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Chemotherapy Knowledge And Health Literacy Among Women With Breast Cancer

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CHEMOTHERAPY KNOWLEDGE AND HEALTH LITERACY AMONG WOMEN WITH
BREAST CANCER

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DEDICATION

This dissertation is dedicated to my grandmother, Nanny. Your kind and gentle spirit guided me along the way and may red birds forever be in my sight. You taught me to see the magic in the world, and may your love never stop flowing in my veins and through my words. I also want to dedicate this dissertation to my parents, Dr. James V. Parker, Jr. and Suzanne deTreville. You felt what I felt and saw what I saw, but always encouraged me to press forward. You endured every obstacle, battle, and joy in this journey at my side. You gave me hope and perspective. Daddy, thank you for your late-night revising sessions, impromptu phone calls, and always reminding me to keep questioning. Momma, words cannot express my gratitude. Thank you for being my strength when I could not stand and constantly reminding me to “hunker down.” May I be a vessel to improve the lives of others through research and bring all of you honor.

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ABSTRACT

Chemotherapy education is imperative for patients to gain the knowledge to manage side effects, adhere to prescribed cycles, and recognize the severity of symptoms that require immediate provider contact. Two vital factors – the readability of teaching materials and the patient’s health literacy – must be considered during chemotherapy education. However, materials are often not assessed for readability. Further, the influence of a patient’s health literacy level and demographic factors on chemotherapy knowledge has not yet been investigated. The specific aims are to: (1) critique the readability and format of chemotherapy education materials; (2) explore how women with breast cancer perceive chemotherapy education; and (3) examine the relationships of a patient’s health literacy level and demographic factors with chemotherapy knowledge.

Forty-six women with breast cancer on intravenous chemotherapy were recruited from a large comprehensive oncology center. The women were surveyed in person and five instruments were administered: (1) demographic data form; (2) chemotherapy educational resource use form; (3) Rapid Estimate of Adult Literacy – Short Form; (4) Short Test of Functional Health Literacy in Adults; and (5) a revised Leuven Questionnaire on Patient Knowledge of Chemotherapy. Readability of the chemotherapy education materials was assessed using the: (1) Flesch Reading Ease; (2) Flesch-Kincaid; and (3) Simple Measure of Gobbledygook. Format of the materials was evaluated using the Suitability Assessment of Materials scoring. Thematic analysis was used to describe the experience of 37 participants undergoing chemotherapy education. Descriptive and

inferential statistics were calculated to identify which factors influenced chemotherapy knowledge.

The readability scores of the chemotherapy education materials ranged from 7th to a 12th grade reading level; areas most challenging for the reader pertained to information about treatment and chemotherapy drugs. The thematic analysis revealed three major themes: (1) finding control in learning; (2) receiving unexpected support; and (3) learning in unforeseen ways. Health literacy, income, and marital status were significantly related to chemotherapy knowledge.

This study highlights the importance of health literacy and social support in positively affecting chemotherapy knowledge despite the challenging reading levels of educational material. Future research should be directed to illuminate the effects of readability and health literacy across a spectrum of patients with a variety of cancers.

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CHAPTER 1

INTRODUCTION

More than 3.5 million women in the United States (US) have a history of breast cancer – the most common cancer among women (American Cancer Society [ACS], 2017a) . Currently more than 252,710 women will receive a new breast cancer diagnosis and an additional 40,610 will die from the disease this year (ACS, 2017a). The incidence rate of breast cancer for women in the US is 124.7 per 100,000, and the incidence rate in South Carolina is slightly increased at 128.3 per 100,000 women (National Cancer Institute [NCI] , 2018a). The current mortality rate of breast cancer for women in the US is 20.9 per 100,000 and the mortality rate in South Carolina is slightly higher at 22.2 per 100,000 (NCI, 2018a).

Age is associated with increased breast cancer incidence and mortality. Breast cancer incidence and mortality increases as women get older (ACS, 2017a). The median age of women diagnosed with breast cancer is 62, and 79% of women with a new breast cancer diagnosis are more than 50 years of age (ACS, 2017a).

Evidence suggests breast cancer incidence and mortality rates are disproportionate among women of different ethnicities. Non-Hispanic White women have the highest incidence of breast cancer across most age groups, whereas African American women have the highest mortality rate at every age. The incidence rate for White women in the United States is 128.7 per 100,000, compared to African American women who have a lower incidence at 125.5 per 100,000 (ACS, 2017a). African American women have an

increased mortality rate of 29.5 per 100,000, whereas the mortality rate is lower for non-Hispanic White women at 20.8 per 100,000 (ACS, 2017a). Alaska Native and American Indian women have a similar breast cancer incidence as Hispanic women of 90.7 per 100,000 (DeSantis et al., 2015). Asian and Pacific Islander women have the lowest incidence (90.7 per 100,000) and lowest mortality rates (11.3 per 100,000) than all other ethnicities (ACS, 2017a).

Lifestyle and reproductive factors contribute to these staggering statistics (ACS, 2016c). Post-menopausal women who exercise regularly have a 10-25% reduced risk of breast cancer compared to women who are inactive (Hildebrand, Gapstur, Campbell, Gaudet, & Patel, 2013; Ibrahim & Al-Homaidh, 2011; Wu, Zhang, & Kang, 2013). Wu, Zhang, and Kang (2013) identified that post-menopausal women who walk less than three hours per week have a 14% increased risk of breast cancer compared to women who walked at least seven hours per week. Lack of physical activity can lead to obesity, which is associated with an increased risk of breast cancer (Calle & Kaaks, 2004). Women who are obese have two times the relative risk of breast cancer than women of normal weight (La Vecchia, Giordano, Hortobagyi, & Chabner, 2011).

Similarly, other factors such as age when giving birth and breastfeeding can impact breast cancer risk (ACS, 2016a; Colditz & Rosner, 2000). Women who do not give birth or give birth after 35 years of age have an increased risk of breast cancer (Colditz & Rosner, 2000). Conversely, women who give birth before 20 years of age have a 50% reduced lifetime risk of breast cancer (ACS, 2017a). Breastfeeding can also reduce breast cancer risk (Collaborative Group on Hormonal Factors in Breast Cancer, 2002). Breastfeeding is inversely associated with the overall risk of breast cancer (Islami

et al., 2015). Women can reduce their risk of breast cancer up to 4.3% for every year of breastfeeding with an additional 7% reduction for each birth (Collaborative Group on Hormonal Factors in Breast Cancer, 2002).

The care of women with breast cancer spans from prevention to survivorship or palliative care. However, breast cancer treatment is most critical to survival (NCI, 2018c). Oncologists determine the treatment plan by a series of characteristics such as type of breast cancer, tumor stage, and location of tumor (NCI, 2018c). Types of treatment include surgery, chemotherapy, hormonal therapy, and radiation therapy (Centers for Disease Control and Prevention [CDC], 2013). The length and frequency of treatment varies depending on certain qualities such as the patient's type of breast cancer, tumor size and grade, and presentation of metastasis (ACS, 2014). Regardless of the various characteristics of a woman's cancer, chemotherapy remains one of the most common treatments for breast cancer.

Chemotherapy

Annually, more than 72,000 women with breast cancer undergo chemotherapy treatment (National Cancer Database, 2018). Chemotherapy is used to destroy cancer cells by ceasing or slowing the growth of the cancer cell's division (NCI, 2011). The goals of chemotherapy are classified into four categories: 1) curative; 2) neoadjuvant; 3) adjuvant; or 4) palliative (Institute for Quality and Efficiency in Health Care, 2016). Curative chemotherapy is designed to eliminate the presence of cancer cells thereby achieving a cure. Neoadjuvant chemotherapy is given to shrink large tumors prior to surgery whereas adjuvant chemotherapy is administered to kill remaining cancer cells after surgery. The purpose of palliative chemotherapy is to reduce tumor size and relieve

symptoms caused by the tumor (Institute for Quality and Efficiency in Health Care, 2016).

Chemotherapy can be administered several ways including intravenous (IV), subcutaneous or intramuscular injection, intraperitoneal, intra-arterial, oral, or topical (Polovich, Olsen, & LeFebvre, 2014). Chemotherapy administered through the IV is the most common and usually requires the patient to travel to an infusion center for a certain number of days during a cycle (ACS, 2015b). The length of chemotherapy cycles varies, but most last three weeks and are designed to promote recovery between doses (ACS, 2015b; Polovich et al., 2014). The type of chemotherapy is determined by a variety of factors including the patient's breast cancer diagnosis (size and grade of tumor and presence or absence of certain receptors), overall health, and response rates of a drug (Polovich et al., 2014). The most commonly prescribed chemotherapy drugs for breast cancer include: anthracyclines (doxorubicin, epirubicin), taxanes (paclitaxel, docetaxel), 5-fluorouracil, cyclophosphamide, and carboplatin. Oncologists often prescribe a combination of two or three of these drugs which is more effective at killing cancer cells (ACS, 2016d).

The most common side effects associated with these drugs include hair loss and nail changes, mouth sores, changes in appetite, and gastrointestinal upset (ACS, 2016d). However, the side effects can vary in intensity based on the drug, dosage, and length of treatment. Specifically, the taxanes, carboplatin, and epirubicin can cause neuropathy, or nerve damage, which creates a painful, tingling sensation in the hands and feet. Doxorubicin can cause heart damage and hand-foot syndrome where hands and feet swell and blister. Additionally, several of the chemotherapy drugs can cause chemo brain

which is described by patients as mental cloudiness and the source of memory problems (Evens & Eschiti, 2009). Chemotherapy can also lower the amount of white blood cells which can lead to potentially life-threatening infections. Patients may also experience increased bleeding with clotting impairments due to thrombocytopenia.

Thrombocytopenia is potentially fatal and requires immediate attention by a health care provider (ACS, 2016d). Given the numerous potential side effects and complications of chemotherapy, patients must learn self-care skills and know when to contact a provider during a life-threatening emergency. Effective chemotherapy education is crucial in equipping patients with the knowledge and skills needed during treatment (Valenti, 2014).

Chemotherapy Education

Patients undergoing chemotherapy treatment have a greater need for education compared to areas of prevention and screening (Hopkins & Mumber, 2009). Patients may be concerned about the decline of their health, upcoming treatment, and confrontation with death (Harrison, Maguire, Ibbotson, Macleod, & Hopwood, 1994). More specifically, patients with breast cancer may experience heightened levels of anxiety when embarking on specific types of treatment like chemotherapy (S. Garcia, 2014; Prouse, 2010). Patients have increased informational needs surrounding chemotherapy treatment making chemotherapy education a necessary and critical element to oncology care (Valenti, 2014).

Chemotherapy education is the impetus to generate and increase chemotherapy knowledge – a concept critical to patients with cancer (Warren, 1979). Chemotherapy knowledge is imperative for patients with cancer equipping them to respond to potentially

fatal side effects like infections (Shah et al., 2016) and increase daily safety precautions such as handwashing (Wai Chi & Ching, 2015). Increased chemotherapy knowledge is associated with patients responding faster to complications like neutropenia and thrombocytopenia (Myers, Davidson, Hutt, & Chatham, 1987; Wai Chi & Ching, 2015). Given the benefit of generating and increasing chemotherapy knowledge, focusing on patient education is imperative to improving overall health outcomes (Rigdon, 2010).

Nurses' Role in Chemotherapy Education

Nurses are instrumental in chemotherapy education and generating chemotherapy knowledge. They are on the forefront of educating patients about chemotherapy, administering the drugs, and guiding patients through treatment (Rieger & Yarbrow, 2003). Ultimately, the goals of chemotherapy education are to teach patients how to manage their side effects, practice self-care to decrease symptom distress, and improve their quality of life throughout the process (Rieger & Yarbrow, 2003; Traeger et al., 2015; Williams & Schreier, 2004). Generating and increasing chemotherapy knowledge among patients is a catalyst in patients practicing self-care while on chemotherapy (Coolbrandt et al., 2013; Warren, 1979).

Nurses may use numerous delivery methods to increase knowledge in chemotherapy education. Examples of teaching materials include, printed materials, verbal instruction, and multimedia programs that use tablets or computers (Henderson, Gosbee, Classen, & Johnson, 2015; Morgan, Laing, McCarthy, McCrate, & Seal, 2015; Valenti, 2014). Printed materials can include complementary medicine brochures, medication inserts, and home care instructions (S. F. Garcia, Hahn, & Jacobs, 2010; P. J. Smith, Clavarino, Long, & Steadman, 2015). Verbal instructions can include teachings

on the purpose of chemotherapy, required dosages, and length of treatment (S. F. Garcia et al., 2010; Rieger & Yarbrow, 2003). Additionally, nurses may include vital information about adverse effects of chemotherapy (Williams & Schreier, 2004). Nurses may choose from a variety of options to supplement their chemotherapy education including interactive software such as CancerHelp®, smartphone applications such as Breast Cancer: Beyond The Shock®, and video programs (CancerHelp Institute, 2016; National Breast Cancer Foundation Inc, 2015; Schofield et al., 2008). Despite a wide array of teaching strategies, nurses need to consider each patient's specific learning needs to maximize comprehension (Dalby et al., 2013).

In summary, the purpose of chemotherapy education is to equip patients with self-care skills by generating and enhancing knowledge of chemotherapy. The patient's comprehension of chemotherapy education is driven by numerous factors including modes of instruction (Felder & Silverman, 1988) and learning styles (Dalby et al., 2013; Foltz & Sullivan, 1999). The most critical of these components to generating and increasing chemotherapy knowledge is her health literacy.

Health Literacy

A patient's health literacy is distinct from his or her general literacy (Schillinger, 2001). Patients may lack understanding of medical information despite overall moderate levels of general literacy (Davis, Williams, Marin, Parker, & Glass, 2002). Though multiple definitions of health literacy exist (Baker, 2006; Berkman, Davis, & McCormack, 2010; Davis et al., 2002), Nutbeam's (1998) definition is one of the most frequently cited.

Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment. Health literacy is itself dependent upon more general levels of literacy. Poor literacy can affect people's health directly by limiting their personal, social and cultural development, as well as hindering the development of health literacy. (Nutbeam, 1998, p. 357).

Baker's (2006) definition of health literacy is also commonly accepted, and includes the role of the health care system.

Thus, "health literacy" is determined by characteristics of both the individual and the health care system. Health literacy is one of many factors (e.g. culture and social norms, health care access) that leads to the acquisition of new knowledge, more positive attitudes, greater self-efficacy, positive health behaviors, and better health outcomes. (Baker, 2006, p. 880).

These definitions of health literacy broadly represent the knowledge and skills a person must have in order to address his or her health demands in a modern society (Sørensen et al., 2012).

Health Literacy in the United States

The National Center for Education Statistics (NCES) administered the National Assessment of Adult Literacy (NAAL) among 19,000 adults in the United States in 2003. The NCES included 28 health literacy items as a major subscale in the instrument

(Kutner, Greenberg, Jin, & Paulsen, 2006). The 28-item subscale is regarded as the first national health literacy survey (National Center for Education Statistics, 2003) in the United States. Respondents' answers were scored and ranked into one of four levels: *proficient*, *intermediate*, *basic*, and *below basic* (Kutner et al., 2006).

According to the most recent survey which was conducted in 2003, 12% of adults with proficient health literacy, 53% with intermediate health literacy, 22% with basic health literacy, and 14% with below basic health literacy (Kutner et al., 2006). In other words, 12% of adults with *proficient* health literacy could calculate health insurance costs, find medical information in a complex document, and evaluate information in a legal document. For the 53% of adults with *intermediate* health literacy, they could correctly identify interactions listed on a label for over-the-counter drugs or determine a healthy weight based on a chart of body mass index (BMI). The 22% of adults with *basic* health literacy could explain two reasons for screening medical tests, and all of those with *below basic* health literacy could identify a date on an appointment reminder card (Kutner et al., 2006). Based on the results of the NAAL survey, only 12% of adults have *proficient* health literacy meaning 78% of adults are limited in some way by their health literacy (Kutner et al., 2006).

Patient implications. Based on the results of the NAAL survey, a surprising amount of adults are restricted in some way by their health literacy. Patients with limited health literacy skills are more likely to have an inadequate understanding of prescription drug labels (Wolf, Davis, Tilson, Bass, & Parker, 2006), and many patients lack the skills to take medications properly (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Patients with limited health literacy skills have difficulty in identifying their disease-

specific medications such as cardiovascular drugs for treating chronic heart disease (Kripalani et al., 2006). Consequently, a significant association exists between poor self-management with a chronic illness such as asthma (Federman, Wolf, Sofianou, Martynenko, et al., 2014; Federman, Wolf, Sofianou, O'Connor, et al., 2014; O'Connor et al., 2015) and diabetes (Bailey et al., 2014; Ferguson et al., 2015), resulting in more frequent hospitalizations (Baker, Parker, Williams, & Clark, 1998; Berkman et al., 2011). Patients with limited health literacy skills are more likely to have difficulties in navigating the health care system (Baker et al., 1996) and more likely to incur higher costs in clinical settings (Haun et al., 2015; Mantwill & Schulz, 2015). Patients with limited health literacy skills pay \$1543 more for each cost of inpatient service than patients with adequate health literacy (Howard, Gazmararian, & Parker, 2005).

Researchers from The George Washington University estimated the economic impact of patients with limited health literacy skills on the national economy to be \$106 billion to \$236 billion annually (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). The authors attributed the financial implications related to problems in completing health insurance applications, following drug prescription labels, and communicating with health care providers (Vernon et al., 2007).

Health Literacy and Chemotherapy Education

Verbal Communication

Nurses must consider a patient's health literacy when educating about chemotherapy (Mann, 2011). Patients may be unfamiliar with vocabulary terms such as *lesion* or *metastasis*, which is challenging for patients to understand cancer-related information (Davis et al., 2001). Topics such as self-monitoring for adverse effects of

chemotherapy may also be difficult for patients (Huynh & Trovato, 2014).

Consequently, patients with limited knowledge about adverse effects of chemotherapy experience greater hospital admissions, increased morbidity, and decreased quality of life (Huynh & Trovato, 2014; Krzyzanowska, Treacy, Maloney, Lavino, & Jacobson, 2005).

Additionally, patients with limited health literacy skills may be unclear about the treatment regimen or necessary chemotherapy cycles (Busch, Martin, DeWalt, & Sandler, 2015). Thus, if patients are unclear about the chemotherapy regimen, they may face difficulty adhering to chemotherapy cycles (Busch et al., 2015).

Readability of Written Communication

Patients may receive several chemotherapy pamphlets especially if they are on multiple drugs (Rigdon, 2010). Some of the materials may seem contradictory for the patients especially if they are taking several different medications (Rigdon, 2010).

Additionally, the materials may not be written in plain language using easy-to-understand words or implement the use of plain language guidelines to aid in patient understanding (Doak, Doak, Friedell, & Meade, 1998; S. F. Garcia et al., 2010; Petty, 2013).

Plain language. Materials with plain language are designed to be quickly and easily understood by the readers (S. F. Garcia et al., 2010). Using plain language, written material allows readers to locate what they need, understand what they read, and use what they find to meet their needs (The Plain Language Action and Information Network (PLAIN), n.d.). Elements of plain language include writing in active voice, avoiding medical jargon, simplifying grammar, and breaking information into smaller segments (S. F. Garcia et al., 2010; The Plain Language Action and Information Network (PLAIN), n.d.). Additionally, certain features should be avoided when using plain language

including, using all capital letters, italics, acronyms, or long lists (Stableford & Mettger, 2007). Instead, materials should include bulleted lists, tables, conversational tone, and implement basic headings to assist in organization (H. Osborne, 2013).

Visuals. The use of visuals and graphics is related to readability and can assist the patient in understanding materials (Doak, Doak, & Root, 1996). Important characteristics for written materials includes: placing images in the appropriate context of the document, allowing for only one message per visual, and employing use of whitespace. Captions should also be brief and the visuals should be concrete. Illustrations and graphics should be clear, show what the words describe, and have captions to help direct the patient's eyes. Using visuals according to plain language guidelines can assist the patient in understanding important information about chemotherapy (Doak et al., 1996; S. F. Garcia et al., 2010).

Literature Overview

The two main concepts to this study are health literacy and chemotherapy knowledge. Much of the research surrounding health literacy in patient education surrounds management of chronic diseases such as asthma, HIV, and diabetes with minimal focus on chemotherapy education for women with breast cancer (Kim & Lee, 2016; O'Connor et al., 2015; Perazzo, Reyes, & Webel, 2016; Valenti, 2014). Even more surprising, health literacy and chemotherapy knowledge has not yet been examined. Research surrounding patient health literacy and chemotherapy knowledge is especially pertinent given the importance chemotherapy education for women with breast cancer (S. Garcia, 2014; Valenti, 2014).

Given this gap in the literature, exploring health literacy and chemotherapy knowledge for women with breast cancer is imperative. Nurses are on the vanguard of chemotherapy education and are essential to effectively teaching and increasing chemotherapy knowledge among patients.

Summary of Aims

Exploring readability of materials, patients' level of health literacy skills, and chemotherapy knowledge of patients with breast cancer is worthy of investigation given the importance of chemotherapy education. Identifying how these attributes influence chemotherapy knowledge may illuminate ways in which nurse educators can positively affect the cancer treatment experience for women with breast cancer.

Thus, the specific aims of this study were to:

- 1) Evaluate the readability and format of commonly used chemotherapy educational materials for women with breast cancer;
- 2) Explore how a sample of women with breast cancer perceive chemotherapy education;
- 3) Describe the relationships of patients' health literacy, demographic factors, and cancer treatment characteristics with chemotherapy knowledge among women with breast cancer.

The methods described in the following section were avenues to answer these research aims.

Methods

A mixed method design was used to illuminate chemotherapy education. I evaluated the readability and format of chemotherapy education materials used by

women with breast cancer, and also explored how these women perceived chemotherapy teaching. I also described the relationships of patients' level of health literacy, demographic factors, and cancer treatment characteristics with the outcome of chemotherapy knowledge using statistical analyses.

Primary data was collected at the recruitment site, South Carolina Oncology Associates (SCOA), in order to address these aims. Recruitment began after patients completed a mandatory chemotherapy education session prior to starting their first round of intravenous chemotherapy. Participants were screened for eligibility based on inclusion and exclusion criteria. I used the Heiney-Adams Recruitment Framework (HARF), which was designed for data collectors to focus on relationship building while maintaining empathy with participants and being sensitive to the participants' time (Heiney, Adams, Wells, & Johnson, 2010; Heiney et al., 2012). Further, each participant was provided with a \$20 cash incentive as a thank-you gift. One hundred ten women were identified as possible participants using inclusion and exclusion criteria. Fifty-five potential participants were successfully reached, and only nine (16.4%) refused to participate resulting in a sample of 46 participants.

Data collection occurred at a location of the participants' choice and lasted approximately 45 minutes. Participants responded to a demographic instrument, a chemotherapy educational resource instrument (Heiney et al., 2012), the Rapid Estimate of Adult Literacy – Short Form (REALM-SF; Arozullah et al., 2007), the Short Test of Functional Health Literacy in Adults (S-TOFHLA; Baker, Williams, Parker, Ganzmararian, & Nurss, 1999), and a revised Leuven Questionnaire on Patient Knowledge of Chemotherapy (L-PaKC; Coolbrandt, Van den Heede, Jans, et al., 2013).

The chemotherapy educational resource instrument was utilized to determine which materials women with breast cancer used and to understand how women perceived such teaching. Patients' level of health literacy was measured using the S-TOFHLA, and their ability to recognize and pronounce words was scored using the REALM-SF.

Chemotherapy knowledge was assessed using the L-PaKC.

The data derived from the chemotherapy educational instrument was used to identify the educational materials for the readability analysis and participant responses for the qualitative analysis as described in Aims 1 and 2. The materials were scored using three readability assessments: (1) Flesch Reading Ease (FRE; Flesch, 1948); (2) Flesch-Kincaid (F-K; Kincaid, Fishburn, Rogers, & Chissom, 1975) ; and (3) a Simple Measure of Gobbledygook (SMOG; McLaughlin, 1969) . The format and presentation of the materials was evaluated using Suitability Assessment of Materials (SAM) guidelines (Doak et al., 1996). Lastly, I used thematic analysis to describe the experience of 37 participants experiencing chemotherapy education (Braun & Clarke, 2006).

The goal of Aim 3 was achieved through conducting statistical tests in order to determine the relationships of participants' demographics, levels of health literacy skills, and cancer and treatment characteristics with the outcome of chemotherapy knowledge. Data were analyzed using descriptive statistical tests of frequencies and means to determine the characteristics of the sample participants. Univariate linear regression models were conducted with the health literacy and word recognition scores as the independent variables and chemotherapy knowledge as the dependent variable. One-way ANOVA models were also conducted for demographic factors and cancer characteristics

as the independent variables and chemotherapy knowledge as the dependent variable. SPSS Statistics 23 was used for all statistical analyses.

Target Journals

The following chapters of this dissertation describe the landscape of chemotherapy education for women with breast cancer. Chapter 2 includes a scoping review of chemotherapy education for women with breast cancer. This review is published in the *Journal for Nursing Education and Practice*.

The subsequent chapters of this dissertation address each of the three specific aims. The results of the readability assessments (Aim 1) and qualitative analysis (Aim 2) are explored in Chapter 3. This manuscript will be submitted to the *Journal for Cancer Education*. Lastly, the investigation of the relationships of patients' health literacy, demographic factors, and cancer treatment characteristics with chemotherapy knowledge (Aim 3) are described in Chapter 4. The manuscript will be submitted to the *Clinical Journal of Oncology Nursing*.

CHAPTER 2

HOW ARE HEALTH LITERACY PRINCIPLES INCORPORATED INTO BREAST CANCER CHEMOTHERAPY EDUCATION? A REVIEW OF THE LITERATURE¹

¹ Parker, P.D., Heiney, S.P., Friedman, D.B., Felder, T.M., Estrada, R.D., Harris, E.H., & Adams, S.A. (2018). *Journal of Nursing Education and Practice*, 8(6), 77-84.
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Abstract

Background: Chemotherapy is commonly used in combination with other treatments for breast cancer. However, low adherence to chemotherapy is a growing concern, particularly among breast cancer patients. Side effects such as nausea and vomiting, fatigue, and arthralgia can contribute to reduced adherence. Other factors such as provider communication and limited insurance coverage can affect adherence. Studies have shown that as much as 28% of patients with breast cancer did not continue with their prescribed dose of chemotherapy. Research suggests that chemotherapy education materials can be critical to addressing problems with non-adherence, and may include written materials, verbal instruction, and multimedia programs. Despite this wide variety, the effectiveness and benefit of chemotherapy education hinges on the patients' health literacy. Breast cancer patients with low health literacy may be unclear about chemotherapy or face difficulty adhering to treatment if they do not understand the information provided to them. Thus, this scoping review summarizes the existing research on how health literacy principles are incorporated into breast cancer chemotherapy education materials.

Methods: Using a combination of keywords (e.g. *chemotherapy, education*) and Medical subject headings (MeSH) terms (e.g., *drug therapy, antineoplastic agents*), we searched five databases (1977-2017): CINAHL, PubMed, PsycINFO, Cochrane Library, and Web of Science.

Findings: Eight of 4,624 articles met the inclusion criteria. Five articles incorporated health literacy principles (e.g., plain language, maintaining an active voice, using white space) into the development of written materials. Few articles used a theoretical framework to guide education material development (n=3). Of the three articles that

described pilot-testing of educational materials, two used post-tests only and one used a pre/post-test design.

Conclusions: Findings indicated that limited research exists regarding the use of health literacy principles in chemotherapy education materials. Much of the development of chemotherapy education is not grounded in theory and the application of health literacy principles are limited. Implementing health literacy principles may improve overall comprehension of education thereby increasing adherence.

Keywords: health literacy, chemotherapy education, breast cancer, review paper

Each year, more than 252,710 new cases of invasive breast cancer and an additional 63,410 cases of in situ breast cancer are diagnosed (ACS, 2016b) . While the risk of breast cancer in men is 100 times less likely than in women, approximately 2,500 men will also receive the diagnosis (ACS, 2016b, 2017c). Currently, more than 3.1 million people have a history of invasive breast cancer (ACS, 2016b). The ACS (ACS) estimates that 40,610 women and 500 men die from the disease annually (ACS, 2016b).

Breast cancer treatment is a significant phase along the cancer care continuum (ACS, 2015a). Chemotherapy is one of the most common treatment options and adherence to chemotherapy treatment is crucial to extending survival (adherence is an agreement on the type, dosing, and frequency of a medication upon between a patient and provider; Iacorossi et al., 2016; NCI, 2018b). However, chemotherapy adherence rates are surprisingly low. For example, Hershman (2005) found that 28% of patients with breast cancer did not receive the expected amount of intravenous chemotherapy. Surprisingly, 31% of African American women received fewer cycles than expected compared to 23% of White women (Hershman et al., 2005). With regard to oral

chemotherapy, the rate of adherence is a staggering 16% (Greer et al., 2016). Reasons for non-adherence include chemotherapy side effects such as nausea and vomiting, arthralgia, and fatigue (Kidwell et al., 2014; Williams & Schreier, 2004). Other factors such as patient medication beliefs, provider communication, and limited insurance can also reduce adherence (Greer et al., 2016). As the treatment landscape continues to shift from intravenous chemotherapy toward immunotherapy, targeted therapy, and oral chemotherapy (Thompson & Christian, 2016), effective chemotherapy education is critical to promote adherence and to ensure a greater quality of life for patients with breast cancer (Muluneh et al., 2016; Partridge et al., 2010). Better understanding of how patients comprehend current chemotherapy educational materials is critical to developing and refining more effective strategies.

Nurses are uniquely qualified to evaluate chemotherapy educational materials, as they are on the forefront of educating patients about chemotherapy, administering medications, and guiding patients through treatment (Rieger & Yarbrow, 2003). The goals of chemotherapy education are to teach patients how to manage side effects, practice self-care to decrease symptom distress, and improve the patients' quality of life throughout the process (Rieger & Yarbrow, 2003; Traeger et al., 2015; Williams & Schreier, 2004). Nurses may use a variety of functional modalities for chemotherapy education including printed materials, verbal instruction, and multimedia programs on tablets or computers (Henderson et al., 2015; Morgan et al., 2015; Valenti, 2014). Additionally, with the emergence of new cancer therapies, nurses may consider developing new or modifying existing chemotherapy educational tools.

Even if the content is appropriate, nurses may consider each patient's specific learning style to promote comprehension (Dalby et al., 2013). Learning styles (visual, auditory, tactile, kinesthetic) affect how patients receive and process information (Felder & Silverman, 1988). However, the patients' reception, retention, and comprehension of information are ultimately influenced by their level of health literacy (Dalby et al., 2013; Foltz & Sullivan, 1999). The Institute of Medicine (Institute of Medicine, 2004) defines health literacy as "the capacity to obtain, process, and understand basic health information and services to make appropriate health decisions" (p. 20). Individuals' health literacy can hinder or promote their comprehension and knowledge of cancer-related information (Davis et al., 2001; Davis et al., 2002). However, patients with low health literacy may be unclear about the treatment regimen or chemotherapy cycles (Busch et al., 2015). Inadequate or erroneous knowledge about adverse effects of chemotherapy results in greater hospital admissions, increased morbidity, and decreased quality of life (Huynh & Trovato, 2014; Krzyzanowska et al., 2005).

Nurses can tailor their teaching methods to adjust for their patients' health literacy level when educating about chemotherapy, including the incorporation of health literacy principles within educational materials and programs to assist the patients' comprehension (Mann, 2011; Petty, 2013). Health literacy principles include using plain language, active voice, friendly tone, simple definitions, graphics, and writing at fifth to sixth grade reading levels (H. Osborne, 2013; Petty, 2013). Materials utilizing plain language are designed to be quickly and easily understood by the readers (S. F. Garcia et al., 2010). Written material with plain language allows readers to locate what they need, understand what they read, and use what they find to meet their needs (The Plain

Language Action and Information Network (PLAIN), n.d.). Elements of plain language include writing in active voice, avoiding medical jargon, simplifying grammar, and breaking information into smaller segments (S. F. Garcia et al., 2010; The Plain Language Action and Information Network (PLAIN), n.d.). Moreover, the use of all capital letters, italics, and acronyms should be avoided (Stableford & Mettger, 2007), but bulleted lists, tables, conversational tone, and implementation of basic headings are helpful (H. Osborne, 2013).

The use of visuals and graphics is related to readability and can assist the patient in understanding materials (Centers for Disease Control and Prevention, 2009; Doak et al., 1998). Important characteristics for written materials include: placing images in the appropriate context of the document, allowing for only one message per visual, and employing use of whitespace (Centers for Disease Control and Prevention, 2009, 2014). Captions can be brief and the visuals should be concrete (Centers for Disease Control and Prevention, 2009; Doak et al., 1996). Illustrations and graphics are recommended to be clear, show what the words describe, and have captions to help direct the patient's eyes (Doak et al., 1996). Using visuals according to plain language guidelines can assist the patient in understanding important information about chemotherapy (Doak et al., 1998; S. F. Garcia et al., 2010). However, little is known as to how nurses use such health literacy principles when educating about chemotherapy. Thus, the purpose of this scoping review is to identify and examine the degree or frequency to which health literacy principles are incorporated within chemotherapy education for patients with breast cancer to serve as a guide for developing or editing materials.

Methods

This scoping review was used to assess the breadth of the available research literature and to examine the extent and range of studies within chemotherapy education (Arksey & O'Malley, 2005; Grant & Booth, 2009). We used a scoping review framework informed by Arksey and O'Malley (2005) to guide our approach. Following Arksey and O'Malley (2005), we embarked on the review and determined the research question (stage 1), identified relevant studies (stage 2), selected studies (stage 3), charted the data (stage 4), and collated, summarized, and reported the results (stage 5).

Identifying Relevant Studies

The authors utilized five databases: CINAHL (Cumulative Index to Nursing and Allied Health Literature), PubMed, PsycINFO, Cochrane Library, and Web of Science. Keywords were *chemotherapy*, *education*, *literacy*, and *low literacy*. Medical subject headings (MeSH) included *drug therapy*, *antineoplastic agents*, *patient education handouts* (publication type), *patient education as topic*, *health literacy*, and *information literacy*. The search strategy using MeSH terms included (("Drug Therapy"[Mesh] OR "Antineoplastic Agents"[Mesh]) OR ("Patient Education as Topic"[Mesh] OR "Patient Education Handout"[Publication Type])) AND ("Information Literacy"[Mesh] OR "Health Literacy"[Mesh]).

Inclusion and exclusion criteria. To be included in the analysis, articles had to be published between 1997 and 2017. Additional inclusion criteria included having: 1) descriptions of health literacy principles; 2) content on intravenous or oral chemotherapy education; 3) focus on education for patients with breast cancer; and 4) applicable to adult populations. The publications were limited to academic journals, dissertations, and

conference proceeding papers in English. Articles pertaining to pediatric populations were excluded. Review articles, quality improvement studies, and editorials were also not included. See Figure 2.1 for detailed description of the inclusion and exclusion criteria.

Two reviewers (PP, EH) collaborated to select the final articles. The reviewers independently selected the articles based on the inclusion and exclusion criteria. Both reviewers agreed upon the final articles and had no discrepancies in their results.

Results

Study Selection

The literature search yielded 4,624 results. After assessing for duplicates and reading through the titles and abstracts, 39 potential publications were identified as meeting the inclusion criteria for full-text review. More than 3,500 results were excluded because the title or abstract were not pertinent to breast cancer chemotherapy education. Of the 39 articles, 31 articles were excluded due to no description of health literacy principles (n = 11); not specific to any cancer (n = 8); specific to cancers other than breast cancer (n = 6); recommendations only for teaching (n = 2); quality improvement studies in education (n = 2); education about cancer risk (n = 2); and education about surgical treatment decisions (n = 1). Eight articles were selected which met the objective of examining health literacy principles in chemotherapy education for patients with breast cancer. See Figure 2.1 for the study selection process.

Overall Findings

Based on Arksey and O'Malley's (2005) framework, we thematically charted the data into three categories: 1) education guided by theoretical framework, 2) application of

specific health literacy principles, and 3) use of pilot testing materials for chemotherapy education.

Theoretical underpinnings. Three articles used theoretical frameworks to guide educational material development (Mann, 2011; Rigdon, 2010; Sullivan et al., 2016). Rigdon (2010) used Orem's general theory of self-care deficit (Orem, 1987). This framework guided the evaluation and development of chemotherapy content and highlighted the importance of chemotherapy knowledge to increase self-care for older adults. The theory emphasizes the role of knowledge of potential health problems in promoting self-care behaviors (Orem, 1987) for older adults undergoing chemotherapy (Rigdon, 2010).

Two studies employed the use of two variations of adult learning theories in developing chemotherapy education interventions (Mann, 2011; Sullivan et al., 2016). Sullivan and colleagues (2016) developed a single source of online materials to educate patients about oral chemotherapy. Adult learning principles described by Best (2001) were implemented when designing the material. Adult learning standards included creating printed materials with larger print, maintaining black lettering on white backgrounds, and using warm colors such as red or orange to enhance visuals (Best, 2001; Duffy & Snyder, 1999; Murphy & Davis, 1997). Though the authors did not measure the participants' literacy prior to the study, they used the adult learning standards to meet diverse learning needs of adult patients (Sullivan et al., 2016). Similarly, the authors in neither of these two studies measured literacy levels prior to chemotherapy education.

Mann (2011) used two theories in a quality improvement project – adult learning theory and King’s (King, 1981, 1992) framework on adult learning and goal attainment – to address three domains of learning (affective, cognitive, and psychomotor) in the study. King’s (1981, 1992) theoretical framework suggests the nurse and patient have a trusting relationship and mutually determine goals for the patient. Verbal and nonverbal communication are critical factors within the nurse-patient relationship. Mann (2011) focused on the nurse-patient communication aspect of chemotherapy education in her quality improvement intervention. Additionally, Mann (2011) used the Outcomes-Focused Knowledge Translation Intervention Framework (OFKTIF) (Doran & Sidani, 2007). The OFKTIF was ideal because the framework provided guidance for improving the initial education programs (Mann, 2011). The four areas of the OFKTIF included facilitation, content, patient preference, and sources of evidence (Doran & Sidani, 2007).

Three articles included the use of theoretical frameworks to improve or to develop chemotherapy educational programs. Though the focus of these articles varied, each of these studies used sound theoretical approaches to guide their research. However, five of the articles were not grounded in theory or theoretical frameworks (Fee-Schroeder et al., 2013; Foltz & Sullivan, 1999; Gonzalez & Stepan, 2006; Jazieh & Brown, 1999; Piredda, Migliozi, Biagioli, Carassiti, & De Marinis, 2016).

Health literacy principles. Five articles included health literacy principles pertinent to written materials (Fee-Schroeder et al., 2013; Jazieh & Brown, 1999; Piredda et al., 2016; Rigdon, 2010; Sullivan et al., 2016). Four articles specifically mentioned reading level and using active voice in written materials (Jazieh & Brown, 1999; Piredda et al., 2016; Rigdon, 2010; Sullivan et al., 2016), whereas authors of three studies

discussed the use of graphics to assist in reading comprehension (Fee-Schroeder et al., 2013; Jazieh & Brown, 1999; Rigdon, 2010).

The authors of four articles mentioned specific health literacy principles to improve and develop their written educational materials. Jazieh and Brown (1999) developed a patient information packet for veterans receiving chemotherapy. The information was written at a sixth-grade reading level, and the font was increased to meet the needs of older patients. Participants rated the patient information packet 3.9 out of 4 on a scale of 1 to 4 from very dissatisfied to very satisfied (Jazieh & Brown, 1999). Participants were “very satisfied” with the large font, readability, and content. Sullivan and others (2016) also incorporated a lower reading level for their educational audiovisual resource. The authors wanted the content to be easily understood and maintained a fifth-grade reading level throughout the source (Sullivan et al., 2016). In a separate study Piredda and colleagues (2016) developed an information booklet about implanted ports for chemotherapy access. The content was written using plain language, attractive design, colors, and graphics. Forty people evaluated the booklet for clarity and readability. The investigators improved the graphics and text based on the feedback (Piredda et al., 2016). Lastly, Rigdon (2010) developed brochures following a review of the literature for teaching patients with low literacy including simple language, large font, and active voice. Participants gave positive feedback on the teaching materials and all but one of the participants found the material to be beneficial. Only one of the participants said she did not recall one of the education sessions but correctly answered every question on the follow-up survey (Rigdon, 2010).

The use of graphics also appeared in three studies (Fee-Schroeder et al., 2013; Jazieh & Brown, 1999; Rigdon, 2010). Jazieh and Brown (1999) used large graphics to alert participants to important information. For example, the stop sign was placed in a chemotherapy teaching booklet to alert the participants to stop and seek help if they experienced sudden complications (Jazieh & Brown, 1999). Rigdon (2010) also used illustrations and images within the educational brochure to highlight chemotherapy side effects. Graphics included an image of a thermometer to remind patients to take their temperature daily. Another image included a man brushing his teeth as a cue for participants to report mouth sores to the clinic nurse to prevent mucositis (Rigdon, 2010). Lastly, Fee-Schroeder and others (2013) designed a DVD with audiovisuals which implemented health literacy principles recommended by expert reviewers. However, the authors did not specifically describe which health literacy principles were used within the DVD (Fee-Schroeder et al., 2013).

Pilot testing materials. Authors of three articles tested materials prior to using with patients (Foltz & Sullivan, 1999; Gonzalez & Stepan, 2006; Piredda et al., 2016). Gonzalez and Stepan (2006) received feedback from patients, families, and nurses prior to formatting an educational booklet. The authors held sessions to encourage feedback while developing the booklet (Gonzalez & Stepan, 2006). Additionally, Piredda and others (2016) used similar testing in developing their information booklet. Forty people with a variety of educational backgrounds reviewed the booklet where the authors made revisions prior to distributing to the participants (Piredda et al., 2016). In contrast, Foltz and Sullivan (1999) tested materials already available to the public. In a series of focus groups participants discussed and explored the layout, content, and wording of two

educational brochures from the NCI (NCI) and the ACS (ACS) (Foltz & Sullivan, 1999). Participants unanimously preferred the ACS brochure for providing more information than the NCI pamphlet. Several of the participants commented that more information should be included about sexuality (Foltz & Sullivan, 1999). The pilot testing of materials of these three studies provided an opportunity for materials to be edited to meet a variety of patients' learning needs.

Discussion

This review demonstrated that few studies use theory to specifically guide the development of chemotherapy education materials. In fact, more than half of the included studies did not use a theory to guide their work. Studies grounded in theory have a framework for creating and implementing effective chemotherapy educational programs (Meleis, 2012). Theory can provide an outline to provide insights into interventions and nursing practice (Meleis, 2012). Additionally, using an appropriate theory may help guide researchers when incorporating health literacy principles within their chemotherapy education materials.

Furthermore, the inclusion of health literacy principles was used sparsely in the chemotherapy education materials for patients with breast cancer. Eleven articles were excluded during the full-text review for lacking a description of a health literacy principles used within the educational materials. Including a description of the health literacy principles could be beneficial for researchers developing chemotherapy education materials. An explicit description using health literacy principles could serve as a guide for creating educational material for not only breast cancer, but also other cancers.

Testing the knowledge gained from the education is critical to measuring the effectiveness of the chemotherapy material (Harris, 1998). However, most of the studies in our review were limited to post-test only and outcome evaluation of the education. Only one article included pre- and post-testing with an outcome of knowledge (Piredda et al., 2016). While educational chemotherapy materials implement health literacy principles, knowledge is rarely examined as an outcome. The limited type of post-test only research designs is not conclusive in establishing a relationship between health literacy principles and chemotherapy knowledge. Furthermore, only in one study did the authors measure participants' health literacy as part of an assessment to measure learning preferences and styles (Mann, 2011). Educational materials may implement health literacy principles, but the effectiveness of such materials should be measured with consideration of the patient's baseline health literacy. This will allow the researchers to determine the effect, if any, of the health literacy principles used in the materials. The educational benefit of these materials has not been consistently demonstrated in chemotherapy education unlike the educational information available for diabetes and heart failure. Investigators found a significant increase in the patients' knowledge after they viewed a multimedia diabetes educational program designed for patients with low literacy (Kandula et al., 2009). Similarly, self-care knowledge of heart failure management increased after patients viewed low literacy educational materials (Dickson, Chyun, Caridi, Gregory, & Katz, 2016).

The evaluation studies offer valuable feedback from patients and demonstrate overall acceptability of the materials. Patients rated print size and readability as very satisfactory in a patient information packet (Jazieh & Brown, 1999). These preferences

illuminate the benefit of specific health literacy principles (active voice, use of bulleted lists, friendly tone) in delivering chemotherapy information.

Even if educational materials are developed using health literacy principles, the impact of the educator, including cancer nurse educators, has not been thoroughly explicated in the breast cancer literature. Much of the literature that includes health literacy principles in educational materials pertains to chronic diseases such as diabetes and asthma (Kim & Lee, 2016; Yin et al., 2013) but not to breast cancer patients thereby warranting further exploration for breast cancer. Most patients receive written chemotherapy information and nurse educators may teach to supplement the materials. Effective teaching can lead to increased patient involvement and retention, whereas ineffective teaching can result in reduced comprehension (A. J. Friedman, Cosby, Boyko, Hatton-Bauer, & Turnbull, 2011; Harris, 1998). Oncology nurses may evaluate current chemotherapy materials and adjust teaching if materials lack health literacy principles. If nurses are concerned that health literacy principles are not being included in the materials, nurses can use techniques to supplement to the materials such as highlighting and underlining important sections within the materials. Nurses may use white space to make bulleted lists to emphasize teaching points (Duffy & Snyder, 1999; Murphy & Davis, 1997). Nurses may also use the teach-back method with patients to correspond with the education materials. The teach-back method could be a supplemental tool to aid in comprehension and retention (Caplin & Saunders, 2015). By including health literacy principles during chemotherapy teaching, the nurse is better able to assist in patient learning and retention of chemotherapy information, which could ultimately improve overall health outcomes and extend quality of survivorship (Valenti, 2014).

Limitations

Our review has limitations. We did not use an international database such as Embase (Excerpta Medica database) which may have prevented us from identifying relevant articles from other countries and in other languages. Secondly, the MeSH terms and keywords may have been limiting; other combinations may have yielded different results.

Future Research

We identified gaps from the limited amount of published literature regarding the incorporation of health literacy principles within chemotherapy education for patients with breast cancer. Much of the chemotherapy education material development lacked the application of health literacy principles and researchers did not test the effectiveness of the materials on knowledge.

Incorporating health literacy principles into chemotherapy education materials for women with breast cancer is imperative. Using health literacy principles should improve overall comprehension of chemotherapy education thereby increasing adherence, assisting with symptom management, and improving quality of life while going through treatment. Furthermore, implementing health literacy principles within immunotherapy and oral chemotherapy materials is vital as patients are increasingly being prescribed these therapies (Sherner, 2016; Thompson & Christian, 2016; Weingart et al., 2008). Specifically, in oral chemotherapy, the application of health literacy principles within educational materials could potentially be even more critical because the patient is responsible for the administration (Barton, 2011; Given, Spoelstra, & Grant, 2011). Effective instruction prior to beginning oral chemotherapy is vital to combat against

barriers to adherence such as poor health literacy, complexity of dosing, and drug side effects (Given et al., 2011). Future research may be directed towards measuring the impact of health literacy principles in chemotherapy education on improving adherence. Researchers may consider testing the effect of education in patients' managing their side effects or promoting better communication with physicians.

Furthermore, researchers did not measure the effectiveness of chemotherapy materials on increasing knowledge. Researchers may consider developing and testing materials prior to disseminating chemotherapy materials to patients to encourage adherence to oral and intravenous chemotherapy. The revision and testing process may continue throughout the material development. Investigators can conduct studies to measure knowledge gained after exposure to materials using reliable and valid instruments. However, patient health literacy may need to be examined at baseline to determine any relationship with knowledge (Kandula et al., 2009).

Conclusion

This review provides evidence of the need for further exploration and implementation of health literacy principles within chemotherapy education for women with breast cancer. Incorporating health literacy principles within chemotherapy education could assist in women's comprehension and retention of chemotherapy education ultimately improving overall health outcomes and extending survivorship.

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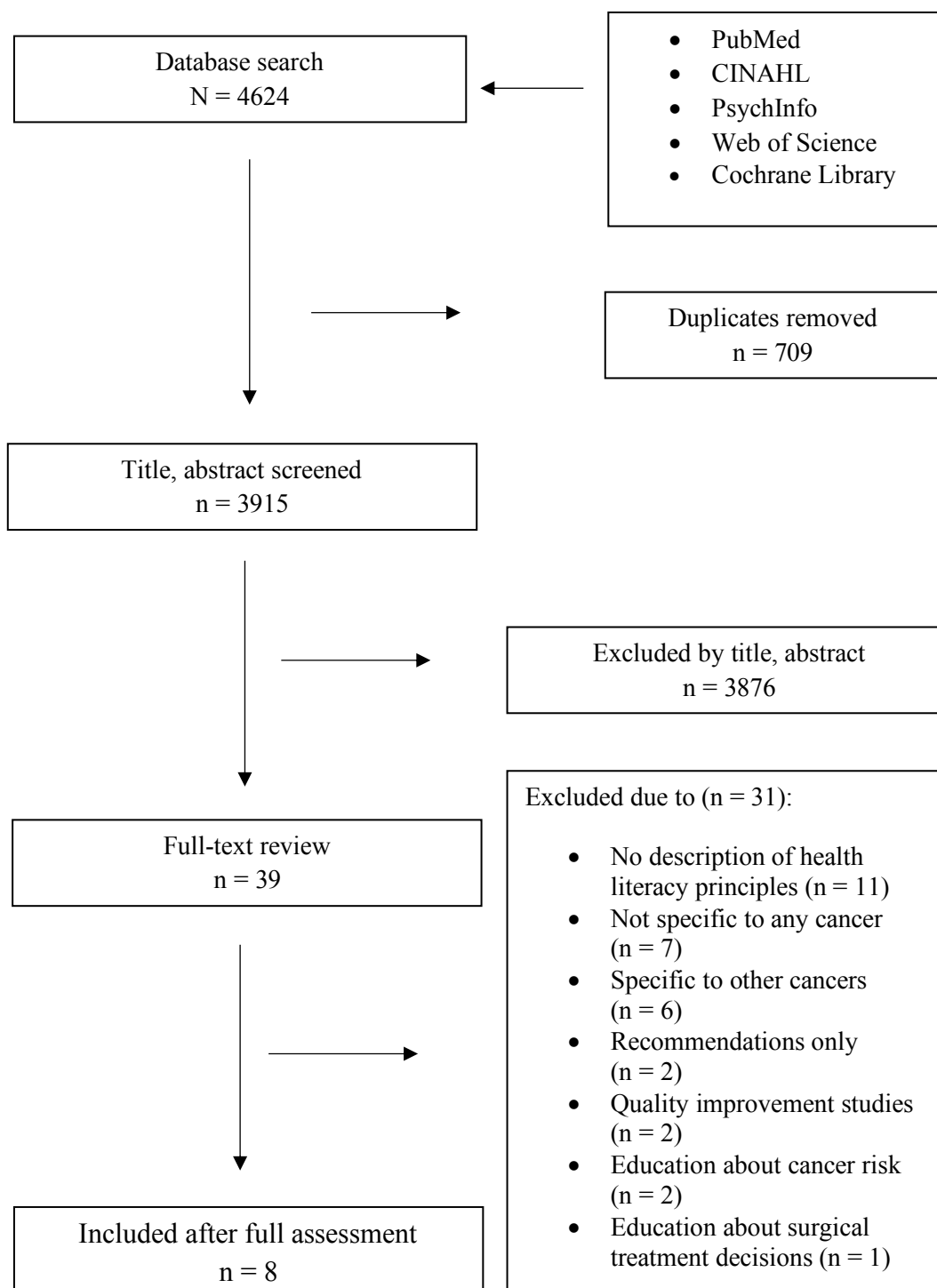


Figure 2.1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Flow Chart for Study Selection.

CHAPTER 3

THE EXPERIENCE OF CHEMOTHERAPY TEACHING AND READABILITY OF CHEMOTHERAPY EDUCATIONAL MATERIALS FOR WOMEN WITH BREAST CANCER¹

¹ Parker, P.D., Heiney, S.P., Friedman, D.B., Estrada, R.D., & Adams, S.A. To be submitted to *Journal of Cancer Education*.

Abstract

Background: Chemotherapy is one of the most common forms of treatment for women with breast cancer. While chemotherapy is often effective, managing side effects can be challenging for patients. Chemotherapy education is critical in assisting patients to manage side effects and to improve the treatment experience. However, materials are often not thoroughly assessed for readability and format which could be problematic for patients learning how to navigate self-care while going through treatment.

Methods: We used a mixed method design to illuminate chemotherapy teaching and focused on readability and format of chemotherapy education materials used by women with breast cancer. We scored the materials using three readability assessments: (1) Flesch Reading Ease (FRE); (2) Flesch-Kincaid (F-K); and (3) a Simple Measure of Gobbledygook (SMOG). We evaluated the format of the materials using Suitability Assessment of Materials (SAM) guidelines. Lastly, we used thematic analysis to describe the experience of 37 women with breast cancer undergoing chemotherapy education.

Results: The mean readability of the materials ranged from ‘difficult’ to ‘fairly difficult’ based on the FRE scoring, and the material was written on a 9th to 13th grade reading level. Most of the materials scored as ‘adequate’ using SAM guidelines, but lacked incorporation of graphics or illustrations. The thematic analysis revealed three major findings: (1) finding control in learning; (2) receiving unexpected support; and (3) learning in unforeseen ways.

Implications: Nurses need to supplement chemotherapy education materials with individualized teaching to ensure comprehension. Additionally, nurses and website

developers may want to consider implementing culturally appropriate information, and use videos to combat challenging readability.

Currently, more than 3.5 million women are breast cancer survivors, and by 2026, the ACS projects this number will increase to more than 4.5 million women (ACS, 2017a). One of the most common forms of systemic treatment for women with breast cancer is chemotherapy. The National Cancer Institute reports that as many as 79.6% of women, aged 20 to 64 years, with breast cancer receive chemotherapy treatment (NCI, 2018c). In fact, 19% of women with stage I and II breast cancers receive chemotherapy or a combination thereof and 61% of women with stage III and 66% of women with stage IV breast cancer undergo chemotherapy (ACS, 2016c).

Chemotherapy is effective at killing fast-growing cancer cells (NCI, 2011), but the treatment regimen has numerous side effects including constipation, diarrhea, nausea, hair loss, mouth sores, and “chemo brain” (ACS, 2017b; Evens & Eschiti, 2009). Possible adverse effects include febrile neutropenia, thrombocytopenia, or chemotherapy toxicity which can lead to fatal outcomes (X. L. Du, Osborne, & Goodwin, 2002; Lyman & Rolston, 2010; Wai Chi & Ching, 2015). In a study in the United Kingdom, 27% of patients with an early breast cancer diagnosis presented to the emergency department with non-neutropenic fever and 24% had a neutropenic fever within 30 days of receiving chemotherapy (Tang, Horsley, & Lewis, 2018). Patients need to know when and how to seek treatment for potentially fatal complications such as a neutropenic fever and know how to manage lesser side effects to improve quality of the treatment experience (Beaver & Magnan, 2016; Valenti, 2014). Thus, receiving appropriate and effective

chemotherapy education is critical, and nurses are on the forefront of such patient teaching.

Effective chemotherapy education is critical to help patients manage and alleviate chemotherapy side effects and improve the treatment experience (Canosa & Gentry, 2012; Sahin & Erguney, 2016; Traeger et al., 2015). Nurses may use a variety of techniques and materials (printed, online multimedia) to teach patients during chemotherapy education, but the patients' comprehension of the information is ultimately influenced by their health literacy (Institute of Medicine, 2015). Health literacy – defined as the “capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p. vi) – plays an instrumental role in comprehending chemotherapy information (Davis et al., 2002). For example, patients with limited health literacy skills may not fully understand about chemotherapy cycles (Busch et al., 2015; Huynh & Trovato, 2014). Insufficient knowledge about chemotherapy's adverse effects such as thrombocytopenia can place patients at risk for increased hospital admissions and decreased quality of life (Huynh & Trovato, 2014; Krzyzanowska et al., 2005).

Nurses often adapt their communication and education methods to accommodate patients' various health literacy levels. Teaching to a patients' level of health literacy may assist with comprehension, thereby positively influencing the patients' treatment and health outcomes (Mann, 2011; Petty, 2013). Nurses need to be able to communicate with patients using easy to understand words and educational materials designed to meet the needs of patients across the literacy spectrum (Valenti, 2014). One central component of educational materials is readability (D. B. Friedman & Hoffman-Goetz, 2006). Two

factors contributing to readability are the reading level and format, which, if the material is thoughtfully selected, should be easily understood by patients with diverse health literacy skills (Albright et al., 1996; Doak et al., 1998).

Readability is defined as the level of difficulty in comprehending printed material and the level of success others have in understanding the content (Flesch, 1948). The format (e.g. content, layout, typography, design) is another component in evaluating cancer education materials. Simple design choices such as using ample white space and implementing bulleted lists can greatly influence the readers' comprehension of the material (Doak et al., 1998). Nurse educators need to evaluate the reading levels of the materials and patients' level of health literacy skills to determine if any potential gaps could exist in learning. Nurses can then modify their teaching to allow for better comprehension (Doak et al., 1998). However, in a recent literature review, the authors concluded that the evaluation of the readability was rarely incorporated into the development of chemotherapy education materials for patients with breast cancer (P. D. Parker et al., 2018). Further, much of the current literature focuses on the experience of chemotherapy-related side effects (Fleischer & Howell, 2017; Hellerstedt-Börjesson, Nordin, Fjällskog, Holmström, & Arving, 2016; Kanaskie & Loeb, 2015), but limited research exists describing the experience for women with breast cancer receiving chemotherapy education. Given this gap in the literature, the purpose of this paper is two-fold: 1) to evaluate the readability and format of commonly used chemotherapy educational materials; and 2) to explore how a sample of women with breast cancer perceive chemotherapy education.

Method

Setting and Participants

This research was conducted at a large comprehensive oncology clinic, South Carolina Oncology Associates (SCOA). Each patient starting chemotherapy attended a mandatory chemotherapy education session with a nurse educator. Following the education session, the Electronic Medical Record (EMR) was updated to reflect completion. The primary author screened the EMR to determine patient eligibility using inclusion and exclusion criteria.

Inclusion and Exclusion Criteria. The inclusion criteria included women who: 1) had a new breast cancer diagnosis in the last three months, 2) could speak English, and 3) were over age 18. Participants were excluded if they had: 1) a stage IV, metastatic breast cancer diagnosis, 2) breast cancer recurrence, and 3) cognitive impairments. Cognitive impairments are defined as any woman with delirium or dementia during the data collection period. They may face greater difficulty in giving consent or answering items for the study (Carlson, 2013; Horner-Johnson & Bailey, 2013).

Recruitment. The primary author called eligible participants weekly after reviewing the EMR. She ceased calling when the patient refused or became ineligible (completed the fourth chemotherapy cycle). The primary author focused on relationship building as outlined by the Heiney-Adams Recruitment Framework (HARF) where important techniques such as being patient-focused, sensitive to time, and empathy were utilized (Heiney et al., 2010). Each participant was provided with a \$20 cash incentive as a thank-you gift for participation.

The primary author called 110 women who met the inclusion criteria to give an overview of the study and ascertain interest in participation. Fifty-five potential participants were successfully reached, and only nine (16.4%) refused to participate resulting in a sample of 46 participants.

Data Collection

We met with participants at the location of their choice to maintain a level of comfort and security. Participants responded to the Rapid Estimate of Adult Literacy – Short Form (REALM-SF; Arozullah et al., 2007), the Short Test of Functional Health Literacy in Adults (S-TOFHLA; Baker et al., 1999), and a chemotherapy educational resource instrument (Heiney et al., 2012). We wanted to determine the participant demographics and levels of health literacy skills using the word recognition test REALM-SF and S-TOFHLA. We used the chemotherapy educational resource instrument to identify the materials for the readability assessment and for the qualitative analysis.

Instruments for Participants

Patient demographics. We gathered information about the participants' education, marital status, income, and ethnicity using a 5-item scale adapted from Heiney (Heiney et al., 2012).

REALM-SF. The REALM-SF is a word recognition test designed to measure participants' ability to read and pronounce health-related words (Arozullah et al., 2007). Participants read aloud a list of seven words including two control words with one point for each correctly pronounced word. A score of 0 represents a literacy level of 3rd grade; score 1-3 is equivalent to a literacy level of 4th - 6th grade; score 4-6 suggests a literacy

level of 7th to 8th grade; a score of 7 is a literacy level greater than 9th grade (Arozullah et al., 2007).

S-TOFHLA. The S-TOFHLA is an assessment tool measuring functional health literacy, comprehension, and numeracy (Baker et al., 1999; R. M. Parker, Baker, Williams, & Nurss, 1995). Results range from 0 to 100; scores of 0 – 53 are equivalent to inadequate functional health literacy; 54 – 66 are representative of marginal functional literacy; and 67 – 100 as adequate functional literacy (Baker et al., 1999).

Chemotherapy Educational Resource Instrument. The 9-item scale, adapted from Heiney and colleagues (Heiney et al., 2012), is used to collect information about sources of chemotherapy education participants may have used in addition to the materials given out during SCOA's chemotherapy education session. The instrument includes questions about knowledge gained from sources outside of the chemotherapy session including: nurse navigator notebooks, pamphlets, videos, webpages, smartphone applications, and sessions with the breast health nurse or chemotherapy infusion nurse.

Data for qualitative analysis. Participants were encouraged to share their thoughts aloud about chemotherapy education as they completed the educational resource instrument. Most of the participants (n = 37) provided detailed feedback about the education sessions and resources used during chemotherapy treatment. The remaining participants (n = 9) opted to not give any additional feedback about the materials. Questions in the instrument prompted many unsolicited responses from the participants which were used for the data analysis. The feedback was handwritten by the primary author and read aloud back to the participants to verify for accuracy. Participant responses were then typed verbatim into a document for the thematic analysis (Braun &

Clarke, 2006). Pseudonyms of participants were used to protect identity and maintain confidentiality.

Selection of Materials for Readability

The printed and online materials were chosen for evaluation based on the participants' responses to the chemotherapy educational resource instrument (Heiney et al., 2012). The first printed material was an 11-page chemotherapy education booklet which was provided to every patient receiving chemotherapy treatment at SCOA (South Carolina Oncology Associates, 2016). The second printed material item was a chemotherapy chapter in a book (Kneece, 2017) which was identified by 78.2% (n = 36) of women as an educational resource.

The three most commonly referenced educational websites were American Cancer Society (n = 10), BreastCancer.org (n = 7), and Susan G. Komen (n = 5). Only the chemotherapy sections of these sites were included in the analysis (ACS, 2017b; BreastCancer.org, 2018; Susan G. Komen, 2018). Each page in the chemotherapy portion of the website was identified initially, and then the primary author chose the content sections which consistently appeared on each website. Seventeen chemotherapy sections were reviewed in total and four content areas were evaluated for readability. The four sections evaluated on each website included: 1) information on chemotherapy; 2) expectations of treatment; 3) chemotherapy drugs; and 4) side effects.

Analysis

Readability Analysis

The printed and online chemotherapy education materials were evaluated for readability using a standardized measure of the Flesch Reading Ease (FRE; Flesch,

1948), Flesch-Kincaid scoring (F-K; Kincaid et al., 1975), and a Simple Measure of Gobbledygook (SMOG; McLaughlin, 1969). The materials were further evaluated using the Standardized Materials Assessment (SAM) described by Doak, Doak, and Root (1996).

Flesch Reading Ease Score

The Flesch Reading Ease Score (FRE) formula was used to evaluate the complexity and difficulty of printed materials (Flesch, 1948). The output ranges from 0 to 100 with the higher number being easier to read. The FRE score was calculated using the readability function within the spelling and grammar function of Microsoft Office Word Software.

Flesch-Kincaid Reading Grade Level

The Flesch-Kincaid (F-K) was another readability formula used to calculate the reading grade level of written material (Kincaid et al., 1975) based on the sentence length and word length. The output represented the reading grade level. The F-K score was determined by the spelling and grammar function of Microsoft Office Word Software.

Simple Measure of Gobbledygook

The Simple Measure of Gobbledygook (SMOG) formula was used to determine readability by taking the square root of the amount of polysyllabic words in 30 sentences (McLaughlin, 1969). The final number then has 3 added to the score to determine the reading grade level. The SMOG score was computed using an online assessment tool (ReadabilityFormulas.com, n.d.).

Suitability Assessment of Materials

The overall format and presentation were assessed using the Suitability Assessment of Materials (SAM) which pertained to content, literacy demand (on the reader), graphics, layout, motivation for the reader, and cultural appropriateness (Doak et al., 1996). The areas were rated a score of 2 (superior), 1 (adequate), or 0 (not suitable).

Qualitative Analysis

Data collection using the instruments and qualitative feedback to the chemotherapy educational resource form began simultaneously using a concurrent triangulation strategy (Creswell, Plano Clark, Gutmann, & Hanson, 2003), and we followed the six phases of thematic analysis (Braun & Clarke, 2006) to describe insights on how women with breast cancer experience learning about chemotherapy. The primary author used Braun and Clarke (2006) as a guide in familiarizing with the data (phase 1) by reading the typed, handwritten notes in an iterative process. Next, she coded the responses (phase 2) by generating labels for key features of the data before searching for themes (phase 3). The primary author's subsequent steps were reviewing the themes (phase 4) and defining and naming the themes (phase 5). Lastly, she concluded the thematic analysis by writing the results (phase 6) in a narrative format using extracted data (Braun & Clarke, 2006).

Results

Participant demographics are in Table 3.1. Participants were, on average, 59 years of age, married, and had a four-year college degree. Most of the women had an income of \$50,000 or greater. The participants' health literacy level was high on the REALM-SF with a score of 6.9 (SD \pm 0.5; literacy grade level above 9th grade). Further,

the participants had adequate functional literacy with a mean S-TOFHLA score of 95.6 (SD \pm 6.2).

Readability Scores of Materials

The mean readability of the two printed chemotherapy education materials ranged from ‘difficult’ to ‘fairly difficult’ based on the FRE scoring. Both of the materials were written on a 9th grade to 10th grade reading level determined by the F-K and SMOG scoring. Neither of the printed materials varied significantly in the scoring. However, the mean readability for the online materials ranged from ‘difficult’ to ‘standard.’ The reading grade level for the online materials ranged from 9th grade to 13th grade. The mean reading grade level of the chemotherapy sections from the American Cancer Society and Susan G. Komen varied between 9th and 10th grade. However, the mean reading grade level for Breastcancer.org was 12th grade and 13th grade. The chemotherapy drug pages had the highest reading grade level for Breastcancer.org (FRE = 25.4, F-K = 12.8, SMOG = 18.2) and the American Cancer Society (FRE = 51.9, F-K = 9.8, SMOG = 16). See Table 3.2 for a detailed description of readability scores. Overall, the FRE and F-K scoring were strongly correlated ($r = .94$) and the SMOG assessment was correlated with FRE ($r = .76$) and F-K ($r = .63$).

Suitability Assessment of Materials

All of the educational materials scored a ‘superior’ rating for content. The purpose was explicitly stated in each material, and the content was focused on the behaviors stemming from chemotherapy knowledge (avoiding crowds, monitoring for fevers). The scope of the material was limited directly to educating patients about

chemotherapy and a summary included with key messages such as reinforcing importance of hand hygiene.

The literacy demands ranged from ‘not suitable’ to ‘superior’ for the materials. The chemotherapy chapter from the *Breast Cancer Treatment Handbook* and chemotherapy sections from the American Cancer Society had the best ratings of the literacy demands category. The chemotherapy education booklet from SCOA, Breastcancer.org, and Susan G. Komen pages scored the lowest; the reading grade level was too high.

The graphics for the materials were mostly scored as ‘not suitable’ due to the absence of illustrations, graphics, pictures, charts, or lists. However, the chemotherapy chapter from the *Breast Cancer Treatment Handbook* included detailed illustrations regarding port placement and how to access the port. This was the only material which utilized illustrations as a supplement.

The layout and typography for the materials received mostly ‘superior’ scores. The messages were written in active voice, directed to the reader, conversational in tone, and sentence length was mostly short for the materials. While the text appeared heavy and condensed in the print materials, the layout of the websites included ample white space and bullets to assist the reader. The learning stimulation, motivation category of the print and online materials were not suitable for two categories: (1) interaction used; and (2) behaviors modeled. The materials did not include any problems for the reader to solve, and behaviors were not demonstrated to the reader. All of the materials scored ‘superior’ for the motivation category; the behaviors described in the materials were simple, direct, and appeared feasible.

Lastly, the materials lacked cultural appropriateness, and all of the materials received a ‘not suitable’ score. No pictures or culturally relevant information specific to women of different ethnicities or cultures were identified. The only graphics used included an illustration of port placement in the *Breast Cancer Treatment Handbook* and photos of lab technicians on the Breastcancer.org pages. All of these graphics were only of White women. See Table 3.3.

Participants’ Experiences with Education

The qualitative thematic analysis revealed three major themes: (1) finding control in learning; (2) receiving unexpected support; and (3) learning in unforeseen ways.

Finding control in learning. Several of the participants discussed ways they found control in learning at their own pace. Participants mentioned the benefit of having constant access to education materials. “I read the book [*Breast Cancer Treatment Handbook*], at my own pace when I was ready to read it,” commented Jennifer. Another woman, Leonora, described how the book was a great reference and said, “it is so nice to go back and forth” whenever she had questions. Having reference materials available when some women were emotionally ready to receive the information was critical to learning. Carla said she received the handbook [*Breast Cancer Treatment Handbook*], but “avoided looking at it [until] later” when she was emotionally ready to receive chemotherapy education.

Lastly, women gained control over their education by limiting the influence of the online materials. Some participants discussed how the online resources provoked fear and hindered comprehension. One participant, Bobbie, said “[Initially] I went berserk on the research when I first found out” but later quit searching so much because she “found

it distressing.” Similarly, Audrey said she was frightened by what was on the Internet. “I no longer read anything on the Internet; all it did was upset me,” she recalled. Katie also had a negative experience and said, “[the people in chat rooms] talked about the side effects of chemo and how they were horrible and got me all worked up, so I don’t go there anymore.” Tasha had a different experience. She looked at only “realistic and reliable sites” and “only went to those pertinent to breast cancer” and mentioned Susan G. Komen as being a positive resource for her. Another woman, Betty, accessed the main breast cancer page of the American Cancer Society as a starting off point for her own research. Ultimately, the participants had to sift through the various materials and decide what was most helpful for their educational experiences, thus gaining control over their own learning experience.

Receiving unexpected support. Some participants described the unexpected support while receiving chemotherapy education. “She [the nurse navigator] gave me so much information... and brought me all kinds of stuff,” Jean recalled as she described her education session. Jean discussed how the nurse navigator was informative and also supportive. “She met me in the hospital before surgery,” Jean said as she tearfully remembered the surgery, and “I am still able to get in touch whenever I need her.” Sally also touched on the emotional support from her nurse navigator who taught her about chemotherapy. “She has been a tremendous assistance.” Sally discussed how she learned a great deal about what to expect from chemotherapy and also felt that the nurse navigator was a friend. “She’s been invaluable,” Sally said. Chemotherapy education was informative for many of participants and also was an unexpected avenue of support to assist women through treatment.

Learning in unforeseen ways. Many of the participants described ways in which they learned about chemotherapy in unforeseen ways. Several participants described the teaching methods which they recalled as very helpful in the learning experience. Beatrice said she “went through the booklet and wrote in the margins” which reinforced the education. Similarly, Josephine said that her nurse navigator “... highlighted, starred, and marked every single page applicable to me.” Another nurse educator used post-it notes to mark important points for future reference. “She used post-it notes throughout the book and highlighted areas... she flagged important areas...,” Sandra commented. Women often mentioned that they did not expect the additional strategies to reinforce the teaching and were often surprised by the positive experience with the nurse educators. Additionally, participants mentioned how they learned about chemotherapy from other women. “I talked with two women I work with; they are breast cancer survivors,” Audrey said as she was reflecting on learning about side effects. Lastly, Bobbie learned more about chemotherapy from her daughter who was an oncology nurse. She described how helpful her daughter was at answering her questions about managing nausea.

Discussion

Chemotherapy education materials are a part of the experience of chemotherapy teaching for women with breast cancer. Nurse navigators are guides in the cancer education experience to help the participants to *find control*. Educators provide patients with materials starting at the initial point of contact with the education session and continue through every time the patient references the book or looks something up throughout treatment. The use of the materials is not limited to one point in time but acts as a reference point to which patients may refer to at any time. In this way, the quality of

the materials gives control back to the participant in her treatment and educational experiences. If the materials are supplemented with additional graphics or detailed illustrations, patients have another medium in which to *find control* through chemotherapy.

Additionally, the experience of chemotherapy teaching offered treatment information, and became a catalyst for *unexpected sources of support*. The teaching sessions usher in opportunities for many women to find support through nurse navigators and friends. Our findings are in support of numerous studies that highlight the role of nurse navigators and community members in improving the treatment experience for women with breast cancer (R. Smith, Mannle, Livsey, Tait, & Rossitch, 2017; Trevillion, Singh-Carlson, Wong, & Sherriff, 2015).

Lastly, many participants describe the *unforeseen ways of learning* while undergoing chemotherapy education. The nurse navigators and chemotherapy nurse educators adapt the material to be more appropriate for patients with various health literacy skills. For example, writing in margins and using sticky notes were recommended for patients with low health literacy (H. Osborne, 2013). Marking and highlighting on various pages assist the participants to recall important topics or reinforce self-management tips, in which case the patient could be guided even while not in the presence of a nurse educator. Including informational videos to websites may be another *unforeseen way to learn* about chemotherapy and be an alternative to reading. Certain side effects like nausea can cause women to not feel well enough to read making videos a unique alternative to traditional materials. These techniques help to offset more challenging readability levels of materials, thereby enhancing the overall experience.

Practice Implications

The readability results revealed that many chemotherapy education materials are too challenging at a 9th grade reading level. The National Institutes of Health recommend readability levels of patient education to be between 7th and 8th grade (National Library of Medicine, 2017). While some printed materials could be revised for a more appropriate grade level, nurses often do not have the time for such tasks. Instead, nurses may consider supplementing the material with personalized teaching approaches such as using the teach-back method (Caplin & Saunders, 2015) or using visuals to show patients what to expect during treatment (e.g., accessing a port). Website developers may consider using videos to deliver information to combat challenging readability of topics like chemotherapy drugs or expectations for treatment.

Apart from the readability, the SAM results revealed a lack of graphics or illustrations in both printed and online materials. Nurses or website developers may want to consider adding in graphics to particularly challenging sections of educational materials. For example, including pictures of the mechanisms of chemotherapy towards fast-growing cells may help explain how chemotherapy works regardless of the level of health literacy a patient may have. Additionally, the SAM results revealed the need for chemotherapy education materials to be more culturally appropriate. Including pictures of women of different ethnicities and topics specific to different cultures such as wigs and hair care after chemotherapy are ways in which nurses and website developers can be more culturally inclusive (Lackey, Gates, & Brown, 2001).

Limitations

One of the limitations of this study is the structure of the readability formulas. Often, readability analyses measure word and sentence length which is problematic when evaluating medical information or polysyllabic words such as chemotherapy (D. B. Friedman & Hoffman-Goetz, 2006). Furthermore, only two standardized chemotherapy education materials were identified by participants treated at one comprehensive cancer clinic. This limited the potential for diverse sources to be examined in this study. Lastly, a limitation is that online materials were evaluated using the same guidelines intended for print materials. While online material development should be adapted for populations with low literacy, the evaluation tool may not be specific to online material (U.S. Department of Health and Human Services, 2015).

Conclusion

The readability, format, and presentation of chemotherapy education materials should be easily understood to patients with a variety of health literacy skills. Chemotherapy education is one part of the treatment experience in which nurses can have the most positive impact on reinforcing information, thereby ultimately assisting patients to improve their overall health outcomes.

Table 3.1

Participant Demographics of the Sample (n = 46)

Variables	Total (n = 46)	
	n	%
Ethnicity		
White	22	47.8%
Black	23	50.0%
Other	1	2.2%
Marital Status		
Married	27	58.7%
Single	7	15.2%
Widowed	7	15.2%
Separated	1	2.2%
Divorced	4	8.7%
Education		
Graduated high school	12	26.1%
Completed technical/trade/Associate's degree	11	23.9%
Completed four-year degree	13	28.3%
Completed Master's degree	9	19.6%
Completed Doctorate degree	1	2.2%
Income		
< \$19,999	5	10.9%
\$20 - \$29,999	2	4.3%
\$30 - \$39,999	5	10.9%
\$40 - \$49,999	4	8.7%
\$50,000 and above	25	54.3%
Prefer not to answer	5	10.9%

Table 3.2

Readability Analysis Scores for Chemotherapy Education Materials

Material	FRE	Flesch- Kincaid	SMOG
SCOA Handbook	57.6	8.6	9.5
(Kneece, 2017) Chapter Breastcancer.org https://www.breastcancer.org/treatment/chemotherapy/how_it_works	53.4	9.3	9.56
Chemotherapy Information	38.2	12.1	10.5
Expectations of Treatment	32.3	13.4	12.4
Chemotherapy Drugs	25.4	12.8	18.2
Side Effects	52.6	9.9	10.6
Mean Scores	37.1	12.1	12.9
Susan G. Komen https://www5.komen.org/BreastCancer/Chemotherapy.html			
Chemotherapy Information	31.1	13.0	12.4
Expectations of Treatment	60.8	8.2	7.5
Chemotherapy Drugs	48	8.8	7.5
Side Effects	55.1	9.1	8.5
Mean Scores	48.8	9.8	9.0

American Cancer Society

<https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/chemotherapy/how-is-chemotherapy-used-to-treat-cancer.html>

Chemotherapy Information	55.5	10.3	8.7
Expectations of Treatment	68	7.7	7
Chemotherapy Drugs	51.9	9.8	16
Side Effects	62.1	8.7	7.8
Mean Scores	59.4	9.1	9.9

Note. FRE Materials with scores ranging from 0 to 30 are considered very difficult to read; 31–50 difficult; 51 – 60 fairly difficult; 61 – 70 standard; 71 – 80 fairly easy; 81 – 90 easy; and 91 – 100 are very easy; F-K and SMOG represent reading grade level.

Table 3.3

Suitability Assessment of Chemotherapy Education Materials

Evaluation Criteria	Teaching Booklet	Kneece Chapter	Breastcancer.org	Susan G. Komen	American Cancer Society
Content					
Purpose	‡	‡	‡	‡	‡
Content about behaviors	‡	‡	‡	‡	‡
Scope is limited	‡	‡	‡	‡	‡
Summary included	‡	‡	‡	‡	‡
Literacy Demands					
Reading grade level	+	‡	-	-	+
Writing style, active voice	+	‡	‡	‡	‡
Common Words	+	‡	+	+	‡
Context given first	‡	‡	‡	‡	‡
Learning aids	+	+	‡	‡	‡
Graphics					
Cover graphic with purpose	+	+	+	+	-
Type of graphics	+	+	+	+	-
Relevance of illustrations	+	+	-	-	-
List, tables explained	+	‡	-	-	-
Captions used for graphics	+	+	-	‡	-

Layout and Typography					
Layout factors	+	‡	‡	‡	‡
Typography	+	‡	‡	‡	‡
Subheads ("chunking")	‡	‡	+	+	‡
Learning Stimulation, Motivation					
Interaction used	-	-	-	-	-
Behaviors modeled and specific	-	-	-	-	-
Motivation— self-efficacy	‡	‡	‡	‡	‡
Cultural Appropriateness					
Match in logic, language, experience	‡	‡	‡	‡	‡
Cultural image and examples	-	-	-	-	-

Note. ‡ = superior rating; + = adequate; - = not suitable.

CHAPTER 4

THE RELATIONSHIP BETWEEN HEALTH LITERACY AND DEMOGRAPHIC FACTORS WITH CHEMOTHERAPY KNOWLEDGE IN WOMEN WITH BREAST CANCER²

² Parker, P.D., Heiney, S.P., Adams, S.A., Friedman, D.B., & Estrada, R.D. To be submitted to the *Clinical Journal of Oncology Nursing*.

Abstract

Background: More than 72,000 women with breast cancer receive chemotherapy treatment each year. While treatments can be life-saving, they often result in a variety of stressful side effects that negatively impact women's quality of life and treatment experience. Patients undergoing chemotherapy have to increase self-care behaviors to manage and decrease treatment-related symptoms. The main concept underlying the uptake of these behaviors is chemotherapy knowledge. While much research exists regarding application of chemotherapy knowledge in self-care behaviors, there is limited investigation on the contributing factors to chemotherapy knowledge – a rudimentary concept driving self-care.

Objectives: Given this gap in the literature, the purpose of this study is to describe the relationships among patients' health literacy, demographic factors, and cancer and treatment characteristics with chemotherapy knowledge among women with breast cancer.

Methods: We used univariate linear regression and ANOVA to identify which factors influenced chemotherapy knowledge among a sample of women ($n = 46$) with breast cancer.

Findings: The REALM-SF ($p = 0.022$) and S-TOFHLA ($p = 0.023$) scores were significantly associated with chemotherapy knowledge. The results showed a significant positive effect of marital status [$F(4,41) = 3.154, p = 0.024$] and increased income [$F(6, 39) = 8.567, p < 0.001$] on improved chemotherapy knowledge.

Keywords: breast cancer, chemotherapy knowledge, chemotherapy treatment, health literacy

Implications for Practice:

- Nurses may want to assess literacy skills prior to chemotherapy teaching using assessments such as the Rapid Estimate of Adult Literacy – Short Form.
- Nurses may consider using the teach-back method to evaluate effectiveness of chemotherapy education.
- Holding educational sessions for family members and friends about managing chemotherapy side effects and knowing when to call the doctor may be an ideal way to utilize social support.

More than 72,000 women with breast cancer receive intravenous chemotherapy annually (National Cancer Database, 2018). While these treatments can be life-saving, they often result in a variety of stressful side effects (e.g., nausea, vomiting, diarrhea, constipation) that negatively impact women's quality of life and treatment experience (Traeger et al., 2015). Further, patients have to adopt lifestyle changes such as avoiding crowds and sick people while going through treatment, which can be isolative at times (Kneece, 2017). Patients undergoing chemotherapy also have to increase self-care behaviors to manage and decrease treatment-related symptoms (Pearce et al., 2017; Valenti, 2014). The main concept underlying the uptake of these behaviors is chemotherapy knowledge. Chemotherapy knowledge is the understanding of chemotherapy-related information including, but not limited to, the goals and duration of treatment, possible side effects, lifestyle adjustments while going through treatment, and pregnancy prevention rationale (Coolbrandt, Van den Heede, Jans, et al., 2013). Adequate application of chemotherapy knowledge facilitates adherence to chemotherapy cycles (Busch et al., 2015; Griffiths & Pascoe, 2014) and increases a patient's ability to

quickly recognize the severity of symptoms that require immediate provider contact (Gonzalez & Stepan, 2006). While much research exists regarding application of chemotherapy knowledge in self-care behaviors (S. Z. Du et al., 2015; Traeger et al., 2015; Zhang, Kwekkeboom, & Petrini, 2015), there is limited investigation of the contributing factors to chemotherapy knowledge – a rudimentary concept driving self-care (Coolbrandt, Van den Heede, Clemens, et al., 2013).

Several individual characteristics can affect chemotherapy knowledge, including a patient's level health literacy, demographic factors, and cancer characteristics (Coolbrandt, Van den Heede, Jans, et al., 2013; Dodd, 1982). Health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p. vi). Based on the most recent National Assessment of Adult Literacy (NAAL) survey, 88% of adults are limited in some way by their health literacy to locate, understand, and navigate information in a variety of documents (Kutner et al., 2006). Patients with limited health literacy skills may be unfamiliar with vocabulary terms used during education sessions, such as *metastasis* (Davis et al., 2001). Additionally, patients with limited health literacy skills are more likely to have an inadequate understanding of prescription drug labels (Wolf et al., 2006), and may lack the skills needed to take medications properly (Berkman et al., 2011).

For patients with breast cancer, health literacy skills can influence the uptake of chemotherapy knowledge. Breast cancer patients with limited health literacy skills may be unclear about the necessary regimen of chemotherapy cycles (time of infusion and rest period) (ACS, 2017b; Busch et al., 2015), or may face difficulty with adherence (Busch

et al., 2015; Griffiths & Pascoe, 2014). Patients with limited chemotherapy knowledge about adverse effects of chemotherapy experience greater hospital admissions (Krzyzanowska et al., 2005), increased morbidity (Krzyzanowska et al., 2005), and decreased quality of life (Huynh & Trovato, 2014; Krzyzanowska et al., 2005).

Other factors can also influence how women learn about cancer and chemotherapy treatment, including demographic factors such as age, income, education, and marital status (Jiang, Sereika, Bender, Brufsky, & Rosenzweig, 2016; Thomas, 2007). Patients with increased age have decreased functional and sensory abilities thereby potentially reducing chemotherapy knowledge (Gausman Benson & Forman, 2002; Thomas, 2007). Further, income and education were found to influence women's knowledge of their breast cancer and recommended treatment (Jiang et al., 2016). Lastly, marital status is often associated with social support – a protective factor in the cancer treatment experience (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006; C. Osborne, Ostir, Du, Peek, & Goodwin, 2005). Social support can be instrumental in how women learn and process information about breast cancer treatment options like chemotherapy (Rubenstein, 2015).

Aside from demographic factors, cancer and treatment characteristics (breast cancer stage and number of completed chemotherapy cycles) are often associated with chemotherapy knowledge. First, more advanced stages of breast cancer lead to greater anxiety among patients (Villar et al., 2017), thereby possibly inhibiting patients' ability to process educational information resulting in lessened chemotherapy knowledge (S. Garcia, 2014). Second, the number of completed chemotherapy cycles (length of treatment followed by a rest period) may influence the level of chemotherapy knowledge

(ACS, 2017b). Repeated exposure to informal chemotherapy education from infusion nurses and treatment team members may increase chemotherapy knowledge (Dodd & Mood, 1981; Rieger & Yarbrow, 2003). However, no literature to date exists supporting how the intersection of these factors – health literacy levels, individual demographic factors, and cancer characteristics – affect chemotherapy knowledge.

Given this gap in the literature, the purpose of this study was to describe the relationships among patients' health literacy, demographic factors, and cancer treatment characteristics with chemotherapy knowledge among women with breast cancer. We hypothesized the following elements would be associated with greater chemotherapy knowledge:

- (H1) individual's increased level of health literacy;
- (H2) demographics such as age, income, marital status, and education;
- (H3) cancer and treatment characteristics (lower stage of breast cancer, increased number of completed chemotherapy cycles).

Further, we hypothesized: 1) the lower the stage of breast cancer, the less anxiety a woman experiences, which may indirectly allow her to gain greater chemotherapy knowledge; and 2) the increased number of chemotherapy cycles may influence chemotherapy knowledge. Identifying how individual characteristics impact chemotherapy knowledge may illuminate ways in which nurse educators can positively affect the cancer treatment experience for women with breast cancer.

Method

Participants and Setting

Patients were recruited from South Carolina Oncology Associates (SCOA), a large comprehensive oncology center. Every patient with cancer starting intravenous chemotherapy treatment at SCOA attended a mandatory chemotherapy education session. The chemotherapy nurse educator inserted a recruitment flier into a chemotherapy education packet for each patient with a new breast cancer diagnosis. Once the patient attended the education session, the Electronic Medical Record (EMR) was updated to reflect completion of the session. The primary author then reviewed the EMR to identify potential participants to be contacted based on completion of the session. She then identified a smaller sample of potential participants using the inclusion and exclusion criteria in the EMR.

Inclusion and exclusion criteria. The inclusion criteria for this study included women with: (1) a new diagnosis of breast cancer in the last three months; (2) can speak English; and (3) over the age of 18. Women were excluded from this study if they had: (1) a stage IV, metastatic breast cancer diagnosis; (2) breast cancer recurrence; and (3) cognitive impairments. Cognitive impairments were defined as any woman with delirium or dementia as these factors can be problematic for patients in giving consent or answering research questions (Carlson, 2013; Horner-Johnson & Bailey, 2013).

Recruitment. The primary author called potential participants about once a week. She used the Heiney-Adams Recruitment Framework (HARF), which was designed for data collectors to focus on relationship building while maintaining empathy with participants and being sensitive to the participants' time (Heiney et al., 2010; Heiney

et al., 2012). Every time she spoke with participants or left voicemails, she expressed gratitude and thanked participants for their time using scripts as templates designed by Heiney and others (2010). She introduced herself, referenced the flier, and ascertained interest in the study. The data collection session was completed before the fourth chemotherapy cycle to control for the frequency of nurse-initiated instruction.

If a woman did not answer the phone, the primary author left a voicemail if possible. The first author stopped calling once a woman became ineligible, or if a woman declined participation. A woman was considered to be ineligible after she completed her fourth chemotherapy cycle. Overall 110 women were contacted based on the screening of the EMR. Fifty-five women did not answer the phone or return the calls, and nine women (16.4%) refused to participate resulting in a sample of 46 women.

Data Collection

Participants met with the primary author at a location of the woman's preference to ensure confidentiality and comfort. Prior to collecting data, participants consented to the data collection and completed a research authorization form. Participant characteristics were obtained using a demographic data form. The primary author then proceeded to administer the remaining three instruments. Word recognition was measured using the Rapid Estimate of Adult Literacy – Short Form (REALM-SF; Arozullah et al., 2007) and functional health literacy was determined using the Short Test of Functional Health Literacy in Adults (S-TOFHLA; Baker et al., 1999). The REALM-SF and S-TOFHLA combined gave a more complete description of the patient's health literacy skills by testing how well patients could read and recognize words and measuring comprehension, and demonstrated moderate correlation (Jewitt et al., 2016; Kirk et al.,

2012). Chemotherapy knowledge was assessed using a revised Leuven Questionnaire on Patient Knowledge of Chemotherapy (L-PaKC; Coolbrandt, Van den Heede, Jans, et al., 2013).

The primary author read the L-PaKC and S-TOFHLA aloud or along with the participant, and the participants to complete the REALM-SF without assistance. Upon completion of data collection, the primary author gave each woman \$20 as a thank-you gift. The total time for data collection was approximately 45 minutes.

Instruments

Patient demographics. The 5-item scale, adapted from Heiney (Heiney et al., 2012), was used to collect information on education, marital status, income, and ethnicity.

REALM-SF. The REALM-SF is a word recognition test which is designed to assess how well patients read and pronounce isolated words they commonly experience in a primary care setting (Arozullah et al., 2007). The REALM-SF instrument consists of seven words including two control words. Participants are asked to read aloud the list of words in descending order. One point is given to each correctly pronounced word. Any word that is mispronounced or not attempted is not scored. The range of the scores is 0 to 7 with 7 representing a literacy grade level of greater than 9th grade. A score of 0 is equivalent to less than 3rd grade literacy level; a score of 1-3 represents a 4th-6th grade literacy level; and a score of 4-6 represents a 7th to 8th grade literacy level (Arozullah et al., 2007).

S-TOFHLA. The S-TOFHLA is designed to measure functional health literacy, comprehension, and numeracy (Baker et al., 1999; R. M. Parker et al., 1995). The S-TOFHLA includes two subscales of four numeracy items and two prose passages to

measure reading comprehension. The four numeracy items include questions measuring the participant's ability to use a: 1) prescription label; 2) blood sugar prompt; 3) appointment card. The second part of the instrument consists of two prose passages which included 36 items regarding the preparation for an upper gastrointestinal series and patient rights and responsibilities within a Medicaid application (Baker et al., 1999). Scores range from 0 to 100 with 0 – 53 representing inadequate functional health literacy, 54 – 66 as marginal functional literacy, and 67 – 100 as adequate functional literacy (Baker et al., 1999).

L-PaKC. The L-PaKC is a 20-item instrument with 12 of the items pertaining to general chemotherapy characteristics, eight are related to treatment-specific knowledge, and three were optional (Coolbrandt, Van den Heede, Jans, et al., 2013). Sample questions for the patients include knowing the duration of chemotherapy, purpose of blood tests prior to infusion, and side effects during treatment. The greater the score, the higher the patient chemotherapy knowledge.

We revised the L-PaKC questionnaire for an audience with limited literacy skills as agreed by the authors (Coolbrandt, 2016).

Analysis

Descriptive statistics of frequencies and means were calculated to determine the characteristics of the sample participants. Due to our small sample size, we ran univariate linear regression models with the health literacy scores as the independent variables and chemotherapy knowledge as the dependent variable. We ran one-way ANOVA models for demographic factors as the independent variables and chemotherapy knowledge as the dependent variable. We concluded our analysis with testing the

association of cancer characteristics (stage and number of completed chemotherapy cycles) with the dependent variable chemotherapy knowledge. We used SPSS Statistics 23 for all analyses.

Results

Participant demographics are presented in Table 3.1. Participants averaged 59 years of age. The majority of the women were married. The education level of the participants ranged from a high school degree to doctoral degree, but the majority of women completed a four-year degree. Most of the women had an income of \$50,000 or greater. Table 4.1 presents additional demographic information. The majority of participants had stage 2A breast cancer and were on docetaxel and cyclophosphamide chemotherapy. More than half of the participants completed one full chemotherapy cycle at the time of data collection.

The participants' scores on the REALM-SF was 6.9 representing a literacy grade level above 9th grade. Further, the participants had a mean S-TOFHLA score of 95.6 which represented adequate functional literacy. Lastly, the women's chemotherapy knowledge was rated as a 91 out of a possible 100 score. See Table 4.2.

Univariate regression modeling results for the health literacy instruments with chemotherapy knowledge as the outcome variable are described in Table 4.3. The REALM-SF ($p = 0.022$) and S-TOFHLA ($p = 0.023$) scores were significantly associated with chemotherapy knowledge. A one-unit increase in the REALM-SF word recognition test resulted in a significant 6.252 increase in the chemotherapy knowledge score. Further, a one-unit increase in the S-TOFHLA score resulted in an increase of 0.453 in the chemotherapy knowledge score. There was a significant positive effect of the marital

status on greater chemotherapy knowledge at the $p < 0.05$ level [$F(4,41) = 3.154, p = 0.024$]. Furthermore, there was significant positive effect of increased income on improved chemotherapy knowledge [$F(6, 39) = 8.567, p < 0.001$]. The remaining demographic variables of education, number of completed chemotherapy cycles, and cancer stage were not associated with chemotherapy knowledge. See Table 4.4.

Discussion

The results of this study highlight how certain individual factors are significantly associated with chemotherapy knowledge. An individual's level of health literacy was significantly associated with chemotherapy knowledge supporting our first hypothesis (H1). These results are supported by the research demonstrating the relationship of health literacy and cancer-related knowledge (Busch et al., 2015; Morris et al., 2013). While research supports the influence of health literacy on cancer knowledge (Oliver et al., 2018), our results were unique in that we demonstrate that health literacy impacted treatment-specific knowledge. Measuring literacy with a word recognition tool with a quick assessment like the REALM-SF may give nurses improved insight on a patient's literacy level. The nurse could then better assess a patient's capacity to understand treatment-related information.

For our second hypothesis (H2) only two factors were found to affect chemotherapy knowledge – income and marital status. These results are supported by current literature documenting the influence of income on cancer knowledge (Jiang et al., 2016). Additionally, marital status was positively associated with chemotherapy knowledge. A potential reason for this is that marital status is often associated with social support and social connection. Marital status is a type of social connection

(Kroenke et al., 2006), a phenomenon in which a woman feels connected with individuals and with her community, thereby improving her cancer treatment experience (Heiney, Tavaloki, Millon Underwood, Wells, & Weinrich, 2013). Similarly, women may seek additional information from their social support network regarding what friends and family members may have learned. For example, a woman may rely on a friend who went through chemotherapy to learn how to manage hot flashes or bone pain associated with chemotherapy. This study provides evidence that marital status as one form of social support can increase a woman's capacity to understand and apply breast cancer information, specifically treatment-related information.

Our results did not support the hypothesis (H3) that cancer and treatment characteristics would be associated with chemotherapy knowledge. We viewed the stage of breast cancer as a potential proxy of anxiety to determine if learning and thereby chemotherapy knowledge was affected. However, our results did not reflect this. The literature does support that the more advanced stage of breast cancer leads to greater anxiety (Villar et al., 2017), but limited research exists regarding the impact of anxiety on chemotherapy knowledge. In the future, researchers may want to directly measure anxiety along with chemotherapy knowledge to test for any mediating effects.

This study highlights the relevance of considering patients' personal qualities when educating about chemotherapy. The intersection of the level of health literacy with income and marital status create a unique set of patient attributes nurses can consider when educating a patient. At this junction, the nurse can mold the extrinsic qualities of chemotherapy education (materials used, teaching style) to supplement a patient's intrinsic qualities (such as her level of health literacy and income and marital status) in

order to achieve more effective chemotherapy teaching (Valenti, 2014). Through tailored chemotherapy education patients can have better chances at increasing their chemotherapy knowledge, which could lead to increased initiation of self-care and enable patients in their decision-making processes throughout treatment (Coolbrandt, Van den Heede, Jans, et al., 2013; Dodd & Mood, 1981).

Limitations

The instruments used in this study had limitations. The S-TOFHLA content consists of questions before an upper gastrointestinal series, which was not relevant to the sample of participants in this study. Also, the primary author read along with or aloud the S-TOFHLA. This could have skewed the results since the instrument was designed to be read without assistance (Baker et al., 1999). REALM-SF is a word recognition and pronunciation test, which does not account for patients of various language and cultural backgrounds who may mispronounce common English words.

Additionally, the characteristics and quantity of this sample were limited. First, the majority of women (50%) had at least a four-year college education, and 54.3% of participants had an income of more than \$50,000 a year. This could be a reflection of the phenomenon that women who are more educated and have greater income are more likely to participate in research studies (Galea, Tracy, Galea, & Tracy, 2007). This could also explain the increased levels of health literacy among the sample of women in this study. Continued investigation with purposeful sampling (women with lower income or less education) may reveal further insights into the role demographic factors play in affecting chemotherapy knowledge.

Despite the limitations of instrumentation and sample size, this study is unique. While health literacy and demographic factors have been explored in cancer knowledge, our study is the first to quantify the impact of these factors and health literacy on treatment-specific knowledge.

Clinical Implications

Based on our findings, nurses may want to assess for literacy prior to chemotherapy teaching using word recognition assessments such as the REALM-SF. A brief assessment that can be administered quickly will help nurse educators measure patients' learning capacities for health-related information. Then, nurses can adapt teaching strategies that are applicable to a variety of patients with differing levels of health literacy skills. For example, nurses may choose to implement strategies such as the teach-back method to reinforce treatment-related teaching during educational sessions to continually evaluate the effectiveness of the chemotherapy education (Caplin & Saunders, 2015; Kountz, 2009).

In addition to health literacy, this study highlights the possible role social support can play in affecting chemotherapy knowledge. Nurse educators should consider strategies that utilize and mobilize social support systems in educating women about breast cancer treatment. For example, nurses may want to lead educational sessions for family members and friends about how to manage side effects and knowing when to call the doctor. This additional support for patients may improve their treatment experience.

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Table 4.1

Summary of Cancer and Treatment Characteristics

Variable	n	Percentage
Breast Cancer Stages ^a		
1A	8	17.4%
2A	18	39.1%
2B	7	15.2%
3A	7	15.2%
3B	1	2.2%
3C	4	8.7%
Chemotherapy*		
AC	15	32.6%
AC-T	6	13.0%
PT	1	2.2%
TC	19	41.3%
TCHP	5	10.9%
Completed Cycles ^b		
0 ^c	2	4.3%
1	31	67.4%
2	5	10.9%
3	8	17.4%

Note. ^aNot yet staged at time of recruitment (n = 1). ^bCompleted cycles at time of data collection. ^cParticipants completed chemotherapy education, but had not yet had first infusion.

*AC (doxorubicin and cyclophosphamide); AC-T (doxorubicin and cyclophosphamide and paclitaxel); PT (paclitaxel and trastuzumab); TC (docetaxel anhydrous and cyclophosphamide); TCHP (docetaxel anhydrous and carboplatin and trastuzumab and pertuzumab).

Table 4.2

Mean Scores for Instruments for Sample (n = 46)

Instrument	Range		Mean	SD
	Min	Max		
REALM-SF	5	7	6.9	0.5
S-TOFHLA	69.4	100	95.6	6.2
L-PaKC	58.8	100	91.0	8.4

Table 4.3

Univariate Regression Models for Sample (n = 46) with Chemotherapy Knowledge as the Dependent Variable

Independent Variables	β	Significance
REALM-SF	6.252	0.022*
S-TOFHLA	0.453	0.023*

Note. * Denotes statistical significance at $p < 0.05$ level.

Table 4.4

ANOVA for Sample (n = 46) with Chemotherapy Knowledge as the Dependent Variable

Independent Variables	df	F	Significance
Education	4, 41	1.850	0.138
Marital Status	4, 41	3.154	0.024*
Income	6, 39	8.567	<0.001*
Number of Completed Cycles	3, 42	2.149	0.108
Cancer Stage	7, 38	0.552	0.789

Note. * Denotes statistical significance at $p < 0.05$ level.

CHAPTER 5

CONCLUSION

Chemotherapy can be an effective cancer treatment but frequently results in a variety of stressful side effects (e.g., nausea, vomiting, diarrhea) that negatively impact women's quality of life and treatment experiences (Traeger et al., 2015). Patients have to adopt lifestyle changes such as avoiding crowds and sick people while going through treatment, which can be isolative at times (Kneece, 2017). Patients undergoing chemotherapy also have to increase self-care behaviors to manage and decrease treatment-related symptoms (Pearce et al., 2017; Valenti, 2014). The main concept behind such self-care behaviors is chemotherapy knowledge. Chemotherapy knowledge is the understanding of chemotherapy-related information including, but not limited to, the goals and duration of treatment, possible side effects, lifestyle adjustments while going through treatment, and pregnancy prevention rationale (Coolbrandt, Van den Heede, Jans, et al., 2013). Patients obtain this chemotherapy knowledge through differing learning modalities including standard chemotherapy sessions, printed and online informational materials, and informal patient teaching delivered by infusion nurses. Patients' comprehension of chemotherapy education is affected by various factors such as instructional methods (Felder & Silverman, 1988) and individual styles of learning (Dalby et al., 2013), but one of the most crucial elements to generating chemotherapy knowledge is health literacy. Ratzan and Parker (2000) define health literacy as the "capacity to obtain, process, and understand basic health information and

services needed to make appropriate health decisions” (p. vi). However, little research exists regarding how nurses adjust for health literacy when educating about chemotherapy (Parker et al., 2018).

The beginning of my research was dedicated to exploring how nurses accommodated for health literacy within chemotherapy education. Specifically, I conducted a scoping review to determine how nurses used health literacy principles (e.g., use of plain language, active voice, graphics) within chemotherapy education sessions. As described in Chapter 2, I identified gaps from the limited amount of published literature regarding the incorporation of health literacy principles within chemotherapy education for patients with breast cancer. Much of the chemotherapy education material development lacked the application of health literacy principles, and researchers did not test the effectiveness of the materials on chemotherapy knowledge. After determining a gap in the literature, my inquiry expanded beyond how nurses applied health literacy principles in chemotherapy education. I broadened my research focus and generated three specific aims dedicated to further understand how extrinsic qualities of chemotherapy education (e.g., delivery of materials, type of materials) and patients’ intrinsic attributes (e.g., demographics, health literacy, cancer treatment characteristics) affect chemotherapy knowledge. The specific aims of this study were to:

- 1) Evaluate the readability and format of commonly used chemotherapy educational materials for women with breast cancer;
- 2) Explore how a sample of women with breast cancer perceive chemotherapy education;

- 3) Describe the relationships of patients' health literacy, demographic factors, and cancer treatment characteristics with chemotherapy knowledge among women with breast cancer.

I explored the first two specific aims in Chapter 3 and gained greater understanding of the extrinsic qualities (readability of materials and perceptions) of chemotherapy education. Nurse navigators and educators were viewed as guides in the cancer education experience to help the participants to *find control* over their learning process. The materials were integral to chemotherapy education and helping patients *find control*, but the results revealed that many of the printed and online materials were written on a challenging reading level and lacked graphics. Additionally, another facet of chemotherapy education was the *unexpected source of support*. The teaching sessions ushered in opportunities where women found additional support through nurse navigators and friends. Lastly, many of the participants described their *unforeseen ways of learning* while undergoing chemotherapy education. The nurse navigators and chemotherapy nurse educators adapted their teaching styles to be more appropriate for patients with various health literacy skills. Marking and highlighting on various pages assisted the participants to recall important topics. Despite the challenging readability of some chemotherapy education materials available, these techniques of assisting patients in *unforeseen ways* enhanced the overall treatment experience.

I examined the third aim through investigating how individual factors were associated with chemotherapy knowledge. The results demonstrated a positive significant relationship between the level of health literacy, income, and marital status with increased chemotherapy knowledge as described in Chapter 4. Participants with

increased health literacy skills were more likely to have greater chemotherapy knowledge. Similarly, participants who were married or had a higher income were more likely to have greater chemotherapy knowledge. However, the stage of cancer or number of cycles completed were not associated with chemotherapy knowledge. The results described Chapters 3 and 4 had significant practice implications for nurses tailoring chemotherapy education.

Practice Implications for Readability of Materials

The readability, format, and presentation of chemotherapy education materials should be easily understood by patients with a variety of health literacy skills. The readability results revealed that many chemotherapy education materials are too challenging at a 9th grade reading level. The National Institutes of Health recommend readability levels of patient education to be between 7th and 8th grade (National Library of Medicine, 2017). While some printed materials could be revised for a more appropriate grade level, nurses often do not have the time for such tasks. Instead, nurses may consider supplementing the material with personalized teaching approaches such as using the teach-back method (Caplin & Saunders, 2015) or using visuals to show patients what to expect during treatment (e.g., accessing a port). Website developers may consider using videos to deliver information to combat challenging readability of topics like chemotherapy drugs or expectations for treatment.

Apart from the readability, the SAM results revealed a lack of graphics or illustrations in both printed and online materials. Nurses or website developers may want to consider adding graphics to particularly challenging sections of educational materials. For example, including pictures of the mechanisms of chemotherapy towards fast-

growing cells may help explain how chemotherapy works regardless of the level of health literacy a patient may have. Additionally, the SAM results revealed the need for chemotherapy education materials to be more culturally appropriate. None of the brochures depicted women of color or discussed hairstyles after chemotherapy or availability of wigs that were culturally relevant to individual patients. These are important topics for nurses and website developers to consider to be more culturally inclusive (Lackey et al., 2001).

Practice Implications for Patients

This study highlights the relevance of considering patients' personal qualities when educating about chemotherapy. The intersection of the level of health literacy with income and marital status create a unique set of patient attributes nurses can consider when educating a patient. At this junction, the nurse can mold the extrinsic qualities of chemotherapy education (materials used, teaching style) to supplement a patient's intrinsic qualities (such as her level of health literacy and income and marital status) in order to achieve more effective chemotherapy teaching (Valenti, 2014). Through tailored chemotherapy education patients can have better chances at increasing their chemotherapy knowledge, which could lead to increased initiation of self-care and enable patients in their decision-making processes throughout treatment (Coolbrandt, Van den Heede, Jans, et al., 2013; Dodd & Mood, 1981).

Based on these findings, nurses may want to assess for literacy prior to chemotherapy teaching using word recognition assessments such as the REALM-SF. A brief assessment that can be administered quickly will help nurse educators measure patients' learning capacities for health-related information. Then, nurses can adapt

teaching strategies that are applicable to a variety of patients with differing levels of health literacy skills. For example, nurses may choose to implement strategies such as the teach-back method to reinforce treatment-related teaching during educational sessions to continually evaluate the effectiveness of the chemotherapy education (Caplin & Saunders, 2015; Kountz, 2009).

In addition to health literacy, this study highlights the possible role social support can play in affecting chemotherapy knowledge. Nurse educators should consider strategies that utilize and mobilize social support systems in educating women about breast cancer treatment. For example, nurses may want to lead educational sessions for family members and friends about how to manage side effects and knowing when to call the doctor. This additional support for patients may improve their treatment experience.

Future Research Directions

Expanding this study to include women of different backgrounds with a variety of cancers may offer additional insights into the roles of readability, health literacy, and demographic factors with chemotherapy knowledge. Additionally, continued investigation with purposeful sampling (women with lower income or less education) may reveal further understanding of the influence of these factors on chemotherapy knowledge. Ultimately, this dissertation is a springboard to study the effect of psychological processes (e.g., anxiety, depression, mood disorders) on how patients learn about cancer treatment. Future research could be designed to further the understanding of the intersection of such psychological processes with health literacy on patient education that influence breast cancer survivorship.

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