ONCOLOGY NURSES' PERCEPTIONS OF EDUCATIONAL NEEDS OF FEMALE CANCER SURVIVORS POST TREATMENT

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Oncology Nurses' Perceptions

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We hereby certify that this dissertation, submitted by your name, conforms to acceptable standards and fully fulfills the dissertation requirements for the degree of Doctor in Education from the College of Saint Mary

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People in my life are like the pillars on a porch. Sometimes they hold you up and sometimes they lean on you. Sometimes it is just enough to know they are standing by. Thank you God for all of the pillars in my life who have inspired me by their faithfulness, generosity and love. I am indeed blessed to have these strong and compassionate companions on my journey through life.

Adapted from Reflective Moments Sr. Norita Cooney

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Abstract

Perceptions of oncology nurses regarding educational needs would assist in gaining more understanding of survivor needs and ultimately provide better quality care to individuals who have completed cancer treatment. Therefore, the purpose of this phenomenological qualitative study was to explore oncology nurses' perceptions of educational needs of female cancer survivors post treatment. Participants consisted of 10 oncology nurses with at least 3 years of experience in an oncology setting. Five themes regarding educational needs of female cancer survivors emerged from this study to include: 1) Follow-up Care, 2) Fear of the Unknown, 3) Sexuality, 4) Positive Outcomes, and 5) No Specific Standards regarding post treatment teaching. Findings supported the need to address educational concerns of female cancer survivors post treatment which will facilitate adjustment to the new role of life after cancer treatment.

CHAPTER I

INTRODUCTION

Cancer diagnosis for a woman changes life in unimaginable ways. The shock and numbness that surrounds the diagnosis and treatment is superimposed on issues of one's own mortality while at the same time engaging in a fight for life. To assist in this process a woman is typically allied with a team of health care professionals who provide care to eradicate the disease. Initially, and during the actual treatment process, extensive teaching is done regarding chemotherapy, radiation, surgery, or a combination of these therapies. However, when treatment ends female cancer survivors may find they are sent home with little more than a form identifying the next follow-up appointment. This is indicative of the health care system tendency to be more focused on *combating the disease* (Hart, 2007). Therefore, just as the realization of the transition to the role of patient with cancer is difficult, the transition at the end of treatment is also alarming because the patient has a "new normal" of life experience. Individuals who looked forward to the end of treatment are often surprised by the void (Rancour, 2008). Feelings of distress, anxiety, and questions regarding the future are common. The focus on oncology nurses "lived experience" as part of uncovering meaning to the female cancer survivor regarding educational needs will provide better quality care to individuals who have completed cancer treatment.

Purpose of the Study

The purpose of this phenomenological qualitative study was to explore oncology nurses' perceptions of educational needs of female cancer survivors post treatment.

Background of the Problem

The assessment of educational needs of female cancer survivors post treatment by oncology nurses is critical to the provision of holistic care. In particular, when female cancer survivors have actively been engaged in fighting cancer with various treatments and then lose their "safety net" interaction with oncology nurses to address educational needs is significant. Educational interventions by oncology nurses at the completions of treatment would provide female cancer survivors with much needed support to continue on the journey of coping with a life-threatening illness.

Research Question

The research question in this study was:

1. What are perceptions of oncology nurses' regarding educational needs of female cancer survivor post treatment?

Assumptions

Following are assumptions identified regarding this study:

- 1. It was assumed the oncology nurse would feel adequately prepared to meet the needs of the female cancer survivor post treatment.
- 2. It was assumed the female cancer survivor would have significant educational needs that should be assessed post treatment.
- 3. It was assumed that information gained from this study would assist oncology nurses in identifying educational needs of the female cancer survivor.
- 4. It was assumed that oncology nurse perceptions of educational needs would assist in the development of teaching plans for the female cancer survivor.

5. It was assumed that nurses would be open and honest regarding their perceptions of their "lived" experience of meeting female cancer survivor educational needs
Significance of Study

Providing competent nursing care post treatment is a priority with the continued increase in the number of cancer survivors. Meeting the recovery needs post treatment should be a priority in assisting with the process and help foster hope, purpose, and meaning to the lives of female cancer survivors. Therefore, the nursing profession should develop nurses who are capable of responding to cancer survivors' educational needs in a competent and sensitive way. This study contributes to the body of literature regarding the importance of incorporating educational needs into post treatment care.

Delimitations

Delimitations are the factors that prevent the researcher from claiming that findings are true for all people in all times and places (Bryant, 2004). Scope of this study was limited to perceptions of oncology nurses' in a Midwest community setting.

Therefore, this purposive sample of Registered nurses from the Midwest may result in geographical and population delimitation. Meeting educational needs in other geographic areas and cohorts may be approached in a different manner. Another delimitation may be the distinct time period of May 2009 through January 2010. The impact of time as oncology nurses become more aware of female cancer survivor needs may influence findings related to educational needs.

Limitations

Limitations are the built-in limits of the methodology the researcher uses to explore the research question (Bryant, 2004). Limitations to this qualitative design included recognizing the possibility that participants might withhold information or not share information in an open and honest manner during the interview process.

Definition of Terms

<u>Female cancer survivor</u>: a woman with a diagnosis of cancer (breast, gynecological, colon, lymphoma, lung, or kidney) who is alive and able to carry on with activities of daily living.

Oncology nurse: a registered nurse with a minimum of three years experience actively employed in an oncology care setting.

<u>Post treatment</u>: period of time at completion of cancer treatment (surgery, chemotherapy, radiation).

<u>Follow-up care</u>: education related to expectations post treatment, resources, activities, routine health care needs and return appointment with oncologist.

Attributes: a named value given to documents in NVivo such as gender "female" or number of years as a registered nurse.

Educational needs: to lead forth, draw out, to provide with information by giving knowledge, instruction, or information (Webster's New Explorer Dictionary, 2005).

Perception: an act or result of perceiving, ability to understand: insight, comprehension (Webster's New Explorer Dictionary, 2005).

CHAPTER II

REVIEW OF LITERATURE

Chapter II includes a literature review related to cancer survivorship and the role of oncology nurses in meeting educational needs of female cancer survivors post treatment.

Historical Context

When someone hears the words *cancer victim* this brings to mind negative and lifethreatening implications. Conversely when someone hears the words cancer survivor this brings to mind positive and hopeful ways of looking at the cancer experience. Miller (2008) stated "The increasing number of cancer survivors living beyond treatment underscores the need to address survivorship care" (p. 479). The number of survivors is expected to double by 2030 as survival rates improve and the United States population ages (The American Cancer Society (ACS): Centers for Disease Control and Prevention (CDC), 2004; National Institutes of Health, 2006). The (ACS) (2006) has also reported that more than 10 million cancer survivors live in the United States. This represents a tripling of the number of survivors since 1971. Despite these facts health care professionals tend to be more focused on "combating the disease" (Hart, 2007). Therefore, nurses are in a position to change this situation and educate women cancer survivors on follow-up care in regards to ways to cope, maintain quality of life, and prevent recurrence.

Cancer Survivorship

Cancer survivorship has evolved as a pertinent and useful concept for individuals diagnosed with cancer. The National Coalition of Cancer Survivorship (NCCS) defined the individual as a cancer "survivor" from the point at which the disease is diagnosed

through the remaining course of the individual's life (The National Coalition for Cancer Survivorship, 2004). Cancer survivorship is furthered clarified by Doyle (2008) "it is a process beginning at diagnosis and involving uncertainty. It is a life changing experience with a duality of positive and negative aspects, and is unique to the individual but has some universality" (p. 500). Ongoing attention to survivorship care provides clients with a focus on hope and control in a potentially traumatizing circumstance.

The role of the nurse in the process of survivorship as educator and client advocate has also changed as improvements in treatment, care, prevention, and diagnosis have increased. Nurses have been able to initiate changes and provide much needed continuity of care. In addition, nursing research has achieved significant outcomes in patient education, cost-effectiveness of health care, and treatment adherence (Mick, 2008). This aspect has allowed evidenced based nursing interventions to be incorporated into clients' plans of care. The challenge of making a difference in the clients' lives after treatment has made this an opportunity for a mutually gratifying and rewarding nurse-client experience.

Fear of Unknown

Adjustment to life following treatment can be a disrupting time of transition and possibly a time of increased distress. A theme that consistently presents itself is the feeling of loss of a safety net. While receiving treatment clients are actively doing something about the disease process (Costanzo, et al., 2007). With the end of treatment clients may experience a sense of loss of control; not only by clients but also by members of the client support systems. Clients may report that after treatment they expected her life to go back to "normal". Expectations that hair should magically be all grown out,

energy levels automatically increased and the capability to return to work at the precancer state are not entirely unique findings.

According to Mellon, Kershaw, Northouse, and Freeman-Gibb (2007) factors that have an impact on the degree of fear of recurrence included the level of concurrent family stressors and the person's own perception of the meaning of cancer. A client with a high degree of family stress and a negative perception of the cancer experience may affect susceptibility to long-term distress in survivors and their family members. In fact, many cancer survivors have reported symptoms similar to a post traumatic stress syndrome. Hodgkinson, et al., (2007) studied 199 survivors from gynecologic cancer and found "about one-fifth (19%) reported symptoms that indicated posttraumatic stress disorder (PTSD) and this rose to close to one-third (29%) for survivors of advanced stage disease" (p. 381). Interestingly, years since diagnosis was not related to distress or need levels. Clearly, this level of PTSD means clients should have education concerning typical feelings post treatment and actions individuals should consider to enhance control and alleviate fears cancer survivors may experience.

Physical Activity

Within recent years physical activity has been studied to determine its impact on the cancer continuum. In particular, it has been found that physical activity may help cancer survivors accelerate the recovery process and lessen acute effects of treatments. Furthermore, research suggested that physical activity interventions may reduce the risk of developing new cancers, prevent recurrence, and improve the health of long-term cancer survivors (Courneya & Friedenreich, 2007). There is also some evidence to support positive effects of self management programs and self-efficacy enhancing

programs on health outcomes. Positive effects were found on aerobic capacity although findings were ambiguous in terms of effects on fatigue. This may have been due to inconsistent defintions of fatigue and physical role functions (Van Weert, Hoekstra-Weebers, May, Korstjens, & Van der Schans, 2008).

Physical activity not only strengthens the body but can positively influence the mind. According to Ingram and Visovsky (2007) endurance training provided protection against cancer by increasing macrophage and natural killer-cell cytotoxic activity. Preliminary evidence also suggested that exercise may prolong survival for individuals with breast, prostate, and colon cancer. In addition, increasing physical activity has been linked to lower levels of circulating estrogen in women with breast cancer, and may lead to improved survival due to decreased estrogen levels.

Gordon (2008) found "exercise allowed her to enter the survivorship stage and see past the statistics, the words, and the forecasts....with a cancer-free mind anything is possible" (p. 216). Therefore, nurse educators should appreciate the importance of establishing an individualized activity plan to fortify clients in mind and body in the fight against cancer.

Psychosocial Support

Cancer survivors need support during the post treatment phase of the cancer journey. Anxiety, denial, loss, fear, difficulty with activities of daily living, and adjusting to work or school are just some of the possible problems post-treatment clients may encounter. Owen, et al. (2007) reported "Health related support groups are used by nearly 1 in 4 cancer survivors, but levels of use differ across subgroups. Assistance in identifying and accessing support groups should be a standard of care for all patients

receiving curative, follow-up or palliative care" (p. 2588). If clients are not referred to the appropriate sources their unresolved psychosocial problems may impact the clients' quality of life.

Multiple resources are available to cancer survivors. In effect, the issue is not the deficiency of resources but lack of proper guidance to access these resources.

Consequently, a systematic method individualized to meet client needs should be employed (McNeil, 2008).

Nurses can play a vital role in providing psychosocial care. One key is direction from health care professionals in terms of access to the multiple resources available. Clients are oftentimes overwhelmed by information or too anxious to know what to read, ask, or believe. This is where nurses can be integral to the supportive process by an individualized one-on-one teaching session at the completion of treatment. Similar to discharge teaching done when patients go home from the hospital, a packet of information and instruction sheet should be given to cancer clients. A follow-up call from the nurse at the clinic would also be beneficial. In conclusion, cancer survivors reported satisfaction with post treatment medical care, but not psychosocial care. Survivors have expressed enthusiastic support for receipt of a written follow-up care plan (Hewitt, Bamundo, Day & Harvey, 2007).

No Specific Standards

Cancer survivors are often lost to systematic follow-up within the health care system and opportunities such as teaching at the end of treatment are missed. Many women finish their primary treatment for cancer unaware of their heightened health risk

and ill-prepared to manage future needs. Furthermore, psychosocial needs are not addressed (Hewitt, 2005).

During active treatment survivors felt there was a plan in place, and they knew what to do and what to expect. Once active care was over, however, they did not know what to do or what to expect, and some felt they were not being cared for. Most nurses reported informal activities (conversations after treatment about the critical importance of follow-up, plans for surveillance, and the schedule for visits) in describing current survivorship care practices but acknowledged that there is no formalized approach to the post treatment transition period. (Hewitt, Bamundo, Day & Harvey, 2007).

Sexuality

Sexuality is a deep, pervasive, and integral aspect of the total human personality (Fogel & Lauver, 1990). As identified in Greenwald and McCorkle (2008) several studies have demonstrated significant challenges in the areas of sexuality and sexual function for female cancer survivors. This includes loss of interest in sex, pain associated with sex, a generally worsened sexual life, and reduced feelings of feminnity. There are also reported challenges for survivors in terms of sexual functioning, childbearing, and marital relations.

Sexual dysfunction is the most common long-term consequence of cancer treatment, affecting 50% of survivors of breast, gynecologic and many other cancers (National Cancer Institute, 2004). Stilos, Doyle and Daines (2008) reviewed factors oncology nurses should consider in addressing sexual issues. The acknowledgement of patients' and their partners sexual issues as unique, the need to make patients feel open to

discussing sexual concerns and evaluate interventions was concluded. This study also stated:

Healthcare professionals should emphasize that it is common to experience changes in sexuality and that these changes may threaten identity and self-esteem Addressing the issues in a tailored and patient-specific manner will allow healthcare professionals to understand what each patient and partner experience, what issues matter to them, and how to improve their sexual health. (Stilos, Doyle & Daines, 2008,p. 461)

Nurses should have a comfort level when addressing sexual concerns of female cancer survivors. Interestingly, it has been reported in several studies that nurses are uncomfortable and do not meet the needs related to answering questions related to sexuality (Stilos, Doyle & Daines, 2008; Sheppard & Ely, 2008).

Cancer Recovery Programs

Utilization of a cancer rehabilitation program has been implemented and is becoming a more popular concept in the provision of follow-up care. According to Korstjens, Mesters, Gijsen, and Van Den Borne (2007) their cancer rehabilitation program incorporating physical training, psychosocial sessions and patient-to-patient contacts provided a powerful and supportive combination. A nationwide survey of the status of cancer rehabilitation programs was also completed in Japan. Based on their survey results it was found that strategies to popularize these programs especially geared to the needs of cancer patients should be considered (Hamaguchi, et al., 2008).

Cancer rehabilitation programs could offer an avenue for a systematic approach to providing follow-up care. Innovative ways could be offered to bring multidisciplinary

groups together and ensure cancer client needs are met. Members of multidiscplinary groups could include the oncologist, nurse, physical therapist, occupational therapist, psychologist, and social worker. Items to include would be psychosocial care, signs and symptoms in regards to the disease process, long term effects from radiation or chemotherapy, physical activity needs, prevention of second cancers, and nutritional concerns.

Shulman et al. (2009) discussed care of cancer survivors and questioned the ability of the healthcare system to meet the needs of cancer survivors. It was emphasized that female cancer survivors completing treatment should be provided with a comprehensive care summary. This "Survivorship Care Plan" could be reviewed with a patient during a formal discharge consultation. Oncology nurses could play a key role in this process (Hewitt, 2005). Further, the Institute of Medicine has convened several committees and workshops to examine the gaps which currently exist in care of survivors. Innovative care models for cancer survivors are currently being developed and tested in a few cancer centers across the country. The use of these models may provide assistance in meeting the needs of female cancer survivors. Each of these include a survivorship visit with a physician extender (nurse practitioner, physician assistant or registered nurse) at the end of active treatment focused on developing and discussing a formal end-of-treatment summary and follow-up care plan developed for cancer survivors (Shulman et al., 2009).

Theoretical Framework

A synthesis of the literature suggested an adaptation to Maslow's hierarchy of needs as proposed by Abraham Harold Maslow in "Toward a Psychology of Being"

(1962). Figure 1. Oncology Nurse Perceptions of Educational Needs Model depicts a representation of oncology nurse perceptions related to female cancer survivor educational needs. Consideration of both female cancer survivor physical and psychological aspects can be instrumental in providing a holistic view in meeting educational needs. Maslow's theory suggested beginning at the physiologic level of basic human needs whereby once those needs are fulfilled individuals progress to the next higher level. At the completion of treatment oncology nurses must determine individual needs of female cancer survivors and capitalize on this assessment to provide teaching that is both meaningful and pertinent. This assessment is an interactive process that begins on the basic physiologic level and then builds in a forward moving direction as oncology nurses perceive the needs of female cancer survivors in a dynamic, everchanging manner. Nurses are challenged with identifying needs at each level with the knowledge that nurses may need to review needs at a lower level as determined by individual female cancer survivors' experiences. Thus, from these concepts put forward by Maslow oncology nurses can give quality care by seeing that every possible level in this process is at least partially met.

Physiologic needs reflect the need to maintain adequate physiological balance that will always be essential (Preston, 2009). Female cancer survivors must resolve these most basic needs at least partially before moving on to more complex needs. Perceptions of needs related to usual health care practices is crucial as part of the process of assisting the survivor in adaptation to a new role. Assessment of survivors' level of knowledge of nutrition, importance of hydration and need for physical exercise should also be emphasized. Oncology nurse perceptions of female cancer survivors comfort with

sexuality should also be determined. Comfort with sexuality includes addressing such areas as sexual functioning, childbearing issues, marital relations and treatment consequences onsexual health. Issues regarding sexuality must be recognized especially in the sense that unless concerns are at least partially met female cancer survivors cannot move on to the next higher level. Needs related to pain management must also be evaluated. Individuals who are in pain at treatment completion may not be in a state of readiness to learn and this may ultimately interfere with the teaching learning process.

The next level, according to Maslow, is safety and security. Maslow considers this process to be a never ending series of free choice situations, confronting each individual at every point throughout life in which choices must be made between delights of safety and growth, dependences and independence, regression and progression, immaturity and maturity. Safety has both anxieties and delights. Growth occurs when the delights of growth and anxieties of safety are greater than the anxieties of growth and delights of safety (Maslow, 1962). Consequently, oncology nurse awareness of female cancer survivors' level of stress and anxieties and delights of growth and safety has an impact on meeting educational needs. Female cancer survivors may question what's next after treatment is done and have feelings of insecurity related to completion of treatment. Evaluation of fear of the unknown with treatment completion and assessment of possible feelings and reactions at the end of treatment should help female cancer survivors in alleviation of feelings of insecurity. In addition, assessment of female cancer survivors' delights of growth and anxieties of safety greater than anxieties of growth and delights of safety should enable the nurse in moving female cancer survivors in the direction of growth and a resulting sense of safety.

Love and belonging needs include assessment of family role, relationships, feelings concerning a sense of belonging and acceptance, body image changes, and need for support/recovery groups. While perceptions of needs in this area are crucial so too are nurses' aptitudes to appraise female cancer survivors esteem needs concerning their abilities to control their own destiny by making choices and assessment of survivor skill in functioning in an environment where there may be lack of respect or ill treatment at a job or by family members. At all times, nurses should consider female cancer survivors' feelings and needs regarding privacy, dignity, and self-respect. Questions regarding feelings of self worth and dignity should highlight pertinent areas of concern of female cancer survivors.

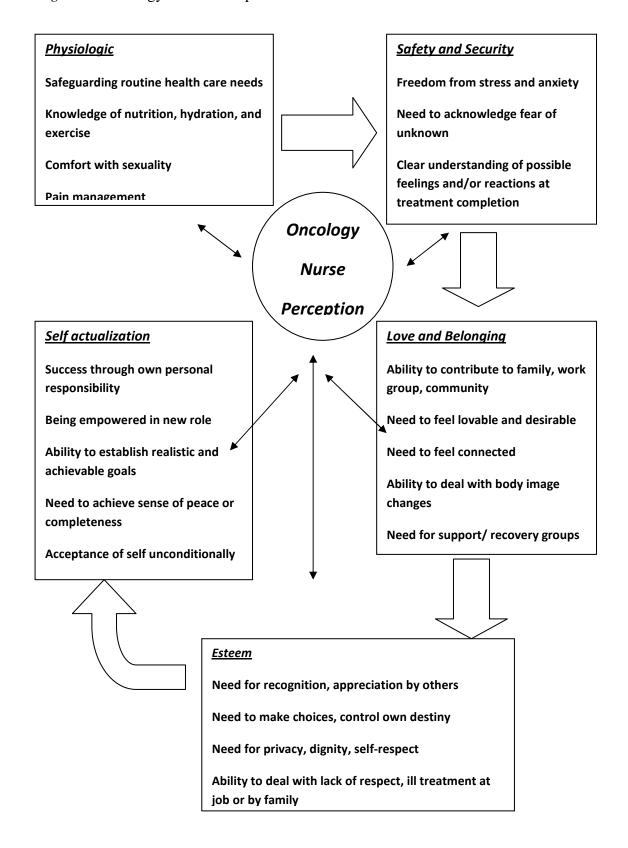
According to Maslow, self actualization is reaching one's highest potential. To reach this level some satisfaction of the first four needs must be achieved. Further, he defines behaviors leading to self-actualization to include:

- 1. Experiencing fully, vividly, selflessly, with full concentration and total absorption
- 2. Life is process of choices toward growth or toward defense, toward not being afraid.
- 3. An individual must listen to impulse voice and let self emerge.
- 4. A person must take responsibility and be honest
- 5. Listen to one's own self and make best choice
- 6. Self actualization is not only an end state but also the process of actualizing one's potentialities at any time, in any amount.
- 7. Peak experiences are transient moments of self-actualization (Maslow, 1971).

Oncology nurses' perceptions of female cancer survivors' discovery of meaning in the experience of having cancer must be determined. Assessment of

survivors' sense of empowerment now that treatment is completed should be evaluated. At this level statements and behaviors of female cancer survivors should also reflect an achievement of a sense of peace or completeness and an acceptance of their life at this point in time. Open expression of thoughts and feelings by female cancer survivors will enable them to have a sense of control and a true sense of self should emerge. Realization that life is a process of choices and responsibilities toward growth should assist in the process of self-actualization.

Figure 1. Oncology Nurse Perceptions of Educational Needs Model



CHAPTER III

METHODS AND PROCEDURES

Research Design

This qualitative phenomenological study explored oncology nurses' perceptions of educational needs of female cancer survivors post treatment. It is important to understand educational needs of female cancer survivors after survivors have completed all treatments. In this study, a phenomenological design was used to describe what perceptions study participants may have in common to answer the following research question: "What are perceptions of oncology nurses' regarding educational needs of female cancer survivor post treatment?"

Data Collection

To fulfill the requirement of the Institutional Review Board (IRB) of College of Saint Mary, the researcher completed the web-based training course "Protecting Human Research Participants" accessed from the National Institute of Health website http://phrp.nihtraining.com/users/olgin.php (See Appendix A). Following IRB approval at College of Saint Mary (IRB #CSM 08-91) the researcher sent invitation flyers to recruit volunteers to participate. The pool of potential participants came from utilizing the snowball or chain type of sampling. This consisted of identifying cases of interest from people who know people who know what cases are information-rich (Creswell, 2007). A registered nurse in the field of oncology was invited to volunteer to participate and share flyers or study information with like participants. Participants were employed in a Midwest health care setting. The study was conducted in a reserved, private area on a Midwest college campus scheduled at the convenience of the participants. Characteristics

of participants consisted of oncology registered nurses with a minimum of three years of experience actively employed in an oncology health care setting. A consent form was signed prior to beginning the interview. The researcher was present to answer any questions regarding the study, the consent form, or any of the participants' rights (See Appendix B).

The researcher assigned a number to each participant interviewed and the number was used to identify audiotapes. No other person had access to information listing names or other identifying information. At no time did the participant's name appear on the audiotape or transcript which upheld privacy. After original transcripts were compared to audiotapes, the researcher returned transcripts to participants to member check validity and accuracy of content.

Participants were interviewed for an average of 20-40 minutes. Interviews were tape recorded utilizing open-ended questions. Participants were available for follow-up interviews. See attached sample of interview questionnaire (See Appendix C).

Identification of Study Participants

A purposive sample of 10 oncology registered nurses with a minimum of three years experience actively employed in an oncology setting were asked to participate in this study. At the time of the study participants were employed in a Midwest health care setting.

Instrument

The interview questionnaire was developed by the researcher and approved by the researcher's committee. The questionnaire consisted of eight to ten open-ended questions designed to answer the research question "What are perceptions of the oncology nurse of

educational needs of female cancer survivor post treatment"? (See Appendix C).

Demographic data was also gathered to include gender, age, years of practice as an oncology registered nurse, health care setting, certification and educational preparation (See Table 1 *Attributes of Nurses*).

Ethical Consideration

Reasonable steps were taken to protect privacy and confidentiality of study data. The only persons who had access to research records were study personnel. Identity was kept strictly confidential. All qualifying participants freely decided whether or not to take part in the research. They were given the opportunity to decide not to be in the research, or to stop participating in the research at any time. Participants were then given a consent form that had been approved by the IRB of College of Saint Mary. A signed consent form was obtained from each participant before beginning the interview. The consent form indicated the study will identify oncology nurses' perceptions of educational needs of female cancer survivors post treatment. In addition, the consent form indicated why the participant qualified for this study and reassurance that all responses would remain anonymous. Each participant was given a copy of *The Rights of Research Participants* along with the consent form (See Appendix B).

The interview did not collect names or other individual identifiers and there were no data sets in which individual identifiers could be extracted. There was no connection between individual participants and their responses. Confidentiality of participants was maintained by storing the hard copy transcripts and audio tapes in a secure, locked cabinet. Audio tapes were destroyed after analysis of data. Transcriptions may be utilized for future analysis by researcher.

Data Analysis

A phenomenological approach was used for data analysis. As described by to Creswell (2007) it is the means of recording significant statements and meanings, and the development of descriptions to arrive at the essences of the experiences. Tape-recorded interviews were transcribed verbatim by a third party and interviews were analyzed for significant statements, textural, and structural descriptions according to qualitative methodology. Comparative analysis guided the data collection process, as significant information obtained during the interviews was clustered into common themes.

In phenomenological research, an accurate and meaningful depiction of the "lived" experience of participants is desired. The researcher, a cancer survivor and registered nurse had a vested interest in having post treatment education that is timely and pertinent so quality care may be provided to female cancer survivors. Further, in order to avoid any personal preconceptions, biases, and assumptions regarding the phenomenon under investigation the researcher utilized reflexivity and bracketing. Polit et al. (2010) stated:

Bracketing refers to the process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon under study. Although bracketing can never be achieved totally, researchers strive to bracket out any presuppositions in an effort to confront the data in pure form. Intuiting occurs when the researcher remains open to the meanings attributed to the phenomenon by those who have experienced it. (p. 268)

During the study, the researcher kept a journal and wrote down feelings, preconceptions, concerns, questions, and assumptions held about the study. The researcher's personal opinions were held in abeyance and set aside while interviewing participants and analyzing findings. This limited possible bias and increased objectivity. Multiple methods of data collection to include interviews, field notes, and observation of participant behaviors and interpretation of data about the phenomenon assisted in convergence on an accurate representation of reality (Polit, 2010). Transcripts were member-checked for accuracy. Horizonalization was accomplished by treating all data with equal importance (Creswell, 2007).

NVivo software (Qualitative Software International, 2008) was used to organize coding by marking and collecting significant statements into themes as tree nodes. Transcript dialogue was organized as child nodes within tree node hierarchy and was linked to corresponding tree nodes which were meaningful units. As well as identifying common themes NVivo software was utilized to determine saturation of identified themes. Validation was done by multiple methods of data collection, data analysis and coding using NVivo, member–checks for accuracy of interview information, review of documents, peer debriefing, and an audit trail.

CHAPTER IV

RESULTS

Introduction

In order to address the educational needs of female cancer survivors post treatment an analysis of oncology nurse perceptions was completed. Oncology nurses are the most likely health care provider available for teaching at this pivotal point in the cancer treatment process. Utilizing in-depth interviews with ten oncology nurses, the researcher sought to describe oncology nurse perceptions of significant aspects of educational needs. The content analysis assessed data from interviews, observations and field notes to determine what the researcher had seen, heard, and read.

Utilizing NVivo software verbatim transcripts from nurse interviews were visually coded (Richards, 1999). The researcher also kept field notes which were added as memo links. Attributes of the interviewees are listed in Table 1.

Table 1
Attributes of Nurses

	Years of practice	Gender	Age	Educational Preparation	Oncology Nurse Certified	Health Care Setting
Interview 1	4	Female	40	BSN	Yes	Hospital
Interview 2	7	Female	42	BSN	Yes	Clinic
Interview 3	16	Female	46	Diploma	Yes	Hospital
Interview 4	16	Female	38	MSN	No	Clinic/Home Care
Interview 5	17	Female	37	BSN	Yes	Clinic
Interview 6	20	Female	53	BSN	Yes	Clinic
Interview 7	27.5	Female	49	BSN	Yes	Clinic
Interview 8	13	Female	36	NP	Yes	Clinic
Interview 9	17	Female	37	ASN	*No	Clinic
Interview 10	20	Female	50	BSN	Yes	Clinic

^{*}Certification exam taken post interview

All of the nurses were female in the age range of 36 to 53 years old. Most of the nurses had their oncology nurse certification except one who was scheduled to take the certification exam post interview and one who did not have oncology nurse certification. The years of practice ranged from four to twenty-seven and one-half. Educational preparation ranged from Diploma, ASN (Associate of Science in Nursing), BSN (Bachelor of Science in Nursing), MSN (Master of Science in Nursing) and NP (Nurse Practitioner).

Results and Data Analysis

Visual coding was accomplished by reading and rereading transcripts, identifying data passages that belonged to categories and creating tree nodes as well as child nodes. The process led to a discovery of significant themes coded as tree nodes, which provided rich descriptions of each unique theme. Each theme was described and illustrated with quotes in the following sections. Table 2 *Tree Nodes as Themes from Nurse Interviews*

show the number of nodes coded as themes for each interviewee and whether memo links or field notes were linked to the nodes. All themes were referenced in the interviews of more than half of the nurses and the number of significant passages ranged from 43 down to 15.

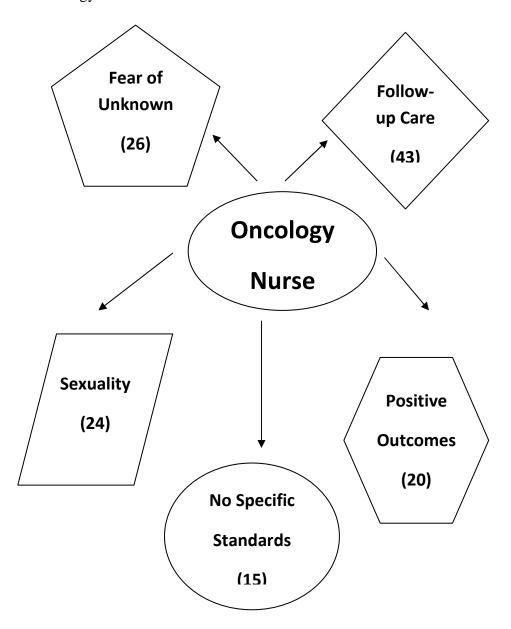
Oncology nurses perceived positive outcomes related to meeting the educational needs of female cancer survivors. Nurses realized a major priority of addressing follow-up care to include such things as yearly physicals, mammograms and referral to resources. Many of the nurses identified there were no specific standards related to educating female cancer survivors. The need to address possible concerns related to sexuality and female cancer survivors' concern of fear of unknown with treatment completion were also identified.

Table 2
Tree Nodes as Themes from Interviews

Туре	Name	Memo Link	Sources	References
Tree Node	Follow up Care-Orange	Yes	10	43
Tree Node	Fear of Unknown-Green		8	26
Tree Node	Sexuality-Blue	Yes	9	24
Tree Node	Positive Outcomes-Red		10	20
Tree Node	No specific standards-Pink	Yes	7	15

Qualitative analysis offered insights into perceptions of the oncology nurse related to educational needs of female cancer survivors. From thorough interviews, five themes emerged and are illustrated in *Figure 2*. Oncology Nurse Interview Themes. The five themes are represented in the model and different shapes represent a new different theme.

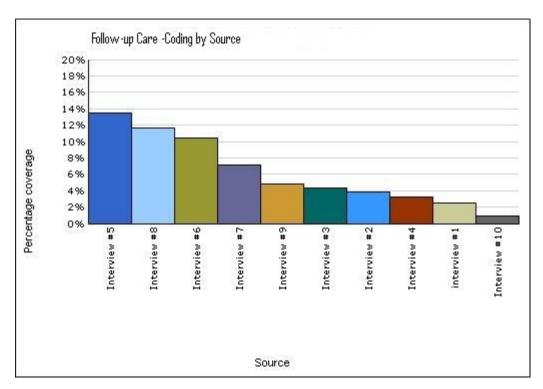
Figure 2. Oncology Nurse Interview Themes



Theme 1: Follow-up Care

The theme with the most number of significant interview passages (43) was follow-up care post treatment. The nurses emphasized the importance of keeping appointments and utilizing resources available for support after treatment is completed. *Figure 3: Percent Interview Coverage-Follow-up Care* represented the percent of each nurse's interview related to follow-up care with female cancer survivors. Both interview # 5 and Interview # 8 worked in a clinic setting and were educated at a minimum of a baccalaureate in Nursing. All ten nurses made comments on aspects of follow-up care they deemed important in the educational process. Nurses who worked in a hospital setting viewed follow-up care at 4.3% and 2.6% respectively. The nurse who worked in a bone marrow transplant unit stated "they follow their patients for their lifetime".





The percent of dialog ranged from 11.7% down to 0.96%. Interview # 5 had the largest percent and shared:

They will need education on and how to deal and cope with their specific treatments or follow up things that they can do and be referred to and then also I think another thing that we try to give teaching on post treatment is the stuff that the doctor usually does but we try to reinforce their follow up check up exam.

She also said:

It's important to follow-up and do that. Then the other things I would say for them is their mammograms, their gynecological exams, keep up on doing that along with the healthy lifestyle and give them a time frame. Let them know, okay, this is how often that we want you to do that and let them know those times and usually that has been scheduled by the doctor.

Interview #8 with 11.7% coverage talking about follow-up care said:

But I think that we do a pretty good job when we see them each time they come in for follow up letting them know that, okay, you're going to need a mammogram at sometimes six months, sometimes annually, whether or not they need a MRI. Those screening tests, you know, I feel like, when they come into the clinic we can kind of help take care of that and educate them as they're going through their follow-up.

And later:

Just educating them on what to look for, the signs of recurrence, when to come into the doctor's office, how important it is, how very important it is that they take the therapy that we prescribe them, the pills as part of their regimen. And then just getting them tapped into various organizations.

Theme 2: Fear of Unknown

The nurses perceived the next important aspect of education as the need to address the concern of fear of the unknown now that treatment was done. The nurses saw female cancer survivors as individuals who need nurses to discuss their fears and concerns as they enter a new status as one nurse referred to as the "new normal". In *Figure 4. Fear of Unknown* eight of the ten nurses commented on fears related to treatment completion. The percent dialog ranged from 22% to 3.2%. Interview #2 related the importance of addressing this theme and was the largest amount any nurse talked about any one theme. The nurse commented:

I think it's a mixture of huge relief that it's over versus the excitement versus kind the fear of the unknown. What's to come forward because you're living on such a schedule, and our schedule, I guess you are living by our schedule, and now all of a sudden it's just kind of over. So, I guess that's it.

She also said:

I ran into one of my old patients post-treatment, probably four months post-treatment or five months post-treatment and she says, "You know..." Cause I said you know, you look great, you are feeling great and she says, "You know, that was probably the second scariest time of my life is walking out of that treatment center not that it wasn't a happy time because she was done with the chemo but she said it was very scary almost as scary as starting treatment because she thought "well now what?"

Field notes related to Interview #2 revealed that the nurse appeared comfortable and answered questions easily without hesitation.

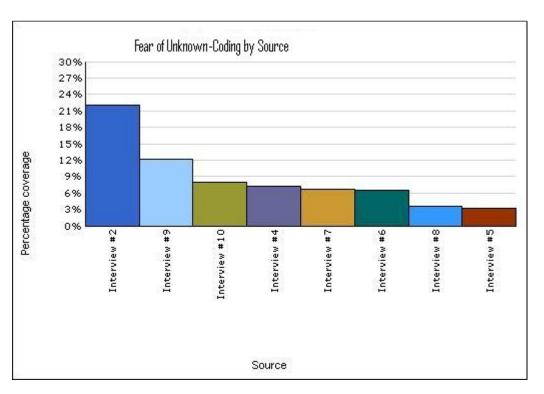


Figure 4. Fear of Unknown

Interview #9 at 8.2% dialog stated:

Scared to death. Their educational needs...they need a lot of support towards the end because they are afraid, um, they don't have that comfort of coming in and having us look at their blood counts and going over things.

And:

In the next few weeks because it's fear of the unknown. Okay, I've been going to treatment and getting my questions answered all of the time. Now what?

Interview # 10 at 5.8% stated:

They're ecstatic about being done but they're a little fearful because they it's kind of like as much as they didn't look forward to coming to get treated there is a kind of camaraderie that's built up with the nursing staff and the patients that they get to see on the day that they come for treatment. Some of it's a little bit of fear that they have.

Theme 3: Sexuality

Nine out of ten interviews mentioned addressing sexuality in their teaching to female cancer survivors. One nurse stated that "I think they feel comfortable talking to (the nurse) I think are the sexual issues. Maybe we'll get those before the regular physicians." All nurses interviewed were female.

Interview #9 at 10% coverage stated:

Just about body image you know especially with breast cancer survivors or you know ovarian cancers just talk about you know need for lubrication and just those kind of things that people don't want to talk about don't want to ask about but need to be mentioned and you know a lot of them just need reassurance that it's okay to have a normal sexual life after chemotherapy and so that's important.

Interview # 6 at 7.8% coverage stated:

You know the sexuality, that they're young and use contraceptives and that avenue, um, you know mostly just keeping their appointments and that support. Their follow up appointments especially if they still have their access device port in place, um, that's just it.

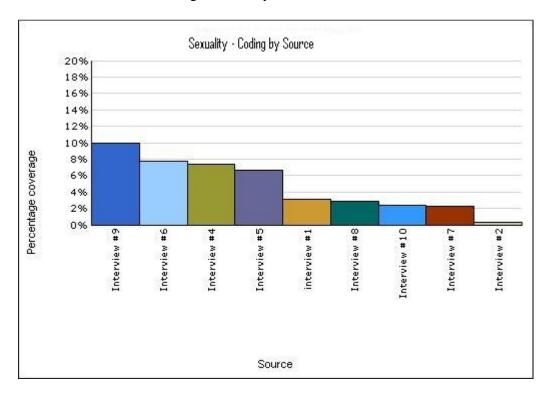


Figure 5. Percent Interview Coverage-Sexuality

Theme 4: Positive Outcomes of Meeting Educational Needs

The next tree node reference was Positive Outcomes of Meeting Educational Needs which is *Figure 6: Percent Interview Coverage-Positive Outcomes of Meeting Educational Needs* and had 20 references. All nurses expressed positive outcomes related to meeting educational needs of female cancer survivors. Interview #9 at 10.3% had the most coverage and stated:

Putting the patient at ease. Giving them the knowledge to not have that fear of the unknown. That's the biggest thing. Hardest at the beginning and afterwards, yes, we need to make sure they need to understand that life will continue on and be okay.

And:

Just offering the support and finding those support groups that are appropriate for them and answering questions and reassurance. A lot of reassurance that it's okay to have questions and to get them answered. If we don't know we will find out.

Nurses recognized education was valued by the patient as one nurse stated "so you know they're the ones that will give you a hug at the end and thank you and they value your input as a nurse." And another comment by this nurse "they are thankful for any helpful education that you give them and so, to me that's great."

Field notes related to Interview #9 revealed that the nurse sat up and leaned forward when discussing positive outcomes for female cancer survivors and herself as a nurse.

Interview #4 with 6.4% commented:

I would want my patients to feel strong and confident and independent women again when they are done. And have all of the tools that they need to go on being successful after they leave the treatment area.

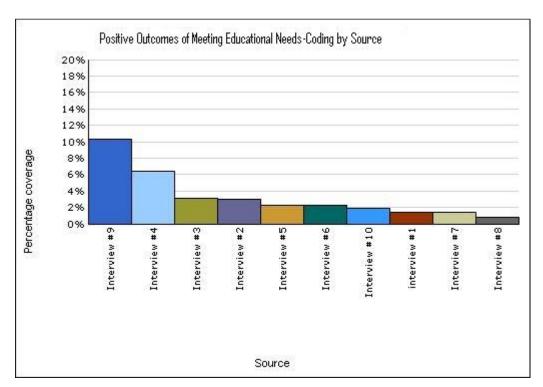


Figure 6. Percent Interview Coverage - Positive Outcomes of Meeting Educational Needs

Theme 5: No Specific Standards

The next tree node group for discussion was no specific standards with 15 references. *Figure 7*. Percent Interview Coverage-No Specific Standards, seven of the ten nurses discussed this theme and spent 10.3% to 1.2% of the interview on this theme.

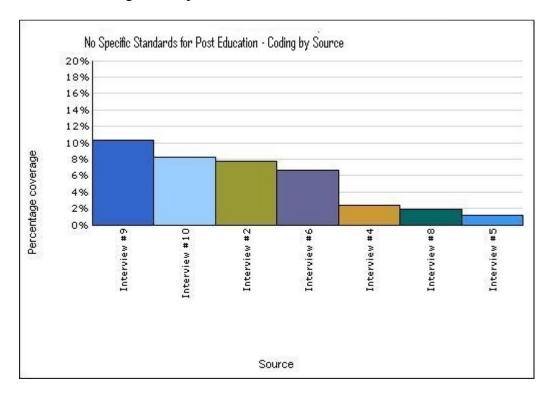


Figure 7. Percent Coverage - No Specific Standards

Interview # 9 had 10.3% of her dialog on no specific standards and said:

It's just making me think of how little education we have for them post treatment. That's what it's bringing to my mind is the actual resources, you know, when we begin treatment we have these handouts and we go through them and every little thing is discussed and I'm thinking that there is just not that much available that we do post teaching. Unfortunately.

Interview #10 had 8.2% on no specific standards and commented:

You know, we do a great job at the beginning with having people consent to treatment because we have to sit there and go through side effects and procedures and follow up, this is this week and this is how often you are going to be treated, this is what we look for when you come in on your off weeks or before you start the next round of

treatment, I think maybe if we could do a post exit interview or a post treatment evaluation we don't have any of that in place. And maybe that would have those women know that it's okay to ask questions at the end even though they do so badly want to be done that it's really okay and maybe it would help us make sure instead of second guessing what they need to know we would have a like a check list or a form or however you want to call it to make it work in that setting then we can make sure that we've addressed those needs because we don't have that in place. So we don't have a good follow up...

Interview #2 had 7.8% on no specific standards and said:

We do not have any specific standards for post education. The post education we give our patients is based on their questions to us and we don't have any standards for post treatment education.

And:

I mean these patients come in to ask for, you know, these life altering treatments and then we just, ok, it's your last treatment, bye, and they don't see us anymore.

Interview #6 had 6.6% on no specific standards and said:

In our office I know there's a sheet made for it. I think we try to do a good job up front trying to give them all the resources and the support group and I think when that ball drops they are just kind of hanging out there.

Results Summary

Results of this study indicate certain themes nurses perceived as important in meeting the educational needs of female cancer survivors. Particular emphasis was placed on encouragement of female cancer survivors to continue with routine physical care,

physician appointments, and use of resources. Discussion of female cancer survivors' fear of the unknown with treatment completion and issues related to sexuality were also identified. Positive outcomes for meeting educational needs of female cancer survivors were identified along with the realization by some nurses that no specific standards were available to meet female cancer survivors' educational needs.

Summary of Analysis

Follow-up care discussion with 43 references was the predominant theme that emerged from the qualitative analysis. All ten of the participants referred to this issue when discussing educational needs of female cancer survivors. The next two themes that emerged were identifying and discussing fear of the unknown with treatment completion with 26 references and issues of sexuality with 24 references. Positive outcomes of providing education with 20 references emerged as well as the theme of no specific standards regarding education post treatment with 15 references.

CHAPTER V

DISCUSSION AND SUMMARY

Introduction

This chapter will discuss the purpose of the study and the interpretation of results with correlation to the literature and the theoretical context. A comparison of research results with relevant literature and theoretical context will be offered to express the meanings and understandings of the lived experience of oncology nurse regarding educational needs of female cancer survivors post treatment. A discussion of limitations of this study and future research will follow.

Purpose of the Study

The purpose of this phenomenological qualitative study was to explore oncology nurses' perceptions of educational needs of female cancer survivors post treatment.

Research Question

The study was devoted to understanding the essence and meaning of the lived experiences of oncology nurses by examining this question: What are perceptions of oncology nurses' regarding educational needs of female cancer survivor post treatment?

Interpretation of Findings: Theoretical Context

An adaptation of Maslow's hierarchy of needs theory was utilized as the theoretical framework in this study. This adapted model provided a means for understanding educational needs of female cancer survivors. Findings suggest nurses perceive special needs at each level that can be identified for each individual. Oncology nurses are challenged to assess needs at each level while at the same time analyzing survivor needs and adapting care based on both input and feedback from female cancer

survivors. Questions on interview guides helped to vet out areas oncology nurses' perceived as critical in meeting educational needs.

Nurses' perceptions of physiologic needs reflected their realization of the importance of recognizing these basic needs as a priority. Nurses reported the necessity of reinforcing teaching concerning maintenance of routine health care issues such as yearly physicals, mammograms and use of available resources as critical to this domain. Nurses' perceptions regarding the importance of assessing sexuality needs was reflected in many of the statements oncology nurses made regarding meeting educational needs of female cancer survivors.

Safety and security is the next step in the growth process. The need to assess female cancer survivors' feelings of stress and anxiety along with fears of the unknown with treatment completion was met. Although the need to contribute to female cancer survivors' clear understanding of possible feelings and/or reactions at treatment completion is part of this level, oncology nurses' perceptions in this area are lacking. Further review of survivor issues in achieving delights of growth and anxieties of safety greater than anxieties of growth and delights of safety should be incorporated into an assessment of educational needs. Nurses should be encouraged to integrate instruction regarding symptoms of possible post traumatic stress syndrome in their evaluation of educational needs. Acknowledgement of fear of unknown post treatment and assessment of possible feelings and reactions at the end of treatment should assist in the alleviation of feelings of insecurity. In addition, assessment of cues and behaviors of female cancer survivors will provide data to determine an individualized teaching plan.

Nurses recognized the importance of survivors' need to feel connected and continue on with their life after treatment completion. Comments made by nurses regarding positive outcomes of education support this need. The importance of support and recovery groups was also addressed by oncology nurses as examples of various organizations and support groups available to survivors were mentioned during interviews. Finally, although not found to be a consistent theme in this study, body image changes is a key component in the educational assessment process at this level.

Nurses' ability to appreciate female cancer survivors' qualities of dignity and self-respect was demonstrated by their comments concerning benefits of caring for oncology patients. One statement by a nurse stood out when she said:

People want to know why I'm an oncology nurse. I think that our patients are grateful for the treatment and the help they get where it's not a chronic disease like heart problem for instance or even diabetes they're not happy, you know, their disease is lifelong and they're grumpy and they're not happy people. But oncology patients are just the opposite of that. They're thankful for the care they get and they can't wait to get going and get it over with and get it done so that they can live on the rest of their lives.

Accordingly, in Maslow's final level of self-actualization, female cancer survivors must come to terms with their new normal of life experience after treatment.

Oncology nurse perceptions regarding female cancer survivors' feelings and future goals needs further development. Nurses recognized some of the aspects of self-actualization but continued education of oncology nurses to integrate these concepts into their assessment would help female cancer survivors in meeting this last developmental level.

In conclusion, perceptions of what constitutes quality care in the context of post treatment experience and identification of unmet needs will help guide nursing actions.

Adequate teaching makes female cancer survivors more secure, can enhance feelings of belongingness and self-esteem, and provides the opportunity for self-actualization.

Interpretation of Findings: Relationship to Literature

Theme 1: Follow-up Care

If clients are not referred to the appropriate sources their unresolved psychosocial problems may impact life in many ways. Owen et al. (2007) reported the need for assistance in identifying and accessing support groups. This aspect was supported by the data derived from this study.

Although the positive relationship between success post treatment and physical activity was demonstrated in several studies this piece of information was not identified as part of a program for health maintenance by oncology nurses.

Theme 2: Fear of Unknown

Results demonstrate a relationship between finishing treatment and a consequential fear of the unknown. Oncology nurses' in this study perceived fear of the unknown as a true concern of female cancer survivors post treatment. Literature supports this aspect as stated in Costanzo et al. (2007) which discusses an individual's loss of a safety net of cancer treatment.

Theme 3: Sexuality

Perceptions of oncology nurses related to the theme of sexuality are confirmed in the literature. Sexual dysfunction is the most common long-term consequence of cancer treatment, affecting 50% of survivors of breast, gynecological and many other cancers (National Cancer Institute, 2004). Stilos, Doyle and Daines (2008) in their article about addressing the sexual health needs of patients with gynecologic cancers also supported nurses' viewpoints evidenced from statements in interviews.

Although literature findings indicate oncology nurses have difficulty addressing sexual concerns, nurses in this study realized the significance of meeting this educational need and identified this area as a critical component of teaching.

Theme 4: Positive Outcomes

The theme of positive outcomes of meeting educational needs was supported in the literature as beneficial to both nurses and female cancer survivors. As identified in Hewitt, Bamundo, Day, and Harvey (2007) survivors have expressed enthusiastic support for receipt of a written follow-up care plan. The primary goal of many cancer support services is empowerment of persons with cancer by educating them about cancer and treatment. An indirect goal is helping survivors adapt to living with cancer, provision of social and emotional support to find purpose and meaning within the context of living with cancer (Coward, 2006). Nurses can perform a vital role in this process.

Theme 5: No Specific Standards

As evidenced in the literature oncology nurses in this study confirmed the lack of post treatment formalized standards of instruction for female cancer survivors. As found in Hewitt et al., (2007) nurses acknowledged that there is no formalized approach to post

treatment transition period. Oncology nurses recognized their role in providing a standardized format as an area that needs attention. As one nurse stated:

It's just making me think of how little education we have for them post treatment. That's what it's bringing to my mind is the actual resources, you know, when we begin treatment we have these handouts and we go through them and every little thing is discussed and I'm thinking that there is just not that much available that we do post teaching. Unfortunately.

Limitations of Study

In the current study, oncology nurses were interviewed from one Midwest geographical setting. Interviews with nurses in other geographical areas may provide further insight into educational needs of female cancer survivors. In addition, practices and resources available to patients in other areas may vary so current findings may not be transferable to other settings.

Future Research

If oncology nurses are to understand more fully the relationship between educational needs and female cancer survivors' experience post treatment further research is required. Continued qualitative research which focuses on impact of post treatment education on female cancer survivors' experience would be illuminative and assist in filling the present gap in holistic care. It is also proposed that in-depth qualitative studies of perceptions of educational needs from female cancer survivors' perspective should also be undertaken. Moreover, research related to the impact of "culture" of clinical environments and the effect on meeting educational needs should be examined.

Research on the effectiveness of oncology nurses as teachers would also be an area for further investigation.

Another implication for future research is to investigate effective development of survivorship care plans or programs. As Travis and Yahalom (2008) indicated we have entered an era of the "problem of success" due to the many new treatments and management strategies that have resulted in improvements in survival. Therefore, individualized care plans and programs should be utilized with every cancer survivor.

Summary

This study has demonstrated the concept of reviewing oncology nurse perceptions is worthy of further investigation. Findings indicate standardized effective strategies should be established. Also, insights gained will enable a holistic picture of female cancer survivors' experience. The challenge for those concerned with optimizing care of female cancer survivors' post treatment teaching is to continue to identify and understand the relationship between post treatment education and female cancer survivors' experience in coping with cancer.

References

- Alfano, C. M. & Rowland, J. H. (2006) Recovery issues in cancer survivorship: A new challenge for supportive care. *The Cancer Journal*, 12(5), 432-443.
- American Cancer Society. (2006). Cancer facts and figures 2006. Atlanta, GA: Author.
- Bryant, M. T. (2004). *The portable dissertation advisor*. Thousand Oaks, CA: Sage Publications.
- Costanzo, E., Lutgendorf, S., Mattes, M., Trehan, S., Robinson, C., Tewfik, F., et al. (2007). Adjusting to life after treatment: distress and quality of life following treatment for breast cancer. *British Journal of Cancer*, 97(12), 1625-1631.
- Courneya, K. S., & Friedenreich, C. M. (2007). Physical activity and cancer control. 23(4), 242-252.
- Coward, D. D. (2006). Supporting health promotion in adults with cancer. *Family & Community Health*, 29(1S), 52S-60S.
- Creswell, J. (2007). *Qualitative inquiry & research design choosing among five* approaches. (2nd Ed.). Thousand Oaks, CA: Sage Publications.
- Doyle, N. (2008). Cancer survivorship: Evolutionary concept analysis. *Journal of Advanced Nursing*, 62(4), 499-509.
- Eastman, P. (2006, November 10). Templates now being designed for cancer survivors' follow-up care. *Cancer Survivorship Research Conference*, 10-13.
- Ellsworth-Wolk, J., Dunson, S., & Pratt, D. (2007). Development and implementation of a cancer rehabilitation/wellness program at a community cancer center. *Oncology Nursing Forum*, 34(2), 505.

- Fogel, C. I., & Lauver, D. *Sexual health promotion*. Philadelphia, PA: WB Saunders, 1990.
- Ganz, P. A. & Hahn, E. E. (2009). Implementing a survivorship care plan for patients with breast cancer. *Journal of Clinical Oncology*, 26 (5), 759-767.
- Gordon, S. (2008). Exercising and surviving: My cancer journey. *Urologic Oncology:*Seminars and Original Investigations, 26, 215-216.
- Greenwald, H. P., & McCorkle, R. M. (2008). Sexuality and sexual Function in long-term survivors of cervical cancer. *Journal of Women's Health*, 17(6), 955-963.
- Hamaguchi, T., Hitoshi, O. N., Abe, Y., Umezawa, S., Kurihara, M., Nakaya, K., Yomiya, K., & Uchitomi, Y. (2008). Survey of the current status of cancer rehabilitation in Japan. *Diability and Rehabilitation*, 30(7), 559-564.
- Hart, J. (2007). Addressing the psychosocial needs of cancer survivors. *Alternative & Complementary Therapies*, August, 183-186.
- Hewitt, M., Greenfield, S., & Stovall, E., (2005). *Cancer patient to cancer survivor: Lost in transition*. National Academies Press.
- Hewitt, M. E., Bamundo, A., Day, R., & Havrvey, C. (2007). Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *Journal of Clinical Oncology*, 25(16), 2270-2273.
- Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G. E., Stenlake, A., Hobbs, K. M., Brand,
 A., & Wain, G. (2007). Long-term survival from gynecologic cancer:
 Psychosocial outcomes, supportive care needs and positive outcomes.
 Gynecologic Oncology, 104, 381-389.

- Hogan, M. (2007). Survivorship care plans: Moving ahead with new templates. *Oncology Times*, 29(13), 19-20.
- Hunter, E. (2008). The legacy of cancer: The importance of passing on beliefs, values and positive health behaviors for women with cancer. *Journal of Psychosocial Oncology*, 26(1), 101-121.
- Ingram, C., & Visovsky, C. (2007). Exercise intervention to modify physiologic risk factors in cancer survivors. *Seminars in Oncology Nursing*, 23(4), 275-284.
- Korstjens, I., Mesters, I., Gijsen, B., & Van Den Borne, B. (2007). Cancer patients' view on rehabilitation and quality of life: A programme. *European Journal of Cancer Care*, 17(3), 290-297.
- Kwekkeboom, K. L., & Seng, J. S., (2002). Recognizing and responding to post-traumatic stress disorder in people with cancer. *Oncology Nursing Forum*, 29(4), 643-650.
- Madden, J. (2006). The problem of distress in patients with cancer: More effective assessment. *Clinical Journal of Oncology Nursing*, *10*(5), 615-619.
- Maher, E., & Makin, W. (2007). Life after cancer treatment-a spectrum of chronic survivorship conditions. *Clinical Oncology*, 19, 743-745.
- Maslow, A. (1968). *Toward a psychology of being*. (2nd Ed.). Princeton, New Jersey: D. Van Nostrand Company.
- Maslow, A. (1971). The farther reaches of human nature. New York: Viking Press.
- McNeil, C. (2008). Institute of medicine says psychosocial care possible in any oncology practice in U.S. *Journal of the National Cancer Institute*, 100(3), 167-168.

- Mellon, S., Kershaw, T., Northouse, L., & Freeman-Gibb, L. (2007). A family based model to predict fear of recurrence for cancer survivors and their caregivers.

 Psycho-Oncology, 16, 214-223.
- Meneses, K. D., McNees, P., Loerzel, V. W., Xiaogang, S., Zhang, Y., & Hassey, L. A. (2007). Transition from treatment to survivorship: Effects of a psychoeducational intervention on quality of life in breast cancer survivors. *Oncology Nursing Forum*, 34(5), 1007-1016.
- Mick, J. (2008). Factors affecting the evolution of oncology nursing care. *Clinical Journal of Oncology Nursing*, 12(2), 307-313.
- Miller, R. (2008). Implementing a survivorship care plan for patients with breast cancer. *Journal of Oncology Nursing*, 12(3), 479-487.
- National Cancer Institute. (2004). Sexual and reproductive issues. Prevalence and the types of sexual dysfunction in people with cancer. Retrieved March 12, 2009, from
 - http://www.cancer.gov/cancertopics/pdq/supportivecare/sexuality/Patient/page2
- Owen, J., Goldstein, M., Lee, J., Breen, N., & Rowland, J. (2007). Use of health-related and cancer-specific support groups among adult cancer survivors. *Cancer*, 109 (12), 2580-2589.
- Pasacreta, J. V., Kenefick, A. L., & McCorkle, R. (2008). Managing distress in Oncology patients. *Cancer Nursing*, 31(6), 485-490.
- Polit, D. F. (2010). *Essentials of Nursing Research*. (7th Ed.). Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins.

- Preston, B. (2009). Maslow's hierarchy of needs. *The Surgical Technologist*, 41(8), 346-353.
- Richards, L. (1999). Using NVivo in qualitative research. Thousand Oaks, CA: Sage.
- Rosenthal, E. (2006). Promulgating the 'survivorship prescription' plan to oncologists.

 Oncology Times, 22(2), 117-125.
- Shulman, L. N., Jacobs, L. A., Greenfield, S., Jones, B., McCabe, M. S., Syrjala, K.,
 Diller, L., Shapiro, C. L., Marcus, A. C., Campbell, M., Santacroce, S., Kagawa-Singer, M., & Ganz, P. A. (2009). Cancer care and cancer survivorship care in the
 United States: Will we be able to care for these patients in future? *Journal of Oncology Practice*. 5(3), 119-123.
- Sheppard, L. A., & Ely, S. (2008). Breast cancer and sexuality. *The Breast Journal*, 14(2), 176-181.
- Stanton, A. L., Ganz, P. A., Rowland, J. H., Meyerowitz, B. E., Krupnick, J. L., & Sears, S. R. (2005). Promoting adjustment after treatment for cancer. *Cancer 104*, 2608-2613.
- Stilos, K., Doyle, C., & Daines, P. (2008). Addressing the sexual health needs of patients with gynecologic cancers. *Clinical Journal of Oncology Nursing*, 12(3), 457-460.
- Travis, L., & Yahalom, J. (2008). Cancer survivorship: Facing forward.

 Hematology/oncology Clinics of North America, 22(2), 365-371.
- Van Weert, E., Hoekstra-Weebers, J. E., May, A. M., Korstjens, I. R., & Van der Schans,
 C. P. (2008). The development of an evidence-based physical self-management
 rehabilitation programme for cancer survivors. *Patient Education and Counseling*,
 71, 169-190.

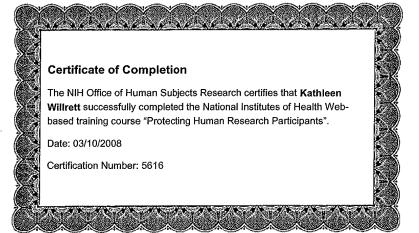
- Ward, S. E., Viergutz, G., Tormey, D., deMuth, J., & Paulen, A. (1992). Patients' reactions to completion adjuvant breast cancer therapy. *Nursing Research*, *41*, 362-366.
- Webster's New Explorer Dictionary New Edition (2005). A Division of Merriam-Webster, Incorporated: Springfield, Massachusetts.

Appendix A

IRB Approval

Protecting Human Subject Research Participants

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Appendix B

The Rights of Research Participants



AS A RESEARCH PARTICIPANT AT COLLEGE OF SAINT MARY

YOU HAVE THE RIGHT:

- 1. TO BE TOLD EVERYTHING YOU NEED TO KNOW ABOUT THE RESEARCH BEFORE YOU ARE ASKED TO DECIDE WHETHER OR NOT TO TAKE PART IN THE RESEARCH STUDY. The research will be explained to you in a way that assures you understand enough to decide whether or not to take part.

 2. TO FREELY DECIDE WHETHER OR NOT TO TAKE PART IN THE RESEARCH.
- 3. TO DECIDE NOT TO BE IN THE RESEARCH, OR TO STOP PARTICIPATING IN THE RESEARCH AT ANY TIME. This will not affect your relationship with the investigator or College of Saint Mary.
- 4. TO ASK QUESTIONS ABOUT THE RESEARCH AT ANY TIME. The investigator will answer your questions honestly and completely.
- 5. TO KNOW THAT YOUR SAFETY AND WELFARE WILL ALWAYS COME FIRST. The investigator will display the highest possible degree of skill and care throughout this research. Any risks or discomforts will be minimized as much as possible.
- 6. TO PRIVACY AND CONFIDENTIALITY. The investigator will treat information about you carefully and will respect your privacy.
- 7. TO KEEP ALL THE LEGAL RIGHTS THAT YOU HAVE NOW. You are not giving up any of your legal rights by taking part in this research study.
- 8. TO BE TREATED WITH DIGNITY AND RESPECT AT ALL TIMES.

THE INSTITUTIONAL REVIEW BOARD IS RESPONSIBLE FOR ASSURING THAT YOUR RIGHTS AND

WELFARE ARE PROTECTED. IF YOU HAVE ANY QUESTIONS ABOUT YOUR RIGHTS, CONTACT

THE INSTITUTIONAL REVIEW BOARD CHAIR AT (402) 399-2400.

*ADAPTED FROM THE UNIVERSITY OF NEBRASKA MEDICAL CENTER, IRB WITH PERMISSION

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Appendix C

Interview Protocol

Field Notes

Interview Protocol: Oncology Nurses' Perceptions of Educational Needs of Female Cancer Survivors Post Treatment

Time of Interview:

Date: Place:

Interviewer:

Interviewee:

Position of Interviewee:

Thank you for agreeing to be interviewed for this research project on oncology nurses' perceptions of educational needs of female cancer survivors post treatment. I want to remind you that your comments will remain confidential and anonymous. Please take your time and read and sign the consent form. You can take a break at any time and please let me know if you have any questions or concerns.

Questions:

- 1. Tell me about your experience with educational needs of the female cancer survivor post treatment.
- 2. Explain your perceptions of educational needs of the female cancer survivor post treatment.
- 3. Describe a time when you met educational needs of the female cancer survivor post treatment.
- 4. What has been the impact of education post treatment on the female cancer survivor and yourself?
- 5. What has been your role in meeting the educational needs of the female cancer survivor?
- 6. What would you see as benefits to meeting the educational needs of the female cancer survivor post treatment?

- 7. Tell me about limitations you see in regard to meeting educational needs of the female cancer survivor.
- 8. If there is something more you'd like to add about educational needs of the female cancer survivor post treatment that I have not asked, please describe that for me.

Additional questions for depth and breadth to the above questions:

Can you expound on that?

Tell me more.

Can you describe that in a different way?

I would like to hear more about that.

Can you clarify that for me?

What were the consequences?

Take me through your thought processes during that time.

Field Notes

Length of activity:

Description	Reflective Notes