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INTERACTIVE HEALTH LITERACY AND SELF-MANAGEMENT OF LUNG CANCER SYMPTOMS

by

Julie Kieffer Campbell

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ABSTRACT

INTERACTIVE HEALTH LITERACY AND SELF-MANAGEMENT OF LUNG CANCER SYMPTOMS

by

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The University of Wisconsin-Milwaukee, 2020
Under the Supervision of Professor Jeanne Erickson

Patients with lung cancer experience multiple symptoms requiring self-management. Health literacy skills are necessary for obtaining and processing information related to symptom self-management. Interactive health literacy involves communicating with healthcare providers regarding health-related information, but the role of interactive health literacy in self-management is not clear. This study used a critical realist approach to address these specific aims: 1) explore interactive health literacy and how it relates to symptom self-management for patients with lung cancer; and 2) describe patients' experiences of interacting with healthcare providers regarding symptom self-management for lung cancer. The study was conducted using a cross-sectional mixed methods design. Participants included 12 adults who were receiving or had recently received treatment for lung cancer. Data collection included a demographic questionnaire, the All Aspects of Health Literacy Scale, the Memorial Symptom Assessment Scale-Short Form, and semi-structured individual interviews. Data analysis followed a critical realist methodology aimed at discovering patterns that explain how interactive health literacy relates to symptom self-management. Findings identified that interactive health literacy skills may play a role in patients' ability and confidence to acquire and process symptom management information through interaction with an oncology provider. Furthermore, the relationship between patients with lung cancer and their oncology providers is a generative mechanism for obtaining credible symptom management information. There are factors related to both structure and personal agency that impact patients' access to and engagement in relationships with providers. Additional research is needed to determine patient-centered strategies that address these factors to promote patient engagement in collaborative patient-provider relationships and effective symptom self-management.

To all patients with cancer and their families,

who face the challenges of this terrible disease

with extraordinary strength and courage

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Introduction:
Interactive Health Literacy and Symptom Self-Management for Patients with Lung Cancer

Background and Significance

Health literacy is commonly understood as some variation of the definition endorsed by the National Academies of Sciences, Engineering, and Medicine in 2004, which reads: "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 4). Over the past few decades, health literacy has been a research priority in the U.S. due its apparent link with a wide range of health outcomes. At the same time, the healthcare system has shifted to a patient-centered approach, in which patients are expected and encouraged to actively engage in self-management of illness in an effort to improve health outcomes while reducing healthcare spending (Sawin, 2017). As the sciences of medicine and technology advance, life expectancy in the U.S. has increased, accompanied by an increase in the prevalence of chronic illnesses, such as heart disease and diabetes. Furthermore, several types of cancer are being increasingly recognized as chronic illnesses rather than terminal diseases as advances in cancer treatment have lengthened survival rates (Husson, Mols, & Fransen, 2015). In fact, approximately half of all adults in the U.S. have been diagnosed with at least one chronic health condition, accounting for nearly 90% of healthcare costs nationwide (Centers for Disease Control and Prevention [CDC], 2017).

As the healthcare system faces the critical task of caring for aging individuals with multiple health conditions, the patient-centered approach has resulted in higher expectations for patients to self-manage their chronic illnesses. Self-management requires a number of health literacy skills, such as reading, writing, numeracy, communication, decision-making, and navigation of the healthcare system (Helitzer, Hollis, Sanders, & Roybal, 2012). The most recent national assessment of health literacy revealed that only 12% of the U.S. adult population meets the criteria for proficient health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006). Yet evidence indicates that healthcare providers, including nurses, often overestimate the health literacy level of patients, placing unrealistic demands on patients to locate, obtain, process, and apply health-related information for their own situations (Dickens, Lambert, Cromwell, & Piano, 2013; Koh, Brach, Harris, & Parchman, 2013; Squiers, Peinado, Berkman, Boudewyns, & McCormack, 2012; Wittenberg, Ferrell, Kanter, & Buller, 2018). Health literacy experts emphasize a link between health literacy and costs of health care, estimating that poor individual health literacy contributes to approximately 3% of health care expenditures. The relationship between health literacy and cost is often inferred from the impact of limited individual health literacy on outcomes such as poor medication management, inappropriate use of health care services, increased hospitalizations, and increased emergency department use (Palumbo, 2017).

The importance of health literacy and self-management of illness is particularly salient for patients with serious life-limiting illnesses, such as lung cancer. Lung cancer is the second most common cancer for adults in the U.S., and it frequently causes multiple distressing symptoms (American Cancer Society [ACS], 2018). Without effective self-management of their symptoms, patients with lung cancer often face reduced quality of life and unnecessary healthcare costs. Research is needed to identify how health literacy is related to symptom self-management for patients with lung cancer, in order to inform nursing interventions that facilitate effective self-management and improve quality of life. The purpose of this chapter is to discuss the importance of this research and outline the purpose and specific aims for the study.

The Concept of Health Literacy

There are three primary limitations with how the National Academies' definition of health literacy has been applied in research. First, it is often conceptualized as a risk, in which an individual with low health literacy is at higher risk for poor health outcomes (Nutbeam, 2008; Pizur-Barnekow, Darragh, & Johnston, 2011). Secondly, health literacy is narrowly referred to as a characteristic of individual patients, overlooking the role of healthcare providers and the wider healthcare system (Ballard & Hill, 2016; Chinn & McCarthy, 2013; Paasche-Orlow & Wolf, 2007; Rudd, 2015; Squiers et al., 2012). Finally, this conventional definition of health literacy has been operationalized primarily in terms of general reading, writing and numeracy skills, with a notable lack of attention to contextual factors that may influence the process of obtaining, comprehending, and applying health information (Chinn & McCarthy, 2013; Nutbeam, 2008; Paasche-Orlow & Wolf, 2007; Rudd, 2015; Sørensen et al., 2012; Squiers et al., 2012).

The last decade has seen growing support for broadening the definition of health literacy to encompass multiple aspects beyond basic literacy and numeracy skills, to shift perspectives toward viewing health literacy as an asset rather than a risk, and to consider how interaction with healthcare providers influences health literacy and its application to health-related decision-making (Nutbeam, 2000; Nutbeam, 2008; Paasche-Orlow & Wolf, 2007; Pizur-Barnekow et al., 2011; Rudd, 2015). In the late 1990s, the World Health Organization endorsed Nutbeam's (1998) definition of health literacy as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (p. 10). In more recent publications, Nutbeam (2000, 2008) describes three dimensions of health literacy: functional, interactive and critical (Figure 1). Functional health literacy is similar to general literacy, meaning reading and writing skills used for everyday tasks. Interactive (or communicative) health literacy refers to the cognitive and social communication skills used to extract meaning from health information. Critical health literacy involves critical analysis of health information for one's own situation or circumstances (Nutbeam, 2000; Nutbeam, 2008).

This definition of health literacy holds marked significance for how health information is communicated between healthcare providers and patients. While acknowledging the importance of foundational abilities to obtain and understand health information, the added interactive and critical dimensions of health literacy offer a platform for expanding the goal of patient education beyond increasing knowledge and promoting rote compliance with treatment plans. Recognizing health literacy as an asset, patients are empowered to engage in confident interactions with healthcare providers as they extract, compare, and analyze health information, and then integrate the meaning of that information into health-related decisions (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015; McKenna, Sixsmith, & Barry, 2017; Nutbeam, 2008; Pizur-Barnekow et al., 2011).

Health Literacy and Self-Management

Conceptualizing health literacy as described by Nutbeam (2000, 2008) is helpful in today's healthcare system, in which a shift toward patient-centered care coupled with efforts to reduce healthcare spending have placed higher demands on patients to self-manage their health conditions. Broadly speaking, self-management involves the actions individuals take to manage treatment regimens as well as symptoms and side effects (Sawin, 2017). Determining appropriate self-management strategies necessitates health literacy skills, yet there is relatively little clear evidence of how these two phenomena relate to each other (Office of Disease Prevention and Health, 2010). Notably, several of the concepts contained in self-management theories overlap with elements of health literacy, although these connections are often not overtly acknowledged or explained.

The Individual and Family Self-Management Theory (IFSMT), a mid-range nursing theory published in 2009, recognizes the multiple dimensions that might explain how patients and families engage in self-management behaviors (Ryan & Sawin, 2009). Ryan and Sawin (2009) define individual and family self-management as “the purposeful incorporation of health-related behaviors into an individual or family’s daily functioning” (Ryan & Sawin, 2009, p. 222). Self-management is dynamic and multidimensional, comprised of context, process and outcomes (Figure 2). Context consists of risk and protective factors that interact with each other, influencing both the self-management process and outcomes. These include: 1) factors specific to the condition, such as how complex and stable the individual/family perceive the condition or treatment to be; 2) factors related to the physical as well as social environment, such as access to healthcare, social capital, and culture; and 3) factors specific to the individual and family, such as learning ability, literacy, and capacity to self-manage (Ryan & Sawin, 2009).

The context factors affect the individual and family’s capacity for engaging in the process of self-management. The IFSMT posits that individuals and families are more likely to incorporate self-management into their daily life if they have adequate knowledge and congruent beliefs about the self-management process. Other process factors are related to self-regulation, which involves goal-setting, decision-making, self-evaluation, and emotional control. Self-management may also be influenced by social facilitation, including social support, social influence, and negotiated collaboration with healthcare providers. According to Ryan and Sawin (2009), these elements of the process dimension interact with each other as well as with context factors. Both the context and process of self-management impact the outcome dimension. Proximal outcomes consist of actual individual and family self-management behaviors, including symptom management, as well as healthcare costs. As these are realized, distal outcomes may also be achieved, such as attenuation or stabilization of a condition, quality of life, and health-related costs. Interventions to improve self-management could be focused on either the context or the process dimension of the IFSMT, or both (Ryan & Sawin, 2009).

Mapping the elements of Nutbeam's (2000, 2008) conceptualization of health literacy onto the context and process dimensions of the IFSMT offers significant potential for developing effective self-management interventions (Heijmans et al., 2015; Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013; Nutbeam, 2000; Nutbeam, 2008). Functional health literacy refers to literacy skills that are required for basic healthcare tasks, such as reading written instructions and completing health-related forms, which provide a foundation for more advanced skills. This level of health literacy implies an emphasis on conventional methods of patient education, involving communication of health-related information to an individual patient for the purposes of increasing knowledge and fostering compliance (Nutbeam, 2000). In the IFSMT, functional health literacy is reflected in the context dimension, where learning ability and literacy are listed as Individual and Family Factors that influence both the process and outcomes of self-management.

Nutbeam (2000, 2008) defines the second level of health literacy as interactive, referring to higher cognitive and social skills for actively engaging in health communication and applying information to dynamic situations. Interactive health literacy skills contribute to motivation and confidence with which individuals are able to act on information received through communication. The IFSMT claims that the process of self-management is influenced by negotiated collaboration, aimed at aligning professional recommendations with individual and family preferences. Interactive health literacy is linked with negotiated collaboration by a shared emphasis on communication between patients and healthcare providers for the purposes of applying information to one's own situation.

The third and final level of health literacy is critical health literacy, or advanced cognitive and social skills necessary for critically analyzing and applying health information as a means to gain control over one's health (Nutbeam, 2000). In other words, as individuals develop progressively higher health literacy skills, they are empowered to make informed health decisions and use healthcare services more effectively. This is echoed in an underlying assumption of the IFSMT, which recognizes that "individual interest and control results in better outcomes than external decisions" (Sawin, 2017, p. 173). Thus, critical health literacy fits best within the IFSMT's process dimension labeled Self-Regulation Skills and Abilities. This category comprises activities such as goal-setting; decision-making, planning and action; and self-evaluation (Ryan & Sawin, 2009).

A Focus on Interactive Health Literacy

As the science of health literacy and self-management continues to advance, it is crucial to identify and clarify key areas of overlap between these two complex phenomena. Most research examining the link between health literacy and self-management focuses on general literacy skills such as reading comprehension of medical information, with inconsistent results across patient populations and disease conditions (Alsomali, Vines, Stein, & Becker, 2017; Geboers et al., 2015; Geboers, de Winter, Spoorenberg, Wynia, & Reijneveld, 2016; Kim & Lee, 2016; McCleary-Jones, 2011). This highlights the need to look beyond functional skills and more fully explore the other two dimensions of health literacy, particularly interactive health literacy. In fact, using comprehensive health literacy measures such as the Functional, Communicative and Critical (FCCHL) scale, researchers have found that interactive health literacy was more strongly correlated than the other levels of health literacy with outcomes such as self-management and confidence in healthcare interactions (Heijmans et al., 2015), and effective patient-provider communication (Inoue et al., 2013).

Elements of the interactive dimension of health literacy are frequently addressed in self-management research, although they are not always explicitly described as health literacy. For instance, two reviews of qualitative studies identified communication as either a facilitator or barrier to self-management (Russell et al., 2017; Schulman-Green, Jaser, Park, & Whittemore, 2015). One review found that patients with chronic obstructive pulmonary disease often received limited or conflicting information from healthcare providers, resulting in frustration and confusion, ultimately impeding their ability to self-manage (Russell et al., 2017). In the other review, patients with chronic illness reported that knowledge about disease processes and treatment regimens was essential for self-management, but more importantly, they needed information regarding how to apply knowledge to their own situation. This required a collaborative relationship with healthcare providers, with open and supportive communication (Schulman-Green et al., 2015).

Self-Management in Patients with Lung Cancer

With this evidence in mind, additional research is needed to explore the role of interactive health literacy in self-management for other patient populations, notably in the context of a complex disease such as lung cancer. Lung cancer is the leading cause of cancer-related mortality in the U.S. (ACS, 2018). A diagnosis of lung cancer is overwhelming for patients and caregivers, with bleak survival statistics and daunting treatment options. It is one of the most frequently diagnosed types of cancer for both males and females in the U.S., yet its five-year relative survival rate is only 20.5% (National Cancer Institute, 2020). This is partially because the disease may already be in advanced stages before it is diagnosed. Presenting symptoms, such as cough and back pain, are often vague and may be initially attributed to other conditions, allowing for tumors to grow and spread without accurate diagnosis and treatment (Vidaver, Shershneva, Hetzel, Holden, & Campbell, 2016). As a result, the majority of patients with lung cancer experience significant physical and psychological symptoms that can be quite distressing. Findings from recent studies indicate a number of symptoms commonly experienced by patients with lung cancer in the first few months after diagnosis. These often occur in clusters of multiple symptoms and can include dyspnea, loss of appetite, pain, coughing, fatigue, anxiety, and sleep issues (Henoch & Lövgren, 2014; Iyer, Roughley, & Taylor-Stokes, 2014; Liao et al., 2014; Maguire et al., 2014). As the disease progresses, symptoms may worsen, and the cumulative effect can be increasingly distressing for patients (Maguire et al., 2014).

Furthermore, advanced and metastatic lung cancer has traditionally been treated systemically with aggressive chemotherapy, which carries its own set of potentially debilitating side effects (ACS, 2018; National Comprehensive Cancer Network [NCCN], 2018; Oncology Nursing Society [ONS], 2018; Wong et al., 2017). Chemotherapeutic agents are cytotoxic, meaning they kill both normal and cancerous cells by interrupting the cell cycle of division and replication. Patients are at high risk for experiencing side effects caused by the death of normal cells, particularly in areas of the body where cells divide rapidly such as the bone marrow, hair and skin, and gastrointestinal tract. Common side effects of chemotherapy include fatigue, loss of appetite, bowel changes, nausea and vomiting, hair loss, dry skin, mouth sores, dysphagia, neuropathy, and mood changes (ACS, 2018). Of note, treatment options for lung cancer have expanded significantly in the past few years, with the discovery of molecular biomarkers and immunotherapies that target them (Cancer Research Institute, 2015). While they are typically better tolerated than cytotoxic chemotherapy, immunotherapies present a new set of symptoms related to the immune response; these are best managed when addressed immediately (Lewis, 2016). In sum, patients with lung cancer face significant challenges in understanding how to manage a life-threatening disease and the myriad symptoms that accompany it for the remainder of their lives.

Purpose and Specific Aims

The high symptom burden of lung cancer, compounded by treatment side effects, often results in healthcare costs, as well as a negative impact on quality of life and functional status (Dean et al., 2013; Iyer et al., 2014; Liao et al., 2014; Maguire et al., 2014). Patients are required to engage in complex self-management strategies, necessitating the health literacy tasks of obtaining and making sense out of a great deal of information in order to apply the information to one's own situation. Yet despite the plethora of research on health literacy and self-management, little is known about how interactive health literacy is related to symptom self-management for patients with lung cancer. There is also an insufficiency of knowledge regarding the experience of interactive health literacy from the perspective of patients. This dissertation study addressed this gap by exploring how interactive health literacy relates to symptom self-management for patients with lung cancer. Specific aims were to:

1. Explore interactive health literacy and how it relates to symptom self-management for patients with lung cancer;
2. Describe patients' experiences of interacting with healthcare providers regarding symptom self-management for lung cancer.

The knowledge developed from this study will be especially significant for oncology nurses, who are often intimately familiar with patients along the cancer treatment trajectory, having important insight into symptom management needs and the expertise to support patients as they learn to self-manage those needs. Furthermore, additional research is needed to develop effective nursing interventions that facilitate self-management, creating an urgent need for nurse scientists to assume a prominent role in contributing to what is currently known in order to influence clinical practice and policy that may ultimately impact the quality of life and outcomes for patients with lung cancer.

Overview of Methods

To address the aims of the study, a cross-sectional design using a critical realist methodology was employed, with the collection and analysis of both quantitative and qualitative data. Participants included 12 male and female adults who were currently receiving treatment for lung cancer, or who had received treatment for lung cancer within the six months prior to enrollment. Recruitment began in late January 2020 at an outpatient oncology clinic in eastern Tennessee that specializes in radiation therapy for adults with solid tumors. In March 2020, due to restrictions imposed by the COVID-19 pandemic, the researcher was no longer permitted to be physically present in the oncology clinic. Recruitment efforts shifted to virtual support groups serving patients with lung cancer throughout the United States. Further details about recruitment procedures are outlined in Chapter 3.

After signing consent for the study, participants completed a self-administered questionnaire that included demographic data questions, the Memorial Symptom Assessment Scale-Short Form (Chang et al., 2000), and the All Aspects of Health Literacy Scale, which includes a subscale focused on interactive health literacy (Chinn & McCarthy, 2013). Qualitative data was collected through an audio-recorded semi-structured individual interview with each participant via telephone. Interview questions were designed to explore connections between interactive health literacy and self-management of symptoms. Collecting and analyzing both quantitative and qualitative data allowed for a more complete picture of the relationship between health literacy and symptom self-management. While the questionnaires offered objective, measurable information about health literacy and relevant contextual factors, the interviews afforded the researcher an understanding of the participants' subjective experience that could not be reduced or quantified. Data analysis followed the six-stage critical realist model developed by Danermark et al. (2002), which seeks to identify and describe patterns of underlying structural mechanisms that explain complex social phenomena by integrating quantitative and qualitative data. The critical realist methodological approach and the specific methods for the study are discussed in greater detail in Chapter 3.

Plan for Manuscripts

This dissertation includes three manuscripts to be submitted for publication in peer-reviewed journals. The first is an integrative literature review focused on health literacy in adult oncology populations in the U.S, which was published in January 2020, in *Oncology Nursing Forum.* The integrative review comprises the majority of Chapter 2. The second manuscript reports themes identified in the data, with attention to critical realism as a method of inquiry, to address the second specific aim of describing patients' experience with interacting with providers about symptom self-management. This manuscript is found in Chapter 4 and will be submitted to *Nursing Inquiry.* The third manuscript makes up Chapter 5 and is focused on the first specific aim, exploring how interactive health literacy is related to symptom self-management. This manuscript also explains how the data supports the integration of interactive health literacy with the Individual and Family Self-Management Theory. It will be submitted to *Cancer Nursing*.

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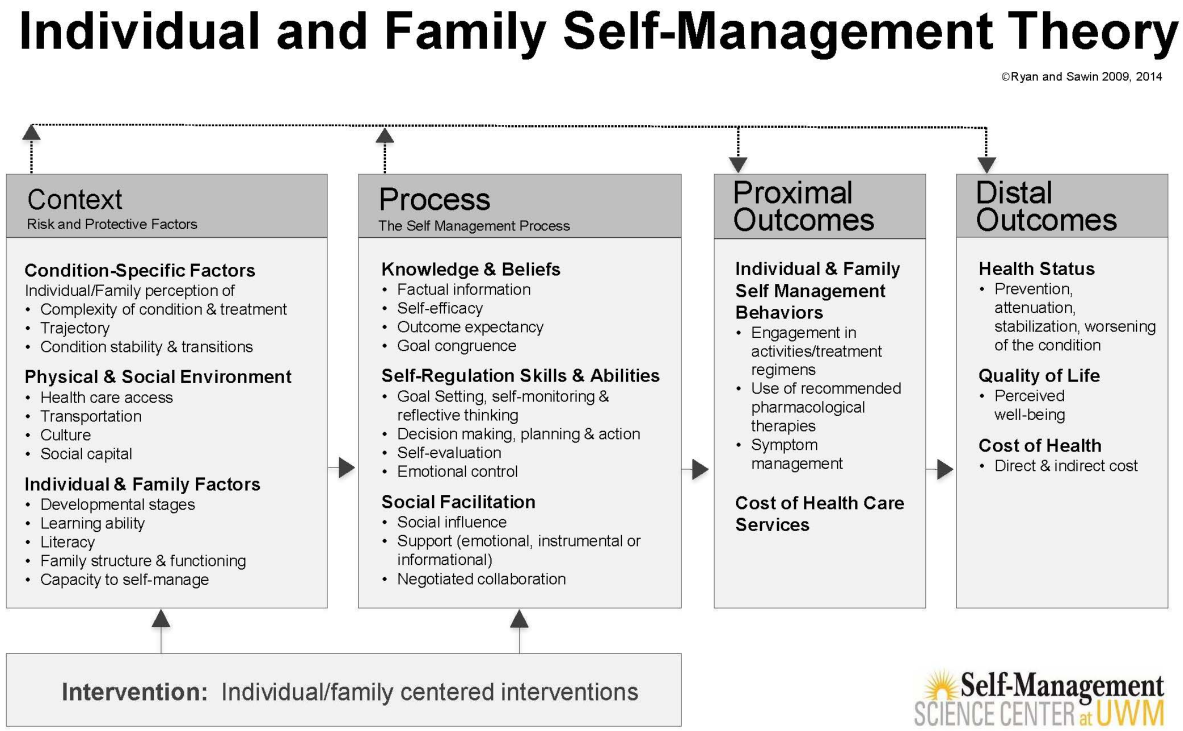
Individual and Family Self-Management Theory

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Context
Risk and Protective Factors

Condition-Specific Factors
Individual/Family perception of
- Complexity of condition & treatment
- Trajectory
- Condition stability & transitions

Physical & Social Environment
- Health care access
- Transportation
- Culture
- Social capital

Individual & Family Factors
- Developmental stages
- Learning ability
- Literacy
- Family structure & functioning
- Capacity to self-manage

Process
The Self Management Process

Knowledge & Beliefs
- Factual information
- Self-efficacy
- Outcome expectancy
- Goal congruence

Self-Regulation Skills & Abilities
- Goal Setting, self-monitoring & reflective thinking
- Decision making, planning & action
- Self-evaluation
- Emotional control

Social Facilitation
- Social influence
- Support (emotional, instrumental or informational)
- Negotiated collaboration

Proximal Outcomes

Individual & Family Self Management Behaviors
- Engagement in activities/treatment regimens
- Use of recommended pharmacological therapies
- Symptom management

Cost of Health Care Services

Distal Outcomes

Health Status
- Prevention, attenuation, stabilization, worsening of the condition

Quality of Life
- Perceived well-being

Cost of Health
- Direct & indirect cost

Intervention: Individual/family centered interventions

Figure 1. Updated IFSMT framework. From "Individual and family self-management theory," by P. Ryan and K. Sawin, 2009, 2014. Retrieved from https://uwm.edu/nursing/wp-content/uploads/sites/287/2015/05/IFSMT_website__2015_07.jpg. Copyright 2009, 2014 by P. Ryan and K. Sawin.

Literature Review

This chapter delineates a review of current literature related to the concepts included in the proposed study. The first part of the chapter is formatted as a manuscript that was accepted in July 2019 for publication in *Oncology Nursing Forum*, comprising an integrative review on how health literacy has been addressed in adults with cancer in the U.S. The second part of the chapter presents a synthesis of literature focused on other relevant concepts, including lung cancer symptomatology, evidence-based symptom management, strategies patients use to self-manage lung cancer symptoms, and interventions that facilitate self-management of lung cancer symptoms.

Health Literacy in Adult Oncology: An Integrative Review

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Abstract

Problem Identification Patients with cancer face high expectations for performing health literacy activities necessary for self-management and decision-making, yet only 12% of U.S. adults are proficient in health literacy. This review explores evidence regarding what is known about functional, interactive, and critical health literacy in adult oncology populations.

Literature Search The review was conducted by searching extensively in the CINAHL database.

Data Evaluation Of 614 articles retrieved from the literature search, 22 were included in the final sample. Most were cross-sectional, descriptive, correlational studies.

Synthesis Health literacy research in the U.S. focuses primarily on functional health literacy, although studies that include interactive and/or critical health literacy indicate their applicability in adult oncology populations.

Implications for Research Additional research is needed to clarify the role of health literacy in cancer care, in order to develop effective interventions that facilitate self-management and decision-making.

Knowledge Translation

- Although comprehensive measures of health literacy have been developed and validated, researchers in the U.S. rely on measures that address only functional skills.
- Lower health literacy is associated with individuals with non-White race/ethnicity, lower income, lower educational level, and less disease-related knowledge.
- Health literacy influences engagement in and satisfaction with treatment decision-making and self-management of illness.

Keywords: health literacy, cancer, malignant neoplasms, adult

Health Literacy in Adult Oncology: An Integrative Review

Health literacy is frequently defined as a variation of the definition endorsed by the National Academies, which reads: “the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer, & Kindig, 2004, p.4). There is a growing number of broadened conceptualizations of health literacy attempting to capture its multidimensional and dynamic nature (Nutbeam, 2008; Pleasant, 2014; Rudd, 2015; Sørensen et al., 2012). One of the most widely studied health literacy frameworks, originally published by Nutbeam in 2000, has been applied across a variety of disciplines and health contexts. Nutbeam (2000, 2008) outlines three hierarchical dimensions of health literacy: functional, interactive and critical (Figure 1).

Functional health literacy refers to foundational skills that are required for basic healthcare tasks, such as reading written instructions and completing health-related forms. This level of health literacy emphasizes conventional methods of patient education for the purposes of increasing knowledge and fostering compliance. Nutbeam (2000, 2008) defines the second level of health literacy as interactive (or communicative), referring to higher cognitive and social skills for participating in health communication and applying information to dynamic situations. Interactive health literacy skills contribute to motivation and confidence with which individuals are able to understand and act on information received through communication. The third and final level of health literacy is critical health literacy, or advanced cognitive and social skills necessary for critically analyzing and applying health information as a means to gain control over one’s health. With this model, proficient health literacy moves beyond reading and writing skills by also addressing the capacity to successfully access and apply health information toward an end result of individual empowerment (Nutbeam, 2000; Nutbeam, 2008).

In today's complex healthcare system in the U.S., health literacy demands attention as focus shifts toward patient-centered care and self-management of health conditions. While there are notable benefits to patient-centered care, it is critical to recognize the health literacy implications of such an approach (Office of Disease Prevention and Health [ODPH], 2010). Assuming a central role in healthcare requires a patient to engage in a number of health literacy skills, such as reading, writing, numeracy, communication, decision-making, and navigation of the healthcare system (Helitzer, Hollis, Sanders, & Roybal, 2012). This becomes especially important in the context of a cancer diagnosis, where patients are faced with numerous decisions about a life-threatening disease, often involving multiple treatment options with complicated regimens (Koay, Schofield, & Jefford, 2012). At the same time, advances in technology and medicine have lengthened survival for several types of cancer, allowing many patients to live with cancer as a chronic illness rather than a terminal disease (Husson, Mols, & Fransen, 2015). The interplay of these phenomena result in high expectations for the health literacy of patients with cancer. Yet the most recent national assessment revealed that only 12% of the U.S. adult population meets the criteria for proficient health literacy, indicated by skills in reading and analyzing lengthy, complex information as well as solving multi-step mathematical problems (Kutner, Greenberg, Jin, & Paulsen, 2006). Considering that nearly 39% of the U.S. population will develop cancer in their lifetime, there is an urgency to develop knowledge regarding the role of health literacy in cancer care (National Cancer Institute [NCI], 2018).

Although health literacy has been widely studied across diverse patient populations and health conditions, there is a relatively small body of evidence specific to health literacy in patients living with cancer. The purpose of this integrative review is to analyze the current state of the science concerning how health literacy has been addressed in adult oncology populations, specifically examining: a) definitions of health literacy; b) instruments used to measure health literacy; c) health outcomes related to health literacy; and d) how each of Nutbeam's (2000, 2008) dimensions of health literacy have been addressed in this population.

Methods

This integrative literature review was conducted using the methodology proposed by Whittemore and Knafl (2005), consisting of five stages: problem identification, literature search, data evaluation, data analysis, and presentation of findings. The Cumulative Index to Nursing and Allied Health Literature Plus (CINAHL Plus) electronic database was searched for peer-reviewed articles published in English in the U.S., using the key terms "health literacy" and "oncology", and "health literacy and "cancer". No timeframe was specified, in order to obtain a comprehensive picture of how health literacy has been researched in adult oncology over time. Of note, Nutbeam's (2000, 2008) levels of health literacy were not utilized as a basis for data collection, but rather as a framework for evaluating which variables related to health literacy have been addressed.

Only original research studies involving adults diagnosed with cancer in the U.S. were included in this integrative review. Direct measurement of health literacy was required. Articles were excluded if the focus was solely on written health information and/or a specific sub-type of health literacy, such as mental health literacy, oral (dental) health literacy, or eHealth literacy. The initial search retrieved 614 articles, with two additional articles identified from reference lists. After removing duplicates, 583 articles were screened, and 482 were excluded for the following reasons: sample from outside the U.S., pediatric sample, sample of family caregivers, address cancer screening/prevention, focus on sub-type of health literacy, not empirical research, not specific to cancer. Of the 101 full-text articles that were evaluated for relevance to the review's purpose, 77 were excluded because health literacy was not measured; the study focused on written health information; or the aim was psychometric testing of a health literacy measure. The remaining 24 studies were appraised for quality. Each study was assigned a score of A (high quality), B (good quality), or C (low quality) using criteria published by Johns Hopkins that considers research design, generalizability, sample size, control, and consistency with existing evidence (Dearholt & Dang, 2012). Two studies received a quality score of C and were eliminated, yielding a final sample of 22 studies (Figure 2).

Data was analyzed in several phases; first, the articles were organized into an evidence table, detailing the following elements: authors and year of publication, quality score, purpose, design, sample characteristics, definition of health literacy, health literacy measure, and relevant findings (Table 1). Studies were initially grouped based on how the authors conceptualized health literacy, and throughout the analysis process the studies were re-organized in various ways to compare specific elements relevant to the purposes of this review. Finally, data was extracted and collated according to the components of Nutbeam's (2000, 2008) framework. Patterns within each of these categories were identified, along with gaps requiring further research.

Results

Because direct measurement of health literacy was an inclusion criterion, all of the reviewed articles were reports of empirical research. Although there were no qualitative studies, two used mixed methods for data collection and analysis (Hendren et al., 2011; Martinez-Donate et al., 2013). The majority of studies included in this review employ non-experimental designs. Most of these (n=17) were cross-sectional descriptive studies, three of which described secondary analyses of previously collected data (Halverson et al., 2013; Halverson et al., 2015; Jiang & Hong, 2018). In addition, there was one study with a longitudinal design (Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013), and two prospective cohort studies (Hendren et al., 2011; Inglehart et al., 2016). Two employed experimental designs, including a randomized posttest-only study (Krieger, Neil, Strekalova, & Sarge, 2017), and a randomized controlled trial (Giuse et al., 2016). Of note, several of the studies reported various analyses on the same datasets (see Table 1). For the purposes of integrative synthesis in this review, these will be discussed as single studies in terms of definitions and measurement of health literacy, and as separate studies in terms of reported findings.

Sample Characteristics

Table 1 summarizes characteristics and results of the 22 reviewed studies, which were published between 1998-2018. Various subpopulations of adults with cancer were represented within the studies, with the two most common being females with breast cancer (Freedman, Kouri, West, & Keating, 2015; Hawley et al., 2008; Hawley et al., 2010; Keim-Malpass, Doede, Camacho, Kennedy, & Showalter, 2018; Livaudais, Franco, Fei, & Bickell, 2013), and males with prostate cancer (Bennett et al., 1998; Mohan, Beydoun, & Barnes-ely, 2009; Pickard, Knight, Wu, Chang, & Bennett, 2009; Song et al., 2012; Song et al., 2014). One study examined patients with oral cancer (Inglehart et al., 2016), and another examined patients with melanoma (Giuse et al., 2016). The remaining ten studies recruited patients with diverse cancer diagnoses (Busch, Martin, Dewalt, & Sandler, 2014; Halverson et al., 2015; Halverson et al., 2013; Hendren et al., 2011; Jiang & Hong, 2018; Krieger et al., 2017; Martinez-Donate et al., 2013; Matsuyama et al., 2013; Matsuyama et al., 2011; Salgado et al., 2017). Two studies included both patients and caregivers in the sample population (Giuse et al., 2016; Pickard et al., 2009).

In seven of the nine studies that included both male and female patients, the percentage of female participants ranged from 50.8% to 63.4%. In one study that recruited participants with either breast or colorectal cancer, 85% of the sample had breast cancer; as a result, 90% of the participants were female (Hendren et al., 2011). Additionally, in the study examining patients with oral cancer, only 24% of the participants were female, likely because the incidence of oral cancer in males is more than twice as high as females (Inglehart et al., 2016; NCI, 2019). Across all 22 studies, the mean age of participants ranged from 49 to 75 years.

Half of the studies intentionally recruited diverse samples for the purpose of exploring racial/ethnic differences in research outcomes, including health literacy levels (Bennett et al., 1998; Freedman et al., 2015; Song et al., 2012, 2014), treatment decision-making (Hawley et al., 2008; Livaudais et al., 2013), health-related quality of life (Pickard et al., 2009; Song et al., 2012), perceptions of care coordination (Hawley et al., 2010), barriers to healthcare (Hendren et al., 2011); information needs (Matsuyama et al., 2011; Matsuyama et al., 2013); disease-related knowledge (Freedman et al., 2015); and patient-provider communication (Song et al., 2014). In 10 of these 11 studies, samples included an average of 47% White/Caucasian (n=10; range 26-67%), 40% Black/African-American (n=10; range 15-71%), 30% Hispanic/Latina/Latino (n=4; range 17-46%), and 3% “Other” (n=4; range 1-5%). Of note, one study’s sample was described as 61% White and 30% “Minority”, without specific delineation of other races/ethnicities (Hendren et al., 2011).

In the other 11 studies, the majority of participants were White/Caucasian (mean 88%; range 78-97%). Six of these studies only reported sample percentages for White/Caucasian, with other races/ethnicities combined into categories labeled “Other,” or “Non-White.” Four studies included sample percentages for Black/African-American (mean 7%; range 4-14%), while one reported 11% Latina and one reported 2% Asian/Pacific Islander.

Nutbeam’s Conceptualization of Health Literacy

None of the reviewed studies included all three dimensions of health literacy as conceptualized by Nutbeam (2000, 2008). Half (n=11) focused only on functional health literacy, in definition, measurement, and outcome variables (Table 2). Three articles addressed the interactive dimension by exploring associations between health literacy and communication or social processes. The remaining eight studies incorporated critical health literacy, either in measurement (n=2), or in associated outcomes including self-management (n=1) and treatment decision-making (n=5).

Definitions of Health Literacy

The majority of reviewed articles referred to a functional definition of health literacy, emphasizing the ability to read and comprehend health-related information. While many authors (n=13) did not explicitly define health literacy, several (n=6) cited the National Academies' definition or an adapted version of it (n=3). None used more comprehensive definitions, such as Nutbeam's (2000, 2008) conceptualization.

Measures of Health Literacy

There were four different methods of measuring health literacy represented in the reviewed articles, all of which focus primarily on functional literacy skills. Self-report was the most common measurement method, and the majority of articles found mean scores in the range of adequate health literacy, with 76-90% of participants classified as moderate or high. The most commonly used instrument, used in five studies, involves three self-report screening questions addressing confidence in completing medical forms and difficulty reading or understanding hospital materials (Chew, Bradley, & Boyko, 2004). The tool has also been validated as a single-item screener using only the question about completing medical forms, which was used in one study (Livaudais et al., 2013). Two authors utilized other adaptations of Chew et al.'s original screener, one of which tailored two of the questions to information about breast cancer (Hawley et al., 2008). Halverson et al. (2013) added a question to address critical health literacy skills needed to apply health information to one's own situation. In their findings, 56% of participants had low health literacy; of note, the mean score was 18.8 (range 4-20), and low health literacy was categorized as any score less than 20 of 20 (Halverson et al., 2013). A self-report approach was also used by two authors who examined questions from the Health Information National Trends Survey (HINTS) 4 Cycle 3, which addressed the ability to find and interpret health-related information (Jiang & Hong, 2018; Krieger et al., 2017).

Six studies measured functional literacy skills using the Rapid Estimate of Adult Literacy in Medicine (REALM), which evaluates the ability to recognize and pronounce 66 medical terms. In studies using the REALM in which the majority of participants were White, mean scores were at least 60 out of 66, indicating literacy at or above a 9th grade level (Hendren et al., 2011; Mohan et al., 2009). Studies with racially/ethnically diverse samples tended to score lower on the REALM; two studies reported that 62-63% of participants scored at the 9th grade level (Matsuyama et al., 2011; Song et al., 2014), while two others found inadequate literacy levels in 68-69% of participants (Bennett et al., 1998; Pickard et al., 2009). The Short Test of Functional Health Literacy in Adults (S-TOFHLA), which measures reading comprehension and basic mathematical skills (numeracy) was used by three authors (Busch et al., 2014; Martinez-Donate et al., 2013; Matsuyama et al., 2013; Matsuyama et al., 2011). Studies using the S-TOFHLA found that most participants exhibited adequate health literacy, with rates ranging from 70-86%. Although one study reported that only 56% of health literacy scores were adequate, its findings indicated that the other 44% did not complete the S-TOFHLA assessment (Martinez-Donate et al., 2013).

Demographic Factors Related to Health Literacy

Seven studies concluded that non-White participants were significantly more likely to have lower health literacy (Busch et al., 2014; Halverson et al., 2015; Jiang & Hong, 2018), specifically African-Americans (Bennett et al., 1998; Hendren et al., 2011; Matsuyama et al., 2011) and non-White Hispanics (Hawley et al., 2008). Lower health literacy was also positively associated with lower educational attainment (Busch et al., 2014; Halverson et al., 2015; Inglehart et al., 2016; Jiang & Hong, 2018; Livaudais et al., 2013); lower income (Busch et al., 2014; Halverson et al., 2015; Inglehart et al., 2016; Jiang & Hong, 2018); and older age (Busch et al., 2014; Jiang & Hong, 2018). Two studies found that males were more likely to have lower health literacy (Busch et al., 2014; Halverson et al., 2015), and one found that lower health literacy was more common in females (Jiang & Hong, 2018). In addition, one study reported that participants living in rural areas had 33% higher odds of having low health literacy than their urban or mixed residence counterparts (Halverson et al., 2013). Socioeconomic status was found to be a mediator between health literacy and urbanicity (Halverson et al., 2015).

Factors Associated with Functional Health Literacy

Functional health literacy was the most commonly addressed level of health literacy among the reviewed studies, particularly in terms of health literacy measurement. In fact, all 22 studies utilized instruments that measured functional health literacy. Lower functional health literacy was found to be associated with poorer mental well-being/emotional health in cancer survivors in general (Jiang & Hong, 2018), and specifically in males with prostate cancer (Song et al., 2012). Low health literacy was also related to less knowledge about one’s own breast cancer (Freedman et al., 2015); knowledge about human papilloma virus in the context of oral cancer (Inglehart et al., 2016); and understanding of randomization procedures for RCTs

(Krieger et al., 2017). Participants with low health literacy tended to be diagnosed with prostate cancer at a later stage (Bennett et al., 1998) and were less satisfied with care coordination for breast cancer (Hawley et al., 2010). Health literacy was not significantly related to information needs (Matsuyama et al., 2013, 2011), physical well-being (Song et al., 2012), or perceived differences in longevity based on treatment options (Mohan et al., 2009).

Factors Associated with Interactive Health Literacy

Although no studies directly measured interactive health literacy, three studies explored interactive health literacy in adults with cancer by addressing patient-provider communication as a research outcome, producing varying results. Song et al. (2014) found that participants' functional health literacy levels did not impact patient-provider communication for males with prostate cancer. On the other hand, Jiang and Hong (2018) reported that functional health literacy was significantly associated with mobile-based patient-provider communication for adults who have survived cancer. Their findings showed that individuals with higher health literacy were more likely to utilize mobile platforms such as email and text messaging to communicate with healthcare providers (Jiang & Hong, 2018). Krieger et al. (2017) identified the tailored use of metaphors as a helpful strategy for communicating complicated information to individuals with low functional health literacy. The authors compared the use of plain language with metaphors—such as the chance a pregnant woman would have a female child—to explain randomization procedures in clinical trials. Health literacy level moderated participants' comprehension of randomization, and using metaphors resulted in better comprehension than plain language for individuals with lower health literacy (Krieger et al., 2017).

Factors Associated with Critical Health Literacy

Only one study measured critical health literacy by incorporating a question about medication adherence in a brief self-report measurement (Halverson et al., 2013; Halverson et al., 2015). Six studies explored how functional health literacy influences critical health literacy outcomes, the most common being treatment decision-making. One study found no relationship between health literacy and surgical treatment decisions in women with breast cancer (Keim-Malpass et al., 2018), while another found that health literacy was positively associated with participants deciding to receive chemotherapy for advanced stage lung or colorectal cancer (Busch et al., 2014). Low health literacy was also positively associated with decision dissatisfaction and regret (Hawley et al., 2008), as well as participants' perception of how much responsibility they bore for treatment decision-making (Livaudais et al., 2013). From the analysis of the qualitative data obtained in their mixed methods study, Martinez-Donate et al. (2013) reported that health literacy was a factor in the need for decisional support in adults with cancer. Health literacy was also found to be related to confidence to self-manage treatment side effects (Salgado et al., 2017).

Discussion

This integrative review sought to explore what is known about health literacy in U.S. adults with cancer, with emphasis on Nutbeam's (2000, 2008) conceptualization of health literacy. Findings from this review revealed that health literacy is widely operationalized both in definition and measurement as functional skills such as reading and completing medical forms, which is consistent with much of health literacy research in general. At its inception in the 1970s, the concept of health literacy was based on the recognition of a gap between the readability of health information and patients' comprehension abilities (Doak & Doak, 1980). This resulted in a proliferation of research focused on the link between functional literacy skills and health outcomes, which in turn resulted in the development of instruments aimed at measuring reading, writing and comprehension abilities. Two of these instruments have widely been considered the gold standard for health literacy measurement over the past few decades (REALM and S-TOFHLA; Haun, Luther, Dodd, & Donaldson, 2012). Many researchers have begun using self-report health literacy screeners that can be quickly and easily administered, such as the tool developed by Chew et al. (2004). While these screening tools offer obvious benefits for identifying patients with inadequate health literacy in clinical settings, their usefulness for research is not as clear because they have been adapted and applied in multiple ways across studies. For instance, among the studies in this review that used Chew et al.'s (2004) screener, there was no consistency in how it was scored, making it difficult to compare and synthesize results.

Defining and measuring health literacy merely in terms of functional skills presents certain limitations for health literacy research. First, this approach lacks attention to contextual factors that may influence the process of obtaining, comprehending, and applying health information (Chinn & McCarthy, 2013; Nutbeam, 2008; Paasche-Orlow & Wolf, 2007; Rudd, 2015; Sørensen et al., 2012; Squiers, Peinado, Berkman, Boudewyns, & McCormack, 2012). Second, functional health literacy is often conceptualized as a risk, in which an individual with low health literacy is at higher risk for poor health outcomes (Nutbeam, 2008; Pizur-Barnekow, Darragh, & Johnston, 2011). Finally, health literacy is narrowly referred to as a characteristic of individual patients, overlooking the role of caregivers, healthcare providers, and the wider healthcare system (Chinn & McCarthy, 2013; Paasche-Orlow & Wolf, 2007; Rudd, 2015; Squiers et al., 2012). These shortcomings have lead to disparate findings among studies exploring functional health literacy skills in various populations.

In this review, functional health literacy was associated with patients' knowledge about cancer and treatment options, but not with perceived information needs, comprehension of expected treatment outcomes, and physical well-being. This is consistent with research involving patients with other long-term illnesses, such as diabetes and chronic kidney disease, in which studies have linked functional health literacy to disease knowledge (Chen et al., 2018; van der Heide et al., 2014). Some studies identified relationships between functional health literacy and outcomes, such as glycemic control (Niknami et al., 2018; Saeed, Saleem, Naeem, Shahzadi, & Islam, 2018; van der Heide et al., 2014) and medication adherence (Fan, Lyons, Goodman, Blanchard, & Kaphingst, 2016), yet others found that functional health literacy was not associated with these same outcomes (Al Sayah, Majumdar, Egede, & Johnson, 2015; Chen et al., 2018). While the inconsistencies of these reports highlight the importance of measuring more than only functional health literacy skills, they also substantiate the need to address the multidimensional nature of health literacy in both research and practice.

Recently, scholars have brought attention to the need for a more comprehensive definition of health literacy that encompasses more than functional literacy (Pleasant, 2014; Rudd, 2015; Sørensen et al., 2012; Squiers et al., 2012). Today, many definitions exist in the literature, and while most have overlapping features, there is little agreement on the specific attributes that constitute health literacy. This causes wide variations in how the concept is operationalized, leading to the development of over 100 different measurement tools with varied purposes and results. Nutbeam's (2000, 2008) framework provides a conceptualization of health literacy that addresses the limitations of research focused primarily on functional health literacy. An explicit assumption of Nutbeam's (2000, 2008) framework is that health literacy is an asset for patient empowerment rather than a risk for negative health outcomes (Nutbeam, 2008). The hierarchical structure of the three levels of health literacy indicates that individuals can develop progressively higher skills, ultimately leading to personal autonomy and empowerment. Advancement through the levels is influenced by personal factors—cognition, social skills, and self-efficacy—as well as the content and method of communication from healthcare providers (Nutbeam, 2000). While the framework was initially developed for use in public health, there is growing empirical support for its use in health literacy research across various settings. Much of this work has been done outside of the U.S. In Australia, Osborne et al. (2013) developed the Health Literacy Questionnaire (HLQ), a valid and reliable instrument that addresses each of the dimensions of health literacy outlined by Nutbeam (2000, 2008). Findings from studies using the HLQ have highlighted its usefulness in measuring all three levels of health literacy and identifying health literacy needs that can be addressed in the clinical setting, particularly in regards to effective communication between patients with cancer and healthcare providers (Goodwin & Chambers, 2018; Hawkins, Gill, Batterham, Elsworth, & Osborne, 2017; Kayser, Hansen-Nord, Osborne, Tjonneland, & Hansen, 2015; Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013).

Consistent with the wider body of health literacy research, critical health literacy in adults with cancer is often captured in outcomes, such as self-efficacy, self-management, adherence, and decision-making. Far fewer studies actually measure critical health literacy, although those that do have found positive correlations with disease-specific outcomes (Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013; McKenna, Sixsmith, & Barry, 2017). Similarly, scant attention is given to the role of interactive health literacy in adult oncology research. None of the 22 reviewed studies measured interactive health literacy, and only three addressed it at all. Yet several national agencies emphasize the importance of clear communication between healthcare providers and patients; in fact, the majority of recommended health literacy strategies revolve around communication of health information (e.g., teach-back; Ask Me 3®; Health Literacy Universal Precautions). This necessitates research focused on interactive health literacy, particularly as patients are facing increasing demands to self-manage complex health conditions such as cancer. Researchers have begun to develop and test more comprehensive measures of health literacy, such as the Functional, Communicative and Critical Health Literacy (FCCHL) scale (Ishikawa, Takeuchi, & Yano, 2008). Studies using this scale have reported that interactive health literacy was more strongly correlated than the other levels of health literacy with self-management and patients' confidence in healthcare interactions (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015), as well as effective patient-provider communication (Inoue et al., 2013).

The significance of health literacy-sensitive communication is reflected in the U.S. Department of Health and Human Services' (2010) landmark report entitled *National Action Plan to Improve Health Literacy* ("Action Plan"; ODPH, 2010). Its recommendations stem from the synthesis of evidence related to health literacy improvement into a comprehensive framework with broad goals as well as specific strategies. The overarching vision of the Action Plan is to create a health literate society, which "provides everyone with access to accurate and actionable health information, and delivers person-centered health information and services" (ODPH, 2010, p. 1). One approach to ensuring access to actionable health information is through the use of health literacy universal precautions (HLUP). HLUP involves delivering health information under the assumption that all healthcare consumers have limited health literacy and would benefit from clear communication. The Agency for Healthcare Research and Quality (AHRQ) cites evidence that healthcare providers do not consistently recognize when a patient or caregiver lacks adequate health literacy, and that stressful situations such as serious illness often impair the ability to understand and apply health information successfully (Brega et al., 2015). HLUP address health literacy limitations by communicating clearly with all consumers and ensuring they understand necessary information, as well as simplifying navigation of the healthcare environment (Brega et al., 2015).

Limitations

Limitations of this review include the use of a single reviewer and a single database, which introduces a risk for potential bias. Limiting the review to U.S.-based research excluded important global efforts to address health literacy, particularly with regards to broader conceptualizations and measures of health literacy beyond functional skills. Theoretical literature was systematically excluded by the inclusion criteria that required measurement of health literacy, resulting in a lack of diversity in the types of studies included. This may have resulted in the omission of important insights into the complexities of health literacy published in non-nursing journals.

Implications for Nursing

Health literacy is recognized as an integral component of patient-centered care in the U.S. Advances in medicine and technology, combined with efforts to reduce healthcare spending, have resulted in high expectations for patients to access, comprehend, and apply a great deal of complex information to their own situations. These situations are often associated with distressing health crises such as cancer, in which the psychological impact of a life-threatening diagnosis may reduce one’s ability to process new information. This challenge for patients and their families has significant implications for healthcare providers as they seek to facilitate self-management and decision-making in the context of complex illnesses such as cancer. Nurses, who provide the bulk of bedside patient care and education, are uniquely positioned to effect change on multiple levels, by engendering greater understanding of what health literacy means both in clinical practice and in research. In practice, oncology nurses must advocate for all information to be accessible and actionable, using an approach such as Health Literacy Universal Precautions. As patients are increasingly expected to engage in healthcare, from assessment using tools such as Patient-Reported Outcomes Measurement Information System (PROMIS®) to treatment decision-making, it is vital for healthcare providers to be aware of and address health literacy in their daily practice. These efforts will require intentional collaboration between multiple healthcare disciplines, system administrators and policymakers, and patients and caregivers.

In research, there is an urgency to expand current knowledge about the role of health literacy in order to improve the quality, safety, and effectiveness of cancer care. This integrative review highlights the lack of adequate attention given to racial/ethnic differences related to health literacy in adult oncology. Furthermore, most of the studies were limited to a handful of cancer diagnoses, indicating a need to expand research to all types of cancer. Other areas to be considered for future research include the role of caregivers in health literacy, technology-based health literacy tools, and the association between health literacy and self-management of illness. Self-management is a key aspect of cancer care, as patients face myriad symptoms of disease as well as treatment side effects. Health literacy and self-management are both considered current research priorities, yet there is relatively little clear evidence of how these two phenomena relate to each other, particularly for patients with cancer. Research should be conducted using a comprehensive definition of health literacy, such as Nutbeam's (2000, 2008) framework, and corresponding measurement tools that address the multiple aspects of health literacy, such as the

Health Literacy Questionnaire. With an expanded understanding of the multidimensional nature of health literacy, it is essential to incorporate interactive and critical health literacy into studies to comprehensively capture how patients process and apply cancer-related information for self-management. This will provide valuable insight to guide the development of evidence-based interventions that facilitate effective self-management for adults with cancer.

Patients with cancer are often overwhelmed by the amount of information about their disease, decisions that must be made regarding treatment options, and self-management needs. This often leads to considerable involvement of caregivers, who may assist patients in obtaining, processing, and applying health information (Edwards, Wood, Davies, & Edwards, 2015; Goldsmith, Wittenberg, Platt, Iannarino, & Reno, 2016; Wittenberg, Goldsmith, Ferrell, & Ragan, 2017). As a result, it is important to understand and address the health literacy of caregivers as well as communication patterns between patients, caregivers, and healthcare providers. Researchers have begun to develop models specifically focused on these phenomena, which will need further studies to provide empirical support and refinement (Goldsmith et al., 2016; Wittenberg et al., 2017; Yuen et al., 2016). Furthermore, as technology assumes a larger role in daily life, it will be important to consider the health literacy implications of technology-based healthcare tools used for accessing, interpreting, and applying health information, such as patient portals (Coughlin, Stewart, Young, Heboyan, & De Leo, 2018) and mobile applications (Mirkovic, Kaufman, & Ruland, 2014). These examples provide significant opportunities for additional research to gain deeper insight into how health literacy interacts with technology in the context of cancer care.

Conclusion

Understanding the complexities of health literacy is critical to ensuring patients are receiving safe, effective, and quality healthcare, particular in the context of a serious illness such as cancer. Health literacy researchers must continue to refine, expand, and support evidence-based conceptual frameworks to guide the development of clinically feasible strategies that measure and address health literacy and its interconnections with other phenomena. Deepening the knowledge base will especially benefit oncology nurses, who hold a unique position with which to champion health literacy in cancer care and ensure the full scope of patients' information needs are met.

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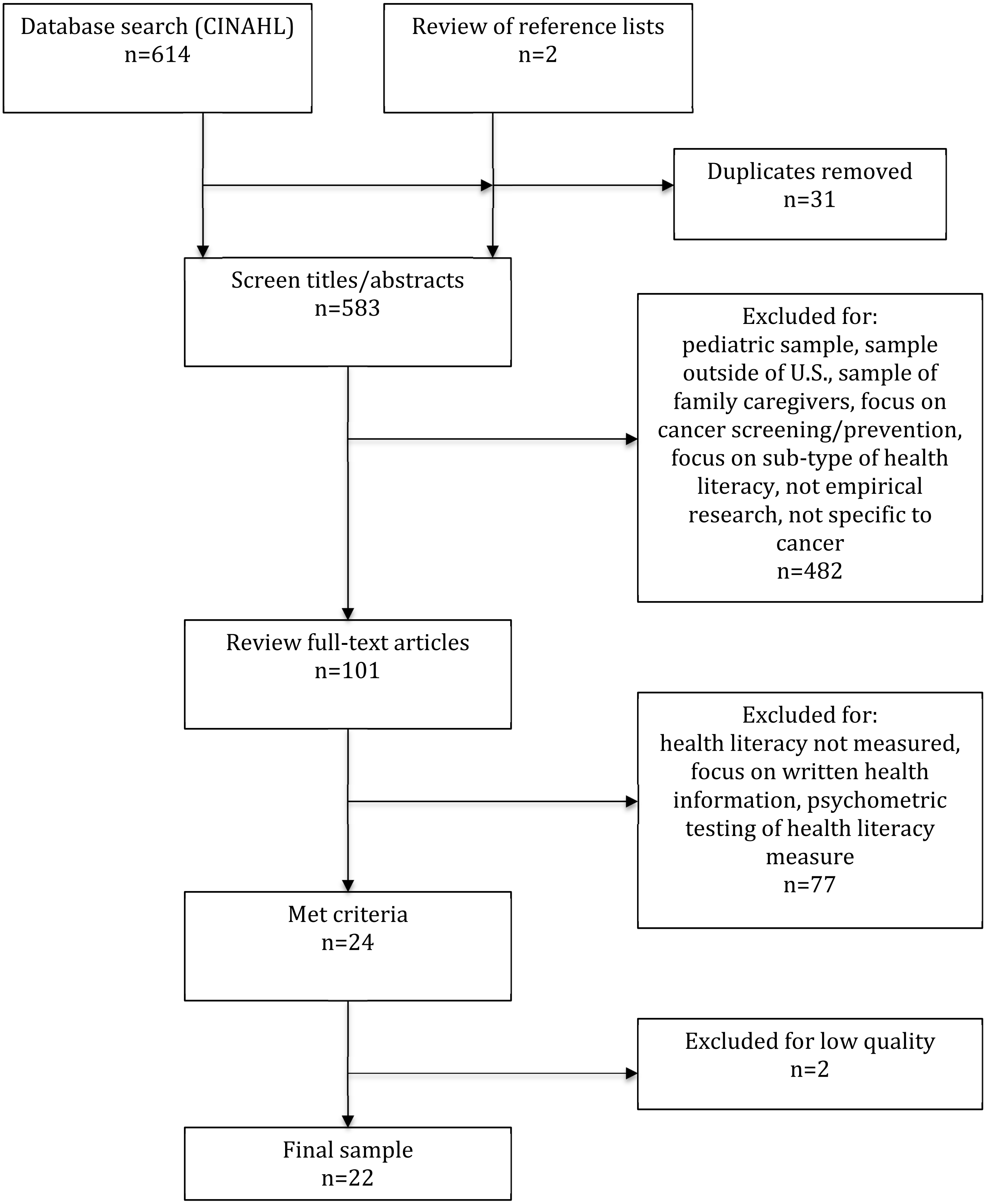

Figure 2.1. Flowchart of literature search methods.

2.1.1

Evidence Table

Author, Year Design Quality Score	Purpose	Sample Characteristics	Definition of HL HL Measure	Findings Related to Health Literacy
Bennett et al 1998 Pilot study Cross-sectional, descriptive, correlational B	Examine relationships between HL, race/ethnicity, and presentation with advanced stage prostate cancer in low-income older men	n=212 males with prostate cancer Mean age 70.8 years 51% Black 49% White	No explicit definition of HL REALM	HL level ≤ 6th grade reported by race: White 8.7% Black 52.3% Lower HL associated with advanced stage of cancer at presentation
Hawley et al 2008 Cross-sectional, descriptive, correlational A	Evaluate participation in and satisfaction with surgical treatment decision-making among Latina women with breast cancer as compared to other race/ethnic groups; explore HL as a potential mechanism for relationships between race/ethnicity and decision-making	n=925 Latina females diagnosed with breast cancer Mean age 59 years 25.2% Latina (Spanish) 20.6% Latina (English) 24% Black 26.1% White 4.1% other race/ethnicity	No explicit definition of HL Two self-report questions adapted from Chew et al. (2004)	Low HL reported by race: English-speaking Latina: 2% Spanish-speaking Latina: 17% Black: 1% White: 1% Spanish-speaking Latina females more likely to have low HL than any other race/ethnic group Low and moderate HLassociated with decision dissatisfaction and regret
Mohan et al 2009 Cross-sectional, descriptive, correlational B	Explore relationships between HL and anticipation of survival for patients newly diagnosed with localized prostate cancer	n=184 males with prostate cancer Mean age 61.5 years 86% White 14% Black 60% some college	No explicit definition of HL REALM	90% ≥ 9th grade HL level No association between HL and perceived decrease in longevity with observation or perceived increase in longevity with treatment

Pickard et al 2009 Cross-sectional, descriptive, correlational B	Compare health-related quality of life (HRQL) between patients with prostate cancer and their caregivers (proxies); identify factors (including HL) that explain differences between proxies’ assessment of HRQL (intra-proxy gap)	n=87 dyads (males with prostate cancer and proxies) Patients: Mean age 75 years 71% Black 73% at least high school (HS) education Proxies: Mean age 62 years 83% female (63% spouses) 70% Black 81% at least HS education	No explicit definition of HL REALM	68% of patients and 46% of proxies had limited HL HL weakly correlated with intra-proxy gap on certain domains of HRQL assessment
Hawley et al 2010 Cross-sectional, descriptive, correlational A	Explore perceptions of care coordination among patients with breast cancer; evaluate associations between HL, race/ethnicity, and perceptions of care coordination	n=2,148 females with breast cancer Mean age 57 years 67.4% White 16.7% Latina 14.8% Black 1.1% Other race/ethnicity	No explicit definition of HL 3-item self-report screener (Chew et al., 2004)	HL scores: Low 15% Moderate 28.6% High 55.5% Low HL associated with low perceived care coordination and low satisfaction with care coordination
Hendren et al 2011 Cross-sectional, prospective, correlational B	Describe healthcare barriers experienced by adults newly diagnosed with breast and colorectal cancer; explore difference in barriers related to HL and demographic characteristics; identify which patients have highest need for patient navigation	n=103 adults with cancer Mean age 55 years 90% female 85% breast cancer 41% HS or lower education	No explicit definition of HL REALM	REALM scores: Mean 18.7 (max 21, higher score indicates higher HL) HL not a barrier to cancer care HL associated with need for patient navigation Race/ethnicity significantly associated with lower HL
Matsuyama et al 2011* Cross-sectional, descriptive, correlational	Evaluate relationships between race/ethnicity, HL, and self-reported information needs among adults newly diagnosed with solid tumor cancers	n=138 adults who would be receiving treatment for stage II-IV solid tumor cancers 45% Black 55% White Mean age 54.7 years	National Academies’ definition of HL REALM S-TOFHLA	REALM results: 62% HS level S-TOFHLA results: 86% adequate HL Black race/ethnicity associated

B		62% female 77.6% at least HS education		with limited HL on both assessments HL not associated with information needs
Song et al 2012** Cross-sectional, descriptive, correlational A	Evaluate relationship between HL and HRQL among males with prostate cancer Part of North Carolina-Louisiana Prostate Cancer Project	n=1,581 males with newly diagnosed localized prostate cancer Mean age 63 years 52% White 48% Black 81% at least HS education	National Academies' definition of HL REALM	REALM scores: 63% ≥ 9th grade HL level Controlling for sociodemographic and disease-related factors, HL significantly related to mental but not physical well-being
Halverson et al 2013*** Cross-sectional, descriptive, correlational; secondary analysis A	Explore relationship between HL and urbanicity; identify factors related to low health literacy among adults with cancer Assessment of Cancer Care and Satisfaction (ACCESS) study	n=1,841 adults newly diagnosed with cancer Mean age 63 years 50.8% female 93% non-Hispanic White 11% less than HS education	National Academies' definition of HL 4 self-report questions adapted from Chew et al. (2004)	56% low HL Low HL significantly associated with rural residence Socioeconomic status fully mediated relationship between HL and urbanicity
Livaudais et al 2013 Cross-sectional, descriptive, correlation; sub-study of parent RCT B	Examine relationship between HL, sociodemographics, clinical factors, and perceived responsibility for treatment decision-making	n=368 female patients who were candidates for adjuvant treatment of stage I or II breast cancer Age range 28-89 years 45% White 20% Black 31% Hispanic 5% Asian/Pacific Islander/other 78% at least HS education	No explicit definition of HL Single-item self-report screener adapted from Chew et al. (2004)	HL scores not reported Low HL associated with lower education Low HL associated with women who perceived "not enough" and "too much" responsibility for treatment decision-making
Martinez-Donate et al 2013 Cross-sectional,	Explore HL barriers and needs for patient navigation among adults with cancer in rural Wisconsin using the Chronic	n=53 adults currently receiving treatment for breast, lung, colorectal, or prostate cancer	Definition of HL: "Individuals' ability to understand and act upon basic health information and	S-TOFHLA scores: 56% adequate HL HL and navigation needs

descriptive, mixed methods B	Care Model (CCM)	Mean age 62 years 63% female 96% non-Hispanic White 84% at least HS education n=41 clinic staff members Mean age 49 years 90% female	services S-TOFHLA Semi-structured individual interviews and focus groups	identified in all 4 CCM dimensions: 1) Community in which healthcare systems are embedded 2) Self-management support 3) Delivery system design 4) Decision support
Matsuyama et al 2013* Descriptive, longitudinal B	Evaluate information needs over nine months related to disease, diagnostic tests, treatments, physical care, and psychosocial resources for patients newly diagnosed with cancer	n=138 adults who would be receiving treatment for stage II-IV solid tumor cancers 45% Black 55% White Mean age 54.7 years 62% female 77.6% at least HS education	National Academies' definition of HL REALM S-TOFHLA	REALM results: 62% HS level S-TOFHLA results: 86% adequate HL HL not associated with information needs over time, although lower educational level was associated with higher information needs
Song et al 2014** Cross-sectional, descriptive, correlational A	Describe how sociocultural factors impact patient-provider communication for patients with prostate cancer Part of North Carolina-Louisiana Prostate Cancer Project	n=1,854 males with prostate cancer Mean age 63 years 50% White 50% Black 80% at least HS education	No explicit definition of HL REALM	61.5% adequate HL Education level, not HL, associated with patient-provider commuication
Busch et al 2015 Cross-sectional, descriptive, correlational B	Examine relationships between HL and stage of disease, patient participation in treatment decisions, receipt of appropriate treatment and survival rates Part of Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)	n=347 adults with lung and colorectal cancer 53% female 78% White 53% age 65 years of older 62% at least HS education	Definition of functional HL: "ability to read and understand medication labels, educational materials, hospital directional signs, and appointment slips" S-TOFHLA	30% marginal or inadequate HL Low HL associated with male gender, non-White race/ethnicity, age ≥ 65, lower income, lower educational level Adequate HL associated with likelihood of receiving

				appropriate treatment
Freedman et al 2015 Cross-sectional, descriptive, correlational A	Evaluate associations between educational attainment, HL, race/ethnicity and knowledge of disease	n=500 females with stage 0 through III who underwent primary surgery for breast cancer 75% ≥ age 50 years 44.4% non-Hispanic White 28.4% non-Hispanic Black 27.2% Hispanic 88.6% at least HS education	No explicit definition of HL 3-item self-report screener (Chew et al., 2004)	Mean HL score 1.78 (range 1-5, lower score indicates better HL) Lower HL and lower educational attainment related to less cancer knowledge HL does not explain racial/ethnic differences in knowledge
Halverson et al 2015*** Cross-sectional, descriptive, correlational; secondary analysis A	Evaluated relationship between HL and HRQL among patients with breast, lung, prostate, and colorectal cancer in Wisconsin Assessment of Cancer Care and Satisfaction (ACCESS) study	n=1,841 adults newly diagnosed with cancer Mean age 63 years 50.8% female 93% non-Hispanic White 11% less than HS education	National Academies' definition of HL 4 self-report questions adapted from Chew et al. (2004)	Average HL score 18.8 (range 4-20, higher score indicates higher health literacy) Low HL associated with male gender, non-White Hispanic race/ethnicity; lower educational level; lower income; rural residence, lung cancer, unknown extent of disease HRQL significantly associated with health literacy
Giuse et al 2016 RCT B	Compare effectiveness of delivering precision medicine information about melanoma via three different mechanisms	n=88 adults with melanoma or caregiver of adult with melanoma 68% patients, 32% caregivers 51% female Mean age 57 years 96.6% White 100% at least HS education	No explicit definition of HL 3-item self-report screener (Chew et al., 2004)	85% adequate HL Adapting genetic information materials based on HL resulted in greater improvements in knowledge
Inglehart et al 2016	Examine relationships between HL, human papilloma virus	n=372 adults with oral cancer Median age 58 years	Definition of HL: "ability to access and effectively utilize	Mean HL score 4 (adequate HL)

Cross-sectional, correlational, prospective cohort B	(HPV) knowledge, and information sources among adults newly diagnosed with oral cancer	76% male 91% White 5% Black 4% Other race/ethnicity 88% at least HS education	health information” 3-item self-report screener (Chew et al., 2004)	20% inadequate HL Higher HL associated with HPV-positive cancer, educational level, income, and HPV-related knowledge
Krieger et al 2017 Randomized post-test only experimental design A	Evaluate the influence of linguistic strategies on comprehension of and participation in RCTs for adults with cancer who have low HL	N=500 adults diagnosed with cancer in previous 24 months Mean age 50 years 63% female 83% non-Hispanic White 11.4% Hispanic 5.6% non-Hispanic Black	No explicit definition of HL HL measured using 4 items from 2013 Health Information Trends Survey (HINTS) Cycle 3 assessing if patients felt they could easily find and interpret cancer information	Mean HL scores ranged from 2.80-2.95 (max 4) HL significantly associated with comprehension of randomization Metaphors are a useful HL strategy but are not equally effective and should be tailored to individual patients
Salgado et al 2017 Cross-sectional, descriptive, correlational B	Examine relationships between HL, patient activation, confidence to self-manage, and medication adherence among patients with cancer	n=125 adults with cancer Mean age 66.2 years 57.7% female 95.1% White 2.5% Black 1.6% Asian/Pacific Islander 0.8% Other race/ethnicity	No explicit definition of HL 3-item self-report screener (Chew et al., 2004)	90.3% adequate HL HL not associated with patient activation or adherence to oral oncolytics Higher HL associated with confidence to self-manage fatigue and diarrhea
Jiang & Hong 2018 Cross-sectional, descriptive, correlational; secondary analysis A	Evaluate relationships between HL, mobile-based patient-provider communication (MBPPC), and emotional health of patients who have survived cancer HINTS Cycle 3	n=459 adults who have survived cancer Mean age 66 years 36.6% male 55% at least some college education 80.6% non-Hispanic White	Definition of HL: “one’s ability to obtain, process and understand health information and services” HINTS Health Literacy Screening Measure	Mean HL score 2.74 (range 0-4) Lower HL associated with female gender, older age Higher HL associated with higher educational level, higher income, White race/ethnicity

				HL positively associated with MBPPC, emotional health
Keim-Malpass et al 2018 Cross-sectional, descriptive, correlational B	Examine relationship between HL and surgical treatment decisions for patients with breast cancer	n=512 patients with breast cancer Mean age 59.2 years 80% White 20% non-White	National Academies' definition of HL 3-item self-report screener (Chew et al., 2004)	25.6% have low HL (limited and marginal) No significant relationship between HL and surgical treatment decisions

HL: health literacy
REALM: Rapid Estimate of Adult Literacy in Medicine
S-TOFHLA: Short Test of Functional Health Literacy in Adults
*, **, *** indicate studies that are based on the same datasets

Table 2.1.2

Levels of Health Literacy Present in Reviewed Studies

	Functional Health Literacy	Interactive Health Literacy	Critical Health Literacy
Bennett et al., 1998	Measure: REALM		
Busch et al., 2015	Measure: S-TOFHLA		Outcome: treatment decision-making
Freedman et al., 2015	Measure: Chew et al.'s (2004) screener		
Giuse et al., 2016	Measure: Chew et al.'s (2004) screener		
Halverson et al., 2013 Halverson et al., 2015	Measure: Chew et al.'s (2004) screener		Measure: additional question addressing adherence
Hawley et al., 2008	Measure: adaptation of Chew et al.'s (2004) screener		
Hawley et al., 2010	Measure: Chew et al.'s (2004) screener		
Hendren et al., 2011	Measure: REALM		
Inglehart et al., 2016	Measure: Chew et al.'s (2004) screener		
Jiang & Hong, 2018	Measure: HINTS screener	Outcome: patient-provider	

		communication	
Keim-Malpass et al., 2018	Measure: Chew et al.’s (2004) screener		Outcome: treatment decision-making
Krieger et al., 2017	Measure: HINTS screener	Outcome: communication	
Livaudais et al., 2013	Measure: adaptation of Chew et al.’s (2004) screener		Outcome: treatment decision-making
Matsuyama et al., 2011 Matsuyama et al., 2013	Measure: REALM		
Martinez-Donate et al., 2013	Measure: S-TOFHLA		Outcome: decision-making and self-management
Mohan et al., 2009	Measure: REALM		
Pickard et al., 2009	Measure: REALM		
Salgado et al., 2017	Measure: Chew et al.’s (2004) screener		
Song et al., 2012	Measure: REALM		
Song et al., 2014	Measure: REALM	Outcome: patient-provider communication	

Lung Cancer Symptom Self-Management

Lung Cancer Symptomatology

Lung cancer is recognized as having a high symptom burden; in fact, research indicates it has the highest symptom burden among solid tumor cancers (Bircan et al., 2020; Cleeland et al., 2013; Lowery et al., 2014). Patients have reported significant prevalence of several symptoms common to lung cancer, including cough (80%; Harle et al., 2020), dyspnea or breathlessness (70%; Damani et al., 2019), fatigue (75-80%; Bircan et al., 2020; Wong et al., 2017), and anorexia (50-80%; Baldwin et al., 2012; Bircan et al., 2020; Wong et al., 2017). Other frequently reported symptoms include anxiety, depression, sleep disturbances, and pain (Bircan et al., 2020; Iyer, Roughley, Rider, & Taylor-Stokes, 2014; Liao et al., 2014; Lowery et al., 2014; Maguire et al., 2014; Wong et al., 2017). Across multiple studies, fatigue is the most prevalent symptom, reported by 75-80% of patients with lung cancer, both as a result of disease and as a side effect of treatment (Bircan et al., 2020; Iyer et al., 2014; Maguire et al., 2014; Wong et al., 2017). Fatigue is also the most distressing symptom, having a strong influence on overall quality of life (Liao et al., 2014; Lowery et al., 2014; Wong et al., 2017).

While the disease process of lung cancer produces a number of distressing symptoms, it is also important to note the exacerbation of these symptoms caused by cancer treatment. When lung cancer reaches advanced stages, treatment no longer holds the potential for cure, only for stabilizing the disease and palliating symptoms. Although there may be a role for surgical treatment options to relieve symptoms or reduce tumor burden, patients with advanced lung cancer require chemotherapy and/or radiation treatment for disease control (American Cancer Society [ACS], 2019; National Comprehensive Cancer Network, 2019). Radiation to the chest can induce dyspnea and coughing and may also cause nausea, vomiting and poor appetite (ACS, 2019). Side effects of chemotherapeutic agents are common and can be both severe and cumulative (see Table 1). Importantly, side effects tend to be worse for patients who are receiving chemotherapy and radiation concurrently (ACS, 2019).

In addition to chemotherapy and radiation therapy treatment options, researchers have recently discovered a number of molecular biomarkers on tumor cells, resulting in the development of targeted therapies. Molecular profiling of tumor cells is now a routine step in treatment planning for patients diagnosed with lung cancer (NCCN, 2019). As evidence continues to build, there are several options currently recommended for patients with lung cancer that contains the molecular targets that have been identified (Table 2). By targeting and killing only malignant cells, as opposed to the cytotoxic mechanism of conventional chemotherapy, targeted therapies generally have less severe side effect profiles (ACS, 2019). Common side effects depend on the type of cells being targeted, and may include gastrointestinal distress, fatigue, and skin rashes and pruritus (see Table 2). Immunotherapeutic agents are the newest development in the treatment of lung cancer, along with other malignancies. These therapies utilize components of the body's immune system to fight cancer cells more effectively. In some patients, the action of these drugs causes the immune system to attack normal cells, initiating immune-related adverse effects (see Table 2).

Overall, multiple studies indicate that for most patients, immunotherapy is better tolerated than conventional chemotherapy for the treatment of lung cancer (Lewis, 2016; Nishijima, Shachar, Nyrop, & Muss, 2017). It is important, however, to keep in mind that only a select portion of patients with lung cancer are eligible for immunotherapy and other targeted therapies based on the molecular makeup of their disease. Thus, the dissertation study included patients who were currently receiving or had recently received any type of pharmaceutical and/or radiation treatment for lung cancer. Patients receiving cancer treatment are at risk of suffering from multiple treatment-related side effects in addition to the disease-related symptoms they are already experiencing. It can be difficult to distinguish whether the root cause of a symptom is the disease process or effects of the treatment. At the same time, it is not uncommon for treatment of the underlying malignancy to palliate some symptoms, such as cough and pain, while at the same time exacerbating other symptoms, such as anorexia and fatigue.

Evidence of the overwhelming burden of disease symptoms and treatment side effects is found in studies such as Wong et al.'s (2017) study, in which patients receiving chemotherapy for lung cancer reported experiencing an average of 14.3 concurrent symptoms. High symptom burden has been associated with poorer prognosis, which may affect a patient's capacity for tolerating treatment (Bircan et al., 2020; Mendoza et al., 2019). As a result, researchers have recently emphasized the phenomenon of symptom clustering, or the experience of several symptoms simultaneously. Concurrent symptoms are considered a symptom cluster when they are distinct from other groups of symptoms and are related to each other because of a common diagnosis, mechanism, or outcome (Barsevick, 2016). There is clear evidence supporting symptom clusters in lung cancer (Maguire et al., 2014; Russell et al., 2019), especially the Respiratory Distress Symptom Cluster comprised of breathlessness, cough and fatigue (Molassiotis, Uyterlinde, et al., 2015; Yorke et al., 2015). Studies have also linked these respiratory distress symptoms with other symptoms, such as pain, anxiety and sleep disturbances (Liao et al., 2014; Lowery et al., 2014; Maguire et al., 2014). While there has been no clear consensus on how to group various symptoms together, the presence and severity of multiple concurrent symptoms have been negatively associated with functional status and quality of life (Henoch & Lövgren, 2014; Liao et al., 2014; Lowery et al., 2014; Maguire et al., 2014; Walker et al., 2017; Wong et al., 2017). Consequently, symptom clusters are increasingly receiving attention in symptom management literature, particularly in cancer care.

Oncology clinicians have historically attempted to manage symptoms individually, in large part because there is minimal evidence of the underlying etiology of symptom clusters (Dong et al., 2016; Kelly et al., 2016). Yet current publications on supportive care have identified symptom control as a primary need for patients with lung cancer, citing a lack of evidence-based interventions that have been effective for managing common lung cancer symptoms, such as dyspnea, cough, fatigue, and anorexia (Hopkinson, 2018; Molassiotis, Uyterlinde, et al., 2015; Turcott et al., 2018). Furthermore, studies investigating strategies to simultaneously manage co-occurring symptoms have produced inconsistent findings, leaving clinical decision-making up to conjecture and intuition (Dong et al., 2016; Kwekkeboom, 2016; Molassiotis, Uyterlinde, et al., 2015; Mosher, Winger, Nasser, et al., 2016).

For instance, a client experiencing a symptom cluster of pain, fatigue and sleep disturbances might be given multiple evidence-based recommendations, including a prescription for an opioid medication for pain, energy conservation strategies for fatigue, and sleep hygiene practices. This regimen creates a high expectation for the client and family to engage in complex self-management routines involving medication management, behavior changes, and coping techniques (Kwekkeboom, 2016). However, there is current preliminary evidence indicating that an exercise-based intervention is an effective strategy to manage the entire symptom cluster by reducing pain, countering fatigue, and improving sleep (Sheikh-Wu, Downs, & Anglade, 2020).

A recently published review of symptom management guidelines from Oncology Nursing Society, National Comprehensive Cancer Network, and American Society of Clinical Oncology found that more than half of the strategies have been recommended for more than one symptom

(Kwekkeboom et al., 2020). These findings move clinicians and patients one step closer to simplifying management of symptom clusters, thus reducing the burden on patients to self-manage symptoms. Additional research is still needed to determine best practices for assessing and measuring symptom clusters, developing an evidence base for management of multiple co-occurring symptoms, and educating clients and families about how to recognize symptom clusters to appropriately self-manage them (Cooley & Siefert, 2016; Kwekkeboom, 2016; Kwekkeboom et al., 2020; Sheikh-Wu, Downs, & Anglade, 2020).

Evidence-Based Management of Symptoms in Lung Cancer

Researchers and clinicians are aware of the wide range of symptom management needs for patients with lung cancer, particularly considering the high burden of symptoms and their negative impact on quality of life and functional status (Bircan et al., 2020; Dean et al., 2013; Harle et al., 2020; Iyer et al., 2014; Liao et al., 2014; Maguire et al., 2014). Current evidence-based recommendations for managing side effects of cancer treatment are readily available on websites designed for patients (e.g., ACS) and clinicians (e.g., Oncology Nursing Society [ONS]). ACS's (2019) website contains self-management information for 29 different side effects commonly experienced by patients with all types of cancer. The information is written for a lay audience and comprises a helpful resource to which nurses can refer patients for evidence-based self-management support (ACS, 2019). ONS maintains a collection of recommendations that have been synthesized by oncology nursing experts based on the most recently published evidence (ONS, 2019). These are listed on the ONS website, providing clinicians with easy access to information that can be used for patient education and care planning to facilitate self-management of cancer-related symptoms and side effects.

A helpful feature of the ONS website is its rating system, in which symptom management interventions are classified into one of six categories based on the strength of current research-based evidence of effectiveness: 1) Recommended for Practice; 2) Likely to Be Effective; 3) Benefits Balanced with Harm; 4) Effectiveness Not Established; 5) Not Recommended for Practice; 6) Expert Opinion. For those with the strongest evidence (Recommended for Practice), there are lists of studies reporting the effectiveness of recommended strategies in controlled research environments (ONS, 2019). The following paragraphs outline current evidence related to management of the top four symptoms most consistently reported by patients with lung cancer: dyspnea, cough, anorexia, and fatigue.

Fatigue

Fatigue has been more widely studied than other symptoms experienced by patients with cancer, yet physical exercise is the only strategy listed by ONS (2019) as Recommended for Practice. Based on evidence from multiple systematic reviews and meta-analyses, exercise can safely and effectively reduce cancer-related fatigue (Brown et al., 2011; Dennett, Peiris, Shields, Prendergast, & Taylor, 2016; Fong, Ho, Hui, Lee, Macfarlane, Leung,…Cheng, 2012; McMillan & Newhouse, 2011; Paramanandam & Dunn, 2014; Puetz & Herring, 2012; Tian, Lu, Lin, & Hu, 2016). Some findings specifically indicate that activity of a moderate intensity is most beneficial (Brown et al., 2011; Dennett et al., 2016). In addition, two meta-analyses found that exercise programs supervised by professionals were more effective in managing cancer-related fatigue than unsupervised exercise (McMillan & Newhouse, 2011; Tian et al., 2016). This finding highlights the need for further research to design and evaluate interventions that patients can use to successfully self-manage fatigue at home.

ONS (2019) rates several strategies as Likely to Be Effective for managing cancer-related fatigue. However, two trends emerge in the evidence supporting these strategies. For some strategies, there is significantly limited literature indicating effectiveness; as an example, there is only one study that examined the use of energy conservation in the management of cancer-related fatigue (Barsevick et al., 2004). Perhaps more importantly, many of the strategies recommended for managing fatigue explore the influence of various interventions on multiple co-occurring symptoms. In fact, there is an entire section within the Likely to Be Effective category focused on "Management of Concurrent Symptoms." This dynamic is also true for some of the specific fatigue management strategies listed as Likely to Be Effective; for instance, studies supporting cognitive behavioral interventions are primarily focused on improving sleep (e.g., Barsevick et al., 2010; Fleming, Randell, Harvey, & Espie, 2014; Tang et al., 2015). Of note, no medications are in the top two PEP categories. The highest level of evidence for pharmacologic management of cancer-related fatigue is the inclusion corticosteroids and erythropoiesis stimulating agents in the Benefits Balanced with Harm category (ONS, 2019)

Dyspnea

According to ONS, the only dyspnea management strategy in the Recommended for Practice category involves administration of immediate release opioids (ONS, 2019). Current evidence supports recommendations for the use of oral or subcutaneous morphine to reduce dyspnea without causing respiratory depression (Kloke & Cherny, 2015; Vargas-Bermudez, Cardenal, & Porta-Sales, 2015; Yamaguchi et al., 2016). Recommendations for the management of dyspnea ranked as Likely to Be Effective include non-invasive ventilation, using fans and/or cool air, transmucosal fentanyl, and psychoeducational interventions (ONS, 2019). Other dyspnea management techniques found in the literature are listed in the Effectiveness Not Established category, such as behavioral strategies including pursed-lip breathing, postural techniques, diaphragmatic breathing, and relaxation (Chan 2011; Greer et al., 2015; Higginson et al., 2014; Kloke & Cherny, 2015; NCCN, 2019). ONS does not endorse the palliative use of oxygen, although supplemental oxygen is recommended by some experts for the treatment of dyspnea in patients who are experiencing hypoxemia (Kloke & Cherny, 2015; NCCN, 2019; Yamaguchi et al., 2016). Research is ongoing to investigate possible pharmacologic interventions, including oxycodone, codeine, benzodiazepines (only in combination with opioids), and systemic corticosteroids for certain dyspnea etiologies (Kloke & Cherny, 2015; NCCN, 2019; Yamaguchi et al., 2016). However, the overall strength of evidence is lower for many of the studies investigating non-pharmacological dyspnea management, mostly due to smaller sample sizes and high risk of bias. There is an urgent need for further research to determine effective management strategies for dyspnea experienced by patients with lung cancer.

Cough

The lack of strong evidence is even more notable for management of cough in patients with cancer, as it is generally given less attention in research. In fact, it is not included on the ONS list of symptoms for which resources have been compiled. Authors of systematic reviews and clinical practice guidelines consistently emphasize the need for rigorous studies that provide a solid understanding of effective cough management strategies. The primary recommendation is brachytherapy if the cause of cough is endobronchial disease (Molassiotis, Bailey, Caress, & Tan, 2015; Molassiotis, Smith, Mazzone, Blackhall, & Irwin, 2017). In addition, there is some evidence of effectiveness for various medications, including butamirate citrate linctus cough syrup; opioids such as morphine, codeine, and dihydrocodeine; and peripheral antitussives, including levodropropizine (Molassiotis, Bailey, et al., 2015; Molassiotis et al., 2017; Yamaguchi et al., 2016). Other potential medications include nebulized lidocaine, gabapentin, diazepam, baclofen, carbamazepine, amitriptyline, and thalidomide, although evidence is limited and none have been shown to be consistently effective (Molassiotis et al., 2017; Yamaguchi et al., 2016). A great deal of further research is needed to identify evidence-based recommendations for the management of cancer-related cough.

Anorexia

Anorexia, or the loss of appetite, is quite common in patients with cancer, affecting as many as 80% (Baldwin, Spiro, Ahern, & Emery, 2012). The two strategies Recommended for Practice on the ONS website include oral nutritional interventions and administration of progestins, while systemic corticosteroids are Likely to Be Effective (ONS, 2019). A recent systematic review and meta-analysis focused on non-pharmacologic interventions for cancer-related anorexia, finding that oral nutritional supplements and dietary counseling significantly improved appetite (Baldwin et al., 2012). Two other systematic reviews indicate that both oral megestrol acetate and oral corticosteroids improve appetite and induce weight gain for patients with cancer (Miller, McNutt, McCann, & McCorry, 2014; Ruiz Garcia, Lopez-Briz, Carbonell Sanchis, Gonzalvez Perales, & Bort-Marti, 2013). However, there remains an absence of a gold standard treatment for anorexia. Additional research is needed to improve the strength of the evidence and to determine specific recommendations related to dosing and timing of both pharmacologic and non-pharmacologic interventions (Baldwin et al., 2012; Miller et al., 2014; Ruiz Garcia et al., 2013). Of note, there must be attention directed toward the psychosocial aspects of eating problems, including knowledge, attitudes and beliefs about dietary habits, caregiver support, and motivation for self-management (Hopkinson, 2018).

Self-Management of Symptoms in Lung Cancer

The evidence about strategies that patients with lung cancer use to self-manage their symptoms is sparse. In general, there is little attention given to patients' perspectives regarding their experiences with symptom self-management; insight into what strategies patients use and why they choose those strategies is lacking. No studies were located that investigated self-management of cough; on the other hand, some symptoms, such as fatigue, have been explored more than others.

Fatigue

In two recent studies, patients with cancer identified a number of different self-management strategies for cancer-related fatigue; of note, physical exercise was not listed in either report. The most common strategy was resting or napping during the day, along with pacing activities, limiting social activity, utilizing distraction and/or relaxation techniques, and dietary modifications. In addition, participants reported techniques to improve nighttime sleeping, including pharmacologic sleep aids, as a way to reduce fatigue (Chan, Yates, & McCarthy, 2016; Loerzel, 2018).

Dyspnea

Most studies about dyspnea self-management focus on chronic obstructive pulmonary disease (COPD) or palliation for advanced cancer near the end-of-life. Findings from a limited number of studies that include participants with lung cancer indicate that portable hand-held fans may be beneficial for self-managing chronic breathlessness (Luckett et al., 2017; Simon et al., 2016). Other common strategies reported by patients include reducing physical exertion, breathing techniques, distraction and relaxation, positioning, and medications such as morphine (Larsen, Petersen, Lisby, & Knudsen, 2018; Liu, Wang, & Xie, 2019; Simon et al., 2016; Tan et al., 2019).

Anorexia

In one study exploring symptom self-management for adults with cancer, more than half of the participants identified lack of appetite as a symptom requiring self-management. Reported strategies included eating small frequent meals, taking nutritional supplements, and trying a variety of foods; about 15% reported doing nothing at all (Loerzel, 2018).

Interventions that Facilitate Self-Management of Symptoms and Side Effects

Nurses are in a key position to provide assistance to patients as they navigate the experience of cancer and its treatment, and the need to develop evidence-based interventions for supporting self-management has been a focus of many recent studies. Unfortunately, there is little consensus as to the content, delivery, and efficacy of self-management interventions for adults with cancer, as indicated by the findings of two recent systematic reviews (Howell, Harth, Brown, Bennett, & Boyko, 2017; Kim, Kim, & Mayer, 2017). In the Individual and Family Self-Management Theory (IFSMT), Ryan and Sawin (2009) suggest that interventions can be directed toward either contextual factors that influence self-management or the self-management process itself, or both, with the goal of increasing engagement in self-management behaviors. The following paragraphs will describe current evidence regarding self-management interventions that address various elements of the IFSMT across various populations of patients living with life-limiting illnesses.

Context Factors

According to Ryan and Sawin (2009), the contextual dimension of the IFSMT includes both risk and protective factors that are related to the individual and family (e.g., literacy, developmental stage, capacity to self-manage), the disease (e.g., complexity, trajectory, stability), and the physical and social environment (e.g., healthcare access, culture). Several descriptive studies have identified a number of context variables within the IFSMT that might be targeted by self-management interventions, although there is limited evidence of interventions that have been developed and tested for efficacy. Health literacy has been found to be associated with successful self-management, especially interactive and critical health literacy (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015; Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013). However, it is important to recognize the impact of functional limitations on one's capacity to self-manage even when health literacy is adequate (Heijmans et al., 2015). There is some evidence that patients' engagement in and need for support with self-management is more common in later stages of the disease or in times of change and/or crisis (Dwarswaard, Bakker, van Staa, & Boeije, 2015). The type and amount of self-management support has been linked to one's cultural background and beliefs about health and healthcare. For instance, ethnic minorities are less likely to participate in self-management support groups due to cultural beliefs about discussing disease, while American Indians tend to value storytelling as a means for sharing health information (Dwarswaard et al., 2015). Age also plays a role, in that self-management information must be appropriate for the individual's developmental stage (Dwarswaard et al., 2015). In sum, interventions need to be tailored based on non-modifiable contextual factors, such as age and disease stage, while aiming to improve modifiable factors, such as health literacy and capacity to self-manage.

Process and Outcomes

In the IFSMT's process dimension, knowledge and beliefs are proposed to influence one's engagement in the self-management process. The process of self-management involves self-regulation skills such as goal-setting and decision-making, as well as social facilitation through social support and negotiated collaboration with healthcare providers. The contextual and process dimensions interact to influence self-management outcomes, including engagement in self-management behaviors, health costs, and quality of life (Ryan & Sawin, 2009).

Knowledge/Beliefs.

Across multiple studies, patients report a preference for receiving factual information about strategies for symptom self-management. Specifically, patients with cancer and other chronic illnesses request information about what symptoms to expect, when it is necessary to call the healthcare provider to report symptoms, and various techniques to choose from for symptom management (Cooley et al., 2017; Dwarswaard et al., 2015; Lin, Cohen, Livingston, & Botti, 2018; Mosher, Winger, Nasser, et al., 2016). Nurses and other healthcare providers are considered to be primary sources of information for understanding how to self-manage adverse effects of treatment (Dwarswaard et al., 2015; Lin et al., 2018; Prip et al., 2018).

Patients also describe a need for healthcare providers to facilitate the development of self-confidence for incorporating symptom management into daily life (Dwarswaard et al., 2015; Prip et al., 2018). Self-efficacy has shown to be positively related to engagement in self-management behaviors (Geng et al., 2018); thus, many interventions address self-management by focusing on self-efficacy. In a systematic review of self-management educational interventions for patients with cancer, 90% of the 42 randomized controlled trials (RCTs) were aimed at facilitating self-efficacy; findings indicated overall effectiveness of the interventions as evidenced by improved self-efficacy skills, reduced symptom severity, and increased quality of life. Unfortunately, there was such wide variability among the content and delivery of interventions that no conclusions could be drawn as to which elements contribute most to effectiveness (Howell et al., 2017).

Self-Regulation Skills.

In a synthesis of 37 qualitative studies exploring self-management of chronic illness, patients indicated that the provision of knowledge by healthcare providers must include assistance with evaluating the information and applying it to individual situations (Dwarswaard et al., 2015). Patients report a preference for interventions that provide support for decision-making regarding self-management strategies, such as decision aids that guide symptom management and indicate when to report symptoms to healthcare providers (Cooley et al., 2017; Lin et al., 2018; Mosher, Winger, Nasser, et al., 2016). Several self-management studies have been focused on self-regulation skills related to decision-making, planning and action. In Howell et al.'s (2017) systematic review, 76% of the self-management education interventions incorporated action plans for engagement in self-management behaviors, which produced widely inconsistent results. Most of the interventions were psychoeducational in nature and examined the effect of stress self-management on symptom severity and overall quality of life. These psychoeducational interventions, including those based on cognitive behavioral techniques, tended to be more effective for psychological symptoms, such as anxiety and depression, and less effective for physical symptoms, such as nausea, pain, and dyspnea (Howell et al., 2017). Findings from studies using behavior-oriented interventions, all of which focused on exercise for cancer-related fatigue management, were also inconsistent. Only one of four studies found that home-based exercise for self-management of fatigue was effective (Howell et al., 2017). Importantly, half of the studies included only patients with breast cancer, and across all studies, the samples were comprised of an average 75% females (Howell et al., 2017).

Social Facilitation.

Most research describing social facilitation of self-management focuses on social support from peers, family members, and friends, and negotiated collaboration with healthcare providers.

Patients report relying on social support for information-seeking and processing, especially for symptom management (Cooley et al., 2017; Lin et al., 2018), and they want caregivers to be included in self-management interventions (Mosher et al., 2017). Although it is difficult to find empirical evidence of effective interventions targeting social support for self-management, one study found that social support had a direct positive relationship with self-care behaviors as well as communication with healthcare providers (Geng et al., 2018). Multiple studies have established that effective communication related to self-management requires attention to health literacy (Heijmans et al., 2015; Inoue et al., 2013; Lai et al., 2013; Papadakos et al., 2018). Patients with cancer and other chronic illnesses value collaborating with healthcare providers (i.e., interactive health literacy) to identify strategies for symptom self-management (Dwarswaard et al., 2015; Lin et al., 2018; Mosher et al., 2016). Furthermore, some patients report that poor communication with healthcare providers limits their ability to effectively self-manage symptoms (Prip et al., 2018). Despite knowledge that communication between patients and providers is a key element of self-management, it is not consistently included as a component in intervention studies (Howell et al., 2017; Papadakos et al., 2018). Howell et al. (2017) pointed out that this could be attributed to the frequent use of psychoeducational and cognitive behavioral design of self-management education interventions, which do not commonly focus on communication skills.

Conclusion

Oncology nurses are intimately familiar with patients along the cancer treatment trajectory, having important insight into symptom management needs and the expertise to support patients as they learn to self-manage those needs. Most current nursing research exploring symptom management for patients with lung cancer focuses on the experience of symptoms and their impact on quality of life. Some evidence-based recommendations are available for nurses to put into practice to relieve common symptoms in patients with lung cancer, such as fatigue and dyspnea, but for the common symptom of cough, there are limited evidence-based recommendations. There is very little evidence that provides insight into exactly what patients with lung cancer use to self-manage their symptoms, whether they use evidence-based strategies, and whether the strategies are effective. A small body of literature shows that interventions to meet patients' needs for knowledge about symptom self-management and interventions that promote self-efficacy and communication with providers may be specific targets to enhance symptom self-management in patients with lung cancer. More research is needed in all of these areas.

There is an urgent need for nurse scientists to assume a prominent role in future research on understanding how to facilitate symptom self-management for patients with lung cancer. Health literacy, particularly interactive health literacy, is infrequently addressed in self-management interventions, signifying substantial opportunity for expanding knowledge of the relationship between these two phenomena. In adult oncology research, most studies investigating interactions between patients and healthcare providers focus on cancer prevention and screening, as well as treatment decision-making; far fewer explore communication in the context of symptom self-management. Furthermore, patients with lung cancer are poorly represented in study samples, highlighting the need for further research focused on self-management for this population.

Research efforts must integrate principles of health literacy and effective communication between patients and providers in order to generate a solid base of evidence on which interventions can be formed. This evidence is especially important for patients with lung cancer, as new treatments are being developed for which symptom management information is limited. It is critical for nursing research to contribute to what is currently known, in order to influence clinical practice and policy that will ultimately impact the quality of life and outcomes for patients with lung cancer.

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Table 2.2.1

Chemotherapeutic Agents for Lung Cancer

Chemotherapeutic Class / Agents	Mechanism of Action	Common Side Effects
Alkylating Agents Carboplatin (Paraplatin) Cisplatin (Platinol-AQ)	Interfere with DNA replication and RNA transcription, causing cell death	Myelosuppression Nausea and vomiting Stomatitis Alopecia Gonadal suppression Renal toxicity (cisplatin)
Topoisomerase II Inhibitors Etoposide (VePesid)	Break DNA strands and prevent cell division	Myelosuppression Nausea and vomiting Diarrhea Skin rash
Antimetabolites Gemcitabine (Gemzar) Pemetrexed (Alimta)	Interfere with DNA synthesis, replication, and repair	Myelosuppression Nausea and vomiting Diarrhea Stomatitis
Plant Alkaloids Vinorelbine (Navelbine)	Prevent DNA and protein synthesis	Myelosuppression Nausea and vomiting Peripheral neuropathy
Taxanes Docetaxel (Taxotere) Paclitaxel (Taxol)	Interfere with metaphase of cell cycle	Myelosuppression Hypersensitivity reactions Alopecia Peripheral neuropathy Mucositis

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Table 2.2.2

Targeted Therapies for Lung Cancer

Type of Targeted Therapy / Agents	Molecular Target	Mechanism of Action	Common Side Effects
Angiogenesis Inhibitors Bevacizumab (Avastin)	Vascular endothelial growth factor (VEGF)	Neutralizes VEGF, which prevents tumor growth by eliminating its blood supply	Hypertension Thromboembolitic events Bleeding Fatigue Headaches Stomatitis Anorexia Diarrhea
Tyrosine kinase inhibitors		Block expression of enzymes involved in cell signals for growth and division	Diarrhea Nausea Vomiting Constipation Stomatitis Anorexia Fatigue Acne-like facial rash
EGFR inhibitors Erlotinib Afatinib Gefitinib Osimertinib	Epidermal growth factor receptor (EGFR)		
ALK and ROS1 inhibitors Alectinib Certinib Crizotinib Brigatinib	Anaplastic lymphoma kinase (ALK) and ROS proto-oncogene 1 (ROS1)		
Immune checkpoint inhibitors Nivolumab Pembrolizumab Atezolizumab	Programmed death ligand 1 (PD-L1)	Block interaction between programmed death 1 (PD-1) on T-cells and PD-L1 on tumor cells to activate immune response against malignant cells	Nausea Bowel changes Loss of appetite Rash Pruritus Fatigue Joint pain Immune-related adverse effects

ACS, 2019; Lewis, 2016; NCCN, 2018; Nishijima et al., 2017.

Methods

Understanding concepts, such as health literacy and self-management, require innovative methodologies that allow researchers to gather and analyze rich information about how individuals experience complex social phenomena, as well as contextual elements that influence their experiences. Traditional research methods have focused on either quantitative techniques that produce numerical data, or qualitative techniques that produce narrative information (Teddlie & Tashakkori, 2009). Quantitative methods are used to establish facts and measure relationships among social phenomena. Qualitative methods seek to understand and describe how individuals subjectively experience social phenomena. Most health literacy studies have employed quantitative measures of functional health literacy and various outcomes, attempting to identify statistical relationships (Chinn & McCarthy, 2013; McKenna, Sixsmith, & Barry, 2017; Papen, 2009). Relative to the volume of health literacy research, few studies have utilized qualitative methods to gain insight into the perspective of patients. Recent conceptual definitions of health literacy have acknowledged that health literacy is multidimensional, dynamic, and context-dependent (Sørensen et al., 2012; Squiers, Peinado, Berkman, Boudewyns, & McCormack, 2012). Quantitative methods alone, in their search for a measurable, objective reality, are insufficient for understanding the real-life experience of how individuals critically interact with health information (Chinn, 2011). Similarly, relying only on qualitative data limits knowledge to individual interpretations of health literacy without attention to quantifiable evidence of its existence and relationships with other phenomena (Danermark, Ekstrom, Jakobsen, Karlsson, & ChKarlsson, 2002; Lipscomb, 2008; Zachariadis, Scott, & Barrett, 2013). Instead, an approach using both qualitative and quantitative data collection was appropriately suited for addressing the aims of this study. The purpose of this study was to explore how interactive health literacy relates to symptom self-management for patients with lung cancer. A mixed methods design allowed the researcher to merge the quantitative and qualitative data analysis to obtain a deeper understanding of the problem from different data perspectives.

The study explored how interactive health literacy relates to symptom self-management for patients with lung cancer. Specific aims were to:

1. Explore interactive health literacy related to symptom self-management for patients with lung cancer;
2. Describe patients' experiences of interacting with healthcare providers regarding symptom self-management for lung cancer.

The study was conducted using a critical realist methodology. Critical realism was originally developed by Roy Bhaskar in the 1970s as a philosophical framework, but it is increasingly being advanced as a useful methodology for investigation of complex social phenomena (Clark, Lissel, & Davis, 2008; Craig & Bigby, 2015; Danermark et al., 2002; Fletcher, 2017; Lennox & Jurdi-Hage, 2017; Lipscomb, 2008; Parlour & McCormack, 2012; Parr, 2015; Schiller, 2016). Ontologically, critical realism maintains a balance between objective and subjective knowledge, claiming that there is an external reality that can only be determined by human experience and interpretation. Its ontology is stratified into three domains: real, actual, and empirical (see Figure 1). The real domain represents structures and mechanisms that exist and exert power in the world independent of human awareness. These structures and mechanisms interact to cause phenomena to occur in the actual domain, which may or may not be observed and interpreted by humans. Research and theory development take place in the empirical domain, comprised of human perception and experience of phenomena (Danermark et al., 2002). Critical realists emphasize the fallibility of empirical representations and caution that they should not be assumed to equal events and situations located in the actual and real domains (Clark et al., 2008).

Grounded in the idea that the world is an open system, critical realism recognizes that the experience of individuals cannot be adequately understood separate from their environment. In other words, events and experiences are generated by structure—contextual factors such as geographical location, social and cultural norms, economics, and politics—and its interaction with agency, or personal attitudes, beliefs, and values. While individuals have agency and are able to make decisions, the structural context induces limits on what decisions are made and how (Harwood & Clark, 2012). The goal of critical realist research is to identify patterns of underlying structural mechanisms (real domain) that explain the occurrence of observable phenomena (actual domain) and how they are experienced (empirical domain), in order to illuminate the interplay between structure and agency (Clark et al., 2008; Danermark et al., 2002; O'Mahoney & Vincent, 2014; Zachariadis et al., 2013). Thus the critical realist approach aligns with process of mixed methods research, which iteratively cycles between inductive inferences used to formulate theoretical frameworks from grounded observations and deductive inferences that use a theoretical framework to predict outcomes (Teddlie & Tashakkori, 2009). The nature of the research questions determines if induction or deduction is used first (Teddlie & Tashakkori, 2009). Importantly, critical realist experts advocate for beginning with a theory, realizing that theories are imperfect, and attempting to refine that theory to develop a more accurate explanation of the phenomena being explore (Danermark et al., 2002).

The researcher values quantifiably measurable aspects of a phenomenon, while recognizing that relying solely on empirical data to develop knowledge contradicts the stratified ontology of critical realism (Danermark et al., 2002; Lipscomb, 2008; Zachariadis et al., 2013). Qualitative methods fit with the epistemological stance of critical realism by constructing knowledge through understanding individual experience, but may fall short of fully explaining patterns of how the phenomenon manifests (Danermark et al., 2002; Lipscomb, 2008; Zachariadis et al., 2013). Using both approaches allows the researcher to integrate quantitative and qualitative data as a means for identifying mechanisms that generate the events experienced by individuals (Zachariadis et al., 2013). While mixed methods can accomplish a variety of purposes, the primary reason in this study was to provide as complete a picture as possible of the experience of interactive health literacy and symptom self-management for patients with lung cancer. The strengths of each method offer both divergent and complementary perspectives of the phenomena of interest. At the same time, the weaknesses of each method are compensated by one another (Zachariadis et al., 2013).

Study Design

Critical realist inquiry does not limit researchers to the dichotomous choice of quantitative or qualitative methods. In fact, its emphasis on understanding the complex nature of social phenomena with multiple layers of influence lends itself to mixed methods research (Lennox & Jurdi-Hage, 2017b; Lipscomb, 2008; Zachariadis et al., 2013). This study employed a cross-sectional design using concurrent quantitative and qualitative methods for data collection, including demographic information, self-reported health literacy and symptom assessment instruments, and semi-structured individual interviews with participants. A critical realist approach allows for flexible adaptation of a variety of methods in order to access a depth of information that will provide insight into all three domains of knowledge regarding a particular phenomenon (Ackroyd & Karlsson, 2014; Clark et al., 2008; Craig & Bigby, 2015; Schiller, 2016). Although this has its advantages, it also presents a challenge in ensuring the robustness and trustworthiness of the methods used in critical realist inquiry. Fortunately, scholars across several disciplines have recently published exemplars of the application of critical realism principles to the exploration of social phenomena (Angus, Miller, Pulfer, & McKeever, 2006; Clark et al., 2008; Craig & Bigby, 2015; Fletcher, 2017a; Lennox & Jurdi-Hage, 2017a; Parlour & McCormack, 2012; Parr, 2015; Zachariadis et al., 2013). Commonalities among these exemplars were used to guide the design of the study and will be discussed in greater detail in the remainder of this chapter.

Ethical Considerations

The act of conducting research in any capacity raises ethical issues that must be addressed, all of which focus on minimizing harm to participants. Potential issues should be anticipated and accounted for in each step of design and implementation of the study. The researcher obtained approval to conduct the study from the Institutional Review Board (IRB) at University of Wisconsin-Milwaukee (UWM) prior to initiating recruitment. Leaders in both the outpatient oncology clinic and the patient support organization reviewed the IRB protocol and UWM's approval letter, and both endorsed the approval. Benefits of the study were outlined and clearly outweighed any risks to participants. Study procedures were designed to prevent and minimize any risks, such as participant burden and fatigue. Because of the breadth and depth of mixed-methods inquiry, it was important to be continually aware of the demands being placed on participants and ensure they were not over-burdened by data collection methods (Bloomberg & Volpe, 2008; Ritchie et al., 2014). Specifically, the student PI allowed for flexible scheduling of interviews, so as not to overwhelm participants when they were already facing physical and emotional challenges of living with cancer.

The researcher ensured all elements of the informed consent process were followed. Participants were fully informed of the aims of the study, the rationale for participant selection, what to expect in terms of data collection, how data will be used, stored and disseminated, and any potential risks to their well-being. While anticipated risks were minimal, it was possible that participants could experience emotional distress when discussing the symptoms and side effects of a serious illness such as lung cancer. Resources for support were identified prior to data collection; as an oncology nurse with telephone triage experience, the student PI is trained to assess for and manage distress during phone conversations. If participant distress were identified, the student PI would stop data collection and offer appropriate support. Depending on the degree of severity and recovery, the student PI would determine whether to resume data collection. If the distress could not be resolved by interventions offered by the student PI, the student PI would obtain participant permission to refer to clinic staff or support group facilitator(s) for further support and resources. In the event that the participant were to exhibit immediate risk of harm to self or others, the student PI would initiate necessary referrals without the participant's permission. Consent to participate was completely voluntary, and participants were allowed to provide only the information with which they were comfortable; this meant they were given the right to decline certain questions or end the interview at any time. In addition, the student PI protected participants' rights to confidentiality and anonymity at all times and to be informed of how this would be maintained, especially when findings are reported (Bloomberg & Volpe, 2008; Ritchie et al., 2014).

Sample

Recruitment was achieved through criterion-based purposive sampling, in which participants are chosen based on key features specific to the phenomenon being explored. This allowed the researcher to purposefully select cases that provided a richness of information to understand the phenomenon and relevant contextual factors in depth (Bloomberg & Volpe, 2008; Patton, 1990; Ritchie, Lewis, McNaughton, Nicholls, & Ormston, 2014). The study's sample included male and female adults (age 18 years or older) who were fluent in verbal and written English and had received pharmaceutical and/or radiation treatment for lung cancer within the past six months. These inclusion criteria allowed the researcher to gain a depth of insight into how individuals understand and apply information related to self-management of side effects after having had at least some experience with cancer treatment. Potential participants were excluded if they were not fluent in verbal and/or written English, or if they had a cognitive or communication impairment limiting their ability for recall, interaction with healthcare providers, or ability to perform self-management activities. The goal was to recruit at least 30 participants to ensure that data would be sufficiently rich for qualitative analysis (Morse, 2000). However, restrictions caused by COVID-19 necessitated changes in the study protocol, particularly in recruitment procedures, resulting in a total sample of 12 participants.

Setting

Initially, the researcher planned to recruit participants from multiple clinical settings in Chattanooga, Tennessee, and surrounding areas. The researcher began the study by recruiting participants at Cleveland Regional Cancer Center (CRCC), a local outpatient oncology clinic located in Cleveland, Tennessee, that provides radiation therapy for patients diagnosed with cancer. Each year, CRCC sees approximately 250 new patients, of which about 60 have lung cancer. Three participants were recruited from CRCC, but only one completed data collection; the other two were lost to follow up. Because CRCC offered a relatively small population from which to sample, participants were also to be recruited from Tennova, a non-profit hospital in Cleveland.

Although Tennova does not operate a cancer center, it houses an infusion center that provides infusion services to patients, including patients with cancer. However, the COVID-19 pandemic halted Tennova's Institutional Review Board's approval process, and recruitment did not commence at this facility.

In March 2020, hospitals and other healthcare facilities across the nation restricted access to only essential personnel. The researcher was not permitted to enter CRCC or any other facilities for the purpose of screening and recruiting participants, particularly in oncology settings where many patients are immunocompromised. In an effort to adjust the study protocol appropriately, the researcher sought methods to shift recruitment to a virtual environment. This resulted in a partnership with a non-profit organization that raises awareness for early detection of lung cancer and provides support and advocacy for patients and families affected by lung cancer. One of the services the organization offers is support groups comprised of patients with lung cancer, caregivers, and advocates. Due to COVID-19, many of these groups were meeting virtually via video-conferencing technology, and the researcher was invited to join several meetings to describe the study and recruit potential participants. Virtual support group meetings took place in Florida, North Carolina, and Michigan.

Data Collection

Both quantitative and qualitative data were collected using more than one technique, namely standardized questionnaires and individual interviews. This is known in mixed methods research as between-strategies data collection or methodological triangulation (Teddlie & Tashakkori, 2009). Critical realism scholars refer to this approach as critical methodological pluralism, which aligns with both the ontology and epistemology of critical realism, recognizing that complex social phenomena and their underlying generative mechanisms cannot fully be explained by quantifiable measures independent of context. Quantitative data identifies patterns of phenomena while qualitative data provides thick descriptions of how those phenomena are experienced. Taken together, mixed methods data has the potential to produce a complete picture of the connection between interactive health literacy and symptom self-management (Zachariadis et al., 2013). Questionnaire data provided a broader understanding of interactive health literacy and symptoms requiring self-management, as well as contextual factors that influence the phenomena of interest. Interview data offered deeper insight into how participants interpret their experience of interactive health literacy and self-management. As the two types of data were integrated, the identification of consistencies between the numerical and narrative findings strengthened the inferences made by the study (Teddlie & Tashakkori, 2009; Zachariadis et al., 2013).

Quantitative Data Collection Instruments

Demographic self-report form. Participants completed a self-report questionnaire comprised of demographic information including age, gender, ethnicity, educational level, household income, relationship status, number of children, and type of health insurance.

Memorial Symptom Assessment Scale Short Form. The Memorial Symptom Assessment Scale-Short Form (MSAS-SF) was used to assess symptom frequency and distress. Modified from the original MSAS, the MSAS-SF is a comprehensive assessment of how patients experience 28 physical symptoms and four psychological symptoms of cancer (see Appendix A and Appendix B). Respondents indicate if they have experienced each physical symptom in the past week and rank the extent of distress it caused. Scores are assigned based on the five-point Likert scale distress ratings: “not at all” = 0.8; “a little bit” = 1.6; “somewhat” = 2.4; “quite a bit” = 3.2; “very much” = 4. Psychological symptoms are assessed only for frequency in the past week:

“rarely” = 1; “occasionally” = 2; “frequently” = 3; “almost constantly” = 4. If the symptom was not experienced, it is scored as a zero on both sections. The mean distress rating of all 32 symptoms is reported as the total MSAS-SF score (Chang et al., 2000).

The MSAS-SF also includes three subscales: global distress index (GDI), physical symptom distress (PHYS), and psychological symptom distress (PSYCH). GDI is calculated as the mean distress rating of six physical symptoms (lack of energy, feeling drowsy, lack of appetite, pain, constipation, dry mouth) and four psychological symptoms (feeling sad, feeling irritable, feeling nervous, worrying). PHYS includes 12 physical symptoms that are prevalent in patients with cancer: lack of energy, feeling drowsy, dizziness, pain, dry mouth, change in taste, nausea, vomiting, constipation, feeling bloated, lack of appetite, and weight loss. PSYCH is comprised of six psychological symptoms: feeling sad, feeling irritable, worrying, feeling nervous, difficulty sleeping, and difficulty concentrating (Chang et al., 2000).

The MSAS-SF can be administered easily and quickly, requiring five minutes or less. Patients can complete the assessment independently, or the questions can be administered verbally by a healthcare provider. Furthermore, the MSAS-SF has been found to be valid and reliable for use in patients with cancer. Initial psychometric testing produced reliability coefficients of 0.87 for the total MSAS-SF, 0.80 for GDI, 0.82 for PHYS, and 0.76 for PSYCH (Chang et al., 2000). Results of validity testing were also strong across a general adult oncology population (Aktas, Walsh, & Kirkova, 2015).

All Aspects of Health Literacy Scale (AAHLS).

The AAHLS was developed as a brief and clinically feasible measure of all three levels of health literacy based on Nutbeam’s (2000) framework. The tool includes three questions on functional health literacy, three on communicative health literacy, and seven for critical health literacy. To simplify self-administration for respondents with lower literacy, a 3-point Likert scale was used for the majority of the items, with possible responses of “often,” “sometimes,” and “rarely.” In the critical health literacy section, two questions require a choice between two dichotomous options. When the tool was developed, psychometric testing revealed a solid reliability coefficient of 0.75 for the scale as a whole. Cronbach’s alpha was 0.82 for the functional health literacy subscale, 0.69 for the communicative health literacy subscale, and 0.42 for the critical health literacy subscale (Chinn & McCarthy, 2013).

Qualitative Data Collection

Collection of qualitative data was focused on understanding participants’ perspectives of how they experience interactive health literacy and symptom self-management. This approach aligns with critical realism, which acknowledges that subjective experiences and derived meanings yield important insight into underlying mechanisms that give rise to social phenomena (Fletcher, 2017; Lennox & Jurdi-Hage, 2017; Lipscomb, 2008; Zachariadis et al., 2013). The semi-structured individual interview provides space for the researcher and participant to collaboratively explore individual experience in depth, which may result in previously unknown information about the phenomena of interest (Ackroyd & Karlsson, 2014; Brinkmann, 2017; Ritchie et al., 2014; Smith & Elger, 2014; Teddlie & Tashakkori, 2009; Zachariadis et al., 2013). Importantly, interview data gets underneath quantitative descriptions of phenomena, which are restricted by categories relevant to an empirical understanding of interactive health literacy and self-management, such as demographic descriptors, symptom frequency and severity, and health literacy scores. Participant interview data gave insight into the how and why questions of the phenomena of interactive health literacy and symptom self-management, e.g., where and how participants obtain self-management information, how they choose self-management strategies, and why they choose the strategies they use. A semi-structured format offered consistency in the content of issues that were covered, while also allowing flexibility to probe more deeply into individual responses and clarify ambiguous or unclear information (Brinkmann, 2017; Teddlie & Tashakkori, 2009; Zachariadis et al., 2013). Critical realists emphasize the benefit of allowing theory to guide the interview structure by informing the development of interview questions as well as awareness of areas that warrant further exploration based on participant responses (Smith & Elger, 2014). In other words, using a theory to shape the content and direction of the interview will help to elucidate the adequacy of the theory to describe and explain the phenomenon of interest.

The interview guide began with questions about symptom(s) the participant was currently experiencing, and which were considered to be of highest priority. Asking these questions in an open format created the opportunity for the participant to determine relevant issues, rather than allowing the researchers' assumptions to guide the interview (Henoch & Lövgren, 2014; Ritchie et al., 2014). Next, questions were asked about the participants' experience of obtaining and processing information related to symptom self-management, followed by questions about interactions with healthcare providers. Examples of questions in this area related to how the participant felt about asking healthcare providers about symptom self-management, and instances when a conversation with a healthcare provider helped the participant with symptom self-management needs. The final questions were intended to provide space for participants to end the interview with positive ideas about their experience with symptom self-management or how it could be improved (Ritchie et al., 2014). In each section, probing questions were included to investigate social processes and contextual factors (as outlined in the IFSMT) that influenced the individual's experience of obtaining and applying health information in the self-management of symptoms and side effects (Table 1).

Procedures for In-Person Settings

1. Staff in the clinical setting notified Student PI of potentially eligible patient.
2. Student PI approached patient in outpatient clinic exam room to explain study and conduct informed consent process by fully explaining study aims, procedures, potential risks and benefits. If agreeable, patient signed informed consent form to enroll in the study.
3. Student PI scheduled agreeable time for participant to complete questionnaires and interview in the outpatient clinic.
4. At scheduled time in the outpatient clinic or infusion center, participant completed demographic form, MSAS-SF, and AAHLS.
5. Participants were interviewed individually by Student PI in a private space in the outpatient clinic, or by phone, to ensure confidentiality and a sense of freedom to speak openly and intimately about their experiences. Each interview was audio-recorded to ensure accurate transcription and analysis of participant responses.

Procedures for Virtual Settings

1. At the invitation of group facilitators, Student PI attended virtual support group meetings.
2. During the virtual meeting, Student PI explained the study aims, procedures, potential risks and benefits, and eligibility criteria. If interested in the study, support group members in attendance who met eligibility criteria were invited to contact Student PI via email or phone to be screened for potential study participation. Recruitment information was also sent by group facilitators via email to absent group members and posted on private Facebook pages open only to support group members.

3. Student PI sent email to interested and eligible participants with digital consent form and instructions for completion. If agreeable, participant signed informed consent form to enroll in the study and emailed it back to Student PI.
4. Once signed informed consent form was received, Student PI emailed link for Qualtrics survey to participant and scheduled agreeable time for phone interview.
5. Participants were interviewed individually by Student PI by phone. Each interview was audio-recorded to ensure accurate transcription and analysis of participant responses.

Data Analysis

In applying a critical realist approach to a research study, Danermark et al. (2002) propose a six-stage model of analysis, with an emphasis that it should not be considered as a template to be strictly followed. These six stages guided the analysis process to address the following research aims: 1) explore interactive health literacy related to symptom self-management for patients with lung cancer; and 2) describe patients' experiences of interacting with healthcare providers regarding symptom self-management for lung cancer.

Stage 1: Description

In this first stage, the phenomena of interactive health literacy and symptom self-management are described using empirical observations. Critical realists recognize that statistical relationships between variables within a study are not sufficient for the identification of generative mechanisms since they only provide information about the empirical domain (Danermark et al., 2002; Lipscomb, 2008; Zachariadis et al., 2013). Instead, the purpose of quantitative data is to numerically describe the existence of phenomena in order to identify patterns, or "demi-regularities," of participants' experiences (Danermark et al., 2002; Zachariadis et al., 2013). Thus quantitative information was entered into a spreadsheet and summarized using descriptive statistics that define characteristics of participants, including demographics, frequency and severity of lung cancer symptoms (as measured by the MSAS-SF), and interactive health literacy scores on the AAHLS subscale. The researcher looked for tendencies, or rudimentary trends in the statistical data.

Individual interviews were audio-recorded and transcribed using NoNotes, a secure web-based and mobile app platform designed for academic researchers. Next, the researcher thoroughly read all transcribed data before beginning to code. From there, the researcher identified common themes (demi-regularities) expressed by participants and entered the themes as codes into NVivo, a software program designed for qualitative and mixed methods data analysis.

Stage 2: Analytical Resolution

Analytical resolution refers to determining how the various components of the data fit together (Danermark et al., 2002). The researcher used a flexible deductive process to establish a list of a priori codes informed by existing literature about interactive health literacy and symptom self-management (Fletcher, 2017). As demi-regularities in both quantitative and qualitative data were identified, they were categorized under codes derived from Nutbeam's (2000, 2008) framework, the Individual and Family Self-Management Theory (IFSMT; Ryan & Sawin, 2009), and critical realist concepts of structure and agency. Codes were added as needed until each piece of data was coded. In this way, the specific details of participant experiences were ordered into an empirical overview of the information (Blom & Morén, 2011).

Stage 3: Abduction/Theoretical Redescription

Abduction refers to redescription, recontextualiation, or theoretical reinterpretation of a social phenomenon. Abduction is based on creative reasoning in which the researcher begins with an established theory and looks for connections that are not obvious, in an effort to situate phenomena within a particular context. In doing so, the theory is used to redescribe events, while the events clarify the theory (Danermark et al., 2002). Concrete individual experiences (particulars) are reinterpreted into abstract expressions of phenomena (general), which eventually lead to the discovery of generative mechanisms (Blom & Morén, 2011). This process of abduction mirrors the synthesis of qualitative and quantitative data to develop meta-inferences in mixed methods inquiry (Teddlie & Tashakkori, 2009; Zachariadis et al., 2013).

In this stage, data was analyzed and reorganized to redescribe the concepts and connections relevant to the phenomena and existing theoretical framework. As each piece of data was coded, categories were added, changed, or eliminated to situate the phenomena in a new context of understanding based on quantitative and qualitative data. Demi-regularities in the data that describe the codes were analyzed for connections that formulate a basis for assumptions that explain interactions between the concepts (Blom & Morén, 2011). Multiple interpretations were generated, compared, and integrated to explain health literacy and self-management of symptoms. As codes were re-organized, a concept map was created based on how the critical realist categories of structure and agency manifested in the data, a process introduced in Fletcher's (2017) publication detailing a methodological application of critical realism (Figure 1). This concept map assisted the researcher in moving into the next stage of analysis, retroduction.

Stage 4: Retroduction

The aim of this stage is to discover what generative mechanisms cause the connections identified in Stage 3 to exist. In other words, what contextual conditions must be in place in order for the relationship between interactive health literacy and symptom self-management to manifest in the way it is observed during this study? Generative mechanisms explain causal powers and liabilities of a concept, which can be likened to strengths and weaknesses. Danermark et al. (2002)

give the example of water, which holds power to extinguish fire but also holds liability to evaporate; similarly, humans have power to procreate and the liability to die. These powers and liabilities inherently exist (real domain), but their occurrence varies depending on various contextual conditions (actual domain), which can be theorized from meta-inferences produced by observable trends (empirical domain; Danermark et al., 2002; Blom & Morén, 2011). Critical realism seeks to discern where powers and liabilities show up in the synthesis of participant narratives. Consequently, retroduction requires deeper analysis than empirical data alone and may require the researcher to engage in "rational judgment," in which the researcher provides further explanation to demi-regularities identified within the accounts and interpretations of participants (Fletcher, 2017, p. 190). This process is informed by assumptions based on theoretical frameworks and literature that explain the phenomena of interest; it is important for the researcher to clearly state those assumptions and determine if they are consistent with the study's findings. Codes that were most prominent within the data were analyzed against existing evidence to uncover issues related to structure and agency that indicated possible generative mechanisms (Blom & Morén , 2011; Fletcher, 2017).

Stage 5: Comparison Between Different Theories and Abstractions

As possible generative mechanisms were identified, they were applied to the data to determine which best explained the social phenomena of interest. The ultimate goal is to support or refine existing theory, realizing that all theoretical descriptions are fallible, but some are more accurate than others. For example, in a sociological study using feminist political theory (FPE) to explore the effects of agricultural policy on farm women in Saskatchewan, Fletcher (2017) identified corporatization of agriculture as a causal structure that limited women's agency in the farming industry. Participants did not specifically discuss corporatization as a concept, yet

Fletcher (2017) recognized it as a common underlying cause of concern (liability) after re-examining the most prominent data codes. At the same time, analysis of participant responses revealed that women's agency in their off-farm work—necessary in order to offset the economic challenges caused by corporatization—represented a power. Fletcher's (2017) findings offer a refinement of FPE, which de-emphasizes agency in favor of structural influences, by highlighting the importance of distinguishing between structure and agency in examining political and economic contexts. Thus this step of analysis has the potential to provide insight into deeper strata of reality that are not readily identifiable through traditional research methods.

Stage 6: Concretization and Contextualization

Concretization refers to exploring how structures and mechanisms operate in concrete situations, including their interaction with contextual factors. The researcher critically examines findings from retroductive analysis by connecting generative mechanisms with specific contexts identified within the empirical data (Blom & Morén, 2011; Danermark et al., 2002). Examples from participant experiences are presented as concrete examples of how a mechanism manifests itself when certain contextual factors are present, thus satisfying the study's aims of examining how interactive health literacy relates to symptom self-management for patients with lung cancer. This step concretizes and contextualizes the study's findings while also providing clear direction for future research that explores generative mechanisms in different contexts in order to support them as causal explanations of phenomena (Blom & Morén, 2011; Fletcher, 2017).

Scientific Rigor

Demonstrating rigor in mixed methods inquiry requires evaluating the data quality of both the quantitative and qualitative data. If both types of data are trustworthy and valid, the evidence is considered to be of high quality (Teddlie & Tashakkori, 2009). This is of particular importance for nursing research, because its goal is to inform practice and policy. Practitioners and policymakers must be confident in the knowledge developed by a study and the procedures used to develop that knowledge (Porter, 2007). Quantitative and qualitative research use different criteria for assessment of data quality; quantitative criteria involve validity and reliability, and qualitative criteria address credibility and dependability. The following paragraphs detail an integration of the two sets of criteria to ensure high data quality in this study.

Validity/Credibility

Validity/credibility refers to how well the findings of a study accurately evaluate what it is intending to, as opposed to some other phenomenon (Teddlie & Tashakkori, 2009). In critical realism, validity/credibility is reflected by empirical indicators of generative mechanisms, descriptions of specific contexts in which generative mechanisms are at work, and the possibility of transferring or generalizing generative mechanisms to other situations or contexts (Zachariadis et al., 2013). In quantitative data collection, it is necessary to use measurement tools that have demonstrated validity in previous studies. As has already been discussed in this chapter, the MSAS-SF and AAHLS have good psychometric properties, indicating validity for measuring symptom experience and health literacy, respectively.

To enhance credibility in qualitative data collection and analysis, the researcher must engage in reflexivity throughout the research process. Thus it will be necessary to be clear about biases that may inform the assumptions produced through rational judgment during retroductive analysis. For instance, the student PI's assumption of power imbalances between healthcare providers and patients may have influenced the process of data collection and analysis regarding interactive health literacy. Once a generative mechanism was identified, it was checked with a content expert on symptom self-management. Findings from the study were also shared with some participants when the student PI revisited one of the virtual support groups. Of note, a critical realist approach specifically supports the validity/credibility of the research process by using existing theory, such as Nutbeam's framework and the IFSMT, to guide the development of research questions, categorization of data, and explanations of connections between concepts (Danermark et al., 2002).

Reliability/Dependability

Reliability/dependability are concerned with consistency of data collection and analysis. Quantitative measures of phenomena are tested for reliability using specific statistical correlations; again, the MSAS-SF and AAHLS exhibited reliability in previous studies. Qualitatively, the researcher demonstrates dependability by explicitly describing how data was collected and analyzed, including any changes in the research process and/or setting (Bloomberg & Volpe, 2008; Teddlie & Tashakkori, 2009; Zachariadis et al., 2013). In critical realist inquiry, the analytic procedures of abduction and retroduction result in provisional explanations of social phenomena and the generative mechanisms that give rise to them, which are then explored for consistency within other contexts. This helps the researcher to avoid premature closure of themes by inviting further inquiry to support findings (Connelly & Peltzer, 2016). Triangulation of methods, or methodological pluralism, offers an advantage for ensuring the overall trustworthiness of data quality in a mixed methods study (Teddlie & Tashakkori, 2009). Collecting both quantitative and qualitative data provided a more complete picture of interactive health literacy and symptom self-management for each participant.

Conclusion

Nurses have a responsibility to generate knowledge that contributes to scientific understanding of phenomena related to health and healthcare. A solid foundation of knowledge informs research, practice, education and policy, and continuing to advance nursing's knowledge base ensures the provision of safe, effective and quality care. Research on interactive health literacy, symptom self-management, and patient-provider interactions as independent concepts continues to grow. Less is known about how the inter-relationships among these concepts impact the patient experience, particularly in the context of lung cancer. Utilizing a mixed methods design underpinned by a critical realist methodology, this study addressed this evidence gap by exploring generative mechanisms that explain connections between interactive health literacy and self-management of lung cancer symptoms. Findings may contribute to theoretical knowledge of how health literacy influences self-management, which will ultimately guide the development of evidence-based interventions to facilitate effective symptom self-management for patients with lung cancer.

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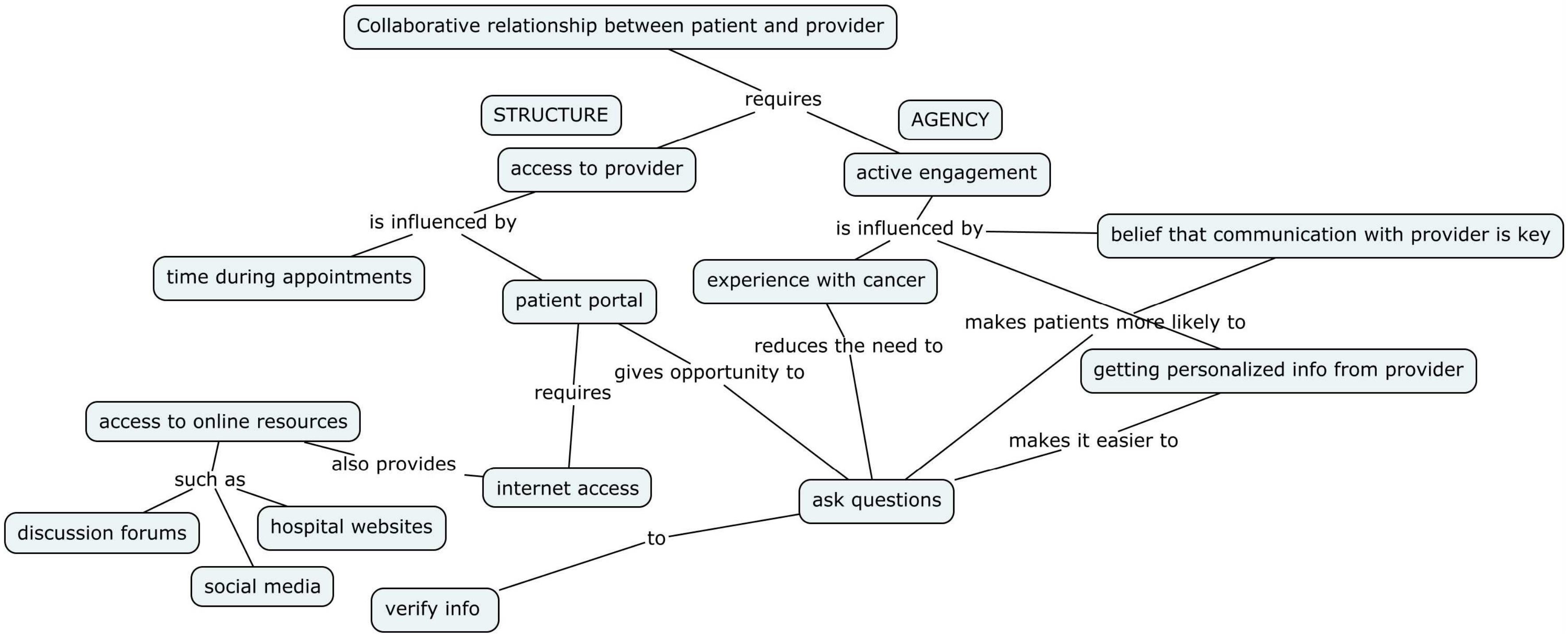


Figure 3.1 Concept map

Table 3.1

Interview Guide

- Describe the symptoms you have experienced since starting treatment. Which symptom would you consider to be your priority and why? Which symptom would you like to talk about? Pick one or two that you find to be the hardest to self-manage. Are there symptoms that you experience together? (clustering)
- Tell me about where/how you get information about how to manage your symptoms.
    - How do you feel about your ability to get the information you need?
    - Can you tell me about a recent example?
- How easy is it to understand the information you get about managing your symptoms?
    - Tell me a time when it was easy to understand information about managing a symptom.
    - Can you give me an example of information that you found difficult to understand?
- How do you decide what information you will use to manage a symptom?
- Tell me how confident you feel about your ability to manage your symptoms with the information you have.
- Tell me how well your symptoms are relieved by the actions you take.
- Think back to your appointments over the past 3 months. How would you describe the conversations you have with your oncology healthcare providers related to managing symptoms?
    - Tell me how you feel about asking questions to get more information and/or better understand the information you've received.
    - Can you give an example?
- Tell me about how talking with healthcare providers helps you manage symptoms.
    - Can you give an example?
- When you are at home, how do you know when to call your healthcare provider about a symptom?
- What would make it easier to talk with your provider about your symptoms?
- Do you have any advice for other patients related to obtaining or understanding information about symptom management? Making decisions about symptom management? Communicating with healthcare providers about symptom management?

  - Tell me about how your caregiver(s) is/are involved with obtaining and understanding information about symptom management.

- Do you have any suggestions for how the process of obtaining information and communicating with healthcare providers about symptom management could be improved?

Appendix A. Institutional Review Board New Study Approval Letter

UNIVERSITY of WISCONSIN
UWMILWAUKEE
Department of University Safety & Assurances

Melody Harries
IRB Administrator
Institutional Review Board
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
(414) 229-3182 *phone*
(414) 229-6729 *fax*

uwm.edu/irb
harries@uwm.edu

New Study – Notice of IRB Exempt Status

Date: December 30, 2019

To: Jeanne Erickson
Dept: Nursing

CC: Julie Campbell

IRB #: 20.141
Title: Managing Lung Cancer Symptoms

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been granted Exempt Status under Category 2 as governed by 45 CFR 46.104(d).

This protocol has been approved as exempt for three years and IRB approval will expire on December 29, 2022. Before the expiration date, you will receive an email explaining how to either keep the study open or close it. If the study is completed before the expiration date, you may notify the IRB by sending an email to irbinfo@uwm.edu with the study number and the status.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. The principal investigator is responsible for adhering to the policies and guidelines set forth by the UWM IRB, maintaining proper documentation of study records and promptly reporting to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

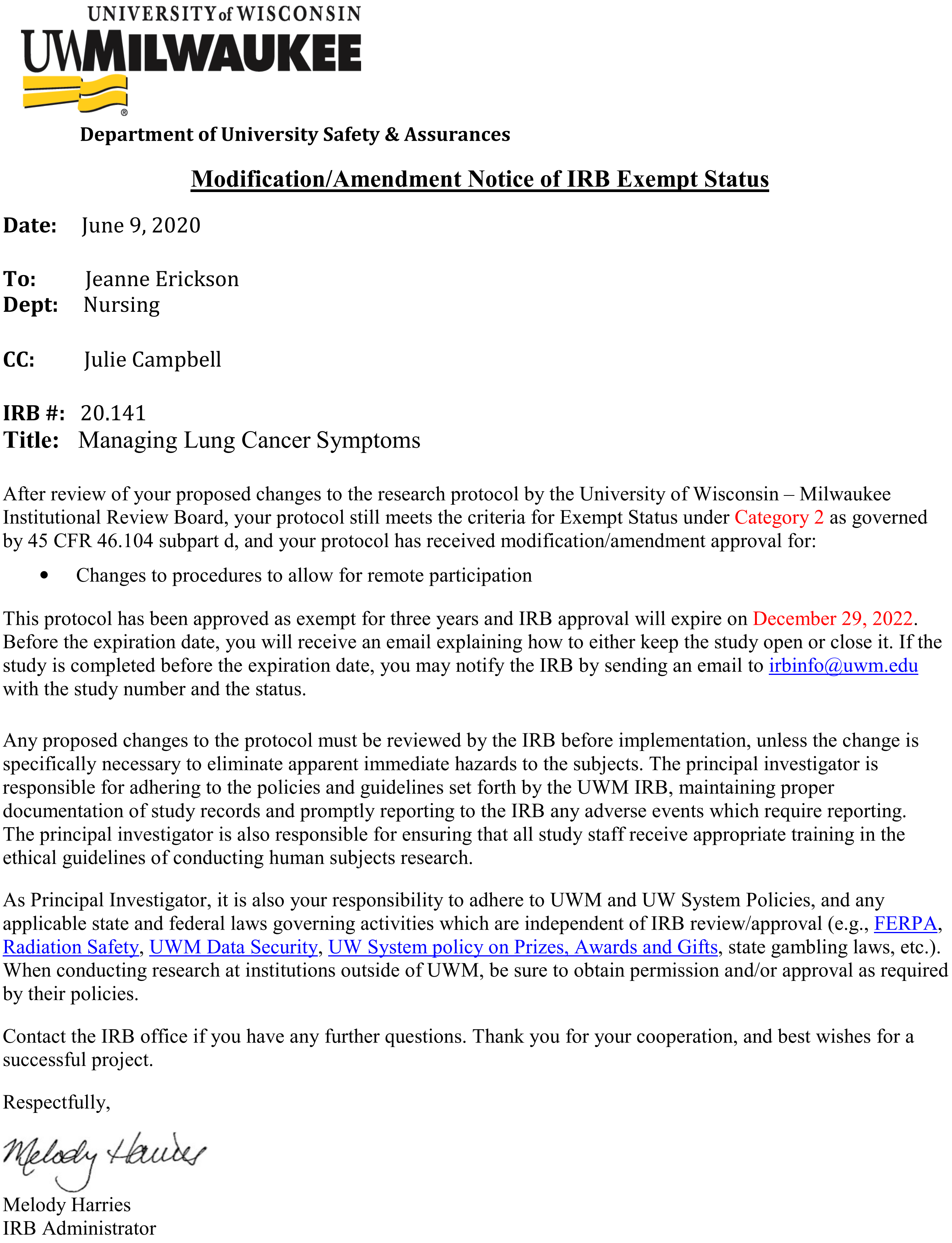
Contact the IRB office if you have any further questions. Thank you for your cooperation, and best wishes for a successful project.

Respectfully,

Melody Harries

Melody Harries
IRB Administrator

Appendix B. Institutional Review Board Amendment Approval Letter



UNIVERSITY of WISCONSIN
UWMILWAUKEE
Department of University Safety & Assurances

Modification/Amendment Notice of IRB Exempt Status

Date: June 9, 2020

To: Jeanne Erickson
Dept: Nursing

CC: Julie Campbell

IRB #: 20.141
Title: Managing Lung Cancer Symptoms

After review of your proposed changes to the research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol still meets the criteria for Exempt Status under Category 2 as governed by 45 CFR 46.104 subpart d, and your protocol has received modification/amendment approval for:

- Changes to procedures to allow for remote participation

This protocol has been approved as exempt for three years and IRB approval will expire on December 29, 2022. Before the expiration date, you will receive an email explaining how to either keep the study open or close it. If the study is completed before the expiration date, you may notify the IRB by sending an email to irbinfo@uwm.edu with the study number and the status.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. The principal investigator is responsible for adhering to the policies and guidelines set forth by the UWM IRB, maintaining proper documentation of study records and promptly reporting to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation, and best wishes for a successful project.

Respectfully,

Melody Harries

Melody Harries
IRB Administrator

Appendix C. Memorial Symptom Assessment Scale – Short Form[1]

Patient's Name ____________________________ Date ___/___/___ ID # ____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. <u>INSTRUCTIONS</u>: Below is a list of symptoms. If you had the symptom <u>DURING THE PAST WEEK</u>, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom DISTRESSED or BOTHERED you.

		➔➔ **<u>IF YES</u>: How much did it DISTRESS or BOTHER you?**				
Check *all* the symptoms you have had during the PAST WEEK.	**Yes [✓]**	**Not at All [0]**	**A little Bit [1]**	**Somewhat [2]**	**Quite a Bit [3]**	**Very Much [4]**
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						

Weight loss					

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[1] From *Memorial Symptom Assessment Scale Short Form (MSAS-SF)*, by V. T. Chang, S. S. Hwang, M. Feuerman, B. S. Kasimis, and H. T. Thaler, 2000. Measurement Instrument Database for the Social Sciences, 2013 (https://www.midss.org/content/memorial-symptom assesement-scale-%E2%80%93-short-form-msas-sf#:~:text=The%20Memorial%20Symptom%20Assessment%20Scale%20%E2%80%93%20Short%20Form%20(MSAS%2DSF,multidimensional%20symptoms%20experienced%20by%20patients). CC BY-NC 3.0.

Patient's Name ________________________ Date __/__/__ ID # ___

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. <u>INSTRUCTIONS:</u> Below is a list of symptoms. If you had the symptom <u>DURING THE PAST WEEK</u>, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom DISTRESSED or BOTHERED you.

		➔➔ <u>IF YES</u>: How much did it DISTRESS or BOTHER you?				
Check *all* the symptoms you have had during the PAST WEEK.	**Yes [✓]**	**Not at All [0]**	**A little Bit [1]**	**Some-what [2]**	**Quite a Bit [3]**	**Very Much [4]**
Hair loss						
Constipation						
Swelling of arms or legs						
"I don't look like myself"						
If you had <u>any other symptoms</u> during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you. 1. ______________						
2.______________						

II. Below are other commonly listed symptoms. Please indicate if you have had the symptom DURING THE PAST WEEK, and if so, how OFTEN it occurred.

		➔ ➔ <u>IF YES</u>, How OFTEN did it occur?			
Check *all* the symptoms you have had during the PAST WEEK	**Yes [✓]**	**Rarely [1]**	**Occasionally [2]**	**Frequently [3]**	**Almost Constantly [4]**
Feeling sad					
Worrying					

Feeling irritable				
Feeling nervous				

Appendix D. MSAS-SF Scoring Information

Memorial Symptom Assessment Scale Subscales

The scoring of the MSAS yields several validated subscale scores.

A 10 item MSAS **Global Distress Index** (MSAS-GDI) is considered to be a measure of overall symptom distress. The GDI is the average of the frequency of 4 prevalent psychological symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and the distress associated with 6 prevalent physical symptoms (lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth).

The **Physical Symptom Subscale** score (MSAS-PHYS) is the average of the frequency, severity and distress associated with 12 prevalent physical symptoms: lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness.

The **Psychological Symptom Subscale** score (MSAS-PSYCH) is the average of the frequency, severity and distress associated with 6 prevalent psychological symptoms: worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating.

The **Total MSAS score** (TMSAS) is the average of the symptom scores of all 32 symptoms in the MSAS instrument. Each symptom score is an average of its dimensions.

In the short form, there is only one dimension for each symptom, distress for physical symptoms and frequency for psychological symptoms.

Memorial Symptom Assessment Scale Short Form Subscales

The scoring of the MSAS-SF yields several validated subscale scores.

A 10 item MSAS **Global Distress Index** (MSAS-GDI) is considered to be a measure of overall symptom distress. The **GDI** is the average of the frequency of 4 prevalent psychological symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and the distress associated with 6 prevalent physical symptoms (lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth).

MSAS SF GDI = (feeling sad, worrying, feeling irritable, feeling nervous, lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth)/10

The **Physical Symptom Subscale** score (MSAS-PHYS) is the average of the distress associated with 12 prevalent physical symptoms: lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness. Note that the scaling is in increments of 0.8, with zero for no symptom, 0.8 for symptom present but no distress, and upwards for increasing levels of distress.

MSAS SF PHYS = (lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness) / 12

The **Psychological Symptom Subscale** score (MSAS-PSYCH) is the average of the frequency associated with 6 prevalent psychological symptoms: worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating. Scoring is in increments of one, with zero for no symptom to 4 for “almost constantly”.

MSAS SF PSYCH = (worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating)/6

The **Total MSAS score** (TMSAS) is the average of the symptom scores of all 32 symptoms in the MSAS instrument.

In the short form, there is only one dimension for each symptom, distress for physical symptoms and frequency for psychological symptoms. The sequence of symptoms in the short form is different from that in the long form.

Scoring of physical symptoms in the MSAS-SF is as follows:

Zero	if the symptom is not present
0.8	if the symptom is present but causes no distress
1.6	if the symptom is present and causes a little bit of distress
2.4	if the symptom is present and causes somewhat of distress
3.2	if the symptom is present and causes quite a bit of distress
4.0	if the symptom is present and causes very much distress.

Scoring of psychological symptoms is:

0	if the symptom is absent
1	if the symptom is present and occurs rarely
2	if the symptom is present and occurs occasionally
3	if the symptom is present and occurs frequently
4	if the symptom is present and occurs almost constantly

Findings

Interactive Health Literacy and Symptom Self-Management in Lung Cancer: A Critical Realist Analysis

Abstract

Patients with lung cancer experience multiple symptoms requiring self-management. Health literacy skills are necessary for obtaining and processing information related to symptom self-management. Interactive health literacy involves communicating with healthcare providers regarding health-related information, but the role of interactive health literacy in self-management is not clear. This study used a critical realist approach to describe the interactive health literacy of patients with lung cancer, by exploring their experience of communicating with oncology providers about symptom self-management. The sample included 12 adults who were currently receiving treatment for lung cancer, or had received treatment within the past six months. Data collection included a demographic questionnaire, a health literacy assessment, and semi-structure individual interviews. Data analysis followed a critical realist methodology aimed at discovering patterns that explain how complex phenomena manifest in patient experiences. Findings identified the relationship between patients with lung cancer and their oncology providers as a generative mechanism for obtaining symptom management information and establishing its credibility. There are both structural and agential factors that impact patients' access to and engagement in relationships with providers. Additional research is needed to determine patient-centered strategies that address these factors to promote collaborative patient-provider relationships and effective symptom self-management.

Introduction

Lung cancer is the leading cause of cancer-related mortality in the U.S. It is one of the most frequently diagnosed types of cancer for both males and females in the U.S., yet its five-year relative survival rate is only 20.5% (National Cancer Institute, 2020). The majority of patients with lung cancer experience significant physical and psychological symptoms that can be quite distressing, such as dyspnea, loss of appetite, pain, coughing, fatigue, anxiety, and sleep issues (Iyer, Roughley, Rider, & Taylor-Stokes, 2014; Walker et al., 2017). In addition, patients are at risk of suffering from multiple treatment-related side effects (Wong et al., 2017). It is not uncommon for treatment to palliate some symptoms, such as cough and pain, while at the same time exacerbating other symptoms, such as anorexia and fatigue.

Strategies needed by patients to self-manage their high symptom burden of lung cancer are often complex. Broadly speaking, self-management is a process that involves confidence in taking action to incorporate behaviors that are necessary to manage complex health conditions into one's daily life (Moore et al., 2016). Determining appropriate self-management strategies requires health literacy, defined by Nutbeam (2000) as skills across three dimensions: functional, interactive and critical. Functional health literacy is similar to general literacy, which are the foundational skills required for reading health-related information and completing forms. Interactive (or communicative) health literacy refers to the cognitive and social communication skills used to extract meaning from health information. Critical health literacy involves critical analysis of health information for one's own situation or circumstances (Nutbeam, 2000).

There is relatively little evidence of how symptom self-management and health literacy are related. Most research examining the link between health literacy and self-management focuses on functional health literacy skills, and the inconsistent results of these studies highlights the need to adopt a more comprehensive approach to health literacy (Alsomali, Vines, Stein, & Becker, 2017; Geboers et al., 2015; Geboers et al., 2016; Kim & Lee, 2016; McCleary-Jones, 2011). In fact, studies show that interactive health literacy is correlated with self-management and confidence in healthcare interactions (Heijmans et al., 2015), and effective patient-provider communication (Inoue et al., 2013). Furthermore, patients identify interactive communication with providers as a facilitator to self-management, citing the importance of collaborative relationships with healthcare providers characterized by open and supportive communication about how to apply knowledge to their own situation (Schulman-Green, Jaser, Park, & Whittemore, 2015).

With this evidence in mind, additional research is needed to understand the role of interactive health literacy in communicating with providers about the self-management of complex diseases with high symptom burden, such as lung cancer. The aim of this study was to use a critical realism approach to describe patients' experiences of interacting with healthcare providers regarding symptom self-management for lung cancer. Critical realism is a philosophical framework that has been developed into an innovative methodology, which is beneficial for the study of multidimensional phenomena (Danermark et al., 2002). Critical realists acknowledge that individual experience must be understood in the context of one's environment. Events are precipitated by the interaction between personal agency, comprised of attitudes, beliefs, values, and decisions, and structures created by one's location in time and space, along with social, cultural, economic, and political influences. The goal of critical realist inquiry is to identify patterns that point to unrecognized mechanisms, which can explain the connections between structural and agential factors and their influence on how phenomena are experienced and observed (Danermark et al, 2002). The data collected in this study were also analyzed to explore how interactive health literacy might be integrated into an existing self-management theory; those findings are reported in a separate manuscript (Campbell, TBD).

Methods

Design and Sample

This cross-sectional study is based on critical realist methodology, using both quantitative and qualitative data to explore interactive health literacy, symptom self-management, and interactions with healthcare providers. Initially, participants were recruited from a small free-standing radiation oncology clinic in a southeastern state of the U.S. Due to restrictions related to the COVID-19 pandemic in 2020, recruitment procedures were shifted to be virtual, and participants were recruited from virtual support groups for patients with lung cancer and their families. Individuals were eligible for participation if they were 18 years of age or older and currently receiving or had received pharmaceutical and/or radiation treatment for lung cancer within the past six months. Potential participants were excluded if they were not fluent in verbal and/or written English, or if they had a cognitive or communication impairment limiting their ability for recall, interaction with healthcare providers, or ability to perform self-management activities. The study was approved by the Institutional Review Board (IRB) at University of Wisconsin-Milwaukee (UWM). Leaders in the radiation oncology clinic and the organization that hosted the virtual support groups reviewed the IRB protocol and endorsed UWM's approval.

Data Collection

After signing the informed consent either on paper or electronically, participants completed a self-report demographic questionnaire and the All Aspects of Health Literacy Scale (AAHLS). The AAHLS is a newly developed self-report tool based on Nutbeam's health literacy framework, with three questions assessing functional health literacy, three assessing interactive (communicative) health literacy, and seven assessing critical health literacy. Most items use a 3-point Likert scale with possible responses of “often” (3 points), “sometimes” (2 points), and “rarely” (1 point). The interactive health literacy (IHL) subscale has demonstrated good reliability (Chinn & McCarthy, 2013) and was used in this study, with a score of 9 indicating high IHL, 6-8 indicating moderate IHL, and 5 or less indicating low IHL. Symptom data was collected quantitatively using the Memorial Symptom Assessment Scale-Short Form, a valid and reliable tool that measures frequency and distress of 32 symptoms commonly caused by cancer (Aktas, Walsh, & Kirkova, 2015; Chang et al., 2000).

Once each participant completed the quantitative surveys, an audio-recorded semi-structured interview was conducted to explore individual experiences related to interactive health literacy and symptom self-management. The interview guide was based on Nutbeam’s conceptualization of interactive health literacy, as well as concepts related to self-management. Questions addressed participants’ need for and experience with obtaining and processing information related to symptom self-management, with special attention to interactions with healthcare providers.

Data Analysis

Data analysis followed the critical realist model outlined by Danermark et al. (2002). First, quantitative data from the surveys were summarized using descriptive statistics and examined for trends. Qualitative data from transcribed individual interviews were read twice, and then common themes expressed by participants were entered as codes into NVivo. Data were then re-categorized under a priori codes derived from Nutbeam’s framework, self-management concepts, and critical realist concepts of structure and agency. Next, qualitative and quantitative data about health literacy and symptom management were synthesized to identify less obvious connections and re-describe participant experiences. Coding categories were added, changed and eliminated to situate participant experiences within particular contexts, leading to the discovery of generative mechanisms through deeper analysis of issues related to structure and agency within the data. A concept map was developed to illustrate connections between structural and agential factors. Finally, possible generative mechanisms were applied to the data to determine which mechanism best explained the relationship between interactive health literacy and symptom self-management as it was observed during this study. The proposed generative mechanism was checked by a content expert and presented back to some of the participants for validation.

Results

Participant Characteristics

A total of 16 potential participants were recruited; three were lost to follow up (one at the outpatient radiation clinic and two from support groups), and one was ineligible due to a delay in starting treatment. The final sample included 12 adults aged 48 to 73 years old (mean age 58.33 years) who were currently receiving or had received pharmaceutical and/or radiation treatment for lung cancer within the past six months. One participant was from the outpatient radiation clinic, and seven participants were recruited from support groups based in North Carolina (n=6) and Florida (n=1). Three participants were recruited from a virtual support group with members in various states (n=3), and one participant was referred to the study from a support group facilitator. Most of the participants were female (n=9/12; 75%), White (n=11/12; 91.67%), and had at least an associate degree or some college (n=10/12; 83.33%). The mean score on the AAHLS interactive health literacy subscale was 8.27 (range 6-9), with eight participants (67%) scoring high, and four participants (33%) scoring moderate. On the quantitative symptom assessment tool, the most commonly reported symptoms were lack of energy, feeling drowsy, and worrying. Priority symptoms identified by participants during qualitative interviews included fatigue, fevers and flu-like symptoms, nausea and vomiting, rashes, eye problems, hair thinning, and weight loss.

Symptom Experience

During individual interviews, participants described experiencing multiple symptoms at once.

> "I had a lot of nausea and vomiting and headaches and constipation and diarrhea, just I didn't have one. I had the other." (Participant #4, 60 y/o female, IHL<9)

> "It [targeted therapy] does make me a little tireder than I might have been. It also affects my nails. They just get really sore, and don't grow right. But it's not all my nails. It's just my right thumb, and my index finger on my left hand, and then my big toe on the right side. And the one on my thumb can get really painful sometimes…it also affects my stomach a little bit." (Participant #12, 68 y/o female, IHL9)

Participants also expressed difficulty with managing certain symptoms, such as fatigue and flu-like symptoms.

> "Well, in specific to fatigue, it has been an uphill battle. Honestly since 2018. I had a couple of events that really took some of the punch out of me, and it's been very difficult to get back to what I would consider a good baseline for me." (Participant #6, 50 y/o female, IHL9)

> "And I had the severe fever, 104, 105. Chills, body aches, headaches, I could not get warm. I had a fireplace in my bedroom and that would be going, electric blanket on high. I had one of those heated pillows or blankets, and I just always was so cold." (Participant #3, 51 y/o female, IHL9)

Obtaining and Processing Symptom Management Information

Three themes were identified from participant responses to interview questions about obtaining and processing symptom management information: 1) patients access symptom management information from many different sources with varying credibility; 2) IHL plays a role in how patients perceive access to oncology providers for obtaining and processing symptom management information; and 3) there are differences in how participants with high and moderate IHL engage with oncology providers regarding symptom management. After analyzing the data from a critical realist approach, these themes were organized into *Structure: Access to symptom management information from multiple sources*, *Structure: Access to oncology providers to discuss symptom management*, and *Agency: Engagement with oncology providers.* Differences were identified in the experiences of participants with high IHL in comparison to participants with lower IHL. Select quotes are included below as examples illustrating common perspectives among each group of participants. Those with high interactive health literacy are labeled as IHL9, and those with lower interactive health literacy are labeled as IHL<9.

Structure: Access to symptom management information from multiple sources.

A key finding was the recognition that there is a vast amount of information available, especially through web-based sources, such as social media outlets, patient support organizations, online discussion forums, and general Internet searches.

> “Well, let's see. There's multiple. So, I would go to, like a Facebook group for lung cancer and the group would depend on the symptoms or the treatment that I'm on. Also, I would go to places like American Lung Association, Lungevity, Inspire. And then, obviously my doctor.” (Participant #2, 51 y/o female, IHL9)

> “I'm a part of [a social media-based patient group]. And all kinds of questions and suggestions are given there. I have spoken with the nutritionist at the cancer center. What? At least two, maybe three times. And of course, ask any and everybody that I talked to I have come into contact with or whatever. How do you gain weight?” (Participant #10, 67 y/o female, IHL<9)

Participants also identified family and friends as a source of information regarding symptoms and how to manage them.

“And my daughter reads up about a lot of this stuff. She tells me what she hears what

> other people were on Tagrisso, so, what they experienced…" (Participant #12, 68 y/o female, IHL9)

> "My brother-in-law even researched and figured out what to buy. And he surprised me and had it sent here to help relieve the symptoms." (Participant #8, 48 y/o female, IHL<9)

> "My friend put me in touch with a doctor friend of his and he's been nothing but amazing. Sending me all kinds of stuff. Saying look, if your fever doesn't go well, here's some other things that you're looking at." (Participant #9, 56 y/o male, IHL9)

Several participants noted that the wide variety of sources can create challenges in determining the quality of symptom management information.

> "Because you don't always trust. I guess if you see it over and over and over again, then you will. But then sometimes I don't know. I'm not going to say negative, but I just don't always believe everything you see on the computer, the Internet, maybe more from the books I have." (Participant #8, 48 y/o female, IHL<9)

> "We all know that you can find whatever you want on the internet, so I try to stay away from there." (Participant #7, 55 y/o male, IHL9)

Structure: Access to oncology providers to discuss symptom management.

Participants with high IHL noted access to oncology providers as a primary source of symptom management information. These participants described overall satisfaction with their interactions with providers, with some highlighting multiple methods of access:

> "[My oncologist] has the best nurse…I have called her with stuff that I thought, uh and you're going to yell at me this time. But it was…she said, look, you never have to apologize for calling us…I'll tell you, [my oncologist] has called me at 4:50 in the afternoon on a Friday because I had a question." (Participant #9, 56 y/o male, IHL9)

> "But even now, like if I ask a question to the oncology infusion nurse, they oftentimes have a little pointer that they've learned. So, that's kind of helpful." (Participant #3, 51 y/o female, IHL9)

> "I have several ways that I can get the answers. I can email my [oncologist] through [patient portal] website. I can call and leave a message and they will get back with me as soon as they can speak to the doctor." (Participant #7, 55 y/o male, IHL9)

On the other hand, participants with lower IHL reported less satisfaction with the quality of provider interactions related to symptoms. Dissatisfaction was sometimes attributed to lack of time during the appointment or lack of individualized answers:

> “I’ve tried to find out what more of symptoms to the radiation and chemo is going to be because they don’t explain it as good as they should.” (Participant #1, 66 y/o female, IHL<9)
>
> “Like [the nurse] has a paper and they're basically just telling me this, this, this and this. But then the other nurse I feel does really try and help you and maybe give you little tips that other people have told her will help, or that would work for her. So it depends who I'm with out of the two of them…sometimes…it's almost like quick, in and out, this, that. Here's your blood work and I'll see you next time. So it's -- you try and then you leave there and you're like, oh, my gosh, I didn't even get to answer after she left. But I have no problem going back on and emailing in the portal. I don't, just to have my questions answered.” (Participant #8, 48 y/o female, IHL<9)
>
> “Sometimes I feel like the answers I get are just book answers rather than answers specific to me. I just feel like I am just a number. Just another one who's going through this same thing.” (Participant #10, 67 y/o female, IHL<9)

Agency: Engagement with oncology providers about symptom management.

Participants with high IHL emphasized communication with their primary oncologist as a foundation for symptom self-management, particularly as a source of credible symptom management information.

> “I talk to my doctor about it. Because another thing that happened earlier when I was taking the medicine, I would break out on my face, and he gave me some cream to put on it. And it helps. If I get a breakout, I put that on and it clears it up.” (Participant #12, 68 y/o female, IHL9)
>
> “Well, when I find the new symptom and I do the research on it, I always take it right back to my doctor because there's good and bad information everywhere. So that's how I start… I don't just do things on my own. I do the research but then I always work with my doctor.” (Participant #2, 51 y/o female, IHL9)

For some participants with high IHL, active engagement with oncology providers resulted in collaborative decision-making about symptom management strategies:

> "With my fatigue my psychiatrist, he prescribes my medication for fatigue and also my sleep medicine. And he's given me the choice of adjusting my dose as I see fit according to how I feel and what I have scheduled for the day." (Participant #6, 50 y/o female, IHL9)

These statements are in contrast to participants with lower IHL, who tended to utilize alternative sources for finding and verifying symptom management information rather than focusing on active engagement with their oncologist:

> "A lot is looking it up, reading. I do have a lot of books that when I first was diagnosed, I mean I do ask my doctor, but I don't know. I feel like I get more information, more in depth information researching on my own or reaching out to maybe one of the groups… it has to seem realistic, not crazy and far because some things are. Some things are very farfetched and crazy. I do try and find it in another spot or two again. I do try and even find possibly a reputable place or a hospital's website or something that you can just rely on a little more. I mean, that doesn't always happen, but I try. I try." (Participant #8, 48 y/o female, IHL<9)

Participants with lower IHL described experiencing difficulty with determining effective symptom management strategies on their own:

> "I have been just reading online and talking to other people. That's what I do…I don't fully understand how this cancer effects weight loss. I don't understand what it is about it that prevents my body from gaining weight or keeping weight...I'm still looking. I just don't understand it. I don't." (Participant #10, 67 y/o female, IHL<9)

> "The headaches…nothing helps. I'm not supposed to take ibuprofen. Tylenol just doesn't do it. Those I just lived with, the headaches I mean." (Participant #4, 60 y/o female, IHL<9)

While participants in both groups expressed some level of comfort with asking oncology providers questions when additional symptom management information was needed, several participants with high IHL recognized that longer experience with symptom self-management reduced the need to contact the oncologist:

> “I guess it [knowing when to contact provider] would be gut feeling, but I haven't had to for a long time since chemo, mainly chemo. So that's been three years. I really, except for my fingers [side effect from current treatment]. And then I did actually went in so they can see me.” (Participant #11, 73 y/o female, IHL9)

> “At first you’re probably telling a lot of the doctors, ‘Oh, I got this. I got that.’ And you know, a lot of patients do that. But I think over time when you can be a little bit more veteran, that's just the new normal.” (Participant #5, 55 y/o male, IHL9).

Discussion

In this study the symptom burden experienced by participants was high, as is expected with lung cancer (Bircan et al., 2020). Participants expressed difficulty with managing certain symptoms, particularly when trying to self-manage multiple symptoms at once. Concurrent symptoms, or symptom clusters, are common in patients with lung cancer and are associated with reduced functional status and quality of life (Henoch & Lövgren, 2014; Maguire et al., 2014; Walker et al., 2017; Wong et al., 2017). Traditionally, oncology providers have addressed symptoms individually, which can increase the demand on patients to implement complex self-management routines comprising several different strategies (Kwekkeboom, 2016). There is growing evidence supporting the development of interventions that relieve concurrent symptoms; additional research in this area has the potential to reduce the burden on patients and improve self-management effectiveness (Kwekkeboom et al., 2020).

One of the aims of critical realist inquiry is to identify the underlying powers and liabilities of social structures that act as either barriers or facilitators for how the structure is actualized in observable situations. Understanding powers and liabilities leads to the discovery of generative mechanisms of complex phenomena (Danermark et al., 2002). This study explored participants’ experiences of IHL and lung cancer symptom self-management and found three themes: 1) patients access symptom management information from a wide range of sources, which may vary in credibility; 2) IHL plays a role in how patients perceive access to oncology providers for obtaining and processing symptom management information; and 3) there are differences in how participants with high and moderate IHL engage with oncology providers regarding symptom management. Access to multiple sources of symptom management information was a power for participants with high IHL and a liability for participants with lower IHL. The nature of the relationship between participants and their oncology providers was a generative mechanism for obtaining and processing symptom management information.

In this study, the availability of multiple sources of symptom management information was a power in the context of high IHL and a liability for those with lower IHL. Participants with high IHL who accessed information online used this information as a basis for discussion with their oncology provider about potential symptom management strategies. Because of their engagement in the patient-provider relationship, these participants tended to rely on their provider for checking the credibility of online information. In some cases, they simply avoided searching for information online because they were comfortable with the amount and quality of information they were able to obtain through access to their oncology provider. On the other hand, participants with lower IHL in this study did not prioritize reaching out to their provider to obtain symptom management information or process the credibility of information found online. For some of these participants, websites, discussion forums and social media were their primary sources of information. Lack of engagement in the patient-provider relationship often left participants with lower IHL to figure out symptom management on their own. Thus, the patient-provider relationship represented an underlying mechanism that impacted how participants obtained and processed symptom management information.

The nature of the patient-provider relationship is influenced by both structural constraints and agential characteristics. Specifically, the optimal relationship is characterized by the patient actively engaging with the provider (agency), and the provider facilitating patient access to quality interactions and helpful information about symptom management (structure).

Participants' active engagement with oncology providers (agency) was shaped at least in part by their IHL. A higher level of IHL presumes the patient has the necessary cognitive and social skills to engage with providers. Participants with high IHL demonstrated these skills through asking questions of providers when information was needed for symptom self-management. Evidence indicates that patients do not always discuss symptoms with providers, even when dealing with disease that are known to cause high symptom burden and distress (Penalba, Deshields, & Klinkenberg, 2019). In some cases, patients are hesitant to report cancer-related symptoms to providers due to uncertainty about whether symptoms are manageable, if symptom management should be a priority during oncology appointments, and how the provider will response to symptom complaints (Schulman-Green, 2015; Turner et al., 2017). It is important for studies that examine engagement with providers to also address IHL, in order to clarify connections between these phenomena. A better understanding of these agential characteristics will inform interventions that assist patients with improving active participation in symptom management, such as question prompt lists that facilitate information exchange between patients and providers during oncology appointments (Barton et al., 2020).

Access to quality interactions with the oncology provider (structure) was influenced by time allowed during appointments, personalized answers to patient questions, and multiple methods of contacting providers between appointments (e.g., phone calls, patient portal through the electronic health record). Previous studies have demonstrated that patients want oncology providers to take adequate time to listen to their concerns and provide information specific to the their personal situation regarding what to expect, how to manage symptoms, and how and when to contact providers (Fitch et al., 2020; Turner et al., 2017). Patient-centered care, which has been a priority in the U.S. healthcare system for the past two decades, recognizes the responsibility of providers to foster patient engagement through attending to patients' needs and promoting quality patient-provider communication (Institute of Medicine, 2001). Asking patients about symptom experience, informational needs, and preferences for symptom management are patient-centered care strategies that may enable self-management and improve quality outcomes (Odai-Afotey, Kliss, Hafler, & Sanft, 2020; Turner et al., 2017). Patients trust providers' expert guidance on symptom management and finding credible information and may gain confidence in self-management through interactions with providers (Dwarswaard, Bakker, van Staa, & Boeije, 2015). Self-management frameworks often address patient-provider interactions as a component of self-management. The findings of this study indicate that provider characteristics are a key underlying structure that impact patient experience with symptom self-management and interactive health literacy. Structural factors such as the availability and willingness of providers to promote patient engagement could be incorporated into existing self-management frameworks to strengthen their description of patients' experiences with self-management.

The patient's perception of provider availability and responsiveness was especially notable for patients who have lower IHL. Patients with lower IHL may have inherent disadvantages due to lower cognitive and social abilities for engaging in collaboration with providers, which highlights an important implication for practice. It is vital for oncology providers to have increased awareness of patients' IHL skills and to meet the social facilitation needs of patients with lower IHL (McKenna, Sixsmith, & Barry, 2017). Provider training directed toward communication skills is a valuable approach to mitigating health literacy disparities and improving patient-provider interactions. For instance, the COMFORT Communication Model has been shown to assist providers with developing skills and confidence in effective health literacy-sensitive communication with patients and promote patient-centered care (Goldsmith, Wittenberg, & Parnell, 2020; Wittenberg et al., 2019). Furthermore, perhaps structural changes at both the broader system level and the individual provider level are keys to enabling individuals with lower IHL to feel more empowered in their abilities to collaborate with providers, thus improving symptom self-management. Structural changes could consist of ensuring adequate appointment time, encouraging questions, and checking for understanding (Fitch et al., 2020). Another potential strategy includes collaboration with oncology nurse navigators who can provide expert guidance and informational support to patients throughout the cancer trajectory (Yackzan et al., 2019). Future research efforts should seek to determine if these interventions improve patients' IHL and engagement with providers and lead to improved outcomes, such as improved symptom management, improved quality of live, and more efficient use of health care services.

Importantly, Internet access can be a structural constraint that affects whether a patient can utilize a patient portal, as well as patient discussion forums, social media groups, hospital websites, and other online health organizations and resources. This raises an important implication for practice, in that patients who do not have Internet access are limited in their ability to obtain certain types of information, and in their ability to engage with providers outside of scheduled appointments and phone calls (Norman & Skinner, 2006). In today's digital age, practitioners must avoid assuming that all patients have equitable access to electronic forms of communication and that patients can make sense of and use online information. Furthermore, lack of Internet access compounds the disadvantages that patients with lower IHL already face in obtaining and processing symptom management information. The concept of eHealth literacy, which refers to skills in obtaining and processing information from electronic sources (Cooley et al., 2017), is gaining attention in health literacy research. Additional research is needed to identify how eHealth literacy influences patient-provider collaboration toward symptom self-management in lung cancer. Specifically, the design and implementation of patient portals as a means of patient-provider collaboration must consider how health literacy and socioeconomic factors impact and perhaps even widen disparities in health care access and utilization (Coughlin et al., 2018).

A limitation of this study was its small and relatively homogeneous sample. All participants had moderate or high interactive health literacy, all but one were actively engaged in support groups, and all spoke English as their primary language. Patients for whom English is not their first language may face additional communication barriers due to limited English proficiency, which will likely have a significant impact on IHL and engagement with healthcare providers. The complex nature of cancer-related information compounds the communication barriers for these patients. There is a dire need for research focused on patients with limited English proficiency and how it affects health literacy and communication with providers, particularly related to symptom self-management, and ultimately, cancer outcomes.

Although this study involved a small homogeneous sample, its findings provide insight into the relationship between IHL and symptom self-management for patients with lung cancer. The findings of this study provide evidence that the concept of IHL plays an important role in self-management, both in terms of patients' personal agency and the structural environment created by oncology providers. Additional research may help determine if the comprehensive concept of health literacy (functional, interactive, and critical) should be explicitly incorporated into self-management frameworks. Further research is also needed to clarify the direction of the relationship between patient IHL skills and engagement with oncology providers. In other words, does high patient IHL improve the patient-provider relationship and symptom self-management behaviors, or does a better patient-provider relationship improve patient IHL, thus improving symptom self-management behaviors?

Conclusion

This study identified the patient-provider relationship as a key mechanism that influences how patients with lung cancer obtain and process symptom management information. While interactive health literacy and self-efficacy for communicating with providers are important patient characteristics, it is essential for researchers and clinicians to address structures at the provider and the organizational level that influence symptom self-management. Patient-centered care strategies that address health literacy and promote patient engagement should be considered as a guide for developing effective interventions in oncology clinical settings. In addition, research should aim to clarify the connections between interactive health literacy and patient-provider relationships and their impact on self-management outcomes.

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The Role of Interactive Health Literacy in Symptom Self-Management for Lung Cancer: Implications for the Individual and Family Self-Management Theory

Abstract

Background: Patients with lung cancer experience multiple symptoms requiring self-management. There is a need for evidence regarding how self-management is influenced by interactive health literacy, which involves communicating with healthcare providers to obtain and process information.

Objective: This study explored how interactive health literacy relates to symptom self-management for patients with lung cancer, and how interactive health literacy might be integrated into the Individual and Family Self-Management Theory.

Interventions/Methods: A cross-sectional, exploratory, mixed methods design was used. Quantitative data included demographics, the All Aspects of Health Literacy Scale, and the Memorial Symptom Assessment-Short Form. Qualitative data were collected through audio-recorded semi-structured interviews.

Results: Twelve adults who were currently receiving or had recently received treatment for lung cancer reported an average of 14 symptoms, with moderate global distress index (mean 1.52; range 0-4). Mean interactive health literacy was moderate (8.33; range 6-9) with 67% of participants in the high range. Participant experiences with the self-management process differed based on interactive health literacy scores.

Conclusion: Interactive health literacy skills may play a role in patients' ability and confidence to obtain and process symptom management information through interaction with oncology providers. Further research should clarify connections between interactive health literacy, self-efficacy, collaboration with oncology providers, and caregiver involvement.

Impact: This study identified the importance of patients' interactive health literacy when engaging with oncology providers regarding symptom self-management. This research has implications for oncology providers who need to implement patient-centered strategies that facilitate patient engagement in collaboration toward effective self-management of lung cancer symptoms.

Introduction

Over the past decade, the U.S. healthcare system has promoted patient-centered care, in which patients are expected and encouraged to actively engage in self-management of illness in an effort to improve health outcomes while reducing healthcare spending.[1] Self-management requires a number of health literacy skills, such as reading, writing, numeracy, communication, decision-making, and navigation of the healthcare system.[2] The importance of health literacy and self-management of illness is particularly salient for patients with serious life-limiting illnesses, such as lung cancer. A diagnosis of lung cancer is overwhelming for patients and their caregivers, with low survival statistics, daunting treatment decisions, and a high burden of disease symptoms and treatment-related side effects. Without effective self-management of their symptoms, patients with lung cancer often face reduced quality of life and unnecessary healthcare costs.[3-7] Research is needed to explore how health literacy is related to symptom self-management for patients with lung cancer, in order to inform nursing interventions that facilitate effective self-management in patients and improve quality of life.

Health literacy is conceptualized by Nutbeam in three dimensions: functional, interactive (or communicative), and critical.[8] Functional health literacy (FHL) refers to general literacy skills that are required for basic healthcare tasks, such as reading written instructions and completing health-related forms. Interactive health literacy (IHL) is defined as cognitive and social skills for actively engaging in health communication, including motivation and confidence to act on information received through communication. Critical health literacy includes advanced skills to analyze and apply information as a means to gain control over one's health.[8]

There are multiple theories that describe self-management, one of which is the Individual and Family Self-Management Theory (IFSMT), a mid-range nursing theory that explains how patients engage in the process of self-management. The IFSMT conceptualizes self-management as a multidimensional and dynamic process in which individuals intentionally adopt health-related behaviors as part of their daily functions.[9] In the IFSMT, self-management is comprised of context, process and outcome concepts (Figure 1). Contextual factors consist of risk and protective factors, such as complexity of the condition, access to health care, and literacy, which interact with each other and influence both the self-management process and outcomes. The self-management process involves knowledge and beliefs, self-regulation skills and abilities, and social facilitation from caregivers and healthcare providers. Based on the tenets of the IFSMT, individuals are more likely to engage in the self-management process when they have factual information, and when their beliefs are congruent with the behavior. These aspects of knowledge and beliefs may impact self-efficacy. Self-regulation skills include goal-setting, self-monitoring, reflective thinking, decision-making, planning and action, and self-evaluation. Social facilitation supports self-management through informational support, social influence, and negotiated collaboration between patients and healthcare providers. Outcomes of self-management can be proximal, such as engagement in prescribed regimens and symptom management behaviors, and/or distal, including stabilization of the condition, quality of life, and reduced health-related costs. Interventions to improve self-management can be focused on either the context or the process dimension of the IFSMT, or both.[9] This study focuses on self-management of symptoms as opposed to self-management of a disease such as diabetes. Symptom self-management is a specific area of self-management defined as “a dynamic, self-directed process of implementing behaviors that recognize, prevent, relieve or decrease the timing (frequency, duration, occurrence), intensity, distress, concurrence, and unpleasant quality from symptoms to achieve optimal performance outcomes.”[10(p19)]

Nutbeam's concept of interactive health literacy seems to align with elements of the IFSMT's process dimension, specifically in terms of knowledge and beliefs, self-efficacy and social facilitation of self-management.[8] The cognitive skills involved in interactive health literacy may play a role in how individuals obtain and process self-management information, their confidence in engaging in these tasks (i.e., self-efficacy), as well as beliefs about self-management behaviors. The social skills involved in interactive health literacy may be reflected in social facilitation of self-management, which recognizes the role of relationships in the self-management process and is comprised of social influence, social support and negotiated collaboration. Social influence occurs when a person with perceived authority and expertise (e.g., a healthcare provider) delivers information to an individual or family in an effort to encourage specific health behaviors. Social support involves emotional, instrumental, or informational support directed at facilitating health behaviors. Negotiated collaboration refers to the mutual respect of individual, family, and healthcare professional perspectives, allowing each to influence goals.[9]

Studying IHL and how it fits with a self-management framework such as the IFSMT offers a potential strategy for developing effective self-management interventions that focus specifically on IHL. The primary aim of this study was to explore how IHL relates to symptom self-management for patients with lung cancer. A secondary aim was to determine how IHL might be integrated with the self-management concepts of the IFSMT. A separate manuscript details findings of a critical realist analysis of this study that explored how patients experience interaction with oncology providers about self-management of lung cancer symptoms (Campbell, TBD).

Methods

Sample and Setting

Eligibility criteria for participation in the study included age 18 or older and receiving treatment for lung cancer within the six months prior to enrollment. Individuals were excluded from the study if they were not fluent in verbal and written English or exhibited a cognitive or communication impairment limiting ability for recall, interaction with healthcare providers, or ability to perform self-management behaviors. Recruitment initially took place in spring 2020 at an outpatient radiation oncology facility in a southeastern state of the U.S. but moved to virtual recruitment due to restrictions imposed by the COVID-19 pandemic. Participants were then recruited from four lung cancer patient support groups who were meeting virtually at the time of data collection. Groups were based in Michigan, North Carolina, and Florida, although participants joined from other states as well. A university's Institutional Review Board (IRB) approved the study. The radiation oncology clinic and the founder of the patient support groups endorsed the university's IRB approval.

Data Collection

To address the aims, this exploratory study employed a cross-sectional mixed methods design. Individuals who agreed to participate in the study completed informed consent either on paper or virtually, then completed a self-administered questionnaire comprised of demographic information, the Memorial Symptom Assessment Scale-Short Form (MSAS-SF), and the All Aspects of Health Literacy Scale (AAHLS). Quantitative data was collected using Qualtrics for virtual participants, and qualitative data was collected through an audio-recorded semi-structured interview with each participant via telephone after the surveys were completed.

MSAS-SF. On the MSAS-SF, participants use a 5-point Likert scale to rank the amount of distress caused by 28 physical symptoms common to patients with cancer. The scale is scored as follows: not at all = 0.8, a little bit = 1.6, somewhat = 2.4, quite a bit = 3.2, very much = 4. Four psychological symptoms are assessed for frequency in the past week, using the following Likert-scale categories: rarely = 1, occasionally = 2, frequently =3, almost constantly = 4. A zero is assigned for physical and psychological symptoms that have not been experienced in the past week. The Global Distress Index subscale determines overall symptom distress and is calculated as the mean distress rating of four psychological symptoms (feeling sad, feeling irritable, feeling nervous, and worrying), and six physical symptoms (lack of energy, feeling drowsy, dry mouth, lack of appetite, constipation, and pain). Possible GDI scores range from 0-4, with a higher score indicating higher overall symptom distress. The MSAS-SF has been found to be valid and reliable for use in patients with cancer.[11-12]

AAHLS. The AAHLS measures health literacy using the three dimensions of Nutbeam's framework, with three functional items, three interactive (communicative) items, and seven critical items. Although the AAHLS is a newly developed tool, its overall reliability is strong, as is the reliability of the functional and interactive health literacy subscales.[13] A 3-point Likert scale is used for the majority of the items, with possible responses of "often," "sometimes," and "rarely." Often was scored as 3 points, sometimes as 2 points, and rarely as 1 point. Only the functional and interactive health literacy subscale scores were used for this study. The AAHLS does not specify a cut-off score for the subscales. For the purposes of this study, a score of 9 was considered high FHL or IHL; scores between 6 and 8 were considered moderate FHL or IHL; and scores between 3 and 5 were considered low FHL or IHL.

Semi-structured interview. Interview questions were designed to explore how IHL affects the participant's abilities and behaviors to self-manage their symptoms and were developed using concepts from Nutbeam's framework and the IFSMT. The interview guide included questions about symptoms requiring self-management, participants' experiencing with obtaining and processing symptom management information, and questions specific about interactions with healthcare providers about symptom management.

Data Analysis

Results from the quantitative data were reported using descriptive statistics and analyzed for trends. Qualitative data from interviews were coded using NVivo software. Categories were initially developed based on themes in participant responses, then re-organized based on a priori codes from Nutbeam's health literacy framework and the IFSMT. Iterative analysis and synthesis of both qualitative and quantitative data was aimed at discovering patterns that explain how IHL related to the process of symptom self-management. Thus, codes and categories were added, removed, and modified throughout the analysis process. Identified themes were mapped to the concepts in the IFSMT in an effort to integrate IHL with the concepts related to self-management; these applications are reported and discussed below. Quantitative data related to IHL and symptom distress were analyzed parallel to the qualitative themes, resulting in integrated findings that provide insight into the phenomenon of symptom self-management.[14]

Results

Quantitative and qualitative data are reported based on the IFSMT dimensions of Context, Process, and Outcomes, along with incorporation of IHL where applicable.

Sample Characteristics

Recruitment resulted in 16 potential participants; one was excluded due to not starting treatment prior to enrollment, and three others were lost to follow up. This resulted in a final sample of 12, one from the radiation clinic and 11 from support groups. Participants were mostly

White (n=11; 91.67%) and female (n=9; 75%). Additional demographic data is presented in Table 1.

Complexity of condition. Based on MSAS-SF responses, all of the participants were experiencing multiple symptoms related to lung cancer and/or its treatment, reporting an average of 14 symptoms at the time of data collection (mean 14.36; range 9-20). The most common symptoms were lack of energy, feeling drowsy, and worrying. The most distressing symptoms were lack of energy, pain, feeling drowsy, and worrying. GDI scores ranged from 0.44 to 2.66 with a mean of 1.52, indicating a low to moderate level of symptom distress. Distress was higher for psychological symptoms (mean 1.57) than for physical symptoms (mean 1.12). MSAS-SF data was missing for one participant. See Table 2 for additional details.

Developmental stage. All of the participants were middle-aged adults, with ages ranging from 48 to 73 years old (mean = 58.33 years).

Learning ability. While learning ability was not specifically measured, most participants reported having at least an associate degree or some college (n=10; 83.33%).

Literacy. On the FHL subscale, the mean score was 8.27, with a range from 7 to 9. FHL data was missing for one participant. Six participants scored a 9 (high FHL; 55%), and 45% scored 7 or 8 (moderate FHL; see Table 3). IHL scores ranged from 6 to 9, with a mean of 8.33. Eight participants (67%) scored in the high range (9), and four (36%) scored in the moderate range (6-8; see Table 3).

Interactive Health Literacy and Self-Management

Qualitative interview data is reported according to components included in the IFSMT process and outcomes dimensions. Table 4 includes key quotes from participants that illustrate how elements of interactive health literacy are related to self-management concepts. Participants are described based on age, GDI score of symptom distress, and IHL score; IHL 9 represents high IHL, and IHL <9 represents moderate IHL.

Definition of self-management.

Most participants, regardless of IHL, defined self-management as some version of “figuring out how to manage my own symptoms on my own” (Participant #2, 51 y/o female, IHL 9, GDI 0.44). Two participants, one with high IHL and one with moderate IHL, described self-management in terms of general lifestyle, such as diet, exercise, and taking medications as prescribed (Participant #12, 68 y/o female, IHL 9, GDI unknown; Participant #10, 67 y/o female, IHL 6, GDI 2.48). While the majority of participants (n=10) specified it as managing symptoms without the help of a provider, two participants, both with high IHL, suggested that self-management included engaging with a healthcare provider.

IFSMT process factor: Knowledge & beliefs.

Participants both with high (e.g., Participant #7) and moderate IHL (e.g., Participant #1) indicated that having clear information that was specific and easy to understand facilitated getting factual information about the self-management of symptoms, particularly at the beginning of treatment and when new symptoms developed. Self-efficacy was primarily reflected in confidence to engage in communication with oncology providers about symptom management. All participants with high IHL expressed confidence in patient-provider interactions and were also confident in managing their own symptoms (e.g., Participant #9). None of the participants with moderate IHL expressed confidence in communicating with providers. In fact, their statements suggested they were uncertain about contacting providers when symptom management information was needed (e.g., Participant #10). Participants who had greater experience with self-management—due to a previous cancer diagnosis or increased length of time since diagnosis—conveyed self-efficacy for symptom self-management. These participants tended not to require assistance from an oncology provider for symptom management (e.g., Participant #5).

IFSMT process factor: Self-regulation skills & abilities.

All participants, regardless of their IHL, described engaging in self-regulation skills and abilities related to their symptoms. For instance, self-monitoring and decision-making was evident when participants determined the need to contact a healthcare provider based on perception of symptom severity and distress (e.g., Participant #6). Eight participants, some with high IHL (e.g., Participant #6) and some with moderate IHL (Participant #10), reported examples of trying various self-management strategies for symptoms, such as fatigue and diarrhea, and evaluating their effectiveness.

IFSMT process factor: Social facilitation.

Social support from caregivers was reflected in monitoring symptoms, as well as informational support for obtaining and processing symptom management information (e.g., Participant #1, Participant #9). All but one participant described social sources of symptom management information, such as patient support groups, online forums, and social media (e.g., Participant #10). All eight participants with high IHL mentioned that they discussed information with their oncology provider before making decisions about using it to manage symptoms (e.g., Participant #12). On the other hand, the four participants with moderate IHL scores were likely to evaluate information without the help of an oncology provider, choosing instead to figure it out on their own (e.g., Participant #4).

Seven of the eight participants with high IHL described the importance of developing and maintaining a relationship with their oncology provider. Four of these participants emphasized their own responsibility to engage in the relationship and initiate conversation when informational support was needed (e.g., Participant #5). Others described characteristics of their provider that facilitated the relationship, such as a patient portal integrated in the electronic health record (e.g., Participant #7). Four participants with high IHL described examples of negotiated collaboration in which provider and patient perspectives were mutually considered when developing symptom management strategies. For instance, one participant described being offered the choice between several options for managing sleep disturbances (Participant #5).

While the four participants with moderate IHL indicated comfort with asking their oncology provider questions, none of them mentioned having a relationship with their provider. In fact, some of them described provider characteristics that made it difficult to interact, such as rushed appointments and generic answers to questions about symptom management. This sometimes resulted in delays in obtaining necessary symptom management information (e.g., Participant #8, Participant #10).

IFSMT outcomes: Self-management behaviors and symptom relief

All 12 participants identified engaging in various self-management behaviors, such as exercising (e.g., Participant #5), performing skin care (e.g., Participant #6), and making dietary modifications (e.g., Participant #10) to manage their multiple symptoms. Taking medication was the most common self-management behavior, mentioned for symptoms such as fever, nausea, pain, and fatigue; only two participants did not discuss medications as self-management strategies, one with high IHL and one with moderate IHL. When asked about how well symptom management strategies relieved symptoms, the majority of participants stated that only some symptoms are effectively managed, regardless of IHL level. Two participants, one with high IHL and one with moderate IHL, both reported the effectiveness of symptom management as

"50/50." The four participants with moderate IHL scores reported higher symptom distress (mean GDI 2.39) than those with high IHL scores (mean GDI 1.03; see Table 2). This difference was also evident in the qualitative data. For example, one participant with high IHL reported 16 symptoms on the MSAS-SF and described multiple symptoms during the interview, but felt they were managed "fairly well" and scored 1.2 on the GDI (Participant #3, 51 y/o female, IHL 9). Another participant with moderate IHL reported 17 symptoms on the MSAS-SF and expressed dissatisfaction with the effectiveness of symptom management, scoring 2.48 on the GDI (Participant #10, 67 y/o female, IHL 6).

Discussion

This study explored how the interactive health literacy of 12 patients with lung cancer could impact the process of symptom self-management as outlined in the IFSMT. In the IFSMT, complexity of condition is a contextual factor influencing the process and outcomes of self-management. Lung cancer is a complex condition with a high symptom burden, as evidenced by these participants, who reported an average of more than 14 symptoms. Distress from their symptoms was moderate.

The IFSMT recognizes literacy in the context domain as either a protective or risk factor for individual self-management.[9] Health literacy, particularly functional health literacy, is important as a contextual factor for obtaining and processing symptom management information, Participants in this sample had moderate to high functional literacy. They consistently discussed reading written sources of symptom management information, including books and printed handouts from oncology providers, as well as Internet-based sources such as health organization websites and patient discussion forums. As Internet-based information becomes increasingly commonplace and more widely utilized, it is vital to consider the impact of health literacy on patients' ability to determine the credibility of symptom management information found online.

As is described in Nutbeam's framework, however, IHL skills encompass cognitive and social skills for communicating with healthcare providers and seem more relevant to the process of self-management as defined by the IFSMT—specifically self-efficacy and social facilitation from providers. These participants with high IHL were actively engaged in their oncology care, demonstrating self-efficacy (confidence in one's ability) in communicating with their oncology provider. Self-efficacy has previously been linked to cognitive and social skills for communicating with healthcare providers regarding symptom management.[15]
Participants with high IHL consistently described positive experiences when obtaining and processing symptom management information through interaction with their oncology providers. These participants reported trusting the information they were given and having their questions answered satisfactorily even when appointment times were brief.

In contrast, participants with moderate IHL in this sample were less likely to rely on oncology providers for informational support and less likely to demonstrate self-efficacy in communication with their oncology providers. These participants tended to obtain information from alternative sources and utilize other healthcare providers, fellow patients, and web-based resources to help determine which symptom management strategies were best. In some cases, participants with lower IHL identified characteristics of the oncology provider or team that did not facilitate positive experiences, including being rushed during appointments and being given answers that were perceived as generic. This dynamic resulted in participants with lower IHL admittedly waiting until symptoms were more severe to ask for assistance, or not having symptoms managed at all.

In the IFSMT, interactive health literacy is conceptualized as social facilitation, a factor contained within the self-management process. According to the IFSMT, social facilitation may support the self-management process, with the assumption that patients are actively engaged in discussing symptom self-management with their healthcare providers.[9] However, patients with low IHL may be ill-equipped for initiating and maintaining this active engagement. The findings of this study are consistent with existing literature that identifies characteristics of both patients and oncology providers affecting communication of symptom self-management information.[16-17] For the participants in this study, IHL skills, self-efficacy, and trust in the oncology provider played a role in better communication about symptom self-management. Providers who were easily accessible, allowed adequate time for appointments, encouraged question-asking, and gave personalized information facilitated greater collaboration toward symptom self-management. Additional research exploring the interconnections between these factors is warranted, as it may strengthen the IFSMT to incorporate provider characteristics that facilitate social facilitation of self-management.

In addition, the recent addition of patient portals as a means of contacting healthcare providers has introduced another aspect to the already complex concept of health literacy. Although it was not a focus of data collection, four participants volunteered information about using patient portals as a means of communicating with their oncology providers. Three of those participants had high IHL; the fourth described using the portal to follow up on questions that were not answered due to rushed appointments. Recent studies demonstrate the advantages of patient portals, namely increased access to healthcare providers and information, increased patient engagement in communication, and increased patient confidence and empowerment.[18-20]

However, additional research is needed to explore disparities in patient portal access and utilization, with particular attention to limited health literacy and other potential barriers.[19, 21]

In Nutbeam's framework, self-regulation skills align more with critical health literacy, which was not explicitly addressed in this study, rather than interactive health literacy, limiting the potential of this study's findings to explain self-regulation as a self-management process. One key finding is that all participants described examples of self-regulation skills, by monitoring symptoms and making decisions about how to manage them and when assistance from a healthcare provider was necessary. Participants who had been self-managing cancer symptoms for a greater length of time described greater independence with self-regulation skills. This supports the IFSMT assumption that self-management comprises iterative processes that require time and repetition.[9]

The IFSMT includes family involvement in the context and process of self-management, and it is possible caregivers also play an important role in IHL and symptom self-management. A limitation of the present study is that caregiver involvement was not explicitly addressed. A few participants, some with high IHL and some with low IHL, suggested that the social influence and informational support of caregivers was an important facilitator of their ability to monitor symptoms, obtain symptom management information, and determine what information to use. Patients often rely on caregivers for support in dealing with the multitude of decisions required in managing a complex illness such as cancer.[17, 22-23] Further research is needed to continue building evidence regarding the role of caregivers, their health literacy, and how healthcare providers can support their involvement in self-management.

Findings suggest that participants in this study who demonstrated higher IHL had lower symptom burden and overall distress, despite experiencing a high number of symptoms. This trend points to a possible relationship between interaction with oncology providers and effective symptom self-management. Self-management of chronic illness has been linked to positive patient-provider relationships characterized by quality communication, active listening, provider support and collaboration with patients in problem-solving.[17] For patients with lung cancer, lower satisfaction with physician communication is associated with higher unmet symptom management needs.[24] The connection between interactive health literacy, collaborative patient-provider relationships, and effective symptom self-management should be explored in future research.

Regardless of IHL level, participants described only partial effectiveness of symptom management strategies, highlighting the need for continued research on managing concurrent symptoms. Increased attention should be directed toward self-management of persistent symptoms such as fatigue, which was the most common and the most distressing symptom, as has been determined by previous studies,[25-26] but also the symptom participants identified as the most difficult to self-manage.

Other limitations of this study include a small sample that is fairly homogeneous and mostly comprised of participants who exhibit a higher degree of empowerment by their active engagement in patient support groups. While the findings of this study are helpful in understanding how patients find and interpret symptom management information, repeating studies similar to this one with a larger sample that includes patients with limited English proficiency, low interactive health literacy, and diverse sociodemographic characteristics, will provide greater insight into the complex and multidimensional relationship between interactive health literacy and symptom self-management.

Conclusion

Patients' interactive health literacy skills may help them access and evaluate self-management information through interaction with their oncology provider, which may lead to more effective symptom self-management behaviors and less symptom distress. This is especially important when patients have a high symptom burden caused by a complex disease such as lung cancer and its treatment regimens. Oncology healthcare providers need to be aware of the importance of fostering a patient-centered relationship with patients, especially in support of their efforts to obtain and process symptom self-management information. This is key for oncology nurses, since nurses are at the forefront of patient education and support. Implications for further research include the role of patient portals, interconnections between interactive health literacy, self-efficacy, trust, and collaboration with providers, characteristics of providers that facilitate self-management, and caregiver involvement.

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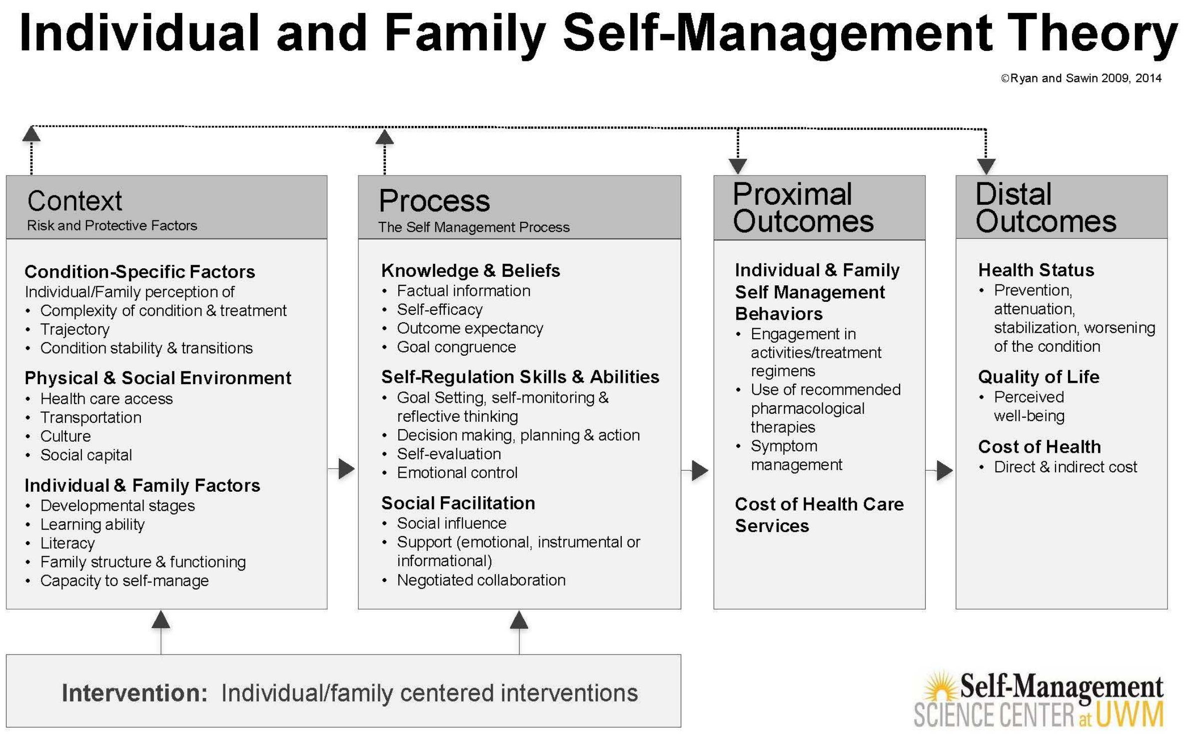

Figure 5.1. Updated IFSMT framework. From "Individual and family self-management theory," by P. Ryan and K. Sawin, 2009, 2014. Retrieved from https://uwm.edu/nursing/wp-content/uploads/sites/287/2015/05/IFSMT_website__2015_07.jpg. Copyright 2009, 2014 by P. Ryan and K. Sawin.

Table 5.1

Demographics

Age	
Mean (SD)	58.33
Median (range)	55.5 (48-73)
Race	**N(%)**
White	11(91.67)
Black	1(83.33)
Ethnicity	**N(%)**
Not Hispanic	10(83.33)
Gender	**N(%)**
Female	9(75)
Male	3(25)
Relationship Status	**N(%)**
Currently married	10(83.33)
Widowed	1(8.33)
Divorced	1(8.33)
Education (highest level completed)	**N(%)**
Some HS or less	1(8.33)
HS diploma	1(8.33)
Associates degree	2(16.67)
Some college	3(25)
Bachelors degree	1(8.33)
Graduate degree	3(25)
Business school	1(8.33)
Household Income	**N(%)**
<25K	1(8.33)
25-49,999	1(8.33)
50-74,999	1(8.33)
75-99,999	2(16.67)
100-124,999	2(16.67)
125-149,999	4(33.33)
150-199,999	0
200K+	1(8.33)
Health Insurance	**N(%)**
Medicare	5(41.67)
Private	7(58.33)

Table 5.2

MSAS-SF Scores

MSAS-SF Scores (n=11)	**Mean (SD)**	**Range**
Number of symptoms reported	14.36 (3.38)	9 – 20
GDI (0-4)	1.52 (0.74)	0.44 – 2.66
PHYS (0-4)	1.12 (0.60)	0.47 – 2.33
PSYCH (0-4)	1.57 (0.72)	0.73 – 3.23
Total (0-4)	1.05 (0.38)	0.63 – 1.87
Most frequent symptoms	**N(%)**	
Lack of energy	10(91%)	
Feeling drowsy	10(91%)	
Worrying	9(82%)	
Difficulty concentrating	8(73%)	
Pain	8(73%)	
Least frequent symptoms	**N(%)**	
Vomiting	1(9%)	
Mouth sores	1(9%)	
Difficulty swallowing	2(18%)	
Weight loss	2(18%)	
Hair loss	2(18%)	
"I don't look like myself"	2(18%)	
Most distressing symptoms	**Mean (SD)**	
Lack of energy	2.55 (1.46)	
Pain	2.04 (1.53)	
Feeling drowsy	2.04 (0.90)	
Worrying	2.00 (1.18)	
Least distressing symptoms	**Mean (SD)**	
Vomiting	0.15 (0.48)	
Mouth sores	0.29 (0.96)	
Weight loss	0.29 (0.74)	
"I don't look like myself"	0.36 (0.83)	

Table 5.3

AAHLS Scores

AAHLS Interactive Health Literacy Subscale Scores (n=12)	
Possible scores range from 3 – 9*	
Mean score 8.33 (SD = 1.07)	**N(%)**
Score 6 / 9	1 (8%)
Score 7 / 9	2 (17%)
Score 8 / 9	1 (8%)
Score 9 / 9	8 (67%)
AAHLS Functional Health Literacy Subscale Scores (n=11)	
Possible scores range from 3 – 9*	
Mean score 8.27 (SD = 0.90)	**N(%)**
Score 7 / 9	3 (27%)
Score 8 / 9	2 (18%)
Score 9 / 9	6 (55%)

*Higher score indicates higher interactive or functional health literacy

Table 5.4

Representative Quotes

Concept	Quote	Participant
IFSMT Process: Knowledge & Beliefs		
Specific, easy-to-understand information	"I guess something easy would have been hey, if you don't want to get sick during your treatment, take these medications two days before, two times a day, and one or two days afterwards your treatment."	Participant #7, 55 y/o male, IHL 9, GDI 1.14
	"Having found out what I could when I first found out I had cancer. I've tried to find out what more of symptoms to the radiation and chemo is going to be because they don't explain it as good as they should."	Participant #1, 66 y/o female, IHL 7, GDI 2.54
Self-efficacy: confidence in engaging with providers	"First of all you need to be willing to engage doctors in conversations to ensure that you understand what they're telling you…With regard to the nausea, I have several nausea drugs...Yesterday was the first day when I woke up actually feeling nauseated. I took one of my nausea drugs and that seemed to work."	Participant #9, 56 y/o male, IHL 9, GDI 1.06
Uncertainty about contacting providers	"That's a good question. When I not only call a provider, but sometimes I don't know which one to call. Should I call my pulmonary or when I have	Participant #10, 67 y/o female, IHL 6, GDI 2.48

	the tube in, is this related to this tube in my body? Or my oncologist is this something a new side effect from the medicine that I'm taking as prescribed from the oncologist?”	
Experience with self-management	“Over time you've learned to adopt to self-managing your aches, pains, rashes, GI issues, stomach issues, taste, affects that from time to time that just kind of come and go.”	Participant #5, 55 y/o male, IHL 9, GDI 1.12
IFSMT Process: Self-Regulation Skills & Abilities		
Self-monitoring	“So some of the smaller ones, new aches or pains I feel like those aren't as critical. But I think especially, I mean, the biggest one to me is my quality of breathing. I know that sounds kind of strange, but I have a 02 monitor and I check my 02 at various times just to see what it's doing, because sometimes I won't realize that it’s slow as it is.”	Participant #6, 50 y/o female, IHL 9, GDI 1.24
Evaluating various strategies	“So, like I said, I've started to adjust my expectations but I've also realized that there are small things that I can do that have seemed to help recently [with managing fatigue]. Things that are not medication-related such as walking, bed time and wake time consistency. And then also medication dosage consistency has helped.”	Participant #6, 50 y/o female, IHL 9, GDI 1.24

	“I think I read or someone told me or talking or something to eat small meals rather than large meals to maybe deal with the diarrhea. And that has seen after I started doing that. So I'm going to say that that that seemed to work for me, too. I don’t eat big meals. I just snack all day I guess, yeah.”	Participant #10, 67 y/o female, IHL 6, GDI 2.48
IFSMT Process: Social Facilitation		
Social support from caregivers	“I’ve had a good friend of mine…she’s helped me try to figure out you know what’s wrong with me and stuff and call doctors and you know ask questions.”	Participant #1, 66 y/o female, IHL 7, GDI 2.54
	“If I had questions, and my wife is always very attentive and always looking out for…I will tell you this. When it comes down to it, I will defer to her 90% of the time. Just because.”	Participant #9, 56 y/o male, IHL 9, GDI 1.06
Social sources of information	“I'm a part of the EGFR resistors group online. That's a Facebook group. And all kinds of questions and suggestions are given there.”	Participant #10, 67 y/o female, IHL 6, GDI 2.48
Discuss information with oncology provider	“I usually run it by my doctor first before I make any changes.”	Participant #12, 68 y/o female, IHL 9, GDI missing
Evaluate information without provider help	“And then if it persisted, I would maybe look it up a little bit more on the Internet sometimes, Dr. Google or I was for a long	Participant #4, 60 y/o female, IHL 7, GDI 1.86

	time.”	
Developing and maintaining relationship with oncology provider	“I think with anything with that it’s managing your relationship with your oncologist. The last thing you want to do is act upon something that a friend or something and social as the next thing you know you're having some sort of adverse drug reaction to your cancer treatment or something to that effect.”	Participant #5, 55 y/o male, IHL 9, GDI 1.12
Patient portal	“I feel fine about [asking question]. I don't have any problem with it. Typically, my questions or when I'm in front of them. But I don't mind that system, that MyAtrium or picking up the phone, I feel like it's -- I don't feel like I'm putting out. They’re always courteous, kind, helpful. It is great.”	Participant #7, 55 y/o male, IHL 9, GDI 1.14
Negotiated collaboration	“Lack of sleep was to a point where I was maybe only getting two or three hours and I did reach out to him to that. And that's where it was kind of suggested what we could do this, this or this, or you can try and since you do need your rest for this, see about taking a nap or whatever.”	Participant #5, 55 y/o male, IHL 9, GDI 1.12
Provider characteristics that make it difficult to collaborate	“I mean, I try [asking questions], I do. But sometimes you could tell everyone is in a hurry.”	Participant #8, 48 y/o female, IHL 8, GDI 2.66

	“The answer is just the generic answer…in the beginning, I felt like I was just…he wasn’t listening to me or hearing me.”	Participant #10, 67 y/o female, IHL 6, GDI 2.48
IFSMT Outcomes		
Self-management behaviors	“So when I do go to the Y I'm working out a good workout in and stuff like that. And that makes a big difference in my day, not just mentally but physically and emotionally because I'm addressing that pain. I'm starting to move, and I can do more things without and live more of a pain free day then.”	Participant #5, 55 y/o male, IHL 9, GDI 1.12
	“Some things I'm comfortable with trying ‘home remedies.’ For example, I've had problems with my skin almost immediately upon beginning treatment…And so I have lots of lotions and ointments that I've discovered my own home remedies.”	Participant #6, 50 y/o female, IHL 9, GDI 1.24
	I try to make my own shakes or sometimes in there, you know what's that? The energy powders and putting stuff in, peanut butter, high calorie stuff to try and put weight on.	Participant #10, 67 y/o female, IHL 6, GDI 2.48
Some symptoms managed	“So I guess it's like 50/50, a half percentage that it works, half it doesn't.”	Participant #8, 48 y/o female, IHL 8, GDI 2.66
	“I would say depending on the treatment. I would say it's like a 50-50.”	Participant #2, 51 y/o female, IHL 9, GDI 0.44

Conclusion

This chapter provides concluding comments to the dissertation study. Specific aims were to:

1. Explore interactive health literacy and how it relates to symptom self-management for patients with lung cancer;
2. Describe patients' experiences of interacting with healthcare providers regarding symptom self-management for lung cancer.

To accomplish these aims, the student PI conducted a cross-sectional mixed methods study guided by a critical realist methodology. Patients with lung cancer were recruited from a small free-standing outpatient radiation oncology clinic and from lung cancer support groups that were meeting virtually due to the COVID-19 pandemic. The sample included 12 adults who were receiving or had recently received treatment for lung cancer. Quantitative data was collected using a demographic questionnaire, the All Aspects of Health Literacy scale, and the Memorial Symptom Assessment Scale-Short Form. Qualitative data collection involved an audio-recorded semi-structured individual interview addressing participants' experience with obtaining and processing symptom self-management information, with a focus on interaction with oncology providers. Both types of data were analyzed using a critical realist approach, which seeks to discover patterns that explain how complex phenomena manifest in real-life situations and events. The critical realist analysis found that the relationship between patients with lung cancer and their oncology providers is a generative mechanism for acquiring symptom management and determining its trustworthiness. Structural factors related to characteristics of the provider and healthcare organizations, as well as agential factors related to patient engagement, have an impact on the nature of the patient-provider relationship. Further analysis using concepts of the

IFSMT revealed that interactive health literacy can be integrated into the process dimension of the IFSMT, namely in regards to knowledge and beliefs, self-efficacy, and social facilitation of self-management. Additional research is needed to clarify connections between interactive health literacy and patient engagement with oncology providers.

The first part of the chapter summarizes additional findings from the data that were not relevant to the two manuscripts comprising Chapters 4 and 5. The second part of the chapter details implications for practice, research and policy based on the study's findings.

Additional Study Findings

In this study, participants' responses to interview questions highlighted two themes that were not relevant to the aims of Chapters 4 and 5: side effects of immunotherapies; and difficulty understanding information early in the disease trajectory.

Side Effects of Immunotherapies

Advances in medical science have led to the discovery of promising new treatment options for patients with cancer, which require updates in the assessment and management of side effects. With the increasing use of immunotherapies for lung cancer, the side effects commonly experienced by patients have changed. Immunotherapeutic agents stimulate the patient's immune system to mount a greater attack on cancer cells. These treatments result in an increased release of cytokines, which activate an inflammatory response. Side effects of cytokine release include flulike symptoms, such as fever and chills. In this study, several participants reported side effects specific to the immunotherapies, including uncontrolled fever (n=3), peripheral edema (n=1), headaches (n=1), nail changes (n=3), and eye problems (n=2). However, these symptoms are not listed on the MSAS-SF, limiting its effectiveness for symptom assessment in patients receiving immunotherapy. As these treatments become more common, there is a need for the development of new symptom assessment instruments that more accurately reflect patient experience. In addition, researchers and clinicians must work toward identifying effective strategies to manage these side effects. It is vital for oncology nurses to be leading these efforts, as we are at the forefront of patient care and education.

Immunotherapies, especially immune checkpoint inhibitors, are quickly becoming the gold standard treatment regimen for non-small cell lung cancer due to their positive effect on disease outcomes (Khozin et al., 2019). The resultant increase in the survival rate for lung cancer means that patients will be living longer with side effects, often for the remainder of their lives. Thus, research is needed to guide evidence-based interventions to relieve symptoms over time.

> "…feel like they're getting worse as I continue, because this is long term, as you know, probably then. It is going to go on for as long as it will work." Participant #3, 51 y/o female, IHL 9)

> "I know the symptoms are not going in anywhere yet. So self-management tells me to change my lifestyle to fit with the symptoms as best I can." (Participant #10, 67 y/o female, IHL <9)

> "I've finally accepted that I likely will never get back to where I was two years ago just because of basically the in increased lung problems that I have, and the fact that likely I mean, I'm going to be on something some kind of anti-cancer treatment for the rest of my life." (Participant #6, 50 y/o female, IHL 9)

Difficulty Understanding Information Early in Disease Trajectory

Two participants, both with high interactive health literacy, described difficulty understanding information about the disease process and treatment regimens early in the disease trajectory. The participants described feeling overwhelmed by several issues that may complicate the ability to comprehend and make sense of cancer-related information: unfamiliar terminology; a large amount of new information provided in a short amount of time; undergoing multiple tests and procedures; and emotional responses to a cancer diagnosis. Furthermore, patients who present with brain metastasis may face cognitive impairment due to the disease process itself.

> "I would say when I was first diagnosed, it was very difficult because you have to learn interpretations the new words that you've never heard before and medical terms and all that. So, for that, I would say not so

> not so easy. But as my treatment has went on and I've become more of an advocate, it's been easier…let's start with the day of diagnosis because I would say actually the first month of diagnosis, because there's so much going on and so much that they're doing testing wise and everything is thrown at you so quickly that it’s just like a fog. So it's hard to interpret or understand anything they're saying. So, you’re like going along with the flow because all you really think about at that time is get this stuff out of me.” (Participant #2, 51 y/o female, IHL 9)
>
> “You know, during that time, the first thing and the foremost was to remove my brain tumor. And, I guess the hardest part to understand was what it could impact, what the possibilities were, and that's just during the surgery. And then, you know what happened if we didn't do the surgery, and then after the surgery? Things were kind of cloudy there to say the least because I guess it was just so much going on, and that was very, very complicated in itself, but I came through it with flying colors and everything was good, but I trusted the professionals before me. And they took care of me. But they did their best so let me know that my vision was involved and if we strike this little section, it might give you double vision. If we strike this little section, you might go blind, but we're fairly confident none of these is going to happen. But we have to make you aware of the possibilities. So you know that's probably the cloudiest that I felt.” (Participant #7, 55 y/o male, IHL 9)

While these participant comments do not relate to symptom management, it is important for clinicians to recognize the challenges associated with understanding complex information at the time of a life-changing lung cancer diagnosis (Ballard 2016). Routine screening for health literacy during healthcare interactions is a critical strategy especially at the time of diagnosis (Keim-Malpass, Dolde, Kennedy, & Showalter, 2017). Oncology healthcare providers, including nurses, recognize that all patients will have higher informational needs and lower ability to process information when faced with a cancer diagnosis (Ballard & Hill, 2016; Papadakos et al., 2018). Efforts should be made to avoid using medical terminology, provide information using plain language, and assess patient understanding (Ballard & Hill, 2016; Wittenberg, Ferrell, Kanter, & Buller; 2018; Wittenberg, Goldsmith, Ferrell, & Ragan, 2018). Also, nurses should develop patient teaching plans so that patients and families receive information in manageable doses over time. In cancer care, patients and caregivers experience a paradox of information overload with information needs that remain unmet at the time of diagnosis and beginning of treatment (Crotty et al, 2020).

Implications for Nursing Practice, Research, Policy

This study aimed to describe patients' experiences of interacting with healthcare providers regarding symptom self-management for lung cancer. The high symptom burden associated with lung cancer was evident in this study, with participants reporting as many as 20 concurrent symptoms. The experience of multiple symptoms requires patients to be able to engage in self-management, which is a multidimensional process. Findings from this study indicate that patients need interactive health literacy skills in order to obtain and process self-management information. Interactive health literacy involves cognitive and social skills, which facilitate patient engagement with providers in order to obtain and process symptom management information. The quality of the relationship between patients with lung cancer and oncology providers plays a key role in the social facilitation of self-management. These findings have important implications for clinical practice, research, and policy, each of which will be discussed below.

Implications for Clinical Practice

First, oncology nurses should consider incorporating health literacy screening into routine patient assessments. A brief self-report instrument, such as the three-item screener developed by Chew, Bradley, & Boyko (2004) is feasible for use even in busy clinical settings (Keim-Malpass et al., 2017). The screening tool asks questions about difficulty reading and understanding health-related materials and completing medical forms; it has demonstrated effectiveness in identifying inadequate health literacy (Chew et al., 2004). Having an understanding of patients' health literacy skills will improve awareness of the need for providers to follow health literacy guidelines and ensure patient understanding of symptom management information.

Second, it is essential for oncology providers, including nurses, to demonstrate a willingness and availability for developing patient-centered relationships that promote patient engagement, invite patients to share their values and preferences, and involve patients in decision-making (Odai-Afotey, Kliss, Hafler, & Sanft, 2020; Turner et al., 2017). Creating access to information and collaboration is one way to increase patient-centeredness. For instance, several participants discussed the value and convenience of being able to contact their oncology provider through a patient portal integrated into their electronic health record. Patient portals are becoming more commonplace, and digital communication is the norm in today's society. However, providers must be acutely aware of how patient characteristics, such as health literacy and socioeconomic factors (e.g., Internet access), impact ability to utilize patient portals. Patients may require specific training for how to access and navigate the patient portal in order to use it effectively (Coughlin et al., 2018). Several participants also mentioned their preference for finding information from books, handouts, and/or online resources. Providing written information and reputable web-based sources of symptom management information may be helpful strategies to ensure patients have their information needs met according to their preferences. In addition, symptom management information should follow health literacy guidelines, such as avoiding technical terminology and using plain language (Wittenberg et l., 2017).

Third, when communicating with patients, providers can facilitate patient engagement and patient-centered care, collaboration, and possibly even improve interactive health literacy skills, in a variety of ways. In this study, a perception that appointments were rushed, as well as generic answers to questions, inhibited participants with lower interactive health literacy skills from having questions answered satisfactorily. Thus, oncology providers should ensure that there is adequate time for each patient appointment and refrain from appearing hurried. This may require a shift in the culture of many healthcare settings toward value-based rather than volume-based care. Patients should be encouraged to ask as many questions as necessary to feel confident in their understanding of symptom management information. Provider responses should be specific and personalized to the patient's current situation (Fitch et al., 2020).

Finally, providers need to work diligently with patients toward effective symptom self-management, particularly for multiple symptoms that occur together. As researchers identify strategies for symptom cluster assessment and management, evidence needs to be translated into practice and incorporated into patient education. Oncology nurses are uniquely situated to ensure patients receive symptom management information in an understandable format.

Implications for Research

Research is needed to develop psychometrically sound instruments to comprehensively assess both disease symptoms and treatment side effects commonly experienced by patients with lung cancer. While several instruments already exist, they must be updated to match the side effect profiles of new treatment regimens such as immunotherapies. The use of outdated instruments will limit the usefulness of research findings, reducing their ability to impact patient outcomes.

Similarly, additional research is needed to identify best practices for comprehensively screening health literacy in the oncology patient population. Several brief screening tools have been developed and found to be feasible in clinical settings. However, these tools are focused only on functional health literacy (i.e., reading and writing skills), and fail to address interactive and critical health literacy. Findings from this study underscore the importance of interactive health literacy skills in cancer care. The interactive health literacy subscale from the All Aspects of Health Literacy Scale is a potential option for a brief screening tool specific to interactive health literacy skills. Research investigating its usefulness and feasibility in oncology settings would be a valuable contribution to the body of evidence.

Furthermore, research is needed to explore strategies addressing limited interactive health literacy for patients with complex conditions that cause a high symptom burden. The multidimensional nature of health literacy has made it difficult to explain and predict how to improve health outcomes for patients with limited health literacy. Additional research examining the role of interactive health literacy and patient-provider collaboration may be a key for improving symptom management outcomes. A focus should be determining if high interactive health literacy increases patient engagement in relationships with providers, or if having a strong relationship with providers improves interactive health literacy skills. Finally, it is essential for studies on the assessment of and interventions to address health literacy to include samples that are diverse in terms of educational level, economic status, and limited English proficiency.

Research into strategies that promote patient-centered care in oncology settings should address provider communication skills that enhance patient engagement and support health literacy needs (Goldsmith, Wittenberg, & Parnell, 2020; Odai-Afotey et al., 2020; Turner et al., 2017). Studies should explore patient preferences for information content and delivery, including the use of technology (Wittenberg et al., 2019). In addition, studies should be done to investigate the feasibility and effectiveness of tools such as question prompt lists to facilitate information exchange during oncology encounters (Barton et al., 2020).

Implications for Policy

Health literacy experts have advocated for nationwide efforts to implement health literacy universal precautions (HLUP) for the past decade. HLUP involves treating all patients in all settings as though they have limited health literacy, thereby reducing the demand on patients to assume full responsibility for obtaining, processing and applying health information (Office of Disease Prevention and Health [ODPH], 2010; ODPH, 2020). A HLUP approach in cancer care places the responsibility on oncology providers to ensure patients have equitable access to credible information in plain language, as well as a clear understanding of what the information means and how it applies to their individual situation (Ballard & Hill, 2016; Papadakos et al., 2018; ODPH, 2020; Wittenberg et al., 2017).

At the individual organizational level, policies might include routine health literacy screening as described above. Oncology facilities might also consider introducing policies regarding early integration of palliative care. Palliative care providers are skilled in providing holistic symptom management for patients with life-limiting illness. Early integration of palliative care for patients with cancer has demonstrated promising outcomes in reducing symptom burden and improving quality of life (Temel et al., 2017; Vanbutsele et al. 2020). For patients with lung cancer who have limited health literacy, having a palliative care provider walk alongside them during their cancer journey may prove invaluable as they cope with multiple symptoms and side effects. Patients with high health literacy would also benefit from the focused symptom management that palliative care provides.

Organizational policies to help patients with low health literacy might include the use of formal patient-provider communication frameworks, such as the COMFORT Communication Model. The COMFORT model is designed to train oncology nurses in patient-centered communication to meet patient information needs throughout the cancer trajectory (Wittenberg et al., 2019). Implementing a nurse navigation program has also demonstrated effectiveness in supporting oncology patients as they deal with the complexities involved in cancer care (Yackzan et al., 2019).

Conclusion

Patients with lung cancer face a daunting diagnosis of a life-limiting illness that is known to result in a high symptom burden. In today's healthcare system, patients are expected to be able to self-manage health conditions, which requires health literacy skills for obtaining, processing, and applying a great deal of complex information. The findings of this exploratory mixed methods study support the concept of interactive health literacy as a key element of engaged patient-provider relationships that promote the self-management process. Structures within the healthcare system, including specific provider characteristics, also play a role in the development of those relationships. Additional research is needed to clarify the interconnections between interactive health literacy, engagement with oncology providers, and symptom self-management for patients with lung cancer.

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JULIE KIEFFER CAMPBELL

Education

Candidate for Doctor of Philosophy in Nursing, December 2020 (anticipated)
University of Wisconsin-Milwaukee, Milwaukee, Wisconsin
Dissertation (in progress): "Interactive Health Literacy and Self-Management of Lung Cancer Symptoms"

Bachelor of Science in Nursing, May 2004
King College, Bristol, Tennessee
Graduated summa cum laude

Teaching Experience

Assistant Professor, Associate Graduate Faculty, 2018 to present
Lee University School of Nursing, Cleveland, Tennessee

Graduate Courses Taught:

- **2019-2020** Philosophical and Theoretical Dimensions of Nursing (online): didactic course addressing scientific underpinnings of nursing knowledge and the interrelationships among theory, research and practice.
- **2020** Advanced Nursing Research Integration and Application (online): didactic course covering the research process, methods and design of a scholarly project, appraisal of published literature, and the utilization of evidence-based practice for the improvement of health care outcomes.
- **2020** Clinical Synthesis Inquiry II (online): didactic course focused on guiding students through implementation of individual DNP scholarly projects.

Undergraduate Courses Taught:

- **2018-2020** Multi-Dimensional Care in Special Circumstances: didactic course with clinical component that addresses holistic nursing care in sensitive healthcare situations, such as oncology and end-of-life care.
- **2020** Introduction to Christian Ethics for the Nursing Profession: didactic course covering legal, ethical and moral responsibilities for holistic professional nursing practice in the context of Christian values and biblical principles.

- **2020** Nursing Research & Evidence-Based Practice Integration: didactic course addressing the relationships between nursing theory, practice and research, with an emphasis on translation of evidence into practice.
- **2019** Nursing Concepts and Competence in Professional Practice: introductory didactic course that prepares students for the nursing curriculum.
- **2018-2019** Competency Lab & Seminar II and III: lab and seminar course that develops nursing knowledge and student competencies focused on specific skills necessary for professional nursing practice.

Other Curricular Endeavors:

- **2020-present** Assist with administrative oversight of graduate nursing program, including recruitment, student advising, and faculty development
- **2020-present** Serve as member of DNP Scholarly Project committee for graduate nursing student
- **2020** Introduction to Christian Ethics for the Nursing Profession: initiated Title III Course Redesign to improve the design and delivery of the course based on student outcomes
- **2018-2020** Multi-Dimensional Care in Special Circumstances: coordinated clinical experiences for students at multiple and varied healthcare settings, including outpatient and inpatient cancer care, hospice, dialysis, and memory care
- **2019** Precepted Masters of Science in Nursing student in classroom and clinical
- **2019** Guest faculty presentation on Writing for Publication in Nursing to senior nursing students
- **2019** Developed online graduate course: Philosophical and Theoretical Dimensions of Nursing

Graduate Teaching Assistant, 2017 – 2018
University of Wisconsin-Milwaukee College of Nursing, Milwaukee, Wisconsin

- Taught Health Assessment and Promotion lab for baccalaureate nursing students
- Assisted with didactic portion of Complex Health and Illness Concepts course

Guest Lecturer, 2014
University of Wisconsin-Parkside Nursing Consortium, Kenosha, Wisconsin

- Presented to undergraduate classes on various topics related to the nursing profession

Course Facilitator, 2013 – 2014
Cancer Treatment Centers of America at Midwestern, Zion, Illinois

- Taught portions of an introduction to oncology course for newly hired nurses

Clinical Experience

Oncology Care Manager, 2009 – 2015
Cancer Treatment Centers of America at Midwestern, Zion, Illinois

- Coordinated health and supportive services to assure continuity of care for patients
- Educated patients and families on disease process, treatment, side effect management

Outpatient Clinic Nurse, 2007 – 2009
Cancer Treatment Centers of America at Midwestern, Zion, Illinois

- Provided direct care and education to patients in an ambulatory oncology clinic
- Collaborated with physicians and other members of the healthcare team
- Served as primary preceptor for all new clinic nursing staff

Outpatient Cardiology Staff Nurse, 2006 – 2007
Condell Medical Center, Libertyville, Illinois

- Provided direct care and education to patients undergoing invasive cardiology procedures
- Performed occasional charge nurse duties, including supervision and assignment of staff

Staff Nurse, 2004 – 2006
James H. Quillen Veterans Affairs Medical Center, Johnson City, Tennessee

- Managed comprehensive acute care for patients on a medical/telemetry inpatient unit
- Performed regular charge nurse duties, including supervision and assignment of staff
- Served as preceptor for nursing students and new employees

Honors and Awards

2020 (May) Campbell, J. K., Student Principal Investigator; Faculty Research Grant, Lee University; "Managing Lung Cancer Symptoms." **Awarded $1,500**

2014 Nurse.com Giving Excellence Meaning (GEM) Award; Regional Finalist for Home, Community and Ambulatory Care; Greater Chicago Region, Illinois

2003 – 2004 Veterans Affairs Learning Opportunity Residency (VALOR); James H. Quillen Veterans Affairs Medical Center, Johnson City, Tennessee

2003 Mother Teresa Award; King College School of Nursing, Bristol, Tennessee

Peer-Reviewed Publications

Campbell, J. K. (2020). Health literacy and self-management in adult oncology: An integrative review. *Oncology Nursing Forum, 47*(1), 18-32.

Kibicho, J., & **Campbell, J. K.** (2019). Community perspectives of second-generation alcohol misuse and HIV risk in rural Kenya: A gendered syndemic lens. *Global Public Health, 14*(12), 1733-1743.

Doering, J. J., Salm Ward, T. C., Strook, S., & **Campbell, J. K.** (2019). A comparison of infant sleep safety guidelines in nine industrialized countries. *Journal of Community Health, 44*(1), 81-87.

Professional Affiliations

Member, Sigma Theta Tau (invited)

Member, Oncology Nursing Society

University Service

Faculty Sponsor, 2019-present
Student Nurses Association, Lee University Chapter

Co-Coordinator for Student Success, 2019-2020
Engage Program, School of Nursing
Worked with at-risk students to promote academic success by discussing study strategies, test-taking skills, and time management

Chair, 2020-present
Member, 2019-2020
Graduate Program Committee, School of Nursing

Member, 2020-present
Faculty Search Committee, School of Nursing

Member, 2019-present
Student Associations and Service Committee, School of Nursing

Member, 2018-present
Nurse Faculty & Staff Organization, School of Nursing

Member, 2018-2019
Undergraduate Admissions, Retention, Graduation Committee, School of Nursing

Community Service

The Mission Cleveland Parish
Assist with children’s ministry, Cleveland, Tennessee, 2019-present

Parish House Anglican Church
Missionary Church Planter, Racine, Wisconsin, 2015-2018

Licenses

Tennessee Board of Nursing
Registered Nurse, License #145137 (multistate), 2020-present