in behavior.
7. Studies of **archived data, records or diagnostic specimens** that are not exempt.
8. Studies involving the **collection of blood samples** by venipuncture, in amounts not exceeding 550 ml (about a pint) in an eight week period and no more often two times per week, from subjects 18 years of age or older and who are in good health and not pregnant.

If your study fits into one of the eight types of participation and required criteria, then your project can receive EXPEDITED REVIEW.

SECTION 4

If your study does not meet exempt or expedited review criteria, then it qualifies for FULL BOARD review.

Full Board Reviews

Protocols that require full board review have the potential for high risks to subjects (physical, psychological or social) or those that have special population consent considerations (research on Native Americans, prisoners, persons who are not legally competent, ethnic considerations).

INVESTIGATOR'S ASSURANCES

This investigation involves the use of human subjects. I understand the university's policy concerning research involving human subjects and I agree...

1. ...to obtain voluntary and informed consent of persons who will participate in this study, as required by the IRB.
2. ...to report to the IRB any adverse effects on subjects which become apparent during the course of, or as a result of, the activities of the investigators.
3. ...to cooperate with members of the IRB charged with review of this project, and to give progress reports as required by the IRB.
4. ...to obtain prior approval from the IRB before amending or altering the project or before implementing changes in the approved consent form.
5. ...to maintain documentation of IRB approval, consent forms and/or procedures together with the data for at least three years after the project has been completed.
6. ...to treat subjects in the manner specified on this form.

Principal Investigator: The information provided in this form is accurate and the project will be conducted in accordance with the above assurances.

Signature:______________________________Print Name: Phyllis Eide, Ph.D., RN, MS, MPH, APRN, BC Date:__________

Chair: This project will be conducted in accordance with the above assurances.

Signature:______________________________Print Name: Professor and Dean, Patricia Butterfield, Ph.D., RN, FAAN Date: ____________

When Section 1 is filled out and fully signed, review the Packet Checklist (Page 1) to complete the packet for review and submission.

Institutional Review Board: These assurances are acceptable and this project has adequate protections for subjects. This project has been properly reviewed and filed, and is in compliance with federal, state, and university regulations.

Signature______________________________Print Name______________________________Date_________

IRB ONLY: This protocol has been given- status. Exempt___ Expedited___ Full Board___

MEMORANDUM

TO: PHYLLIS EIDE and Michelle Bartholet,

FROM: Malathi Jandhyala(for) Kris Miller, Chair, WSU Institutional Review Board (3005)

DATE: 2/8/2008

SUBJECT: Certification of Exemption, IRB Number 10257-001

Based on the Exemption Determination Application submitted for the study titled Mothers With Cancer: A Qualitative Study, and assigned IRB # 10257, the WSU Institutional Review Board has determined that the study satisfies the criteria for Exempt Research contained in 45CFR 46.

Exempt certification does not relieve the investigator from the responsibility of providing continuing attention to protection of human subjects participating in the study and adherence to ethical standards for research involving human participants.

This certification is valid only for the study protocol as it was submitted to the IRB. Studies certified as Exempt are not subject to annual review. If any changes are made to the study protocol, you must submit the changes to the IRB for determination that the study remains Exempt before implementing the changes. Request for Amendment forms are available online at http://www.irb.wsu.edu/forms.asp.

In accordance with federal regulations, this Certification of Exemption and a copy of the study protocol identified by this certification must be kept by the principal investigator for THREE years following completion of the project.

It is important to note that certification of exemption is not approval by the IRB. The study materials should not include the statement that the WSU IRB has reviewed and approved the study for human subject participation.

Washington State University is covered under Human Subjects Assurance Number FWA00002946 which is on file with the Office for Human Research Protections.

If you have questions, please contact the Institutional Review Board at (509) 335-3668. Any revised materials can be mailed to the Office of Research Assurances (Campus Zip 3005), faxed to (509) 335-6410, or in some cases by electronic mail, to irb@mail.wsu.edu.

Review Type: New Protocol
Review Category: Exempt
Date Received: 2/7/2008
Exemption Category: 45 CFR 46.101 (b)(2)
OGRD No.: N/A
Funding Agency: N/A

Appendix F

Oncology Nursing Forum Publishes Manuscript Requirements

The *Oncology Nursing Forum* (*ONF*) publishes manuscripts that focus on nursing achievements in the field of oncology including, but not limited to, clinical advances, research findings, educational developments, administrative issues, and role and theory development.

Manuscripts are accepted for consideration with the understanding that they are contributed solely to this journal, that the material is original, and the articles have not been published previously. If a work has multiple authors, the paper is reviewed on the assumption that all authors have granted approval for submission. All submitted papers are subject to blind peer review. Papers will be judged on the quality of the work and suitability for the audience. Questions should be sent directly to

ONF Editor
Rose Mary Carroll-Johnson, MN, RN
661-257-6932 (phone and fax)
ONFEditor@ons.org

Manuscript Submission

To submit a manuscript, go to http://mc.manuscriptcentral.com/onf (or go to www.ons.org and select Manuscript Central from the *Oncology Nursing Forum* section in Publications). Full instructions for this process are available on the site, and help also is available from Administrative Assistant Natalie Tooch at 412-859-6303 or pubONF@ons.org.

Financial Disclosure

Each author must disclose any financial interest in products mentioned in the manuscript or in the company that manufactures the products, as well as any compensation received for producing the manuscript. A submitted manuscript that is the result of funded research must cite the funding source on the title page. A manuscript that originated as a thesis or dissertation prepared by an author on an educational scholarship must cite the name of the scholarship. In general, this disclosure will not preclude publication in *ONF* providing that the manuscript meets the appropriate standards for acceptance. When appropriate, this information is shared with *ONF* reviewers and readers.

Manuscript Preparation

Papers should be prepared using standard manuscript form according to the *Publication Manual of the American Psychological Association* (APA), 5th edition (2001). (Visit www.apastyle.org for assistance.) Length should be 12-15 pages (4,000 words), exclusive of tables, figures, and references.

1. **Title page:** Include names, credentials, titles, and affiliations of all authors.
2. **Structured abstracts:** An abstract is required for **all** articles.
    a. **Research abstracts:** The following headings for reports of quantitative research **must** be included. Variations for reports of qualitative research are in *italics*.
        1. Purpose/Objectives
        2. Design/Research *Approach*
        3. Setting
        4. Sample/*Participants*
        5. Methods/*Methodologic Approach*

        6. Main Research Variables
        7. Findings
        8. Conclusions
        9. Implications for Nursing/*Interpretation*
    b. **Abstracts for clinical, review, or theoretical papers:** The following headings **must** be included in the abstract:
        1. Purpose/Objectives
        2. Data Sources
        3. Data Synthesis
        4. Conclusions
        5. Implications for Nursing
3. **Key Points:** Prepare three or four statements that cover main points readers should remember on the topic in general. Content of these points should not duplicate information in the abstract.
4. **Text:** Use headings and subheadings as appropriate. If you must use the trade name, use the register (®) or trademark (™) symbol on first reference in the text, and in parentheses include the manufacturer's name and location (city and state) in parenthesis.
5. **Tables:** Each should be typed, double spaced on separate pages placed at the end of the text. Every table must be referred to in the text.
6. **Figures:** Include on separate pages at the end of the manuscript.
   Every figure must be referred to in the text.
7. **References: Authors are responsible for the accuracy and correct formatting of all reference citations. References will be checked for accuracy at the time of editing. Manuscripts found to contain errors are subject to delays in publication.**
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9. **Acknowledgments:** Any acknowledgments should be submitted with the final version of the manuscript following acceptance for publication.

Appendix G
Questionnaire for Women with Cancer

1.) Do you have a significant other? Yes ☐ No☐
Does he/she know you have cancer? Yes ☐ No☐ N/A

2.) Do you have children? Yes No
Do they know you have cancer? Yes No N/A

Do you need assistance with this? Yes ☐ No☐

3.) Would you like to have a family conference scheduled? Yes ☐ No☐
This is to assist with any questions you or your family may have.

4.) List the positive and negative support groups you currently have in your life:

Positive	**Negative**

5.) Do you need assistance with finances? Yes ☐ No☐

6.) Do you have health insurance? Yes ☐ No☐

7.) Do you work? Yes ☐ No☐
If yes, how many hours? ________________________________

8.) Are you planning to continue to work during your treatment? Yes ☐ No☐

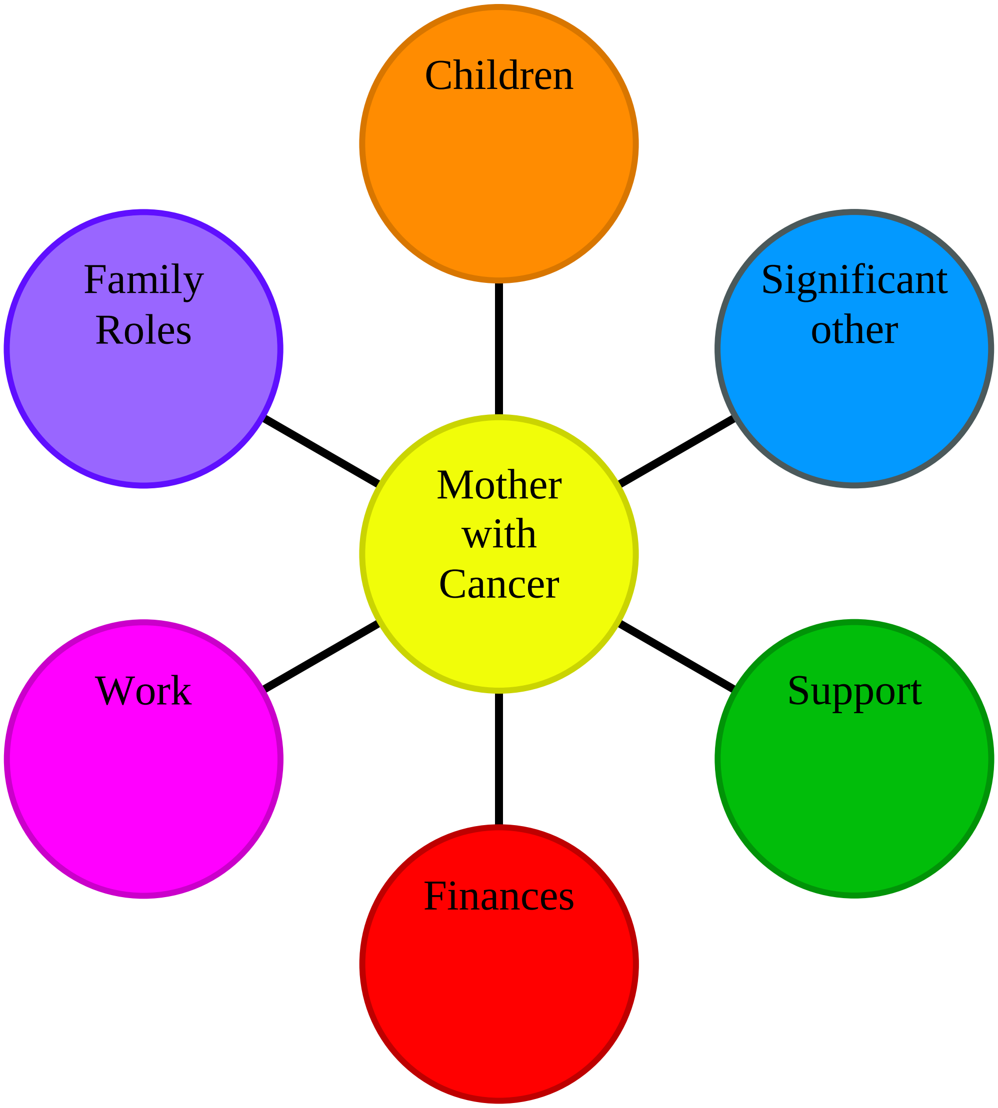
9.) Do you need assistance with informing your work place of your plans or your diagnosis and treatment? Yes ☐ No☐

10.) List your family roles (duties, chores, etc.):

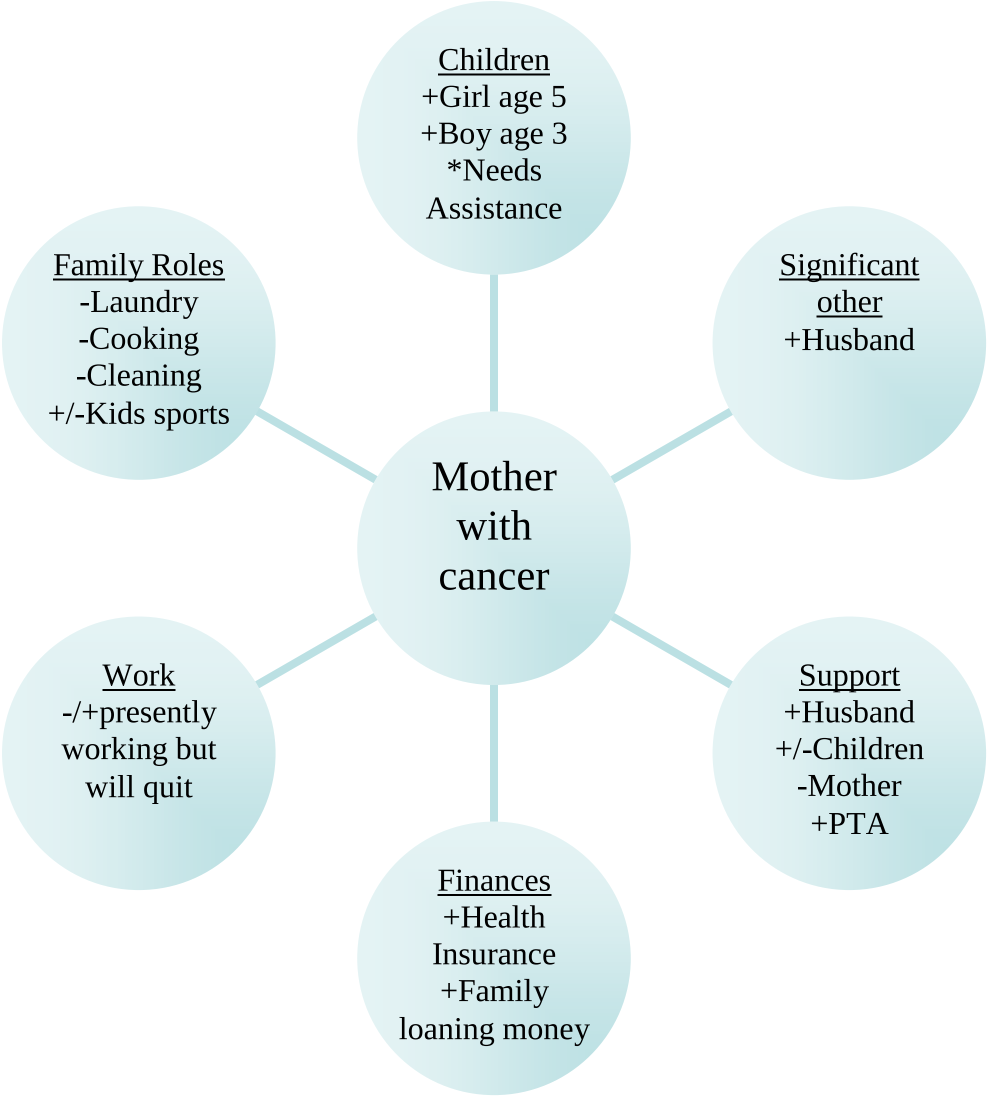
By your list of family roles, place a + sign by the activities you enjoy to do and a – sign by the areas you do not enjoy.

If you feel you need assistance with any of these areas place a * (star) by those areas.

Appendix H


Children
Family Roles
Significant other
Mother with Cancer
Work
Support
Finances

Appendix I


Mother with cancer
Children
+Girl age 5
+Boy age 3
*Needs Assistance
Significant other
+Husband
Support
+Husband
+/-Children
-Mother
+PTA
Finances
+Health Insurance
+Family loaning money
Work
-/+presently working but will quit
Family Roles
-Laundry
-Cooking
-Cleaning
+/-Kids sports