

PATIENT'S PERCEPTION OF THE HELPFULNESS OF
EDUCATION MATERIALS FOR BREAST CANCER

By

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ABSTRACT

Breast cancer is the most widely diagnosed cancer among women and the second leading cause of death after lung cancer. “Many women with cancer describe the moment they found out about their diagnosis as truly devastating” (National Breast Cancer Organization [NBCO], 2000, p.1). There are numerous ways in which women cope during this upsetting time. Two ways to help women cope is to encourage them to understand their new diagnosis through education and exploring all available treatment options. There is a shortage of documentation on breast cancer education and few studies have examined patients’ perception of breast cancer education. The target population for this study was adult women with a diagnosis of breast cancer who received treatment from a medium sized northwestern cancer clinic. The population and the sample consisted of residents from urban and rural regions of central Montana. A convenience sample of persons eighteen years and older consisting of the 168 women who are on the breast cancer survivors’ monthly mailing at the cancer clinic were invited to participate in the study; the actual sample consisted of 59 women. The sample was self-selecting and participation was voluntary. A descriptive, retrospective, cross-sectional design was used as the framework for this study. The questionnaire that was developed for this study was used to collect data that explored participants’ perceptions of the education received. Participants were asked where they received their education about breast cancer and 71.2% said that they received their educational materials from the cancer treatment facility. A large majority (79.7%) indicated that immediately after breast cancer diagnosis they felt ready to learn. Almost half (42.4%) felt acceptance of their breast cancer diagnosis. A total of 63% felt that their educational materials were either very helpful or helpful.

CHAPTER 1

INTRODUCTION TO THE STUDY

Introduction

Every two minutes, a woman in the United States is diagnosed with breast cancer (Crockett-Maillet, 2008). Breast cancer is the most widely diagnosed cancer among women and the second leading cause of death after lung cancer (Rosenzweig, Rust, & Hoss, 2000). The alarming statistics about breast cancer prevail and to a newly diagnosed woman, breast cancer can be over whelming and distressing. “Many women with cancer describe the moment they found out about their diagnosis as truly devastating” (National Breast Cancer Organization [NBCO], 2000, p.1). There are numerous ways in which women cope during this upsetting time. Two ways to help women cope is to encourage them to understand their new diagnosis through education and exploring all available treatment options (NBCO). There is a shortage of documentation on breast cancer education and few studies have examined patients’ perception of breast cancer education (Crockett-Maillet).

Madison (2007) described one woman’s feelings upon diagnosis: “when you’ve just been diagnosed with breast cancer, you can’t remember things; you can’t think straight” (p.2L). The time between diagnosis and treatment can be one of the hardest phases (Madison). Women diagnosed with breast cancer are inundated with information and need help to understand their diagnosis and treatment. Education about care and management is becoming more complex, and patients lose their rightful key position in

the decision-making process if information is not clear or meaningful (Rosenzweig, Rust, & Hoss, 2000). When providing information and education to the patient, the timing of presentation and quantity of educational materials are critical.

Another important aspect of patient education is the quality of the relationship between the patient and the healthcare provider; communication must be two-way (American Cancer Society, 2004). Back and Arnold (2006) found that a majority of patients want to discuss prognosis, however, the depth of conversation differs from patient to patient. Some patients want to be realistic, others may want to be optimistic, and some want to avoid discussion. Some women may be too upset with the diagnosis; others do not know what questions to ask (Sepucha, 2003). Patients often arrive unprepared to their appointments, and do not know what they want to learn. Back and Arnold recommend that healthcare providers ask their patients how much they want to know and use the answer as a basis of discussion. Rosenzweig, Rust, & Hoss (2000) point out that every diagnosis of breast cancer is a “specific, individualized assessment” (p.277). Each woman copes with the diagnosis in her own way.

A diagnosis of cancer can provoke emotions such as depression, helplessness, anxiety, and fear. According to Meechan, Collins, Moss, and Petrie, (2005) simply having to explore breast cancer symptoms is a distressing experience for most women. Winokur (2006) interviewed former New York City mayor Rudy Giuliani about his diagnosis of prostate cancer: “The time that I was really in danger was the day before I knew I had prostate cancer. Now I knew what was going on in my body and I could do something about it” (p.53). Due to this stress, a majority of patients state that support and

education provided prior a cancer diagnosis is given may be helpful (Meechan, et al.). This education and knowledge will help the patient avoid emotional turmoil and unnecessary worry.

Lobb, Butow, Kenny, & Tattersall (1999) suggest that patients' misunderstanding is partly responsible for women's confusion about breast cancer diagnosis and treatment. "Reeling from the diagnosis and overwhelmed by the many treatment options available, patients with breast cancer may feel unable to make decisions about their care and treatment without additional education and support" (Crockett-Maillet, 2008, p.53). Patients often do not understand the tests they are undergoing and what the results could imply. Even if information has been provided, patients often have difficulty recalling what they have been told about their breast cancer (Lobb et al.). To help avoid confusion, clinicians should use a diversity of techniques to communicate information. Since a single session providing information may not be retained by the patient due to stress of diagnosis or the timing of when healthcare workers offer education, patient education should be an ongoing process.

Background and Significance of Study

In 2007, more than 178,480 women were diagnosed with breast cancer (Crockett-Maillet). Although the incidence of breast cancer has decreased from previous years, it remains the number one cancer threat specific to women in the United States. According to the American Cancer Society (2007) one in seven women will at sometime receive a diagnosis of breast cancer. Currently 89% of women diagnosed will reach their five-year

survival mark (Lester, 2007). This high survival rate is due to screening programs, research advancements, and education. Nurses and the health care team have countless opportunities to make a difference in early detection and survival through education.

Effective education can improve patient outcomes. Geffen (2006) recommends education for breast cancer, advocating that it empowers a patient to actively participate in and obtain the greatest possible benefit from care. Understanding medical care is a fundamental part of achieving the best outcome and allows patients to feel clear and confident about their treatment plan. Taking time to gain information about breast cancer treatment and prognosis will become an important part of the patient's healthcare process (Crockett-Maillet, 2008).

Patient education can optimize the quality, costs, and outcomes of healthcare by providing necessary information (Donaldson, Rutledge, & Pravikoff, 2000). Thorough education provides helpful information about breast cancer, treatment options, medication, food and diet. Education should be sensitive to the patient's reading level and culture, and should be grounded in evidence-based principles of teaching and learning. Every patient should have "access to appropriate and culturally sensitive information, be allowed to participate in decision making, and have full informed consent" (Rosenzweig, Rust, & Hoss, 2000, p.277). Assistance in exploring and comprehending the complexity of breast cancer is essential. Weaver (2006) stresses that "from the moment of diagnosis it is important for patients to proactively manage all aspects of their treatment which will give them confidence, comfort, and help patients maintain a sense of normalcy in their life" (p.14).

The environment of patients needs to be identified when healthcare providers are considering the education component. This study will involve participants from both rural and urban areas. The urban community of focus in the study has a population of 56,690 (United States Census Bureau [USCB], 2000) and provides medical care for multiple rural communities in central Montana. Cancer care is not readily available in rural communities; women with breast cancer must commute in order to obtain treatment. This creates extra financial burdens and strains. “Rural residents worldwide experience the extra burden associated with high costs incurred while traveling in order to secure required health care. For most, this traveling necessitates days or weeks away from family and social support, not to mention the incurred costs for sustenance and accommodation” (Ryan-Nicholls, 2004, p.246).

Purpose

The purpose of this study was to explore woman’s perception of the helpfulness and quality of educational materials women receive at the time of their diagnosis for breast cancer at one medium-sized, northwestern cancer clinic. The study was conducted in order to assist cancer treatment centers to provide helpful information for breast cancer patients. The aims of this study were:

1. Identify educational materials patients received at diagnosis of breast cancer.
2. Investigate patients’ perception of the educational materials received.
3. Identify types of education that patients found most helpful at the time of diagnosis.

Statement of Problem/Research Question

This study examined the perceptions of cancer education among women diagnosed with breast cancer. The problem is that either too much information/education is given at the time diagnosis, wrong type of information/education, or not a sufficient amount is provided to breast cancer patients. This study answered the following questions:

1. What types of education were patients offered: written hand-outs, counseling, or support groups?
2. Did patients with breast cancer find the education that was provided at the time of diagnosis helpful in preparation for treatment decisions?
3. What were the patient's perceptions of additional information/education provided that would have been helpful for woman with breast cancer?

Theoretical Framework

Adult Learning Theory was the theoretical framework chosen to guide this study. Part of effective education consists of understanding how adults learn. Malcolm Knowles was the first to theorize how adults learn, introducing the concept that adults and children learn differently (Russell, 2006). Knowles proposed that adult learning is a process of self-directed inquiry. In order to be effective, teaching should take place in a cooperative learning climate. "Six elements Knowles' work outlines promoting optimal learning are:

1. A need to know
2. A responsibility for one's own learning
3. The role of experience as a resource in one's learning
4. A readiness of applicability of the information to one's life situation
5. Motivation to learn
6. Problem-centered learning with real-life problems" (Mitchell & Courtney, 2004, p. 258)

These elements will not always occur together; however, adult education can aspire to cultivate these elements. In adult education the teacher (in this case, the healthcare provider) needs to develop an understanding of the learner and initially give substantial direction. All adults learn in their own way and will be different kinds of learners. Some may learn better by audio or visual while others may be a hands-on learner. Also a key concept with adult learners it to assess what they already know. Knowles understood that adults learn when they can apply information to build on previous information. Therefore healthcare educators want to tap into resources and use them to expand and enhance learning (Mitchell & Courtney, 2004).

Another aspect of "Adult Learning Theory" is motivation. "Often a life-experience or situation stimulates the motivation to learn" (Russell, 2006, p.349). This life situation might be an illness, such as breast cancer. The best way to motivate adult learners is to explain the benefits of learning to them (Lieb, 1991). Winokur (2006) states that knowledge is the most powerful tool to guide a patient through a cancer diagnosis. Understanding a cancer diagnosis will empower and thereby motivate the patient.

In Adult Learning theory, the environment is seen as enhancing learning (Knowles, 1970). The educator needs to build a mutually trusting relationship with the patient. A climate for learning is established when the patient believes that the educator (or healthcare provider) takes a personal interest in his or her well-being. Warmth and respect should be conveyed to the patient.

Assumptions

Assumptions are innate beliefs held by the researcher about phenomena that the researcher accepts as truths without proof or empirical evidence (Talbot, 1995).

Assumptions help form the basis of the investigation. In the planning of this study it was assumed:

1. Respondents received education at diagnosis of breast cancer and that a variety of education was received.
2. Respondents receiving care from this regional medical clinic included Montanans living in rural and urban areas.
3. Identifying educational needs and preferences improve the worth of breast cancer education.
4. A returned questionnaire warranted that the respondent could read and write English and had agreed to participate as a respondent in this study.

Summary

Breast cancer has become a common topic. Women are openly discussing their experience, pink ribbons are everywhere, and the month of October is dedicated to National Breast Cancer Awareness (Madison, 2007). Breast cancer plays a significant role in the health of countless women. Without proper education women can be left feeling helpless about the treatment process. Few studies have been done to explore the helpfulness of education from the patients' perceptions. This study examined the patient's perception of the helpfulness of education materials for breast cancer.

CHAPTER 2

REVIEW OF LITERATURE

Introduction

This study reviews the literature on breast cancer, adult education, and rural nursing. Breast cancer literature reviewed included pathophysiology/epidemiology, risks factors, screening, therapy and treatment. The adult education component reviewed different articles explaining adult learning techniques and how adults learn best. Adult learning theory was also reviewed. The review defined the unique challenges facing women, especially breast cancer patients, who live in a rural community. Pubmed Central (PMC) and the Cumulative Index to Nursing Allied Health Literature (CINAHL) were utilized for the literature review.

Breast Cancer Incidence and Prevalence

Breast cancer is the most commonly diagnosed cancer in women in the United States (Lester, 2007). According to the American Society of Clinical Oncology (ASCO) (2006), an estimated 212,920 women in the United States were diagnosed with breast cancer and an estimated 41,430 deaths occurred. These numbers are predicted to decline gradually, with approximately 178,480 women in 2007 being diagnosed and 40,460 dying (Lester). Between 1990 and 2000, the number of women who died of breast cancer dropped 2% each year. Currently, more than two million women in the United States have been diagnosed with and treated for breast cancer (ASCO).

Breast Cancer Risk Factors

In 75% of women with breast cancer there are no known risk factors for breast cancer aside from age and gender (Buttaro, Trybulski, Bailey, & Sandberg-Cook, 2008). Some of the known risks factors are family history of breast cancer, biopsy-confirmed atypical hyperplasia, early menarche and/or late menopause, nulliparity or history of first child after age 30, obesity after menopause, postmenopausal hormone replacement therapy, or excessive alcohol consumption (Norman, et al., 2007). Some of these risk factors are modifiable, while others are not. Current studies are exploring a link to breast density and physical inactivity but no known connection has yet been identified. Only 5% of breast cancers are related to the genes BRCA1 and BRCA2 so general screening of the population for these genes is not recommended (Buttaro et al.). Screening is expensive and not all screening methods are covered by insurances.

Women can be diagnosed with breast cancer at any age. However, statistically speaking, age is the most important risk factor for breast cancer, with the majority of breast cancers occurring after age 50 and the highest incidence occurring in women aged 75-79 (Heidrich, Egan, Hengudomsub, & Randolph, 2006). Life expectancy for women has increased, so therefore older patients with breast cancer are usually coping with multiple co-morbidities and associated symptoms. Education should be provided specific to each client's needs and age. When co-morbid illnesses are present, there needs to be special information presented in education about other disease processes. In addition, more women are surviving breast cancer due to advanced screening and treatment

methods (Radina, Armer, Culbertson, & Dusold 2004). Women who are breast cancer survivors need education that discusses follow-up appointments, long-term side effects, and possible maintenance therapy (Jahanzeb, 2006). Regardless of any known risks factors all women should be following the screening guidelines.

Breast Cancer Screening/Early Detection

Survival rates for all cancers continue to rise, with approximately 9.8 million people living with a history of cancer (Mellon, Northhouse, & Weiss, 2006). There is strong evidence for a reduction in mortality in women between the ages of 50 and 69. The American Cancer Society [ACS] (2007) recommends that all women have an annual screening mammography beginning at age 40 (Buttaro, Trybulski, Bailey, & Sandberg-Cook, 2008). Women with a strong family history should begin screening with a clinical breast exam (CBE) every 6-12 months and obtain an annual mammogram at least 5-10 years before the age of which the youngest family member was diagnosed with cancer (Lester, 2007). The ACS has dropped its recommendations for monthly breast self-examinations, leaving it an option, but comments that research has supported self-awareness as more effective than a structured examination (Buttaro et al.). Women in their twenties and thirties should have clinical breast examinations every three years and starting at age 40 or older women should have one annually. Studies have found that women are more likely to find lumps when going about daily activities such as dressing or showering, so clinicians are encouraged to teach patients to remain aware.

Signs and Symptoms

Many breast cancers develop with no symptoms. People with known risk factors or whose screenings were suspicious should be evaluated further for signs and symptoms of breast cancer. Some tumors may be visible on a mammogram before symptoms develop. Women must be familiar with the appearance, feel, shape and texture of their breasts in order to detect changes as soon as possible. The common symptoms of breast cancer are new lumps, nipple tenderness, discharge, skin irritation or changes, warmth, and sometimes pain (ASCO, 2006).

Early detection is critical to early treatment and remission, as a tumor stage is the most important prognostic factor in breast cancer (Samant, Olivotto, Jackson, & Mates, 2001). According to Samant et al. the median diameter of invasive breast cancers diagnosed with Mammography was 1.4 centimeters. Often, breast cancers are detected when they are less than 1.5 centimeters. A mammogram can detect tumors as small as 1 millimeter (Buttaro, Trybulski, Bailey, & Sandberg-Cook, 2008). By the time a tumor is palpable it is on average around 2 centimeters (Samant et al.). The number one way women are diagnosed with breast cancer is by routine screening mammography which detects 80% to 90% of breast cancers (Buttaro et al.). Most women do not present to the healthcare office suspicious that they have breast cancer due to the limited signs and symptoms of breast cancer.

Breast Cancer Therapy/Treatment

A woman who has just been diagnosed with breast cancer may be introduced to several healthcare providers. Following initial diagnosis, a team of medical experts is assembled to be responsible for different aspects of care. There may be a medical oncologist, nurse practitioner, an oncology nurse, a radiation oncologist and surgeon. Sometimes occupational and physical therapies are initiated (Weaver, 2006). Among all these possible healthcare providers, communication can break down and the patient may never receive proper education or instructions about illness and treatment.

Communication with all members of the team is critical in helping women understand and participate in all aspects of their cancer care (Weaver). All providers on the healthcare team need to help guide, educate, answer questions, and provide treatment.

Therapy options for cancer diagnosis depend on the staging of the cancer and often involve the patient's input. Understanding treatment options is important and with expanding technology, there are more therapies than ever available (Galleshaw & Jahanzeb, 2006). Treatment options range from surgery, radiation, chemotherapy, hormonal therapy, as well as complementary alternative therapy (Galleshaw & Jahanzeb). Essentially therapy options can be broken down into two basic categories: local therapies and systemic therapies. Local therapies destroy local tumors that have not spread elsewhere in the body; surgery and radiation are examples. Systemic therapies go into the bloodstream and circulate all through the body; chemotherapy and hormonal therapies are examples (Galleshaw & Jahanzeb). With all these options for treatment it is imperative

for the patient to work with the medical team to choose the most appropriate plan based on an individual's circumstances and diagnosis.

In the past 30 years new drugs and therapies have expanded treatment options. For patients attempting to stay informed about their diagnosis and treatment, the number of new drugs and their effects may be overwhelming (Winokur, 2006). Patients may also be asked to participate in clinical trials. Involvement in a clinical trial is an important decision with unknown consequences. Patients need to learn as much as possible about the study and how they can benefit. While this can be helpful to medical advancements, patients need more education to understand their rights of human participation. Procedures that will be performed and what the patient can expect throughout the process needs to be addressed (Winokur).

Support Systems

A patient who has just been diagnosed with breast cancer may be reluctant to share her diagnosis with their family and friends. She may be afraid of pain or death and dying. She may fear becoming a burden. Although everyone reacts differently, it is critical to communicate with family and friends to establish support. Vivar and McQueen (2005) suggest that all women need support and educational services. Social support plays a vital role in giving emotional help. While everyone's support system is different, nobody goes through cancer alone (National Breast Cancer Organization, [NBCO], 2000). Family, friends, other patients, and the healthcare team become important sources of support.

Many women consider attending a support group; however few actually go, citing fear, lack of patience, energy, empathy (NBCO). Some breast cancer patients value their privacy, while others find comfort in discussing their illness with other women who are experiencing the same. According to one breast cancer survivor, “knowing you’re not alone is really worth a lot” (Madison, 2007, p.L2). No one should face cancer alone and reassurance can be provided in talking openly about breast cancer with other breast cancer patients. In a 2006 interview, Rudy Giuliani urged cancer patients to “find a support group. You’ll find that people who have had cancer are almost always willing to help other people who have cancer. I certainly feel that way” (Winokur, p.56).

There are numerous national and local programs to offer support for people with cancer. One popular program is Reach to Recovery which helps women meet the physical, emotional, and cosmetic needs related to breast cancer and/or its treatment (Reach to Recovery, 2006). Trained survivors volunteer to offer one-on-one support and information to patients living with breast cancer. The volunteers respond in person or by phone to the concerns of people facing breast cancer diagnosis, treatment, recurrence, or recovery (Reach to Recovery). Long-term breast cancer survivors report that physicians and oncology teams had not given them the information that they had sought and a support systems might have been able to supply some of this information (Vivar & McQueen, 2005).

In addition to social support systems, financial support also needs to be reviewed. Diagnostic studies, medication, surgery, and doctor visits can become very expensive for a woman with breast cancer. Determining up front what insurance will pay for can help

put patients at ease (Buell, 2006). There are two main sources of medical insurance: private or government-funded. Even if patients do have insurance, a portion of costs will come from “out-of-pocket” (Buell, p.53). Some patients do not have insurance coverage, but drug assistance programs, foundations, and local charities supplement costs when patients qualify on a need basis.

Adult Education/Learning

Often healthcare providers and patients enter into a “teaching-learning” relationship when information important to the patient’s well being is necessary (Russell, 2006). It is imperative for a patient with breast cancer to embark on a teaching-learning relationship because knowledge will help guide her decisions about treatment and care. In order for teaching to be effective, it is crucial to know how adults learn. Adults remember approximately 20% of what they hear, 10% of what they read, and 30% of what they see (Masek, 2000).

“Adults learn best when convinced of the need for knowing the information” (Russell, 2006, p.350). It may take a life situation or change in health such as a diagnosis of breast cancer to serve as motivation to learn. Motivation and environment influence the patient’s readiness. Adults tend to be more autonomous and self-directed learners (Mitchell & Courtney, 2005). It is critical to assess adults’ existing familiarity since adults tend to build on current knowledge base (Masek, 2000). Adults have an accumulated foundation of life experiences and knowledge that influences future learning

(Mitchell & Courtney). Adults desire a reason for learning new information; they are relevancy-oriented (Mitchell & Courtney).

Each patient may have his or her own learning style, but adults do learn best when teaching strategies combine visual, auditory, and kinesthetic approaches (Russell, 2006). “Data from studies of patient education indicate that patients are most likely to achieve the goals of educational interactions when they receive well thought-out, strategically planned educational interventions combining several methods of teaching” (Donaldson, Rutledge, & Pravikoff, 2000, p.73). Donaldson et al. add that research is needed to differentiate quality, outcomes, and costs of education efforts.

The adult learner must be ready to learn and the environment will play a key role in the learning process. An ambient room and atmosphere should be provided to help facilitate learning (Russell, 2006). Hearing or vision impairments need to be assessed, as both can impact the education process. The environment should convey warmth and respect which will help facilitate learning by making the learner feel comfortable (Mitchell & Courtney, 2005).

A potential barrier to effective education is stress; both physical and emotional stresses. Unlike children, adults have many responsibilities that they must balance against the demands of learning (Mitchell & Courtney, 2005). Donaldson et al. indicates that “at a time in which patients are most unable to learn optimally because of conditions affected by their health, they are confronted with huge informational needs such as new and sometimes frightening self-care routines” (p.74). Functional literacy of patients can be affected by stress.

With all patients it is imperative to convey respect to the learner (Russell, 2006). Also, make sure the patient is able to read and comprehend the material. When talking to the patient, the provider must have “patience in limitless quantities” (Masek, p.32). The patient must have ample time to discuss everything and to ask questions.

Rural

According to the United States Census Bureau (2000) a county or town of fewer than 2500 people is “rural”. However, health researchers often define “rural” in terms of population density, distance, availability of health care services, and time required to travel to a regional health care center (Koehler, 1998). This study defines a rural community as one with a population of 2,500 people or less, and 40 miles or more from a community of 50,000 or more people with a regional health care center.

Rural communities are faced with increased challenges to obtain healthcare due to distance and limited availability of services. “People in rural communities have poorer health status and greater needs for primary health care, yet they are not as well served and have more difficulty accessing health care services than people in urban centers” (Ryan-Nicholls, 2004, p.245). Some of the characteristics that define a rural community are isolation, remoteness, distance, and lack of services (Lee, 1991). The characteristics of a rural community will greatly affect the healthcare available and also the healthcare choices of the residents. Not only do rural communities have distinctive characteristics, but so do the people who live in them. “Rural dwellers define health primarily as the ability to work, to be productive, to do usual tasks” (Lee & McDonagh, 2006, p.20). Most

rural residents only seek healthcare when absolutely necessary and “often delay seeking healthcare until they are gravely ill or incapacitated” (Lee & McDonagh, p.15). This distance provides an additional challenge for healthcare providers because they must be able to deliver preventative health, education, and to be non-judgmental of people who have delayed treatment.

A factor that may relate to delayed treatment, or not going to their health care provider is isolation (Lee, 1991). Isolation means being separated from others (Hewitt, 1992). Available health care in a rural community is usually not just around the corner, and services are limited. A commute to the urban community will require time and money. For people with serious illnesses, such as breast cancer, this commute can become tiring and expensive. The distance and isolation can result in non-compliance, missed treatments, and poor follow-up (Lee & McDonagh, 2006). A resident of a rural community will have a reduced amount of access to specialty services than someone who is living in an urban area. Distance and isolation make access to healthcare a challenge (Hewitt).

Treating someone with breast cancer is difficult, especially for someone who lives in a rural area. “Rural persons with illnesses have unique health care access challenges related to available health care personnel to provide services, distance to services, and fiscal resources to obtain services” (Scott, 2000, p.21). A patient’s residence needs to be taken into consideration.

Culture

Education needs to be individualized to the target population. “The American Cancer Society specifically recommends that cancer education programs meet the special needs of local populations” (Patterson, 2000, p.187). It is important for healthcare workers to incorporate adults’ learning needs and for the providers to be sensitive to their cultural beliefs. “The effectiveness of patient education as a therapeutic intervention requires strategies that are population-specific, logically linked to targeted outcomes” (Donaldson, Rutledge, & Pravikoff, 2000, p.72).

Breast cancer is more common in some ethnic groups than others. Research suggests part of the explanation can be found in the level of estrogen present after menopause- which varies by ethnicity (Setiawan, 2007). The higher the estrogen level, the more likely it is for breast cancer to result. “White women have a higher age adjusted incidence of breast cancer than do Black women, Hispanic women, and other ethnic groups. However, despite having the highest incidence of breast cancer, White women do not have the highest mortality” (Lantz, et al., 2006, p. 2173). The ethnic makeup of the community of focus in this study is 90% White, 5% Native American, 1 % African American and 4% other (United States Census Bureau, 2007).

Summary

Breast cancer is an overwhelming diagnosis, one that is accompanied by fear of the unknown, fear of treatment and death, and financial strain. There is a possibility that patients are oblivious to the meaning of their diagnosis. Education materials may be too

overwhelming when all the components of cancer are taken into consideration. Education needs to be individualized for each patient since each person diagnosed with cancer will have different staging and different treatment options available and his or her own learning style. Therapy and treatment options will also vary from one location to the next.

There is a growing amount of literature on breast cancer. There also is a plethora of literature about adult education. However, there is a dearth of documentation on breast cancer education and a lack of studies on patient satisfaction with their breast cancer education.

CHAPTER 3

METHODOLOGY

Population and Sample

The target population for this study was adult women with a diagnosis of breast cancer who received treatment from a medium sized northwestern cancer clinic. The population and the sample consisted of residents from urban and rural regions of central Montana. Eligible participants were eighteen years and older, comprehended English, and diagnosed with breast cancer. A convenience sample of persons that consisted of the 168 women who are on the breast cancer survivors' monthly mailing at the cancer clinic were invited to participate in the study. The sample was self-selecting and participation was voluntary. The survey was mailed out one time only. According to Dillman (2007) the average response rate of a mailed out study with no incentive offered is 28%. However Dillman suggests one mailing with two reminder postcards and he concluded that a 28% response was expected.

Design

A descriptive, retrospective, cross-sectional design was used as the framework for this study on breast cancer education. The questionnaire that was developed for this study was used to collect data that explored participants' perceptions of the education received. A questionnaire was developed for this study to collect data on demographics/ sociodemographics and the participants' perception of the educational materials received

and how the materials helped with treatment decisions. The design for this study allowed the researcher to collect a plethora of data in a short period of time.

Data collection began after Montana State University (MSU) Institutional Review Board (IRB) approval and the internal approval from the Director of Oncology Services at the northwestern cancer clinic (see Appendix D). Data collection took place over a 6-week period from November 28, 2007 to January 9, 2008.

Procedures for Data Collection

The sample selected for this study received a research packet from the Principal Investigator (PI) that was included in a monthly mailing to breast cancer survivors that are patients of the cancer clinic. The packet contained a letter inviting people to participate in the study (see Appendix E), a questionnaire, and a postage pre-paid sealable envelope for confidential return of the completed questionnaire was included. The invitational letter described the study's purpose and the importance to nursing and included all the components of an informed consent. The returned completed questionnaire constituted the respondent willingness to participate; therefore a signed consent was not necessary. No identifying information (such as name, address, social security number) was collected in order to protect confidentiality. Participants were assigned an identification number to assist data organization. All data were kept in a locked cabinet in the PI's office.

Of the 168 woman who were invited to participate, 39.2% (n=66) agreed to participate and completed the questionairre. The return response was nearly 15% higher

than Dillman's prediction of 25% (2007). Three of the surveys received were incomplete and therefore not included in the study. An additional four were received after the January 9th deadline and were also not included in the study. A total of 59 participants were included in the final data analysis.

Instrumentation

The questionnaire consisted of thirty questions divided into two sections: the first section was demographics/sociodemographics questions (see Appendix B) and the second section asked for information about breast cancer education (see Appendix C). The questionnaire consisted of multiple choice questions and fill-in-the-blank when "other" is chosen as a response. Time to complete the survey was approximately 10 minutes.

The demographic/sociodemographic section contained eleven questions which collected information including: age, height, weight, marital status, race, formal education, occupation, religion, living arrangement, population of community of residence, and commute to healthcare. Additionally in this section were seven questions regarding breast cancer risk factors. These included: age at first menstruation, age at menopause, age at first pregnancy, number of children breast fed, other family members affected by breast cancer, history of hormone replacement therapy, and amount of alcoholic beverages consumed on a weekly basis.

The second section contained one question assessing the year the participant received her breast cancer diagnosis and nine questions regarding the participants' breast

cancer education experience. The focus was on exploring the types of educational materials received upon diagnosis, who informed the participant of the breast cancer diagnosis, initial reaction to the diagnosis of breast cancer, readiness to learn about breast cancer, and where their current knowledge of breast cancer was learned. The final two questions assessed overall how prepared the participants felt to make choices about treatment and what additional information provided would have been helpful.

Before the questionnaire was mailed to participants, a panel of advanced practice registered nurses (APRN) reviewed the questionnaire. The APRN's suggestions were incorporated for content validity. Additionally the director of oncology services and patient care coordinator/counselor at the northwestern cancer clinic reviewed the questionnaire prior to mailing it out to participants. It was not tested for reliability or validity.

Discussion of Rights of Human Subjects and Consent Process

The study was approved by Montana State University Institutional Review Board (IRB). Permission to conduct the study was also obtained from the Director of Oncology services and the internal approval from the cancer center at which this study is taking place. Participants were informed that this study was voluntary and self-selecting. Additionally, at anytime participants could drop out of the study without affecting care received by the cancer clinic.

Planned Statistical Analysis

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 16, 2008. Responses to the survey were entered into the database by the researcher. Descriptive statistics, such as frequencies, percentages, means and standard deviations were used to summarize the data. Independent *t*-tests were used to look at mean differences between two variables using an internal Likert scale and Levene's tests were utilized to test for significance. The results are presented in Chapter 4.

CHAPTER 4

RESULTS

Introduction

The findings from the study are reported in this chapter. The demographic and sociodemographic information collected from participants is presented first. Next questions pertaining to health and experiences coping with cancer is discussed. Lastly, four independent samples *t*-tests were conducted to determine if a relationship existed between the types of educational information received and how prepared patients felt about their breast cancer treatment.

Demographics and Sociodemographics

Fifty-nine individuals participated in the study. The frequencies and percents for the nominal and ordinal scaled demographic and sociodemographic variables are listed in Table 1. A large majority (56, 94.9%) of the participants were Caucasian. Most (37, 62.7%) of the participants indicated that they were married and that they lived with their spouses. Thirty-five (59.3%) of the participants indicated that they had a high school diploma, and 15 (25.4%) had a Bachelor's degree. A majority (34, 57.6%) of the participants stated that they were Protestant.

Table 1

Descriptive Statistics for the Participants' Demographics

Variable	n	%
Ethnicity		
Caucasian	56	94.9
Hispanic	1	1.7
Native American	2	3.4
Marital Status		
Single	3	5.1
Married	37	62.7
Divorced	8	13.6
Widowed	11	18.6
Education		
High School Diploma	35	59.3
Bachelor's Degree	15	25.4
Master's Degree	3	5.1
Other	6	10.2
Religion		
Catholic	18	30.5
Protestant	34	57.6
Jewish	1	1.7
Latter-Day Saint	1	1.7
Other	5	8.5
Living Arrangement		
Self	17	28.8
With Spouse	37	62.7
With Significant Other	3	5.1
With Sibling	1	1.7
With Other	1	1.7

Table 2

Descriptive Statistics for the Participants' Community

Variable	n	%
Community Size		
Less than 500	8	13.6
500 to 2,499	6	10.2
2,500 to 10,000	12	20.3
Greater than 10,000	33	55.9
Distance from Great Falls		
Less than 10 miles	1	4.0
10 to 49 miles	4	16.0
50 to 99 miles	8	32.0
Greater than 100 miles	12	48.0

The participants also were asked to respond to a number of questions pertaining to their health and experiences coping with cancer. The means and standard deviations for the ratio scaled health items are listed in Table 3. The frequencies and percents for the nominal and ordinal scaled health items are listed in Tables 4 - 6.

Table 3 lists information about Health related variables that may contribute to breast cancer. The mean age of participants was 64.14 with a standard deviation of 10.56. The mean age of first menstruation was 12.84. Fifty seven of the participants had indicated a pregnancy, with the mean age of first pregnancy being 21.51. Eleven participants did not answer the age of menopause either due to forgetting that age or

because they are not in menopause yet. Additionally, thirty four (57.6%) participants indicated that they have been on hormone replacement therapy.

Table 3

Means and Standard Deviations of Health Related Variables

Variable	M	SD	N
Age	64.14	10.56	58
Years with cancer	3.88	4.05	59
Height (inches)	64.07	3.04	59
Weight (pounds)	160.17	32.86	59
Age at first menstruation	12.84	1.55	58
Age at menopause (if applicable)	47.69	6.84	48
Age at first pregnancy (if applicable)	21.51	5.61	57
Number of children breastfed (if applicable)	1.46	1.48	52

Table 4 is a continuation of health variables and this table included frequencies and percents. Ten participants (16.9%) reported a history of a maternal aunt having breast cancer, and nine participants (15.3%) had a history of maternal grandmother having breast cancer. Eight participants (13.6%) had a sister or paternal aunt with a history of breast cancer.

A majority of participants forty four (74.6%) were given pamphlets that discussed treatment options. Nine participants (15.3%) were given magazines, five (8.5) were given video or DVD's. Seventeen (28.8%) indicated "other". Respondents either left the

“other” blank and two wrote “don’t remember”. A greater part of participants 42 (71.2%) indicated that their main source of knowledge about cancer was from materials received at the cancer facility.

Table 4

Frequencies and Percents for Health Variables

Variable	Yes		No	
	n	%	n	%
Family history of breast cancer				
Mother	7	11.9	52	88.1
Sister	8	13.6	51	86.4
Maternal Grandmother	9	15.3	50	84.7
Paternal Grandmother	2	3.4	57	96.6
Maternal Aunt	10	16.9	49	83.1
Paternal Aunt	8	13.6	51	86.4
Types of information given that discussed treatment options				
Pamphlets	44	74.6	15	25.4
Magazines	9	15.3	50	84.7
Video or DVD	5	8.5	54	91.5
Other	17	28.8	42	71.2
Source of knowledge about cancer				
Materials at facility	42	71.2	17	28.8
Physician	43	25.4	16	74.6
Nurse	26	44.1	33	55.9
Internet	26	44.1	33	55.9
Family	16	27.1	43	72.9
Additional information that would be helpful				
Complementary alternative therapy	16	27.1	43	72.9
Dietary supplements/eating habits	17	28.8	42	71.2
Breast cancer prevention	16	27.1	43	72.9
Therapy	15	25.4	44	74.6

Table 5 explores the types of educational materials the participants received. A majority (72.9%) of participants were offered written materials that explained breast cancer. Thirty seven (62.7%) indicated that they were given written educational materials upon diagnosis. A little over half (57.6%) were offered counseling and 78% were told about support groups.

Table 5

Frequencies and Percents for educational materials

Item	Response	n	%
Were you offered written material that explained breast cancer?	Yes	43	72.9
	No	16	27.1
When you received your diagnosis did someone hand you educational materials?	Yes	37	62.7
	No	22	37.3
Were you offered any counseling?	Yes	34	57.6
	No	25	42.4
Were you told about support groups?	Yes	46	78.0
	No	13	22.0

Primary care providers informed sixteen (27.1%) participants of their diagnosis. A majority of participants, thirty two (54.2%) indicated “other” and wrote in surgeon. Almost half of participants (42.4%) indicated that their initial reaction to the diagnosis of breast cancer was acceptance. Roughly a quarter (25.4%) indicated grief. Ten participants indicated “other”. Additional comments wrote in were “shock”, “fear” and “disbelief”. One participant wrote “I just wanted to know what the next step was”.

A large majority of participants 47 (79.7%) felt they were immediately ready to learn about breast cancer. Six participants (10.2%) were ready within a month, antoehr three (5.1%) felt they would be ready within one to six months. Two participants (3.4%) indicated they would never be ready.

Thirty seven participants (62.7%) felt that they information was either helpful or very helpful in preparing them to make choices about treatment. Eleven (19.6%) participants indicated that the information was somewhat helpful. Lastly, eight (14.3%) people felt the information they were provided was not helpful.

Table 6

Participants' breast cancer experience

Item		N	%
Who informed you of your diagnosis?	Primary care provider	16	27.1
	Gynecologist	5	8.5
	Oncologist	3	5.1
	Nurse	3	5.1
	Other	32	54.2
What was your initial reaction to the diagnosis of breast cancer?	Acceptance	25	42.4
	Anger	5	8.5
	Denial	4	6.8
	Grief	15	25.4
	Other	10	16.9
After diagnosis, when do you think you were ready to learn about breast cancer?	Immediately	47	79.7
	Within a month	6	10.2
	One month to 6 months	3	5.1
	Six month to 1 year	1	1.7
	Never	2	3.4
How much did the information prepare you to make choices about your treatment?	Very helpful	22	39.3
	Helpful	15	26.8
	Somewhat helpful	11	19.6
	Not helpful	8	14.3

Educational Materials

An independent samples *t*-tests was conducted to determine if individuals who received educational information after receiving their diagnosis significantly differed from individuals who were not given educational information on feelings of preparation to make treatment choices. The means and standard deviations for both groups are listed in Table 7. Levene's test was not significant, suggesting the two groups had equal variances on the dependent variable. The *t*-test did not reveal a significant difference between the two groups, $t(54) = 0.46, p > .05$.

Table 7

Means and Standard Deviations for Educational Materials

Received Educational Materials	N	M	SD	SE
No	20	3.00	1.08	0.24
Yes	36	2.86	1.10	0.18

Written Materials

An independent samples *t*-tests was conducted to determine if individuals who were offered written material that explained breast cancer significantly differed from individuals who were not offered written material that explained breast cancer on feelings

of preparation to make treatment choices. The means and standard deviations for both groups are listed in Table 8. Levene's test was not significant, suggesting the two groups had equal variances on the dependent variable. The t -test did not reveal a significant difference between the two groups, $t(54) = -0.24, p > .05$.

Table 8

Means and Standard Deviations for Research Written Materials

Offered Written Material Explaining Cancer	N	M	SD	SE
No	13	2.85	1.07	0.30
Yes	43	2.93	1.10	0.17

Counseling

An independent samples t -tests was conducted to determine if individuals who were offered counseling significantly differed from individuals who were not offered counseling on feelings of preparation to make treatment choices. The means and standard deviations for both groups are listed in Table 9. Levene's test was not significant, suggesting the two groups had equal variances on the dependent variable. The t -test did not reveal a significant difference between the two groups, $t(54) = 0.01, p > .05$.

Table 9

Means and Standard Deviations for Counseling

Offered Counseling	N	M	SD	SE
No	23	2.91	1.04	0.22
Yes	33	2.91	1.13	0.20

Support Groups

An independent samples *t*-tests was conducted to determine if individuals who were told about support groups significantly differed from individuals who were not told about support groups on feelings of preparation to make treatment choices. The means and standard deviations for both groups are listed in Table 10. Levene's test was not significant, suggesting the two groups had equal variances on the dependent variable. The *t*-test did not reveal a significant difference between the two groups, $t(54) = -0.31, p > .05$.

Table 10

Means and Standard Deviations for Support Groups

Told About Support Groups	N	M	SD	SE
No	11	2.82	1.17	0.35
Yes	45	2.93	1.07	0.16

Additional Information

The last question asked what additional information provided would have been helpful. Sixteen (27.1%) of the participants indicated that information on complementary alternative therapy would have been helpful. Seventeen (28.8%) of the participants indicated that information on dietary supplements and eating habits would have been helpful. Another sixteen (27.1%) indicated that literature about breast cancer prevention would have been helpful. And lastly, fifteen (25.4%) indicated that more literature about therapy would have been helpful.

Further comments that were delivered at the end of the survey regarding what additional information participants would have liked included “a visit right away with another breast cancer survivor” and “more support groups” and “financial assistance”. One participant indicated that “everything moved way too fast from the time of diagnosis- I wish I had time to talk to others”. Another respondent indicated that counseling for their family members would have been helpful. Three people indicated that they had all the information they wanted- “anymore would have been too much. I would have been on overload”. And two participants indicated that they were disappointed in not receiving enough; “anything would have been helpful. I was really disappointed”.

Summary

The data reported in this chapter consisted of the demographic and sociodemographic information and the interpretation of the questionnaires answered by participants in this study. The data included information regarding breast cancer risk factors, education received, and perceptions of education received. The evaluation of these results will be discussed in the next chapter.

CHAPTER 5

DISCUSSION

Introduction

A discussion of the findings is presented in this chapter, beginning with the findings concerning demographics, risk factors, and breast cancer education. The results of the following three research questions are then discussed: (1) What types of education were patients offered? (2) Did patients with breast cancer find the education helpful in preparation for treatment decisions? (3) What additional education would be helpful for women with breast cancer? The chapter concludes with a discussion of the study's limitations and implications for nursing and health care providers, followed by recommendations for future research.

The purpose of this study was to explore women's perception of the helpfulness and quality of educational materials they received at the time of their breast cancer diagnosis. The data from this study identified the quality and quantity of educational materials patients' received at the time of their diagnosis of breast cancer. This study also investigated the patients' perception of the materials they received. Additionally, the respondents were asked to identify the types of education that they found most helpful.

Evaluation of Results

The sample of participants was recruited from a monthly mailing to breast cancer survivors who were clients of the cancer clinic. A total of 168 women who met the

inclusion criteria were invited to participate in the study, and a total of 59 participants were included in the final data analysis. Protocols for the protection of human research participants were carefully followed during all stages of data collection and participant confidentiality was maintained during every phase of the study.

Demographics

The majority of respondents were Caucasian (n=56, 94.9%). This result was expected because the population of Montana is 90% Caucasian (United States Census Bureau [USCB], 2007). The mean age of respondents was 64 years old, with ages ranging from 42 to 80 years old. Heidrich (2006) identified the main risk factor for breast cancer as age; therefore, the reported age of the respondents was expected.

The educational attainment of the respondents matched the state average in Montana. All respondents (100%) had a minimum of a high school diploma. One quarter (25.4%) had a bachelor's degree, and 15.3% had a master's degree or higher. According to the USCB (2000), 87% of Montana's population aged 25 years or older are high school graduates, and 24% hold a bachelor's degree or higher.

The distribution of religious affiliations for participants also reflected that of the State of Montana. Over half (57.6%) of the respondents reported that they were Protestant, and 30.5% reported that they were Catholic. The USCB reported that 55% of Montana Residents are Protestant, while 24% are Catholic (2007).

Risk Factors

According to Buttaro, Trybulski, Bailey, & Sandberg-Cook (2008) a known risk factor for breast cancer is family history. A positive family history was reported in 16.9% of participants. “The risk of breast cancer development related to family history increases with the number of affected relatives, specific lineage, and age at diagnosis” (Lester, 2007, p.620). Women with a family history of breast cancer should obtain as much information as possible about affected relatives (Buttaro et al., 2008). A thorough cancer family history can help to more accurately decipher a hereditary connection. However, this study did not get into detailed specifics about cancer family history.

Postmenopausal hormone replacement therapy (HRT) is also a risk factor, and 57.6% (n=34) of participants indicated that they had taken hormone replacement therapy. Substantial evidence suggests that HRT increases the risk of initial diagnosis of breast cancer. Until recently, advice about HRT was mixed. However, in December of 2003, multiple clinical trials found a statistically significant increased risk of breast cancer related to HRT (Norman et al., 2007). A limitation of this study was that it did not examine when the participants took HRT, and only asked if they had ever taken any HRT. Though the findings concerning risk factors were not statistically significant, the data was interesting.

Breast Cancer Education

Education can improve outcomes and optimize quality of care and healthcare costs (Geffen, 2006; Donaldson, Rutledge, & Pravikoff, 2000). Therefore, education is a critical part of the pre-treatment phase of a cancer diagnosis. Participants were asked

where they had received their educational materials about breast cancer, and 71.2% responded that they had received their educational materials from the cancer treatment facility. One fourth (25.4%) of the respondents said that they were educated by their physicians, and another 44.1% claimed they were educated by their nurse. Lobb, Butow, Kenny, & Tattersall (1999) discussed the importance of the role the healthcare provider plays in not only providing materials to the patients, but also in taking the time to discuss the diagnosis and treatment.

The American Cancer Society (2004) stresses the importance of the patient-healthcare provider relationship, as it becomes a critical component of relaying information and communication. Over half (54.2%) of the respondents in the study reported that they were informed of their diagnosis by their surgeons and 27.1% reported that they were informed by their primary care providers. Back and Arnold (2006) concluded that after diagnosis, a majority of patients want to discuss prognosis, and they stress the importance of discussing with patients all of the information that they patients desire to know.

Almost half (42.4%) of the respondents reported that they felt they had already accepted the diagnosis before it was received. Meechan, Collins, Moss, and Petrie (2005) urge healthcare providers to begin education before a diagnosis is given, when symptoms of cancer are being explored. The majority of participants have already accepted a breast cancer diagnosis; therefore, it may be beneficial to begin education immediately. A large majority of respondents (79.7%) indicated that immediately after their breast cancer

diagnosis, they felt ready to learn. Another 10% indicated that within one month, they felt ready to learn.

If education is begun earlier in the process of breast cancer diagnosis, the patients may begin to accept their diagnosis sooner. The process of being diagnosed with breast cancer can last a few weeks. Usually, a woman has a mammogram followed by an ultrasound and then a biopsy (Buttaro, Trybulski, Bailey, & Sandberg-Cook, 2008). These medical tests often do not all occur in the same day, so women are sent home to worry about their test results. After all this worrying, it may be a relief to finally have a diagnosis, even if that diagnosis is breast cancer. This time lapse provides one explanation for why nearly half of the respondents felt they had accepted their breast cancer diagnosis before they were given the diagnosis. Additionally, the medical testing period gives patients time to prepare for learning.

This study yielded a high return rate of completed surveys from a single mailing, nearly 40%. Dilman (2007) suggests a minimum of three mailings may provide a response rate of only 25%. Due to time and money limitations, only one mailing was sent. After the survey deadline, candidates were still calling to see if they could mail in their surveys. Participation in a research study was clearly an important issue to breast cancer survivors. There are multiple reasons for this high response rate. All the respondents had survived breast cancer; therefore, it is possible they wanted to help others.

Educational Materials Offered to Patients

A majority of participants (74.6%) reported that they were given pamphlets, and 15.3% reported that they were given magazines. Both of these materials are considered

written materials for the patients to read on their own. According to the literature (Masek, 2000), adults will only remember 10% of what they read. Additionally, 8.5% of participants were given a video or DVD to watch.

All adults learn differently; some are visual learners, while others are audio learners (Russell, 2006); therefore, it would be helpful to incorporate various learning styles and tailor the materials to the learning needs of each individual. When providing written hand-outs, the educator must assess the reading level and cognitive capacity of the patient (Donaldson, Rutledge, & Pravikoff, 2000). Additionally, according to Masek (2000), with adult learning theory, it is critical to find out “what they already know” (p.35) and aim to build upon their knowledge base.

Patterson (2000) recommends targeting education to the population’s needs and preferences, together with the available facilities and resources. By targeting education to the specific population, education outcomes can be improved by identifying specific learning styles. This study’s participants were mostly Caucasian women in their 60s or 70s. It may be beneficial to further explore the learning needs of older adult women.

Helpfulness of Education in Preparation for Treatment Decisions

A total of 22 (39.3%) participants felt that the education they were given was “very helpful” in treatment choices, whereas another 15 (26.8%) felt that the education was only “helpful.” Eleven (19.6%) indicated that the education was “somewhat helpful,” and 8 (14.3%) felt that the education was “not helpful” in providing information about treatment choices.

Four independent sample *t*-tests were conducted on the data to see if there was a mean difference between respondents who answered “yes” and those who answered “no” on the following questions in terms of their feeling of preparation to make treatment decisions at the time of their diagnosis. A critical question in this questionnaire was research question two: How much did the information you received prepare you to make choices about your treatment? The respondents answered the feelings of preparation based on a scale of “very helpful; helpful; somewhat helpful; or not helpful.” This question was used as the dependent variable and the following four separate questions from the questionnaire were used as the independent variable: 1) When you received your diagnosis, did someone hand you educational information? 2) Were you offered written material that explained breast cancer? 3) Were you offered any counseling? and 4) Were you told about support groups? The significance level for these *t*-tests was set at 0.05 (which is an acceptable level for a study) and all four *t*-test values were above 0.05. Therefore, they failed to reveal significance between the two groups on the independent variables of “yes” and “no”.

Several factors can explain why the *t*-tests were not statistically significant. First, the sample was small (59). Second, the sample was homogenous. The participants, for the most part, fit a similar profile: female, Caucasian, and over the age of 50. Thirdly, the questions may not have been clear-cut to the participants and since it was a mail survey, there was no chance for participants to inquire about questions they may not have understood. There were no significant statistical differences. However, there were interesting differences found in the data explained in the next paragraph.

The four independent sample *t*-tests failed to show significance, however, the respondents who received educational material and/or were offered counseling felt slightly better prepared to make decisions about their cancer treatment. However, those who received written materials and/or those who were offered support groups at the time of diagnosis said they felt slightly less prepared to make decisions about treatment. With written educational materials, as well as with support groups, there would be no assurance that the patient actually read or went to the support group. This could be one explanation for why they felt less prepared.

Additional Education Perceived Helpful for Women with Breast Cancer

A majority of respondents felt that more information would have been helpful. Almost a third (28.8%) wanted more information on dietary supplements and nutrition. Another third (27%) felt information on complementary therapy and breast cancer prevention would have been helpful. Lastly, 25.4% felt that they needed more information on treatment options. These high numbers indicate that several areas of learning are still not being adequately addressed.

Back and Arnold's (2006) study concluded that at least 80% of patients want detailed information. With a high percentage of respondents indicating a need for additional education, providers need to offer more detailed information to patients. Back and Arnold (2006) suggest asking patients what information they want to know, as well as what they don't want to know. By asking patients about their needs, explicit discussions that meet individual patients' needs can occur.

Limitations

Findings from the present study should be interpreted with care for several reasons. The sample was recruited from the patient population of one medium-sized cancer clinic in northwestern Montana and was not available to the general population of breast cancer patients and survivors. The sample was a convenience sample of self-selecting adult women with breast cancer who were patients of the cancer clinic. A convenience sample will limit the generalization of results because essentially all respondents of a convenience sample may have commonality.

The present study was retrospective. As with all retrospective data, the findings reflect limitations in measurement sensitivity (Gordis, 2004). All respondents were on the breast cancer survivor mailing list of the cancer clinic. When recalling events, particularly during a stressful time such as a breast cancer diagnosis, respondents may not remember accurately. They may want to block out the bad memories and only remember what was good about their experience. This would be considered recall and information bias, which are common in retrospective studies (Gordis, 2004).

The cross-sectional design of the study was a limitation because it provided a snap shot of time, and therefore the data may not be accurately applied to another timeframe. However, this is a benefit of the cross section design and allowed the researcher to collect a large amount of data in a short period of time.

The study was a mail survey, so there was no personal contact with respondents, and therefore no control over the surveys. Furthermore, as there was only one mailing for

this study, this may have limited the amount of responses the researcher was able to collect (Dillman, 2007).

The questionnaire developed for this study was comprised of multiple choice questions, leaving the respondents with limited choices. There is a possibility that respondents may have answered the questions differently had other options been available to them. There was only one question concerning the perceived helpfulness of the education. Lastly, the questionnaire was not tested for reliability or validity.

Implications for Nursing Practice

Despite the identified limitations, the results of this study have implications for the practice of nursing and nursing research. This study highlighted the importance of educational needs for breast cancer patients. When providing education to the patient, it may be best, as previously noted, to initiate the education process earlier than at the time of the diagnosis. According to Meechan, Collins, Moss, and Petrie (2005), “Studies have shown that women with benign breast symptoms and those with breast cancer experience similar levels of anxiety in the time from initial symptom discovery until receiving a definitive diagnosis” (p. 239). Worry will begin even before a diagnosis is given. Therefore, education should be provided as soon as the symptoms of breast cancer are discovered or manifested.

To optimize learning, a combination of educational materials may be the most effective. For example, healthcare workers need to distribute handouts prior to a patient’s appointment and allow the patient to read and visualize the materials and then have the

health care provider explain the materials (Masek, 2000). Additionally, patients need to be instructed to come in with a list of questions for their healthcare providers. The stress of a cancer diagnosis may overwhelm the patient, but by arriving at appointments prepared, the patient will be less likely to forget important questions. At a time when patients are least likely to learn optimally because of conditions affected by their health, they are confronted with huge informational needs (Donaldson, Rutledge, & Pravikoff, 2000). Healthcare providers can help breast cancer patients become proactive in their treatment.

A number of participants indicated that additional information would have been helpful. Further education in the following areas was recommended: complementary alternative therapy, dietary supplements, nutrition, breast cancer prevention, and therapy. These findings are supported by Lobb, Butow, Kenny, & Tattersall (1999), who suggest investigating patients' knowledge to ensure that patients have a thorough understanding of treatment.

Implications for Nursing Research

The implications for future research were derived from a review of the literature and the results of this study. For example, research identifying when women begin to gain knowledge about breast cancer is needed. Though this study identified the sources women consult to gain information about breast cancer and pinpointed when they feel prepared to learn, it failed to explore when they actually began their education. Based on the level of acceptance of diagnosis and the desire to immediately learn, it would be

valuable to explore if women are receiving an adequate education prior to breast cancer diagnosis.

Findings from this study did not match the current (American Cancer Society) identifiable risk factors for breast cancer; therefore, future research re-evaluating risk factors for breast cancer would be valuable. A majority of women in this study did not have any known risks factors for breast cancer. Though this study was a descriptive design, it laid the groundwork for future research. This study could provide a foundation for a comparative study that examines written versus verbal education, or for a study comparing educational pamphlets versus DVDs.

Conclusions

This study was designed to contribute information to cancer clinics concerning breast cancer education. The Adult Learning Theory provided the framework used to guide this study. Knowles theorized that adult learning is promoted when a need for the adult to learn and a readiness of applicability of the information to one's life situation exist (Russell, 2006; Mitchell & Courtney, 2006). For the purpose of this study, it was assumed that the diagnosis of breast cancer served as motivation to learn. In adults, the adult is responsible for his or her own learning (Mitchell & Courtney, 2006). Therefore, the healthcare provider cannot force the adult to learn, but can provide the adult with materials necessary for learning to take place.

Findings from this study provided important information about breast cancer education and the perceived learning needs of women who have survived breast cancer.

Healthcare providers are in a pivotal position to provide crucial educational information to patients. As this study has shown, education can improve outcomes. Well thought out and strategically planned educational interventions should combine several methods of teaching. Implications for both nursing practice and research have been presented. Determining the educational needs of breast cancer survivors requires further research.

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APPENDICES

APPENDIX A

CONSENT LETTER

Title: Patient's Perception of the Helpfulness of Education Materials for Breast Cancer.

Principal Investigator: Kimberly Keough Heck, RN, BSN

Co investigator (Instructor): Clementine Rice, PhD, RN, CNS.

INFORMATION LETTER

A. Introduction and Purpose

You are being asked to participate in a research study conducted by a graduate nursing student from Montana State University, College of Nursing. The purpose of this study is to explore the current quality of educational materials women receive at the time of diagnosis for breast cancer and to identify various types of education the patient believes would be helpful.

B. Procedure

You will be asked to complete the questionnaire that has been handed to you by the oncology nurse at the clinic where they are receiving treatment. The estimated completion time for this instrument is 10 minutes.

C. Benefits

There is no direct benefit to you if you participate in this study. The results from this study will provide information that may be used to help cancer treatment centers provide appropriate helpful information for their future patients.

D. Risks

No risks or additional effects are likely to result from your participation in this study. In the unlikely event of harm arising from your participation, no reimbursement, compensation, or free medical treatment will be offered by Montana State University, or the researcher. If you become distressed due to the questions on the study questionnaire you will be referred to discuss this with your oncologist.

E. Voluntary Participation/Withdrawal

Your participation in this study is voluntary and you are free to withdraw at any time. If you should choose to withdraw from the study you will in no way be compromised. Because we are not asking you to sign this survey or for any

other identifier, after your information has been entered into the computer it will no longer be identifiable.

F. Costs

There are no costs involved in your participation in this study.

G. Compensation

There is no compensation being offered for your participation in this study.

H. Confidentiality

All information collected from the course of this study will be kept confidential to the extent permitted by law. All identification in the research records will be by ID number only, and the completed questionnaires will be stored in a locked file cabinet that will be accessible only to the investigator and instructor. All results will be summarized and presented in aggregate; no individual participant will be identifiable.

I. Questions

If you have any questions about the items on the questionnaire or the purpose of the study, please feel free to contact the investigators at your earliest convenience. Ms. Heck or Dr. Rice can be contacted at 406-771-4450. If you would like information regarding your rights as a research participant, please feel free to contact Dr. Mark Quinn, chairman of Montana State University, Internal Review Board 406-994-5721.

J. Consent to participate in a research study

The return of your completed questionnaire is evidence of your willingness to participate in this study. You will not be asked to sign a separate “willingness to participate” document because of participant anonymity. Please retain this information letter in case you have any questions or would like additional information about this study.

APPENDIX B

DEMOGRAPHIC DATA SHEET

Demographics/Sociodemographics

Please fill in blank or circle answer

Date: _____

ID number (Particpate, leave blank):

- (1) Year of birth: _____
- (2) Height: _____
- (3) Weight: _____

- (4) Current marital status:
 - a. single
 - b. married
 - c. divorced
 - d. widowed

- (5) Race:
 - a. African-American
 - b. Asian
 - c. Caucasian
 - d. Hispanic
 - e. Native American
 - f. Other (explain) _____

- (6) Years of education:
 - a. high-school diploma
 - b. bachelor's degree
 - c. master's degree
 - d. PhD
 - e. Other (explain) _____

- (7) Occupation/profession: _____

- (8) Religion:
 - a. Catholic
 - b. Protestant
 - c. Jewish
 - d. Latter-Day Saint
 - e. Other (explain) _____

- (9) With whom do you currently live?
- Self
 - Spouse
 - Significant other
 - Parent(s)
 - Sibling
 - Other (explain)_____
- (10) Size of community you live in:
- Less than 500
 - 500 to 2499
 - 2500 to 10,000
 - Greater than 10, 000
- (11) If you live outside Great Falls, how many miles away:
- Less than 10
 - 10 to 49
 - 50 to 99
 - Greater than 100
- (12) Age at first Menstruation_____
- (13) Age at Menopause, if applicable_____
- (14) Age at first pregnancy, if applicable_____
- (15) Number of children breast fed, if applicable_____
- (16) Family history of breast cancer (circle all that apply)
- Mother
 - Sister
 - Maternal grandmother
 - Paternal grandmother
 - Maternal aunt
 - Paternal aunt
 - Other (explain) _____

(17) Have you ever been on hormone replacement therapy?

- a. Yes
- b. No

(18) On an average, how many alcoholic beverages do you consume in a week?

- a. 1-2
- b. 3-7
- c. 7-10
- d. 10 or more
- e. None

APPENDIX C
QUESTIONNAIRE

f. Questionnaire for participants

- (1) What year did you receive your diagnosis of breast cancer? _____
- (2) When you received your diagnosis did someone hand you educational information?
- a. Yes
 - b. No
- (3) Were you offered written material that explained breast cancer?
- a. Yes
 - b. No
- (4) Were you offered any counseling?
- a. Yes
 - b. No
- (5) Were you told about support groups?
- a. Yes
 - b. No
- (6) What types of information were you given that discussed treatment options?
(Circle all that apply)
- a. Pamphlets
 - b. Magazines
 - c. Video or DVD
 - d. Other (explain) _____
- (7) Who informed you of your diagnosis?
- a. Primary care provider
 - b. Gynecologist
 - c. Oncologist
 - d. Nurse
 - e. Other _____

(8) What is your recollection of your initial reaction to the diagnosis of breast cancer?

- a. Acceptance
- b. Anger
- c. Bargaining
- d. Denial
- c. Grief
- d. Other (explain)_____

(9) After diagnosis, when do you think you were ready to learn about breast cancer?

- a. Immediately
- b. Within a month
- c. One month to 6 months
- d. Six months to one year
- e. Greater than one year
- f. Never

(10) Where did you learn what you currently know about breast cancer? (Circle all that apply)

- a. Materials provided for you at facility
- b. Physician
- c. Nurse
- d. Internet
- e. Family
- f. Other (explain) _____

(11) How much did the information prepare you to make choices about your treatment?

- a. Not helpful
- b. Somewhat helpful
- c. Helpful
- d. Very helpful

(12) What additional information provided would have been helpful?

- a. Information on complementary alternative therapy
- b. Information on dietary supplements, eating habits
- c. Literature about breast cancer prevention
- d. Literature about therapy
- e. Other (explain)_____

APPENDIX D

INTERNAL REVIEW APPROVAL LETTER

November 26, 2007

Kimberly Heck is authorized to add a survey to the regular monthly mailing to breast cancer survivors from the Great Falls Clinic. The surveys were mailed out by the Great Falls Clinic and the returned surveys will remain anonymous. Respondents will not be asked to sign or identify themselves. The return of the completed survey will constitute informed consent of the volunteer participants. Mrs. Heck will have no personal contact with the respondents for this study.

Dr. Christine Kowalski EdD., MIA
Director of Oncology Services: Clinic Cancer Care

Kimberly Heck BSN, RN
Graduate MN student

APPENDIX E

LETTER OF INSTURCTION

Montana State University, College of Nursing
400 15th Ave South, Suite 106
Great Falls, MT 59405
November 27, 2007

Dear Breast Cancer Survivor

My name is Kimberly Heck and I am a graduate student in the Family Nurse Practitioner (FNP) program at Montana State University, College of Nursing. I would like to invite you to participate in a nursing research study that I am conducting at the Great Falls Clinic (GFC). The purpose of this study is to look at the quality and quality of educational materials you received at the time of your diagnosis of breast cancer. Additionally the study will explore with you, the various types of educational materials and/or programs, you believe would have been helpful to you and your family.

You will be asked to complete the questionnaire that is included in this mailing from the GFC. Please return your completed questionnaire in the pre addressed stamped envelope that has been provided. In the interest of confidentiality, you are asked not put your return address or your name anywhere on the questionnaire because the information that you provide will remain anonymous. All information collected from this study will be kept confidential to the extent permitted by law. No individual participant will be identifiable and the data you provide will be presented in aggregate in any future publications.

There are no risks or additional effects that are likely to result from your participation in this study. If however any of the questions cause you discomfort or anxiety you are asked to discuss this problem with your health care provider at your next scheduled visit to the GFC. Your participation in this study is voluntary and you are free to discontinue your participation at any time during the course of the study. If you decide to discontinue your participation in this study, your care at the GFC will not be compromised in any way.

There are no costs involved nor compensation offered for your participation in this study. If you have any questions about the questionnaire, please feel free to contact me at (406) 406-771-4450 or my advisor Dr. Clementine Rice at (406) 771-4450. If you would like information regarding your rights as a participant, please feel free to contact Dr. Mark Quinn, the chairperson of MSU, Bozeman, internal review board (406) 994-5721

The results from this study will provide information that may be used to help cancer treatment centers provide appropriate helpful information for their future patients.

I would like to thank you in advance for your participation in this study.

Sincerely

Kimberly Heck, RN BSN (MN Student)