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Understanding Health Literacy Skills of Patients With Cardiovascular Disease and Diabetes

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2015

Abstract

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MBA, Indiana University, 1991

MS, Purdue University, 1986

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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Community Health Education

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Abstract

Health literacy is the ability to understand and act on health information and is linked to health outcomes. It is unclear how health literacy skills are developed in patients with complex conditions, such as cardiovascular disease and diabetes. The purpose of this grounded theory study was to gain perspectives of both patients and healthcare professionals on how health literacy skills were developed in patients with cardiovascular disease or diabetes. The research questions addressed how knowledge and skills were acquired, the role of digital tools, instructional strategies used by healthcare professionals, and how the instructional strategies of the healthcare professionals matched the learning preferences and needs of the patients. A social ecological framework was used, which underscored the importance of understanding health literacy from multiple sources. Semistructured interviews were conducted on 19 healthcare professionals and 16 patients. Emergent key themes included: (a) social support plays an important role as a learning opportunity; (b) many patients get their information from internet searches; (c) instructional strategies should be personalized, interactive, social, and relevant; and (d) patients are self-directed learners. Linking of these themes led to the development of the health literacy instructional model, which is a 3-step approach, including an emotional support, behavioral approach, and instructional strategy. Social support was the common element in all 3 phases and was perceived to be key to developing health literacy skills, resulting in the key implication for social change. Recommendations are to consider social support in the development of health literacy instructional strategies.

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Dedication

This work is dedicated to all of the teachers in my life, and to the patients who have taught us well.

Acknowledgments

First I would like to thank my family for supporting me through this endeavor. I come from a family of educators and lifelong learners. I would like to thank my professors and classmates at Walden University who have helped me learn and have been a wonderful support system. I would especially like to thank Dr. Margaritis for his excellent guidance as my chair and to thank Dr. Anderson for her feedback and support as my committee member.

I would like to thank Scott Conard and John Osborne for their support, not only for participating in this study, but also in teaching me about prevention and wellness. I would like to thank Patrick Wayte and my colleagues at the American Heart Association for their support and interest in my work. I would like to thank Allison Puckett for being another set of eyes and to Penny Pitts for helping me with my figures. I would like to thank Karen Milheim and my colleagues in the Academic Skills Center for their role in helping me to understand adult learning.

I have had other mentors and support systems that have played a role, both directly and indirectly, in my professional development. These mentors have played an important role in my own understanding of cardiovascular disease prevention, patient education, and health literacy. While their names are not mentioned, their contribution to my work is greatly appreciated. The patients that I have worked with over the past 30 years have also played a significant role. Finally, I would like to thank and acknowledge all of the patients and healthcare professionals that participated in my study. If I could mention all of you by name, I would, but of course I cannot.

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Chapter 1: Introduction to the Study

Health literacy is the ability of a person to understand and act on instructions given by a healthcare professional on how to manage a health condition (Parker & Ratzan, 2012). More than assessing reading level, health literacy includes numeracy, which is the understanding and manipulation of numbers; navigating the healthcare system; communicating with their healthcare team and care givers; and decision making (Nielsen-Bohlman, Panzer, & Kinzig, 2004). Health literacy is described by Parker and Ratzan (2012) as the intersection between the demands and complexity of the condition and the skills and ability necessary to manage the condition.

Cardiovascular and metabolic conditions including coronary artery disease, hypertension, heart failure, lipoprotein disorders, and diabetes are complex, demanding conditions requiring skill and knowledge on the part of the patient (Artinian et al., 2010). Compared to a condition that is simple to detect and simple to treat, the management of cardiovascular disease and diabetes requires a much higher level of patient involvement (Smith et al., 2013). Health literacy skills described by Smith et al. (2013) include knowing what, when, and how to monitor key biometrics, understanding nutrition labels and medication instructions, and being able to communicate symptoms.

Current estimates find as many as 90 million Americans lack health literacy skills, resulting in the need for health literacy to become a public health priority (Kutner, Greenber, Jin, & Paulsen, 2006). The U.S. Department of Health and Human Services, Office of Health Promotion and Disease Prevention (2010) developed an action plan calling for innovative and evidence-based approaches to promote health literacy and the creation of a vision for a more health literate population. The action plan led to research focused on the prevalence and health impact of low health literacy (Kutner et al., 2006; Berkman et al., 2011), and a better understanding of the causal pathways linking low health literacy to poor health outcomes (Paasche-Orlow & Wolf, 2007). Policies, strategies, and interventions are based on the use of plain language and clear and concise messaging (Koh et al., 2011).

In this chapter, I identified the background of the study, including gaps in the literature and in practice. The problem statement, purpose of the study, and research questions will be described in relation to these gaps. The theoretical framework and nature of the study were based on the problem statement, purpose of the study, and research questions. Definitions, assumptions, scope and delimitations, and the limitations will be identified. Finally, the significance of the study, including contributions to both knowledge and practice and implications for social change will be reviewed.

Background

Despite the attention given to health literacy, research on the health impact of strategies designed to build knowledge, health literacy, and self-management skills is mixed (Taggart et al., 2012). Quantitative studies have focused on self-management skills and health outcomes rather than on the improvement in knowledge and health literacy (Berkman et al., 2011; Taggart et al., 2012). In the quantitative studies, health literacy is represented as an ordinal value, grouped as *below basic*, *basic*, *intermediate*, and *proficient* (Berkman et al., 2011; Taggart et al., 2012). The emphasis on linguistic skills has led to debate about the very definition of health literacy and uncertainty about the extent to which health literacy scores can be improved (D’Eath, Barry, & Sixsmith, 2012). Assessments of health literacy focus on reading skills rather than functional measures such as navigation, communication, and decision-making (D’Eath et al., 2012).

Qualitative studies have focused on barriers encountered by patients with low health literacy skills and the attributes necessary to build health literacy skills, especially the communication skills of patients and their healthcare providers (Easton, Entwistle, & Williams, 2013; Edwards, Wood, Davies, & Edwards, 2012; Jorden, Buchbinder, & Osborne, 2010). Neither quantitative nor qualitative studies have addressed how health literacy skills are developed in patients with cardiovascular disease or diabetes.

The use of digital tools and mobile technology, for example smartphones, tablets, and devices that can monitor biometric data including blood pressure, heart rate, and calories, has fundamentally changed how individuals with chronic health conditions find and use health information (Beatty, Fukoaka, & Whooley, 2013). An increasing number of patients are using web-based tools to find information on diseases, conditions, and treatments, and mobile devices to track their results and communicate with their healthcare team (Lefebvre & Bornkessel, 2013). Of the adults who live with a chronic health condition, 72% of them use the Internet (Fox & Duggan, 2013). People with chronic health conditions use the Internet for many health-related activities such as gathering information about their medications, conducting research on alternative approaches, and reading about other people’s experiences (Fox & Duggan, 2013).

The majority of research on developing literacy skills is in children and adolescents (Lesgold & Welch-Ross, 2012). Educational models designed for classroom instruction, such as Bloom's taxonomy (Krathwohl, 2002), Vygotsky's zone of proximal development (Shabani, Khatib, & Ebadi, 2010), and the theory of multiple intelligences (Gardner, 2002), have been used in adult education programs, including English as a second language, but not specifically in adult health education. Baker et al. (2011) developed an educational intervention for heart failure patients designed to build health literacy skills, but empirical data are not available. The work by Baker et al. (2011) may demonstrate the impact of building health literacy skills. Although developed with a focus on patients with heart failure, the intervention by Baker et al. (2011) may translate to other groups with cardiovascular disease and diabetes.

The Agency for Healthcare Research and Quality published a health literacy toolkit designed to improve spoken and written communication, as well as tools for promoting empowerment and self-management (DeWalt et al., 2010). Simple messages, as described by Stableford and Mettger (2007), may help an individual with low literacy skills to understand the information but are not designed to build literacy skills and develop the patient's ability to manage their condition. The use of plain language and clear and concise messages does not explain how individuals recently diagnosed with a chronic health condition are able to find and use health information to build their knowledge and skills.

The teach-back method is a well-established strategy used in health literacy in which the patient is asked to repeat back what he or she has just heard. The teach-back method, however, is a test of understanding and implies that this information has already been received (DeWalt et al., 2010). Healthcare professionals have limited training and education in effective methods of teaching health literacy skills to their patients (Nielsen-Bohlman et al., 2004). Healthcare professionals, therefore, have a difficult time building health literacy skills in their patients.

Although research on behavior change theories conducted in patients with cardiovascular disease, including on the transtheoretical model (Beckie, 2006) and the health belief model (McCorry et al., 2009), may explain an individual's motivation, readiness for change, and self-efficacy, these models do not explain how the information, knowledge, skills, decision making, and communication skills are obtained in an individual with no prior experience with the condition. These theoretical and conceptual frameworks do not fully explain how new communication technologies can be brought directly to patients in their natural setting and used to build knowledge and health literacy.

The gap in the literature is in the basic understanding of how patients with cardiovascular disease and diabetes learn the information they need to manage their condition. Behavior change theories used in health literacy research focus on factors like motivation, readiness for change, and self-efficacy, not on learning. Strategies and methods, for instance the use of plain language and teach-back, focus on understanding but not on learning. Additionally, there is a gap in how digital tools and technologies can be used to build health literacy skills in patients with cardiovascular disease and diabetes. Healthcare professionals have limited training regarding effective methods for teaching new concepts (Nielsen-Bohlman et al., 2004). I explored the initial process of learning from the perspective of both the patient and the healthcare provider in patients with a new diagnosis of coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes.

Problem Statement

The Institute of Medicine report, *Health Literacy: A Prescription to End Confusion*, recommended assessing the approaches to increasing health literacy in the United States and abroad (Neilsen-Bohlman et al., 2004). These recommendations led to the national action plan to improve health literacy with the goal of pursuing a more health literate society (U.S. Department of Health and Human Services, Office of Health Promotion and Disease Prevention, 2010). To become a more health literate society requires building health literacy skills, especially the 90 million Americans who have below basic health literacy skills (Kutner et al., 2006).

Lesgold and Welch-Ross (2012) pointed out that there is a large body of research in the education literature on improving literacy skills, but there is little research in adults, especially in regards to the development of health literacy skills. Current strategies, policies, and interventions designed to mitigate the impact of low health literacy focus on the use of plain language and clear and concise messaging with an emphasis on improving the readability of printed and digital educational materials (Koh et al., 2011). Healthcare professionals are encouraged to use the health literacy toolkit as a resource to address health literacy in their patients (DeWalt et al., 2010). While there is an emphasis on reducing jargon and using plain language, a patient with cardiovascular disease or diabetes must eventually confront terms that are long, unfamiliar, and used by healthcare professionals and in educational materials (Smith et al., 2013).

The health literacy action plan provides recommendations for healthcare professionals and educators on best practices to promote health literacy, including readability and cultural and linguistic appropriateness (U.S. Department of Health and Human Services, Office of Health Promotion and Disease Prevention, 2010). Terms like cholesterol, angina pectoris, and the names of medications are frequently used by healthcare providers, and are important in self-management of cardiovascular disease (Smith et al., 2013). In the case of cardiovascular disease and diabetes, trade-offs must be made by healthcare professionals between readability, understanding, and an accurate description of the treatments, procedures, and tests that must be explained.

Many of the strategies to build health literacy skills are based on adult learning theory that emphasizes self-directedness, observational learning, and an accumulated reservoir of personal experiences (Clapper, 2010). Individuals who survived their first heart attack, however, do not have a personal experience to rely on. Even if they are motivated and self-directed, they still need to know how and where to find the information, be able to validate it as credible information, and be able to apply the information to their specific circumstances (Smith et al., 2013).

The gap in understanding how health literacy skills are developed has led to simplified approaches that do not emphasize the development of new skills. In the case of complex chronic conditions like cardiovascular disease and diabetes, gaining perspectives from patients and healthcare professionals leads to a better understanding of how health literacy skills are developed in patients who are newly diagnosed and do not have their own personal experiences to draw from. The insights and perspectives of the actions and processes used by patients and healthcare professionals to build health literacy skills are intended to result in strategies designed to improve health outcomes.

Purpose of the Study

The purpose of this study was to explore the gap in the literature by gaining perspectives of patients and healthcare professionals in the development of health literacy skills in patients who have been diagnosed with cardiovascular disease and diabetes within the past 12 months. This includes how healthcare professionals assess and build health literacy skills, as well as how patients find and use health information. Healthcare professionals include not only providers of medical care but also health educators and administrators. The intent was to go beyond the description of the low health literacy groups, the challenges, or the motivational issues and instead to focus on factors related to health literacy instruction to explore the process of learning and how new resources that are now available to patients are used.

The central phenomenon of this qualitative study was the process and actions from the perspectives of both patients and healthcare professionals in the development of health literacy skills. The central phenomenon of learning may be impacted by the instructional strategy and format of the healthcare professionals, and the use of technology, such as social networking sites, digital tools, web-enabled apps, and devices, including blood pressure monitors, scales, and physical activity trackers, that can be accessed directly by the patient (Beatty et al., 2013). Beatty et al. noted that patients can use search engines to learn more about their condition, track their own data using connected devices, and interact directly with other patients using social networks. A better understanding of how health literacy skills are developed must go beyond the description of the phenomenon using a grounded theory approach. I attempted to fill the gap in the literature of how health literacy skills are developed by gaining greater insights from both patients and healthcare professionals.

Research Questions

The primary research question was, how do individuals who have been recently diagnosed with a chronic health condition acquire knowledge and learn skills necessary to manage their condition? Specifically, the research questions included:

RQ1: What are the perspectives of patients and healthcare professionals in the development of health literacy skills in patients who have been recently diagnosed with a coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes?

RQ2: What are the perspectives of patients and healthcare professionals in the use of new technologies to build health literacy skills?

RQ3: How do healthcare professionals and health educators assess and build health literacy skills in their patients?

RQ4: How are instructional strategies designed to build knowledge and health literacy used by healthcare professionals aligned with the process of learning described by the patients?

These research questions were explored through interviews of patients newly diagnosed with a chronic health condition and healthcare professionals who treat and educate these patients, including how educational resources were selected, validated, and used to build knowledge and health literacy skills. The format and style of the information, including video, audio, print, or face to face, and whether that information is accessed via the Internet or in a healthcare facility were explored. In looking for insights into the research questions, the gender, age, ethnicity, education level, and prior knowledge of the condition were considered. In interviewing healthcare professionals, the training, experience, and emphasis placed on health literacy by the healthcare professionals were considered. How healthcare professionals assess health literacy skills and use this information to build knowledge, health literacy and self-management skills were explored. In both patients and healthcare professionals, the use of technology, including digital tools and mobile technology, was explored. Finally, gaps in the teaching strategies of the healthcare professionals and the learning strategies of the patients were examined.

Theoretical Framework

The social-ecological model is the primary theoretical framework for this study. Using a grounded theory approach allowed the development of a new theory to provide a better understanding of the development of health literacy skills. Adult learning theory, the health belief model, and the transtheoretical model have been used in health literacy research. The social-ecological model is a multilevel approach, including individual factors, genetic and constitutional factors, social factors, and economic policies (Sallis, Owen, & Fisher, 2008). The multiple levels of influence of the social-ecological model, as noted by Sallis et al. (2008), include an intrapersonal level, involving the characteristics that influence behavior; the interpersonal level involving relationships with family, friends, and peers; and the community level, involving institutional factors like rules and regulations; community factors, including social networks; and public policy factors including laws and regulations. Health literacy is a product of individual, social, and environmental factors that are mediated by education, culture, and language (Nielsen-Bohlman et al., 2004). In this social-ecological framework, health outcomes and the costs of health literacy result from the intersection of the healthcare system, the educational system, culture, and society (Nielsen-Bohlman et al., 2004). The social-ecological model fits the conceptual model for the development of literate practice, described by Lesgold and Welch-Ross (2012). This multilevel approach to improving health literacy skills includes the learner, such as their knowledge, education, and linguistic background; the learning context, like culture and experience; the teaching methods and tools; and the literacy activity and purpose (Lesgold & Welch-Ross, 2012).

Discrepancies in the very definition of health literacy have led to an inconsistent application of a theoretical or conceptual framework (Schecter & Lynch, 2011). Health literacy is defined in terms of reading skills, numeracy, navigating the health system, and communicating with healthcare professionals, which does not explain how an individual recently diagnosed with a chronic health condition is able to identify or access key information needed to manage their condition (Parker & Ratzan, 2012). Educational theories such as Bloom’s taxonomy (Krathwohl, 2002), Vygotsky’s zone of proximal development (Shabani et al., 2010) and Gardner’s (2002) theory of multiple intelligences are being used in adult education, including ESL training, and provide a theoretical framework for teaching and learning in these populations. These teaching methods are based on the development of foundational skills to the point of mastery. A better and updated understanding of how this information is obtained is necessary for these new instructional strategies to be effective. *Teach to Goal* is an example of an intervention designed to build health literacy skills by staging and delivering small segments of educational material over time to patients with heart failure (Baker et al., 2011).

Nature of the Study

A grounded theory approach was used in this study to explore the perspectives of patients who have been diagnosed with coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes within the past 12 months, and the healthcare professionals who treat those patients. The grounded theory process described by Corbin and Strauss (2015) was used to gain a better understanding of the actions and processes of building health literacy skills, leading to a new theory. This theory may lead to new insights into the people, resources, and medium used to acquire the information, how to evaluate and act on that information, and address the barriers they encounter related to the building of knowledge, health literacy, and self-management skills, leading to better health outcomes. Grounded theory was selected because it goes beyond a description of the phenomenon of a common experience to a unified theoretical explanation of the process or action (Corbin & Strauss, 2015). This distinction is important due to the gaps in the theoretical and conceptual frameworks that do not fully explain the process of building knowledge, health literacy, and self-management skills in the case of a new experience, such as when someone is diagnosed with a chronic health condition. Regardless of whether a new theory emerges from this research, new insights into this important dynamic between the patient and their healthcare professionals are sure to be gained.

Interviews were conducted with 16 people who have recently been diagnosed with a chronic health condition. Interviews were conducted with 19 healthcare professionals and educators to gain their insights and approaches to health literacy instruction. Two sets of semistructured interviews were conducted, one for the patient and one for the healthcare professional. Selection of participants representing patients recently diagnosed with heart disease, heart failure, hypertension, diabetes, or a lipoprotein disorder was done with a theoretical sampling methodology as recommended by Corbin and Strauss (2015). The subjects were selected based on their ability to provide insights necessary to fully develop or saturate the model needed to build a new theory, as recommended by Creswell (2013). Participants were recruited from social networking sites that target patients with heart disease and diabetes. Flyers were distributed to a cardiac rehabilitation program, a cardiology practice, and a primary care medical practice.

Using constant comparison based on open coding, I looked for causal conditions, strategies, intervening conditions, and consequences; through this analysis, categories and themes were determined through a process described by Corbin and Strauss (2015). These findings led to axial and then selective coding methods. Constant comparison requires continual revision throughout the course of the study until saturation of the themes and categories have been achieved, leading to a new, or updated theory of how knowledge is acquired and skills are learned (Corbin & Strauss, 2015).

Definition of Terms

Critical health literacy: Higher level health literacy skills, including the ability communicate and interact with healthcare professionals and process information necessary for decision-making (Nutbeam, 2008).

Functional health literacy: Beyond reading literacy, functional health literacy takes other factors related to the definition of health literacy into consideration like numeracy and navigation of the healthcare system (D'Eath et al., 2012).

Healthcare professionals: Healthcare professionals include providers of medical care, including physicians, physician assistants, nurse practitioners, nurses, dietitians, and exercise physiologists, as well as those who provide health education, develop educational materials, and work as administrators.

Health literacy: The degree to which individuals have the capacity to understand basic health information and services needed to make appropriate health decisions (Ratzan & Parker, 2012).

Literacy or reading literacy: A more traditional definition of literacy, which includes prose literacy and document literacy (Kutner et al., 2006). Prose literacy is the ability to read and comprehend information from continuous sources, such as newspapers, magazines, and books. Document literacy is the ability to read and comprehend information from non-continuous sources like medications and food labels (Kutner et al., 2006).

Navigating the health system: The understanding of how the healthcare system works, including when and where to use the healthcare system (D'Eath et al., 2012).

Numeracy: The ability to understand and manipulate numbers. An example is the ability to balance a checkbook. In a health literacy context, numeracy is the ability to calculate calories from a food label, or to calculate insulin requirements based on the blood sugar (Kutner et al., 2006).

Self-management skills: Self-management skills are actions taken by the patient to manage their condition, such as physical activity, following nutritional guidelines, taking medications as prescribed, and monitoring key health metrics, including signs, symptoms, and health data, including blood pressure, weight, and physical activity (Smith et al., 2011).

Assumptions

The assumptions for this study were that the participants were truthful in their responses and be able to accurately describe their experiences. It was assumed that the participants, selected purposefully, were a rich source of information allowing for saturation of the topic, resulting in a new theory and greater insights into the development of health literacy skills. Assumptions about the patients were that their healthcare professionals diagnosed them accurately with a chronic health condition. Assumptions about the healthcare professionals were that they received accurate and complete information in making the diagnosis.

Scope and Delimitations

The chronic conditions in this study were cardiovascular and metabolic in nature, such as coronary artery disease, high blood pressure, heart failure, lipid disorder, metabolic syndrome and diabetes. These conditions were selected because they are complicated, require the manipulation of numbers, and require action (Smith et al., 2011). For example, a person with diabetes must understand the meaning of terms and concepts including carbohydrates, glucose, and insulin; be able to balance physical activity, nutrition, and medications to achieve desired blood glucose; and know how much insulin to take. Infectious diseases and other chronic diseases like cancer were not considered in this study. This research study was delimited to those newly diagnosed within the past 12 months to improve their recall and because of the recent growth in the use of the Internet, smartphones, and digital tools. Although there is no standard definition of the timeframe for being newly diagnosed, the most common timeframe is within the past 12 months (Vamos et al., 2012). The participants represented a mixture of gender, education level, and race.

Limitations

A limitation of this study included the use of small sample sizes that may not be generalizable to other groups and the possibility that the qualitative methods distort the observations or responses due to personal bias (Patton, 2002). Another limitation was that there is no measurement of health literacy. Therefore, it will be unknown whether the process described by patients and healthcare professionals resulted in an improvement in health literacy or self-management skills. The study participants, the healthcare professionals, and the researcher have biases related to the development of health literacy skills. To mitigate this bias, I as the researcher focused on the process of building knowledge and skills rather than focusing on opinions. Recall bias may have occurred if participants had different levels of accuracy regarding the same event (Aschengrau & Seague, 2008).

Significance

This research regarding patients' and healthcare professionals' perspectives of health literacy plays an important role in the development of strategies and interventions. As patients and healthcare professionals have become more accountable for adopting prevention and self-management behaviors, more effective solutions are required. The perspectives of the patients and healthcare professionals will lead to greater insight into the processes and actions leading to improved health literacy. These perspectives and insights provided by patients will allow healthcare professionals and health educators to better align their instructional strategies. These better aligned instructional strategies may ultimately lead to more opportunities for patients to improve their health literacy skills, resulting in better health and improve health outcomes.

Interventions designed to actually improve health literacy skills may have social change implications, such as better health for this group of patients, and may apply not only to those with inadequate health literacy skills but also to those with adequate, above average, and proficient skills who want to improve their learning. For these strategies to have this desired impact, it is necessary to understand how these people know what to do, where to get the information, as well as how to evaluate that information. New insights into these underlying concepts, using grounded theory, may lead to a new theory and greater insights into the process of building health literacy skills, resulting not only in better improvements in knowledge, health literacy, and self-management skills, but also to better health outcomes, leading to a new theory that can be used to develop policies, strategies, and interventions designed to improve health literacy.

The practical implication for the patient is that they will better understand the terms and concepts, and be able to scale and manipulate the numbers that are relevant to their condition, allowing them to know when and where to access healthcare services, and have a more informed communication with their healthcare professional, resulting in shared decision making in the development of their plan. For the healthcare professional, the practical implication is a better understanding of the process of learning for their patients, resulting in a more focused plan designed to build knowledge, literacy, and self-management skills. Better understanding of the development of health literacy skills may result in more effective educational strategies by healthcare professionals. Finally, a practical application is for patients and healthcare professionals to have a better understanding of how communication technology and digital tools can be used to build knowledge, literacy, and self-management skills.

The social change impact is based on the desired goal, established by the U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion (2010), supported by the social-ecological model, to create a more health literate society. By becoming more health literate, patients will be able not only to understand the basic concepts of their health, but also be able to advance to a higher level of knowledge and skills. Healthcare professionals will be able to communicate more effectively with their patients, use strategies designed to build knowledge and skills, or direct the patient to resources designed to promote health literacy. Finally, makers of educational resources and digital tools will design their products in a manner consistent with a health literate society.

Summary

Health literacy is a public health priority, resulting in a vast amount of research on the definition and health impact of health literacy. This research has led to strategies and policies focused on using plain language with clear and concise messaging. It appears, however, that little research has been conducted on strategies to build health literacy skills. Current theories explain motivation and self-efficacy, and strategies focus on making sure that the patient understands the material. Neither the theories nor the strategies fully explain how to get this information in the first place. I applied a qualitative approach using grounded theory to better understand the process of learning. In Chapter 2, a more detailed review of the literature identifying the key issues and gaps related to this study will be provided. In Chapter 3, a detailed description of the methodology will be provided.

Chapter 2: Literature Review

Introduction

Commonly used theoretical models for behavior change such as the health belief model (McCorry et al., 2009), the transtheoretical model (Beckie, 2006), and adult learning theory (Claper, 2010) are based on motivation, readiness for change, and self-efficacy, but do not explain how knowledge and skills are developed. Conceptual approaches including the use of plain language with clear and concise messaging (Koh et al., 2011) do not explain how individuals diagnosed with coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes are able to build the knowledge, health literacy, and self-management skills necessary to manage their condition.

The purpose of this study was to gain greater insights into how these skills are developed, including instructional approaches by their healthcare professionals and the use of digital tools and technology leading to the development of a new theory for health literacy instruction. These insights and theory can be applied to policies, strategies, and the development of new interventions designed to build knowledge, health literacy, and self-management skills for patients with cardiovascular disease and diabetes. In this chapter, the literature search strategies, theoretical foundation, and the conceptual framework will be reviewed, followed by a review of the literature related to health literacy, including the definition, assessment, causal pathways, and health impact of health literacy. Finally, educational and digital strategies using both qualitative and quantitative methods for patients with coronary artery disease, heart failure, hypertension, lipid disorder, metabolic syndrome, and diabetes will be reviewed.

Literature Search Strategy

The primary literature search strategy included the use of the Walden Library, Google Scholar, and the references cited in review articles. The Walden Library included the search engines in health sciences and educational databases: CINAHL, Medline, PubMed and ERIC, as well as multidisciplinary databases, such as ProQuest and Science Direct. References identified through Google Scholar or through the reference lists of other articles were searched for in the Walden Library to gain access to the full manuscript. Search terms included: *health literacy, functional health literacy, critical health literacy, health literacy assessment, numeracy, readability, adult education, teaching literacy*, *patient education*, *instructional strategies, health literacy and heart disease, health literacy and high blood pressure*, *health literacy and heart failure, health literacy and diabetes, health literacy and knowledge*, *health literacy and self-management skills*, *health literacy and digital tools*, and *health literacy and mobile devices*. The date ranges in the literature searches were primarily studies published within the past 5 years, but earlier studies that were relevant to the topic were included.

Theoretical Foundation

Behavior Change Theory

Researchers use behavior change theory inconsistently in health literacy research due to discrepancies in the very definition of health literacy (Schechter & Lynch, 2011). The primary behavior change theories used in health literacy research includes the social-ecological model (Warf-Higgins Begory & MacDonald, 2009) and adult learning theory (Clapper, 2010). Key elements of andragogy, or adult learning theory, like self-directedness and drawing upon a reservoir of personal experiences, however, do not explain how information is gained in an individual with a new diagnosis of a chronic condition (Grace, 2011). The primary theoretical framework in this study was the social-ecological model due to the multilevel nature of the model, including individual factors as well as environmental and population-based factors (Sallis et al., 2008). For example, the healthcare professional may discuss the topic with the patient at an intrapersonal level; the patient may discuss the topic with friends and family or use social media at an interpersonal level; the patient may read a brochure or watch a video on the topic provided in a worksite setting; and these educational materials may have been produced using guidelines or recommendations of following health literate practices.

The use of social media provides opportunities for building and expanding interpersonal networks. The social-ecological model is aligned with the Institute of Medicine report on health literacy, which stated that health literacy is the product of individual, social, and environmental factors (Nielson-Bohlman, Panzer, & Kinzig, 2004). In addition to individual treatment strategies developed by healthcare professionals, many patients are now influenced by a new digital environment that includes the Internet and e-mail, smartphones, tablets, apps, and connected health devices that can measure, monitor, and store health information in the cloud (Beatty et al., 2013).

The origin of the social-ecological model is from a variety of sources with core principles comprising multilevel interventions including interpersonal, intrapersonal, organizational, community, and public policy levels with an emphasis on how behaviors are influenced across these different levels (Sallis et al., 2008). Another key principle of the social-ecological model is reciprocal causation, meaning that individuals influence and are influenced by other people and their environment (Sallis et al., 2008). Therefore, the instructional strategies of the healthcare professional and the readability of the educational materials they are exposed to will influence the individual’s ability to understand and act on that information. The social-ecological model has been applied to health behaviors including diabetes self-management, tobacco prevention, physical activity, and the management of multiple behaviors that are required to successfully manage complex conditions such as heart disease, heart failure, lipoprotein disorders, and hypertension (Sallis et al., 2008). A multilevel approach is recommended by the American Heart Association for the dissemination of health information designed for cardiovascular prevention and disease management (Pearson et al., 2013). The social-ecological model applies to the development of health literacy skills as individuals must navigate instructions from their healthcare professional, messages from social and mass media, and the influence of friends and family, but this model still does not explain how these skills are developed.

Educational Theory

While the primary theoretical framework in this study is the social-ecological model, the development of health literacy skills involves a process of teaching and learning. Health literacy is at the intersection of the healthcare system, the educational system, culture, and society (Nielsen-Bohlman et al., 2004). Educational theory, including the linguistic background of learners, their knowledge, culture, learning context, and exposure to experiences and teaching methods, must be considered (Lesgold

& Welch-Ross, 2012). Common educational theories and models used in literacy include Bloom's taxonomy (Krathwohl, 2002), Vygotsky's zone of proximal development (Shabani et al., 2010), and Gardner's (2002) theory of multiple intelligences.

Bloom's taxonomy is a hierarchical educational framework beginning with foundational skills that build to the point of mastery (Krathwohl, 2002). A revised taxonomy takes into account the cognitive process dimension that is a broader range of factors that impact teaching and learning. This taxonomy includes remembering, understanding, applying, analyzing, evaluating, and creating (Krathwohl, 2002). This applies not only to teaching reading, vocabulary, and math to children, but also to teaching terms, concepts, and decision making to adults that can be applied to health literacy. The theory of multiple intelligences is used to apply different styles of learning, like visual, auditory, and kinesthetic to build knowledge (Gardner, 2002). The theory of multiple intelligences educational model integrates with the social-ecological model by providing different formats for learning at different levels, including face to face interaction, reading an article or brochure, watching a video, or interacting with an app on a smart phone. Using the social-ecological theory, the theory of multiple intelligences can be applied at different levels. The zone of proximal development and problem-based learning are theories of cognitive development that use the metaphor of a scaffold to support individuals' learning needs through their learning zone (Richard-Amato, 2003). The use of plain language is an example of establishing understanding at the base of the learning zone. Bloom's taxonomy, the theory of multiple intelligences, and the zone of proximal development can be applied to the development of health literacy skills for patients with cardiovascular disease and diabetes.

While these teaching and learning methods were designed for children and adolescents to teach literacy skills in the classroom, it is unclear how they apply to adults. The high adoption rate of the Internet, e-mail, smartphones, and connected health devices in older adults, including those with chronic health conditions, indicates that learning is possible, since these tools were not available when these people were in school (Fox & Duggan, 2012).

Conceptual Framework

The U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion (2010) developed an action plan for becoming a more health literate population. This action plan encourages the dissemination of evidence-based health literacy practices and has led to a better understanding of the low health literacy population. A hallmark of these strategies is the use of clear and concise messaging in plain language (Koh et al., 2012). Koh et al. (2012) described the cycle of care where patients become passive participants in their own plan of care and lack the basic knowledge and skills necessary to manage their condition, resulting in the need for additional medical care. To break this cycle of care, Stableford and Mettger (2007) recommended the avoidance of medical jargon and the use of plain language to simplify the message. Although this strategy is appropriate for individuals with low literacy skills, these are communication strategies, and it is unclear that these strategies will result in the development of new skills, which are necessary for complex conditions including heart disease, heart failure, hypertension, and diabetes. The use of an educational model such as Bloom's taxonomy (Krathwohl, 2002) or the zone of proximal development (Shabani et al., 2010) using plain language with clear and concise messaging is the first step in the process of learning, but both models progress to higher levels of understanding and development.

The conceptual models for the development of health literacy skills begin with health knowledge. What is unclear is how that knowledge is initially acquired. Speros (2004) pointed out that the concept of health literacy, including the abilities and experiences of the patients, the causal relationship, and health impact, has become a public health issue among healthcare professionals. Using multiple conceptual models, Sorensen et al. (2012) created an integrated conceptual model of health literacy with a multilevel approach including four dimensions of health literacy— access to information, understanding of the information, appraisal, and application—and three health domains—healthcare, disease prevention, and health promotion.

Jordan, Buchbinder, and Osborne (2009), using grounded theory to study patients with chronic disease in both emergency room visits and the general population, identified the abilities necessary to find and understand the information presented to them by their healthcare professional. These abilities included knowing when and where to seek health information, verbal communication skills, assertiveness, literacy and application skills, and the ability to process and retain the information (Jordan et al., 2009). These abilities form a conceptual model of the patient's journey from identification of the health issue, to accessing the healthcare system and communicating with healthcare professionals, resulting in a resolution of the issue (Jordan et al., 2009). This process requires the interaction of the abilities of the patient with healthcare professionals and other environmental factors.

Using a longitudinal qualitative approach, Edwards et al. (2012) identified a conceptual model for the development of health literacy skills, beginning with establishment of health knowledge, the development of skills and actions, and leading to the identification of options and more informed decision making. This progression relies on the motivation of the patient and approach of the professional (Edwards et al., 2012). Although this progression of knowledge, skills, and decision making provides important insights, it is unclear how the knowledge and skills are developed.

The development of health literacy skills is a process—from knowledge to skills development and decision making, and the level of health literacy may impact the individual's ability to progress. Smith, Dixon, Trevena, Nutbeam, and McCaffrey (2009) found that patients with higher education and functional health literacy skills became active participants in the medical decision-making process, while patients with lower education and functional health literacy skills were less involved in medical decision making. The process of building health literacy skills is a hierarchical approach, much like the educational models used to teach reading and mathematics.

In this study the conceptual model for the development of health literacy skills was explored. Cardiovascular disease and diabetes are complex, chronic conditions. The process of developing health literacy skills in patients with a new diagnosis, and do not have an experience to draw from, will be explored. The gap in these models is the initial step of developing the knowledge necessary for the development of functional and critical skills. For example, a patient with diabetes that does not learn the basic knowledge of the disease may have difficulty with functional and critical decision making skills. The recommendations from the healthcare professional and access to digital tools both play a role in this conceptual model. How patients use medical advice and digital tools and technology in the process of knowledge building and skills development were explored in this study.

Figure 1 is a conceptual model of the sources used to build knowledge and health literacy, based on the conceptual models of Parker and Ratzan (2012), Nielsen-Bohlman et al. (2004), Jordan et al. (2009), and Edwards et al. (2012). This process includes prior knowledge as well as medical advice from healthcare professionals, health education materials from printed and digital sources, and nonmedical sources, such as friends and family.

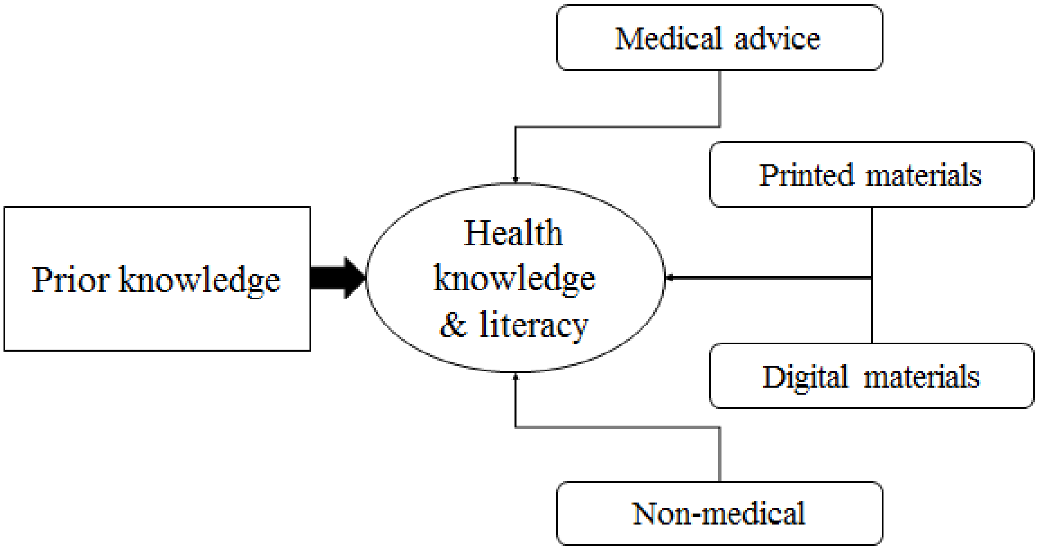

Figure 1. Sources used in the development of health literacy skills.

Literature Review Related to Key Components of Health Literacy

While health literacy is a public health priority in the United States, it is not a new concept, and it is a global public health concern (Pleasant, 2011). Nutbeam (2000) described health literacy in three levels, including functional health literacy, which is the use of health information to manage health and navigate the healthcare system, interactive health literacy, which is the development of interpersonal and communication skills, and critical health literacy, which is the ability to act on and make health-related decisions. To achieve health benefits, health education must go beyond the dissemination of information to the achievement of all three levels of health literacy (Nutbeam, 2000).

The results of the National Assessment of Adult Literacy (NAAL) were reported by Kutner et al. (2006) and revealed that 90 million Americans may have below basic health literacy skills. The NAAL, administered to over 19,000 adults over age 16, measured three domains of literacy, prose, document, and quantitative, that classified individuals as below basic (14%), basic (22%), intermediate (53%), and proficient (12%) (Kutner et al, 2006). It is important to note that classification of health literacy tracks with other social determinants of health, such as income, education, and access to health insurance (Kutner et al, 2006).

Following the release of the NAAL (Kutner et al., 2006) the Institute of Medicine released "*Health Literacy: A prescription to end confusion"*, making health literacy a public health priority (Nielsen-Bohlman et al., 2004). This Institute of Medicine report (Nielsen-Bohlman et al., 2004) set the agenda for creating a more health literate culture, including both the healthcare and education systems, leading to the national action plan for health literacy (US Department of Health and Human Services, Office of Health Promotion and Disease Prevention, 2010).

Health literacy is not just a public health issue in the United States. Health literacy is considered a public health priority in Europe with a broad and more inclusive definition of health literacy by the World Health Organization Regional Office for Europe (Kickbusch, Pelikan, Apfel, & Tsouros, 2013). The European definition of health literacy includes knowledge, motivation, competencies to access and apply health information, and the ability to make judgments concerning their health.

While differences in methodologies and populations make it difficult to compare rates of low health literacy in the United States to other parts of the world, there is an increase in the number of peer reviewed publications and public health initiatives that address health literacy worldwide (Pleasant, 2011). Pleasant and Kurvuvilla (2008) found a difference in clinical and public health perspectives in China, Mexico, Ghana, and India, suggesting challenges in both assessing and developing health literacy. In the European Health Literacy Project (2012) 47% of the population had limited health literacy skills. The European Health Literacy Survey was scientifically grounded, derived from the definition and concepts, and pre-tested and field tested with input from health literacy experts, and was carried out in cooperation with partners in the Netherlands, Greece, Ireland, Austria, Poland, Spain, Bulgaria, and Germany and in collaboration with over 20 academic institutions and public health agencies (European Health Literacy Project). Cathery-Goulart et al., (2009) administered a translated version of the Test of Functional Health Literacy in Adults (TOFHLA) to 312 healthy individuals in Brazil, finding that 32% had limited health literacy skills.

The Scope of Health Literacy

Health literacy is generally described as the ability of individuals to access and make use of health information necessary to manage their health. While closely associated with literacy in terms of reading and speaking skills, health literacy requires additional skills, such as numeracy, communication, and decision making (Parker & Ratzan, 2012). Numeracy is a key aspect of health literacy as it relates to the understanding of numbers, which are important for the management of weight, blood pressure, and glucose (Baker, 2006). Discrepancies in the definition of health literacy created a gap in the understanding of the impact and application of functional and critical health literacy skills, including navigating the healthcare system, communicating with healthcare professionals, and making decisions (Ishikawa & Yano, 2008).

While the broader definition is more inclusive, Easton et al. (2010) note that this provides challenges to healthcare professional in identifying the hidden population of patients that have good language skills, but lack critical navigation, communication, and decision-making skills, while other patients may have language or cultural barriers, or otherwise have the capacity to learn new skills. Furthermore, Peerson and Sauders (2009) make a clear distinction between literacy, health literacy, and medical literacy. Literacy refers not only to reading and writing, but also to the general understanding of the topic, while medical literacy refers to healthcare-related skills, like reading and understanding medication instructions and nutrition label information (Peerson & Sauders, 2009). Health literacy refers to the ability, or capacity, to apply higher level skills, such as communication, navigation, and decision making, to the more factual orientation of literacy and medical literacy (Peerson & Saunders, 2009).

Different definitions of health literacy have resulted in different approaches (Nutbeam, 2008). Consideration of health literacy as a risk factor for poor health outcomes led to the identification of individuals with low health literacy skills and strategies designed to mitigate the impact of low health literacy (Nutbeam, 2008). Consideration of health literacy as an asset that can be built requires educational and adult learning strategies to build these skills (Nutbeam, 2008). Nutbeam observed that while significant progress was made in the identification of individuals with low health literacy skills, resulting in more effective health literate practices, more research is required to build health literacy skills. D'Eath et al., (2012) have similarly identified research gaps related to health literacy interventional strategies. In this study, perspectives of health literacy instruction from patients and healthcare professionals, using the broader definition of health literacy, navigation and communication, and critical skills, including decision making were explored across all literacy levels, not just those with low health literacy skills.

Health Literacy Assessment

An individual's capacities, such as reading fluency and prior knowledge, including vocabulary interact with the complexity of the message, which then translates to health literacy (Baker, 2006). While reading level and word recognition can be measured, these factors alone do not adequately measure functional or critical health literacy (Baker, 2006). The NAAL is a direct measurement of literacy, defined as prose literacy, which is the ability to understand continuous texts, including magazines, brochures, or instruction manuals, document literacy, which is the ability to understand non-continuous texts, like medication and food labels, and quantitative literacy, which is the ability to understand and manipulate numbers, such as balancing a checkbook (Kutner, Greenberg, Jin, & Paulsen, 2006). The NAAL did not test functional health literacy and cannot be completed in a clinical setting. Tests of functional health literacy that can be conducted in a clinical setting and used by the healthcare professional to target interventions are needed for a more complete assessment of health literacy (Baker, 2006).

Health literacy is not consistently measured, both in research as well as the clinical setting, making it difficult to interpret and compare data from an individual and population level (Jordan, Osborne, & Buchbinder, 2011). Jordan et al. evaluated 19 health literacy measurement instruments and three measurement protocols, advocating for a more standardized way to measure health literacy, while developing measures to assess the broader definition of health literacy. For example, numeracy skills are part of the broader definition of health literacy. Golbeck, Ahlers-Schmidt, Paschal, and Dismuke (2005) provided a definition and operational framework for the measurement of numeracy as “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, bio statistical, and probabilistic health information to make effective health decisions. Huizinga, Beech, Cavanaugh, Elasy, and Rothman (2008) demonstrated that low numeracy skills are associated with a higher body mass index.

The Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) are the most common validated tests of functional health literacy (Berkman et al., 2011). The REALM tests word recognition, while the TOFHLA tests how well the individual can interpret what is read as well as what numbers that are presented to them mean (Berkman et al,, 2011). A shortened form of the TOFHLA, the S-TOFHLA is shorter, easier to administer, and compares favorably to the TOFHLA (Baker, Williams, Parker, Gazmaranian, & Nurss, 1999). The S-TOFHLA uses a modified Cloze procedure where the subject reads a health-related passage in which every fifth to seventh word is omitted, and the correct word is selected from a choice of four options (Baker et al., 1999). Linear regression was used by Baker et al. to determine the individual weights of the reading comprehension and numeracy items. Cut points for literacy categories of inadequate, marginal, and adequate were based on age and years of school (Baker et al., 1999). Each selection is scored 1 for a correct response and 0 for an incorrect response (Baker et al., 1999). In an assessment of 1,549 new Medicare enrollees, Gazmaranian et al., (2006) demonstrated that a measure of functional health literacy, using the S-TOFHLA, is a predictor of poor medication refill compliance in patients with cardiovascular disease.

The Newest Vital Sign is a general assessment of health literacy that takes only three minutes to administer, is easy to use and is comparable to more extensive tests of health literacy (Ciccarelli-Shaw, West, Bremmeyer, & Savoy-Moore, 2010). The Newest Vital Sign compared to the REALM and the S-TOFHLA, however, is not associated with health outcomes (Osborn et al., 2007). In a sample of almost 10,000 participants, the Demographic Assessment for Health Literacy (DAHL) is a predictor of the S-TOFHLA using age, gender, race and years of school completed, which is used by insurance companies, including Prudential (Hanchate, Ash, Gazmaranian, Wolf, & Paasche-Orlow, 2008). Hahn, Choi, Griffith, Yost, and Baker (2011) tested HealthLitt, a health literacy assessment, in 608 participants using touchscreen technology and item response theory. While there was no measurement of health, the HealthLitt met psychometric standards and may be used in digital tools to assess and build health literacy skills (Hahn et al., 2011). Finally, Chinn and McCarthy (2013) developed the All Aspects of Health

Literacy Scale (AAHLS) which includes measures of functional, communicative, and critical health literacy with adequate reliability.

While the majority of health literacy assessment tools measure general health literacy across the population, there are tools that measure specific skills within disease states. Jeppeson, Coyle, and Miser (2009) developed and tested a single item literacy screening tool on a cross section group of patients with diabetes. Since health literacy assessments are done infrequently and are not easily administered by healthcare professionals, this tool demonstrated that health literacy assessments can be done by healthcare professionals and correlated with the S-TOFHLA (Jeppeson et al., 2009).

In addition to evaluating the health literacy skills and capacity of individuals, there are tools for evaluating the readability and health literacy demands of health education materials. The Roundtable on Health Literacy (2013) and the Preventive Health Partnership have established guidelines for the development of educational materials aligned with the Department of Health and Human Services Office of Disease Prevention and Health Promotion (2010) national action plan, including keeping documents at less than a 5th grade reading level, keeping sentences to less than 15 words, and avoiding the use of multi-syllable words. The majority of documents do not meet this goal and are at the 12th grade level or higher (Hill-Briggs, Schumann, & Dike, 2012). Taylor-Clarke et al., (2012) found that patient education materials commonly used in heart failure clinics are not suitable for the average patient. Kaphingst et al., (2012) developed the health literacy INDEX comprising of best practices in the development of health education materials. These best practices included using plain language, having a clear purpose, supporting graphics, skills-based learning, and audience appropriateness, which were compared to and correlated with expert feedback, and reliability testing (Kaphingst et al., 2012).

In qualitative studies the primary assessment tool for health literacy is the researcher using structured and semi-structured interviews, focusing on actions and behaviors of the participants, rather than on their health literacy skills or knowledge. Jordan et al. (2009) conducted structured face to face and telephone interviews on 48 participants, focusing on the journey and navigation of the patient, identifying key skills. Skills for building health literacy included the process of seeking health information, verbal skills, assertiveness, and the capacity to process, retain, and apply knowledge and skills (Jordan et al., 2009). It is important to note that these skills are not measured in standard health literacy assessment tools, such as the TOFHLA, REALM, or Newest Vital Sign (Jordan et al., 2009). Edwards et al. (2012) conducted serial, semi-structured interviews on 18 participants over a 9 month period to investigate the development of health literacy skills, finding a trajectory from knowledge to literacy and skills, to the identification of options and informed decision making. Smith et al., (2009) combined interviews with quantitative measures of health literacy and level of education to investigate the role of health literacy on medical decision making, identifying that patients with low literacy and education do not take an active role in decision making. These qualitative studies provide important insights into the process of developing health literacy skills, and the importance of establishing baseline knowledge, but did not explore how that knowledge is initially acquired.

Causal Pathways

While low health literacy is associated with poor health outcomes, it is linked to behaviors that impact the prevention, treatment, and self-management of the health condition. The conceptual model describing the causal links between health literacy to healthy behaviors is proposed by Paasche-Orlow and Wolf (2007). Components of this causal link between health literacy and health behaviors include access, relationships with the health care professional and the ability to manage their own care. Individuals with low literacy avoid or delay care because they are unaware of critical information, such as prevention guidelines or signs and symptoms (Paasche-Orlow & Wolf, 2007). Patients with low health literacy feel less comfortable interacting with the healthcare system and may be less adept at navigating the system (Paasche-Orlow & Wolf, 2007). Social factors, such as social support, income, culture and language, cognitive/physical factors including money, vision and hearing, and demographic factors, like race/ethnicity, education and age determine health literacy resulting in improved health outcomes (Paasche-Orlow & Wolf, 2007). Social factors result in a limited ability of low literacy patients to self-manage their own healthcare, including following prevention based strategies, participation in screening and managing chronic diseases (Paasche-Orlow & Wolf, 2007). Extrinsic factors adversely affect patients with low literacy, including the ability to understand how to take their medications, how to use medical equipment like a glucometer or insulin pump, how to use more advanced technology, including internet based applications, and how to interpret instructions given to them by their healthcare professional such as how to take their medicine (Paasche-Orlow & Wolf, 2007).

Social determinants of health, including levels of education and income, as well as ethnic, cultural and linguistic factors are key components of the action plan to create a more health literate culture (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010) and the Health Literacy Toolkit (DeWalt et al., 2011). Ethnic factors like language barriers and cultural considerations may impact the individual's ability to understand the information being presented to them, while education and economic factors may impact their capacity to use the information (Nutbeam, 2008).

An important aspect of the causal pathway between health literacy and health is the ability to navigate and access the healthcare system (Paasche-Orlow & Wolf, 2007). Cho, Lee, Arozullah, and Crittenden (2008) interviewed 489 individuals with low health literacy to explore the association with healthcare utilization and health status, looking at the intermediate steps of disease knowledge, self-care behaviors, use of preventive health care, and compliance with medication. Health literacy is associated with health outcomes and none of the intervening steps confounded this relationship (Cho et al., 2008).

Age is a factor in the relationship between health literacy and health. In older adults with chronic conditions, such as heart disease, heart failure, and stroke, the relationship between age and health literacy is confounded by cognitive impairment and memory deficits (Baker et al., 2011). Studies of health literacy in older adults reveal an association with poor health, but the rate of chronic disease is much higher in this cohort. Older age does not inhibit the development of knowledge or the building of self-management skills (Baker et al.).

Mottus et al. (2014) compared health literacy, using the REALM, S-TOFHLA, and Newest Vital Sign to measures of physical health and fitness and cognitive ability in 730 older people. Lower health literacy scores were associated with worse health outcomes, but after adjusting for covariates, only physical fitness was associated with health literacy (Mottus et al, 2014). Ownby, Waldrop-Valverde, and Taha (2012) studied those who participated in the NAAL and were over age 40, finding that health literacy was associated with social determinants of health and self-reported health outcomes. Even after controlling for other explanatory variables, health literacy was a significant predictor of health status (Ownby et al., 2012).

The causal relationship between health literacy, behaviors and specific health conditions is established. Osborn, Paashe-Orlow, Cooper Bailey, and Wolf (2011) validated the conceptual model proposed by Paasche-Orlow and Wolf (2007) in 330 patients with hypertension. Using path analytic models, significant paths were identified between health literacy and knowledge, knowledge and self-efficacy, self-efficacy and physical activity, and physical activity and health status, demonstrating the role health education interventions play in the development of self-management skills and desired health outcomes (Osborn et al., 2011). In a study of 605 heart failure patients, Macabasco-O’Connell et al. (2011) examined the relationship between health literacy and heart failure related quality of life and explored the relationship with self-efficacy and knowledge. Low health literacy was associated with lower knowledge and quality of life, self-care, and self-efficacy, but the authors could not explain how these differences affected the relationship between health literacy and heart failure related quality of life

(Macabasco-O’Connell et al., 2011). In a cross-sectional analysis of the relationships between health literacy and heart failure, Chen et al. (2014) found that health literacy influences knowledge of heart failure, but not self-care behaviors. Gazmararian et al. (2006) evaluated the factors associated with medication refill adherence in patients with cardiovascular disease. The odds ratio of low health literacy to low refill compliance was significant in univariate analysis, but was not statistically significant in multivariate analysis, demonstrating the complex relationship between health literacy and self-care behaviors (Gazmarianian et al., 2006).

Health Impact

Chronic conditions that are cardiovascular and metabolic in nature, including coronary artery disease, heart failure, hypertension, lipoprotein disorders, and diabetes are the leading cause of death and disability in the United States (Go et al., 2014). According to Go et al., 15.4 million Americans are living with coronary artery disease, 5 million Americans have heart failure, 78 million Americans have high blood pressure, and 29 million Americans have diabetes. Qualitative studies, cross sectional studies, prospective observational studies and randomized, controlled trials have been conducted on patients with diabetes and hypertension, heart failure and obesity, as well as many other health conditions to investigate the relationship between health literacy and health-related outcomes (Berkman et al, 2011). The variables used in studies of health literacy and health outcomes included knowledge, self-management skills, improved control of risk factors, such as blood pressure, cholesterol, and glucose, hospitalizations and mortality, but the results are inconsistent (Berkman et al., 2011). Berkman et al., reviewed 96 studies on health literacy or numeracy, and found that low health literacy was associated with greater healthcare utilization, such as readmissions and emergency care, lower utilization of preventive measures, like vaccination and screening programs, lower adherence with self-care, including taking prescription medications as prescribed, and poorer health status and medical outcomes, including mortality. Fewer studies have been conducted on numeracy skills alone, resulting in less consistent outcomes (Berkman et al., 2011). In a cohort study of 709 heart failure patients, McNaughton et al. (2013) found that patients with low numeracy and low health literacy increased odds of being readmitted to the hospital within 30 days.

In a large, multi-site, prospective study of enrollees in a Medicare managed care plan, conducted from 1997 through 2003, Baker et al. (2007) compared the hazard ratios of patients with adequate, marginal and inadequate literacy. Mortality rates were significantly higher in participants with inadequate health literacy than participants with adequate health literacy (Baker, 2007). Inadequate reading fluency had a hazard ratio of 1.52 for all-cause mortality while there was no association with years of education (Baker et al. 2007). Baker, Wolf, Feinglass, and Thompson (2008) found that health literacy and cognitive ability, such as the delayed recall of items, and serial subtraction of numbers, were independent predictors of mortality in elderly persons.

Health literacy is related to the prevention, control, and self-management of various health/disease conditions, including coronary artery disease, heart failure, hypertension, and diabetes. These diseases are similar in that they are complex conditions, are chronic conditions that can become acute and life threatening if uncontrolled, and have a strong lifestyle component (Smith et al., 2011). Martin et al., (2010) compared reading, numeracy, and oral communication skills using the Woodcock Johnson III Test of Achievement to the Framingham 10 year risk of coronary artery disease in 409 participants. When compared individually, reading, numeracy, and oral communication skills were associated with the risk of coronary artery disease, but multivariate analysis indicated an interaction between numeracy and language skills. A scientific statement from the Heart Failure Society of America (Evangelista et al., 2010) recommended that, while literature on health literacy in heart failure is limited, health literacy principles can be used in patients with heart failure to improve safety, quality, and health outcomes. In a retrospective cohort study, Peterson et al., (2011) conducted a survey of health literacy in 2156 patients with heart failure. With a response rate of 72%, patients were categorized as low or adequate health literacy skills (Peterson et al., 2011). Low health literacy was associated with all-cause mortality and an odds ratio of 1.97, but it was not associated with hospitalization (Peterson et al., 2011).

There is a substantial body of knowledge demonstrating the effects of self-management skills, including dietary and physical activity interventions, on hypertension (Appel et al., 2006). Maintaining or achieving a desirable body weight by balancing physical activity and caloric intake, reducing sodium intake, consuming more fruits and vegetables, reducing saturated fat and cholesterol, increasing potassium intake, and consuming alcohol only in moderation are effective strategies for achieving blood pressure control (Appel et al., 2006). In a cross sectional study of 402 patients with hypertension and 114 patients with diabetes, Williams, Baker, Parker and Nurss, (1998) found that patients with lower health literacy scores, as measured with the TOFHLA were significantly less likely to identify a normal blood pressure or blood glucose reading than patients with high health literacy scores. This poses a significant barrier to teaching self-management skills.

Diabetes and hypertension have strong numeracy components, not only in managing blood pressure and glucose numbers, but also in relating these numbers to sodium, carbohydrate intake and medication management. Diabetes and hypertension have important ethnic and cultural considerations due to the high rate of hypertension in the African American population, and the high rate of diabetes in the Hispanic population that result in dietary and language challenges (Go et al., 2014). Diabetes health literacy is related to knowledge, self-efficacy, self-care behaviors and glycemic control (Cavanaugh, 2011). Understanding health literacy requires a greater appreciation for racial and cultural considerations (Cavanaugh, 2011). Tang et al. (2007) conducted a cross-sectional study of health literacy, complications, and diabetic control in Chinese patients with diabetes and found that health literacy is associated with diabetic control. Osborn et al. (2011) used path analytics to explore the pathways between health literacy, numeracy, adherence to medications, and race in patients with diabetes. Health literacy was associated with medication adherence, while numeracy was not (Osborn et al., 2011). McCleary-Jones (2011) found that diabetes knowledge and self-efficacy were independent risk factors for self-management skills. Self-efficacy is the sole predictor of foot care, and health literacy is highly influenced by demographic factors in African Americans with diabetes (McCleary-Jones, 2011).

While health literacy and its related attributes, including knowledge, numeracy, navigation, communication, and decision making are key components of managing chronic conditions, these relationships are complex. A key aspect of health literacy is being able to navigate the healthcare system (Paasche-Orlow & Wolf, 2007). In a cross-sectional study of 1224 hypertensive patients, comparing blood pressure to the REALM, Powers, Olden, Oddone, Thorpe, and Bosworth (2008) used multiple linear regression and found that the challenges of navigating the healthcare system have an interactive effect on the relationship between health literacy and systolic blood pressure, but not diastolic blood pressure. Pandit, Tang, Bailey, Davis, and Bocchini et al. (2009) found that low education and limited literacy were significant predictors of blood pressure control and that literacy is a mediator in the relationship between education and knowledge. Persell, Bailey, Tang, Davis and Wolf (2010) found that medication discrepancies and incorrect medication reconciliation are very common in hypertensive patients, further complicating this key step in the treatment of these patients.

Instructional Strategies

One of the aims of this study is to qualitatively explore health literacy instructional strategies in people with a new diagnosis of cardiovascular disease or diabetes, including coronary artery disease, heart failure, hypertension, lipoprotein disorder, and diabetes. Since the majority of studies that have investigated these instructional strategies have used health literacy as an ordinal value, low compared to adequate, or have used a treatment endpoint, such as blood pressure or blood glucose control, it is unclear whether health literacy is improved, or whether their environments are adapted to mitigate the lack of skills. In this section three groups of health literacy instruction will be examined, including children and adolescents, apparently healthy adults, and adults with cardiovascular disease or diabetes.

Literacy instruction in children and adolescents. While it is unclear that adults learn differently than children and adolescents, there are two main differences (Lesgold & Welch-Ross, 2012). Differences between adults with cardiovascular disease and children and adolescents include the possible loss of cognitive function in the elderly, and the life experiences that adulthood brings (Lesgold & Welch-Ross, 2012). Despite these differences, and because of the paucity of research on the development of health literacy skills in adults, much can be learned from children and adolescents (Lesgold & Welch-Ross, 2012). An individual that has recently been diagnosed with cardiovascular disease or diabetes does not have a personal life experience to draw from. Manganello (2007), however, pointed out that the research conducted on children and adolescents focuses on reading, and math skills, but has not addressed functional and critical health literacy issues, like navigation of the healthcare system, communication with healthcare professionals, and medical decision making.

Brown, Teufel and Birch (2007) surveyed health and health literacy in adolescents and found that the belief that they had control over their future health is related to their interest in health. Girls were more likely to get health information from their parents, teachers and healthcare professionals, and older adolescents were more likely to get their information from the internet (Brown et al., 2007). Schools are often listed as a source of health information at the higher grades, while parents are the primary source in lower grades (Brown et al., 2007). If the schools do not provide adequate health information, the students are more likely to turn to other sources for their information, including the internet (Brown et al., 2007).

A significant psychological factor is how the health literacy of the parent affects the behavior of the adolescents. Janisse, Naar-King and Ellis (2010) reported a significant relationship between the parents' reading level and adherence to diabetes self-management for adolescents with type 1 (insulin dependent) diabetes. Managing the balance between glucose, insulin, carbohydrate intake and physical activity is complicated for anyone, and reading skills are essential for understanding instructions and communicating with the physician (Janisse et al., 2010).

Adolescents use technology, including the internet, more than any other age group (Warf-Higgins et al., 2009). Warf Higgins et al. developed a social ecological framework to examine the impact of health literacy on adolescent behavior, including knowledge and skills, communication and interaction skills and health policy. While health education is only one component of health literacy, it is critical for behavior change (Warf Higgins et al., 2009). While adolescents are high users of the internet, their skills in searching and comprehension must be developed, and parents, teachers, and healthcare professionals must have the instructional skills to develop these skills (Skopelja, Whipple, & Richwine, 2008). The Health Education Assessment Project provided resources for educators to develop these skills which focused on health education and healthcare decision making (Marx et al., 2007). Educational resources have been developed to teach students how to validate the information (Brey, Clark, & Wantz, 2007). Adults using the internet to search for and learn about their health condition must also learn and develop searching and validating skills, so that they know how to find information, and know, once they have found it that it is the information they needed.

Health literacy instruction in apparently healthy adults. Since low health literacy is associated with the development of chronic diseases and a barrier to optimal treatment, healthcare professionals must build health literacy skills in their patients (Cutilli, 2007). In a review of health literacy interventions, Schaefer (2008) pointed out that while health literacy involves reading, numeracy, comprehension, and decision making, the majority of health literacy interventions are focused on making educational materials easier to read. More consideration needs to be made for developing strategies and best practices that are beneficial to a broader group of patients (Shaefer, 2008). In a review of evidence based practices for individuals with low health literacy, Sudore and Schillinger (2009) identified three levels of interventions, including clinician to patient, the system to patient, and community to patient to improve outcomes. Clinician to patient intervention includes patient centered communication, using clear communication, and confirming understanding (Sudore & Schillinger, 2009). System to patient interventions includes using health education materials that use standard terminology (Sudore & Schillinger, 2009). Community to patient interventions includes addressing health disparities and campaigns designed to build knowledge and skills (Sudore & Schillinger, 2009). Consistent with the social ecological model, Sudore and Schillinger recommended this approach to benefit patients of all literacy levels.

Several reviews of health literacy instructional strategies have been conducted, and while there are many examples of interventions with successful outcomes, the overall results are mixed. This finding is expected due to the variability in the interventions and populations studied, and the lack of consistency in the definition of health literacy, the endpoints measured, and the assessment tools used to measure health literacy. Taggart et al., (2012) reviewed 52 studies of interventions to improve health literacy and behavior change in the primary care and community setting. The interventions included group education and individual counselling sessions for smoking cessation, nutrition, use of alcohol, physical activity, and weight management (Taggart et al., 2012). Lower intensity interventions, such as clear and concise messaging, demonstrated a higher rate of significant results than high intensity intervention (Taggart et al., 2012). Lower intensity interventions include counseling and group education, but the overall results were inconsistent, depending on the setting, type of intervention, and intensity of the intervention (Taggart et al., 2012). For example, smoking cessation is more effective in the primary care setting, while physical activity and weight management were more effective in the community setting (Taggart et al., 2012). The RE-AIM framework is a method of assessing the internal and external validity of programs that are translated from research to practice based on the components of reach, efficacy and effectiveness, adoption, implementation, and maintenance (Allen, Zoellner, Motley, & Estabrooks, 2011). Allen et al. used the RE-AIM framework in a review of health literacy interventions. The authors suggest that there is insufficient data to conclude that health literacy interventions are sustainable, but provide recommendations for future research.

In a review of interventions to improve health outcomes in patients with low health literacy skills, Pignone et al. (2005) found mixed results due to different objectives and measures, limitations in the research designs and the heterogeneity of the results. In a follow up review from the same team, Sheridan et al. (2011) found that the evidence for the effectiveness of interventions to improve health literacy is limited and mixed, but the use of multiple interventions seems to have promise. In a review of multifaceted interventions in patients with low health literacy or numeracy, Clement, Ibrahim, Crichton, Wolf, and Rowlands (2009) found that knowledge and self-efficacy were the intermediate variables most likely to improve, both of which were identified as part of the causal chain described by Paasche-Orlow and Wolf (2007).

An area that relates to the prevention and management of cardiovascular disease is nutrition. The Stanford Nutrition Action Plan randomized 351 participants to a 12 week education program or usual care and demonstrated greater increases in nutrition knowledge, attitudes, and self-efficacy with a program focused on cultural, economic, and learning needs for low health literacy and low income adults (Howard-Pitney, Winkleby, Albright, Bruce, & Fortmann, 1997). In a randomized trial of 29 participants and 27 controls, Jay, Adams, Herring, Gillespie, Ark et al. (2009) found that brief multimedia interventions, including a video and food label pocket cards could improve food label comprehension, as measured by a nutrition quiz ($p< .05$), but actual dietary changes or health related outcomes were not assessed. In a cross-sectional study of 200 primary care patients, Rothman, Housam, Weiss, Davis, Gregory et al. (2006) found that poor food label understanding was correlated with low literacy, as measured by the Wide

Range Achievement Test. Even patients with high literacy skills had trouble interpreting labels (Rothman et al., 2006).

Educational models have been used to teach literacy skills. Shabani et al. (2010) describe how Vygotsky's zone of proximal development, an educational theory designed to teach children to read is used in adult education such as English as a second language courses. The zone of proximal development is an effective teaching strategy in health and physical education (Barker, Quennerstedt, & Annerstedt, 2013). Since people that are diagnosed with a new chronic health condition must learn new terms, new concepts, new numbers, and new rules, this teaching method may have application to the development of health literacy. Nimmon (2010) used a qualitative study of linguistic and informational barriers in English as a second language for immigrant women to illustrate the need for cultural considerations in health literacy. Mogford, Gould, and Devoght (2010) created a curriculum designed to teach critical health literacy by empowering people to achieve health equity. These language and cultural barriers, as described by Nimmon and health equity issues described by Mogford et al., may lead, not only to helping an individual understand the information, but also build knowledge and skills.

Health literacy interventions in adults with cardiovascular disease and diabetes. Coronary artery disease is a disruption of blood flow to the coronary arteries, due to atherosclerosis, resulting in angina pectoris (chest pain), or myocardial infarction (heart attack), resulting in 379,559 deaths and 1,346,000 hospitalizations annually in the United States (Go et al., 2014). In the communication of health information to patients with cardiovascular disease, Oats and Paasche-Orlow (2009) recommended being clear and concise, specific, using multiple forms of communication, allowing for questions, and testing comprehension using the teach-back method. Cardiac rehabilitation is a program of secondary prevention for patients following a cardiovascular event, and is an ideal setting for building knowledge, health literacy, and self-management skills (Gallagher et al., 2012). Using a pretest, posttest design with 137 participants, Gallagher et al. compared knowledge of their symptoms and appropriate responses at baseline and the conclusion of a 6–8 week cardiac rehabilitation program, finding significant improvements in knowledge of symptoms, but no improvement in response time. In a randomized trial of 64 participants with a 20 item instrument designed to test knowledge and satisfaction, DeVon, Rankin, Paul, and Ochs (2010) demonstrated that a slide presentation conducted at baseline, two months, and four months resulted in improved knowledge and satisfaction compared to a control group.

Heart failure is a weakening of the heart muscle resulting in the inability of the heart to meet the demands of the body, affecting 5.1 million Americans, which results in over 1 million hospitalizations and a cost of over $30 billion annually (Go et al., 2014). Dewalt et al. (2006) randomized 123 heart failure patients with low levels of literacy to a program of self-management skills. This program included daily weight monitoring, medication management and symptom recognition or usual care, which resulted in an adjusted incidence rate of .53 for reduced risk of hospitalization and death in the intervention group compared to the usual care group (DeWalt et al., 2006). In another randomized trial, DeWalt et al. (2009) described a study design for a randomized, controlled trial comparing a one-time educational session to an educational intervention designed to improve self-management skills in patients with heart failure.

The theoretical and methodological basis for the study by DeWalt et al., (2009) was described by Baker et al., (2011). One reason for the lack of scientific inquiry into the development of health literacy skills, as noted by Baker et al., is the difficulty in doing so. Baker et al. points out those patients with low literacy skills may have language barriers as well as difficulty with reading and comprehension, difficulty in understanding and manipulating numbers, and may have lower baseline knowledge of health. Elderly patients, including those with heart failure, may have cognitive and memory deficits (Baker et al.). Mastery learning theory, which posts that while people may learn at different rates, material can be mastered if given multiple opportunities, is the theoretical basis of *Teach to Goal* (Baker et al., 2011). The educational curriculum, therefore, includes a defined set of learning objectives, presented in discrete units, or chunks, focuses on the use of clear communication and plain language, requires confirmation of understanding of the material, and links knowledge to specific skills and goals (Baker et al., 2011). A heart failure-specific educational curriculum is organized into five discrete units, including an overview of heart failure, medication adherence, salt avoidance, exercise, and daily assessments (Baker et al., 2011).

Also known as high blood pressure, hypertension is a chronically elevated resting pressure, greater than 140 mmHg systolic or 90 mmHg diastolic, known to be an independent risk factor for coronary artery disease and stroke, affecting 77.9 million Americans (Go et al., 2014). Bosworth et al., (2005) randomized 588 participants to a telephonic intervention administered by nurses to manage blood pressure compared to usual care. Knowledge, health literacy, and patient-provider communications were among the interventions, resulting in greater confidence in following the regimen (Bosworth et al., 2005). Using the same intervention with 636 randomized patients, Bosworth et al., (2008) demonstrated an increase in medication adherence of 9% in the intervention group compared to 1% in the usual care group. In a randomized trial of hypertensive patients, Bosworth, Olsen, Grubber, Neary, and Orr et al. (2009) found that blood pressure monitoring and tailored telephone intervention resulted in significantly better blood pressure control compared to a usual care group. They found racial differences in this intervention, with virtually no changes in blood pressure among white participants but significant improvements in blood pressure among non-white participants.

Diabetes is an elevated fasting glucose, greater than 125 mg/dl due to a diminished ability to produce insulin that is a major risk factor for cardiovascular disease and stroke (Go et al., 2014). Strategies for addressing low health literacy and numeracy in diabetes include using plain language, asking open ended questions, using the teach-back method, and using print educational materials that are designed with health literacy in mind (Osborn, Cavanaugh, & Kripalani, 2010). The Diabetes Literacy and Numeracy Toolkit (DLNET) is a diabetes-specific program used to address both health literacy and numeracy to improve knowledge and care in patients with diabetes (While, Wolff, Cavanaugh, & Rothman, 2010).

Low health literacy was shown to be a significant barrier to an intervention designed to improve glycemic and blood pressure control in 217 patients with diabetes who were enrolled in a randomized, controlled trial (Rothman et al., 2004). Patients with low literacy skills were more likely to achieve their HbA1C goal than their controls, while patients with high health literacy skills had similar odds of achieving their goal as high literacy controls, indicating the importance of health literacy in the achievement of clinical goals (Rothman et al.). Following the intervention, patients with low literacy reported better adherence to diet, self-glucose management and foot care (Kim, Love, Quistberg & Shea, 2004). Kim et al. investigated the relationship between diabetes health literacy and diabetes self-care, knowledge and diabetes self-management in 92 patients. Diabetes education classes, led by diabetes educators were conducted on patients with adequate health literacy and low health literacy and were found to improve diabetes self-management skills, knowledge as well as glycemic controls (Kim et al., 2004). At 3 months, self-management skills were higher in the low literacy group than the adequate literacy group, illustrating the need for and benefit of diabetes education for all patients (Kim et al). Wallace et al., (2008) demonstrated that literacy centered educational materials and brief behavior change counseling in 250 patients resulted in improvements in psychosocial and behavioral changes in patients with diabetes, especially in Spanish speaking participants. Kandula et al., (2009) demonstrated that knowledge could be increased with a multimedia educational program for 190 patients recruited from a federally qualified health center and an academic center with diabetes, but these differences did not overcome the learning gap between individuals with low health literacy skills compared to those with higher health literacy skills.

Health literacy instructional strategies for healthcare professionals. Whether the healthcare professional is the source for building knowledge and health literacy skills, they are certainly the source by which the patient learns of their diagnosis. The Health Information Literacy Research Project surveyed hospital administrators and healthcare providers (Shipman, Kurtz-Rossi, & Funk, 2009). Shipman et al. found that the majority of respondents believed that health information is critical to their mission and could improve patient care. The authors noted that medical librarians can play a key role in supporting health information and health literacy resources.

Some healthcare professionals, however, did not recognize low health literacy or its impact on their patients (Macabasco-O'Connell & Fry-Bowers, 2011). An aim of this study is to gain insights and greater perspectives into how healthcare professionals address health literacy in their patients, including their plans for building knowledge, health literacy and self-management skills. A health literate care model, proposed by Koh, Brach, Harris, and Parchman (2013) would embed health literacy and patient engagement into all aspects of planning and operations, decision support, health information technology, and clinic to community partnership, with the intended impact of improved quality, better outcomes and lower costs. To achieve the objective of improved quality, better outcomes and reduced costs, however, healthcare professionals must become more effective, not only at assessing health literacy and identifying those with low health literacy skills, but also in developing the capacity and building the knowledge and skills in their patients (Dennis et al., 2012). This has important implications for the training of healthcare professionals and the use of non-medical personnel to support lifestyle change (Dennis et al., 2012). Healthcare professionals must be aware of the stigma of low literacy among their patients, which can have a significant impact on the effectiveness of written and oral communication between the patient and their healthcare professional (Easton, Entwistle, & Williams, 2013).

In a mixed-methods cross-sectional study of 76 nurses, Macabasco-O’Connell and Fry-Bowers (2011) found health literacy knowledge among registered nurses to be limited and a low priority in the delivery of healthcare services. Stiles (2011) suggested that low health literacy in patients with diabetes can be mitigated by improved communication between patients and their healthcare professionals. Using surveys and latent class analysis, Frick, Gutzwiller, Maggoirini, and Christen (2011) assessed patient satisfaction and health knowledge in over 2000 patients with acute coronary syndrome, finding that healthcare professionals tended to overestimate the health literacy skills of their patients, especially in regards to lifestyle change. To improve medication adherence, Bowskill and Garner (2012) recommended that healthcare professionals improve communication techniques for patients with low health literacy, including slowing down when speaking, repeating the information, using plain language, avoiding medical jargon, and using teach-back.

While these recommendations are consistent with current strategies for building health literacy skills, there is no study demonstrating that they result in improved health literacy skills. Seligman et al., (2005) reported that while physicians responded to notification of the health literacy status of their patients, and were more likely to use recommended strategies, they were less satisfied with their visits. Devraj, Butler, Gupchup, and Poirier (2010) developed an active learning curriculum, using teaching methods with pharmacy students as participants, to help healthcare professionals become more aware of health literacy, identify patients with low health literacy, and improve communication techniques.

Digital Tools and Technology

Digital tools and technology, such as smart phones, tablets, apps, and connected health devices, including blood pressure, weight, and physical activity, are being used in cardiac rehabilitation and other secondary prevention programs to build knowledge, health literacy and self-management skills (Beatty et al., 2013). While limited empiric data exists, Beatty et al., (2013) argued that the features and functionality of these devices are compatible with the core components of cardiac rehabilitation and are aligned with patient-centered outcomes.

Multimedia education is used in education and business, and has the potential to be effective in health care, but current evidence is limited (Wofford, Smith, & Miller, 2005). Bastain (2008) described efforts in Germany to create national standards in the development of web-based tools and technologies, with a focus on patient centeredness.

In a Cochrane Collaboration review of interventions designed to improve online health literacy, Lang, Ung, and Majeed (2011) reported that while the hypothesized pathway indicates that online resources can be used to build health literacy skills, and evidence favors the intervention compared to controls, the current level of data is insufficient to draw broad conclusions. In an Institute of Medicine report on the digital infrastructure for a learning health system, Grossman, Powers, and McGinnis (2011) described the characteristics of a learning health system, which embedded a health literate culture into the healthcare system to improve safety and quality, and reduced medical outcomes, adverse events, and cost. In this system, teaching and learning is a two-way street, with patients and healthcare professionals communicating and learning from one another (Grossmanet al., 2011). In a review of 24 studies on health literacy and diabetes, Boren (2009) argued that information and communication technology provided opportunities to help mediate the impact of low health literacy. While the findings of intervention studies were mixed, they represent significant opportunities, including interactive media, computer based algorithms, decision support tools, and telephonic interventions (Boren).

Whitten, Buis, Love, and Mackert (2008) demonstrated that knowledge and engagement can be improved in patients with diabetes using a web-based application, but more effective ways could be developed for broader utilization. Sarkar et al. (2010) evaluated an internet-based portal designed to improve health literacy and self-care in 14,102 patients with diabetes, including 6099 with a health literacy limitation. While the program was effective in patients with good computer and literacy skills, patients with low health literacy were less likely to access the program, potentially creating a greater divide between those with low health literacy and adequate or good health literacy skills (Sarkar et al.). Yehle et al., (2012) conducted a qualitative assessment of the challenges and feasibility of improving dietary adherence with web based and mobile nutrition tools in patients with coronary artery disease. Using surveys and focus groups, Yehle et al. determined that mobile technology can be useful in meal planning, portion control, and carbohydrate intake. Jay et al. (2009) randomized low income participants to a multimedia intervention designed to better understand food labels, finding that while there was an overall improvement in comprehension, there was no improvement in those with low health literacy. Santo, Laizner, and Shohet (2005) explored the value of using audiotapes in improving health literacy, determining that it is unclear whether they are an effective strategy or create an additional barrier.

Summary and Conclusions

Health literacy has been a public health priority since the release of the NAAL, which estimated that 90 million Americans lack the skills necessary to understand and act on health information (Kutner et al., 2006). This led to a large body of research on health literacy, with much of the focus of research, and resulting policy recommendations centered on identifying the low health literacy population and developing health education materials that can be more easily understood. Low health literacy is linked to a causal chain leading to poorer health outcomes (Paasche-Orlow, 2007). This causal chain is validated through multiple studies, demonstrating that low health literacy is associated with the development and worsening of many health conditions, including cardiovascular and metabolic diseases that have a strong prevention and lifestyle component (Berkman et al., 2011). Discrepancies in the very definition of health literacy, including a focus on linguistic skills, or a broader definition to include functional health literacy, including numeracy, and navigating the health system, and critical health literacy, like communication and decision making skills, resulted in mixed results regarding interventions to build health literacy skills. New digital tools and technologies have recently emerged and are increasingly playing a role in how people manage their health (Nutbeam, 2008).

Although being sensitive to health literacy concerns is recommended by the American Heart Association, the Preventive Cardiovascular Nurses Association, and the Society of Behavioral Medicine, their strategies for promoting lifestyle change for cardiovascular risk reduction focused on motivation, readiness for change, supporting self-efficacy, modeling, and problem solving, but they did not emphasize developing knowledge and building skills (Artinian et al., 2010). The Agency for Healthcare Research and Quality published a toolkit of best practices in supporting health literacy (DeWalt et al., 2010). The toolkit used the term universal precautions since it is not always apparent which patients may be affected. The tools were designed to raise awareness of health literacy, improve spoken and written communication, improve self-management and empowerment, assess the environment and improve the system, but did not include principles of teaching and learning. For example, the teach-back method is a test of the patient’s understanding of the information and can be used to identify a learning gap, but is not an instructional strategy.

Table 1 is a summary of selected approaches to health literacy instruction. A gap in the literature that I intend to fill in this study is understanding how health literacy skills were developed in people who have been recently diagnosed with a chronic health condition, such as coronary artery disease, heart failure, hypertension, lipid disorders, metabolic syndrome, and diabetes. Theoretical models focusing on individual behavior change include motivation, self-efficacy, and personal experience, but it is unclear how these factors are used to build health literacy skills. Strategies, policies, and interventions focus on simplifying the message through clear and concise communication, but this strategy is based on accommodating individuals with low health literacy, and is not intended to build health literacy skills. Conceptual models described the process from knowledge and skill development to communication and decision making, but how the knowledge and skills were actually developed was not considered by the authors. A qualitative approach using grounded theory was used to develop a new theory of how health literacy skills are developed in patients with a new diagnosis of a chronic health condition. The gaps in the literature identified in this chapter have been used to form the purpose of the study and research questions presented in Chapter 1 and are used in Chapter 3 to determine the methodology.

Table 1

Health Literacy Instructional Approaches

Instructional approach	Application	Population	References
Individual counseling	Self-management skills	Heart failure	Baker et al., 2011; DeWalt et al., 2009.
	Intensive training with pharmacist and diabetes educator	Diabetes	Rothman et al., 2004
	Counseling and educational materials	Diabetes	Wallace et al., 2008
Group education	Nutrition (low fat)	Apparently healthy	Howard-Pitney et al., 1997
	Heart attack warning signs	Cardiac rehabilitation	Gallagher et al., 2012
	Self-management skills	Diabetes	Kim et al., 2004
Print materials	Educational materials	Diabetes	White et al., 2010
Digital media	Diabetes education	Diabetes	Sarkar et al., 2010
Multimedia	Nutrition (food labels)	Apparently healthy	Jay et al., 2009
	Diabetes education	Diabetes	Kandula et al., 2009
	Slide presentation on symptoms and risk factors	Coronary artery disease	DeVon et al., 2010
Telephonic	Daily monitoring, education, follow up	Heart failure	DeWalt et al., 2006
	Nurse administered telephone intervention	Hypertension	Bosworth et al., 2009, 2008, 2005

Chapter 3: Research Method

Introduction

The purpose of this study was to explore the gap in the literature by gaining perspectives of patients and healthcare professionals in the development of health literacy skills in patients who have been diagnosed with cardiovascular disease or diabetes within the past 12 months. This includes assessment and instructional strategies used by healthcare professionals, as well as the acquisition of health information by patients, including the sources of information and the tools that are used. The intent of this study is to go beyond the description of the low health literacy groups, the challenges, or the motivational issues, to factors related to health literacy instruction. The intent is to develop a better description of the processes and actions related to health literacy by exploring the process of learning, and how new resources that are now available to patients, such as digital tools and technologies are used by patients and healthcare professionals.

In this chapter the research design and rationale will be reviewed, including the central concepts and phenomenon, the research tradition, and the rationale for the chosen tradition. The role of the researcher, including any biases and how those biases will be managed will be discussed. The methodology, including the selection of the participants and sites, sampling methods, and data collection procedures will be described. The sites, the study population, and process of recruiting patients will be discussed. The instruments used for interviewing will be presented. The data analysis plan including the coding methodology and use of software programs will be described. Issues of trustworthiness and ways to ensure credibility, transferability, and confirmability will be explored. Finally, ethical considerations, including informed consent, agreements to gain access to participants, institutional permissions, recruitment, data collection, storage of the data, and confidentiality will be examined. Consent forms, letters of cooperation, interview guides, and the recruitment flyer will be found in the Appendix.

Research Design and Rationale

The primary research question is how do individuals who have been recently diagnosed with a chronic health condition acquire knowledge and learn skills necessary to manage their condition. The data collection, including interviews of patients and healthcare professionals, the writing of analytic memos, and data analysis process, including coding were focused on answering the research questions. Specifically, the research questions include:

RQ1: What are the perspectives of patients and healthcare professionals in the development of health literacy skills in patients who have been recently diagnosed with a coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes?

Q2: What are the perspectives of patients and healthcare professionals in the use of new technologies to build health literacy skills?

RQ3: How do healthcare professionals and health educators assess and build health literacy skills in their patients?

RQ4: How are instructional strategies designed to build knowledge and health literacy used by healthcare professionals aligned with the process of learning described by the patients?

The central concepts/phenomenon in this study is the development of health literacy skills in a person with a new diagnosis of a cardiovascular disease or diabetes. These factors include the sources of information, how that information is found, accessed and validated, the format and learning style, the timeframe, and the perceived effectiveness of these sources in building health literacy skills, reaching goals, and improving outcomes. These factors and the central phenomenon are impacted by direction and guidance from healthcare professionals, health education materials and content found in books, magazines and other periodicals. The central phenomenon is impacted by instructions found in medication inserts and food labels, the influence of friends, family, and other patients with the same condition, the development of social networking sites, digital tools and web enabled apps and devices that can be accessed directly by the patient (Beatty et al., 2013). While in the past patients may have relied on the information presented to them by their doctor, they can now use search engines to learn more about their condition, track their own data using connected devices, and interact directly with other patients in a manner that was not possible even a few years ago (Beatty et al., 2013).

The term health literacy implies linguistic skills, including the ability to read and understand written and oral communication. The broader definition of health literacy, as described by Nutbeam (2008) includes reading and comprehension necessary to understand written and oral instructions, and numeracy was used in this study. Figure 2 illustrates these five components of a broader view of health literacy that goes beyond simply being able to read the instructions on a medication label. While there is no data indicating the interdependence of these skills, they do seem to form a natural progression from reading and comprehension to understanding the numbers to accessing the healthcare system, to communicating with healthcare professionals, and finally to medical decision making. The core phenomenon explored in this study is how these skills are acquired and developed.

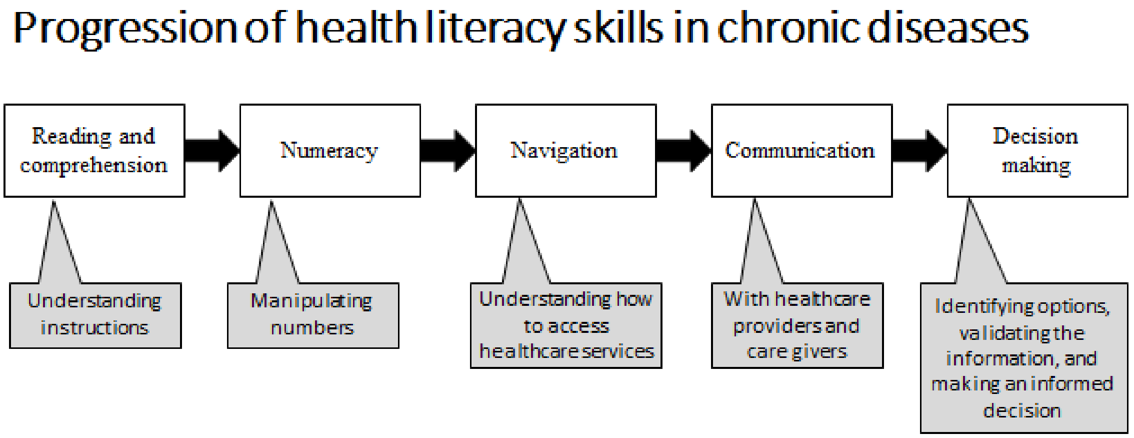

Figure 2. Progression of health literacy skills in chronic diseases.

A qualitative approach using grounded theory is selected as the research tradition and was used in this study as a way to gain greater insights into the process of developing health literacy skills, leading to a unified theoretical explanation, or theory (Creswell, 2013). Qualitative methods are gaining acceptance, even in areas dominated by quantitative, hypothesis driven research, such as cardiovascular research (Krumholz, Bradley, & Curry, 2013). Qualitative and mixed methods research should be used to investigate complex phenomena that are difficult to measure providing a deeper understanding and leading to better approaches, strategies, instrumentation, hypotheses, and outcomes (Curry, Nemhard, & Bradley, 2009). Qualitative methods can stand alone as another form of inquiry and not simply a precursor to quantitative research methods, especially in complex areas where little information is available, or where there is a high degree of variability in results from quantitative studies. The inconsistent results of quantitative studies investigating the health impact of health literacy interventions is an indication that more information is required to develop more effective instructional strategies (Berkman et al., 2011; Taggart et al., 2012).

A grounded theory approach was used to gain perspective and a greater insight into the process of learning, the building of knowledge and the development of health literacy skills in patients diagnosed with a chronic health condition. Grounded theory was discovered by Glaser and Strauss (1967) as a method of developing theory from empirical data, rather than simply testing hypotheses based on classical theories. Grounded theory is becoming increasingly accepted and prominent in medical education research (Watling & Lingard, 2012). While other qualitative approaches, including ethnography, phenomenology, narrative and case studies could be used in this study, grounded theory is the best methodological fit because it goes beyond the description of the phenomena to the development of a theory or model, designed to better explain the process and actions, which could lead to improved methods for becoming a more health literate culture (Creswell, 2013).

While grounded theory is increasingly used in medical research, Sbaraini, Carter, Evens, and Blinkhorn (2011) note that there are several forms of grounded theory, based on the interpretive approach. The original grounded theory method, developed by Glaser and Strauss (1967) comes from a postpositive framework. Glaser and Strauss eventually developed their own separate methodology for grounded theory (Creswell, 2013). Charmaz (2014) developed a grounded theory method from a constructionist framework, and Clarke (2005) developed a grounded theory method from a postmodern framework. The grounded theory approach used in this study is based on the methods described by Corbin and Strauss (2015), which emphasize an iterative approach, using theoretical sampling, constant comparison, the use of analytic memoing, and saturation. The postpositive interpretive framework, used by Corbin and Strauss, and secondarily a constructivist approach, as described by Charmaz, is used in this qualitative study. While the patient's experience of living with chronic illness may be a constructed reality, as described by Charmaz (1990), the disease process that is being addressed is based on laws of nature. This framework is selected because it is more closely aligned with a scientific approach, favored by the group for whom this research is directed, which are clinicians and researchers focused on cardiovascular health and cardiovascular disease management (Creswell, 2013).

The methodology of grounded theory described by Corbin and Strauss (2015) involves a back and forth between data collection and data analysis and will focus on distinct steps including theoretical sampling, constant comparison, and theoretical saturation. According to Health and Cowley (2004) the approach to grounded theory described by Strauss and later by Corbin and Strauss is more structured than other approaches. While the grounded theory approaches described by Glaser (1992) and

Charmaz (2014) allow the theory to emerge from the data more naturally, they also require skills beyond the scope of a researcher new to qualitative research and grounded theory (Heath & Cowley, 2004). The trade-off between structure and the natural process is intentionally designed to strengthen the validity of the findings and describe a more logical, scientific based approach to the target audience of healthcare professionals.

Role of the Researcher

The researcher was the primary data collection tool for this qualitative study by coordinating and communicating with the organizations who serve as the source of study participants; designing the interview; conducting interviews with patients and healthcare professionals; and coding the interview data into categories and themes, designed to describe the process of developing health literacy skills. While I know some of the healthcare professionals, there is no supervisory or instructional relationship with either the healthcare professionals, or the patients. A researcher bias could be the belief that patients have the ability to develop health literacy skills, including those with language barriers, cognitive deficits, and who have lower levels of formal education (Baker et al., 2011). Additionally, a researcher bias in this study may be the belief that some healthcare professionals are ill-prepared to provide instructional strategies designed to build health literacy skills in their patients. These biases were managed by focusing on the research question and the data generated from the interviews. The study was done outside of my work environment and there were no conflict of interest or power differentials between the participants and myself. Study participants received a $10 gift card for participation, and every effort was made to conduct the interviews and observations at a time that is most convenient to the participants.

Methodology

Participant Selection Logic

The study population included a homogeneous group of patients who have been diagnosed with cardiovascular disease or diabetes within the past 12 months and healthcare professionals who treat or educate these patients. The subjects in this qualitative study were chosen using theoretical sampling (Creswell, 2013). The participants who comprise this theoretical sample were drawn from a primary care medical practice, a cardiology practice, patient centered programming offered by the American Heart Association, and social networking sites, including Facebook and Twitter, targeting patients with cardiovascular disease and diabetes. The primary care medical practice provides a lifestyle change program, as well as the diagnosis and treatment of high blood pressure, lipid disorders, metabolic syndrome, and diabetes (Courtney et al., 2011). This program is run by a medical doctor who is board certified in family medicine, and a nurse practitioner, and is based in Dallas, Texas. The cardiology practice is run by a board certified cardiologist and a nurse practitioner, and is focused on early detection and diagnosis of coronary artery disease, angina pectoris, and heart failure, and well as cardiac rehabilitation and secondary prevention for patients who have had a myocardial infarction, percutaneous coronary interventions, and cardiac surgery. I have no relationship with either the primary care practice or the cardiology practice.

The American Heart Association provides patient centered programs that target individuals with various forms of cardiovascular disease. The patient support platform is an online community for patients with heart disease that is administered by the American Heart Association (American Heart Association, 2014). Patients were directed to the Support Platform through social media sites managed by the American Heart Association. A discussion in the support platform with information on becoming a study participant was started. The citizen scientist panel is a group of patients that provide input to the American Heart Association on patient centered programming and research priorities. Although I am employed by the American Heart Association, I have no connection to the citizen scientist panel or the patient support platform. I created a Facebook and Twitter account that was used to recruit patients.

Table 2

Cooperating Sites and Sources of Study Participants

Types of site	Relationship to researcher
Primary care medical practice, based on Dallas, Texas	No relationship.
Cardiology practice, based in Grapevine, Texas	No relationship.
Patient centered programs provided by the American Heart Association	I am employed by the American Heart Association but do not work with these programs.
Social media sites	Twitter and Facebook accounts created by me.

Healthcare professionals from the primary care and cardiology practices, and the American Heart Association, using theoretical sampling were interviewed by the researcher. These three organizations represent health literacy instructional practices conducted in the acute, outpatient, and community settings. Healthcare professionals, including physicians, physician assistants, nurse practitioners, nurses, dietitians, exercise physiologists, social workers, health educators, and administrators, who educate or treat patients with cardiovascular disease or diabetes, were included in the study.

This theoretical sample included patients who have been diagnosed with a chronic health condition within the past 12 months, including coronary artery disease, hypertension, heart failure, hypertension, metabolic syndrome, or diabetes. There is no assessment of health literacy and the samples are intended to include patients throughout the range of knowledge, health literacy, and self-management skills. The cooperating sites were provided a one-page flyer describing the study to the patients. A recruitment flyer for patients and a separate recruitment flyer for healthcare professionals were posted in the waiting area of the medical clinics. Participants who were interested in participating in the study were asked to contact the researcher. The phone number and email address of the researcher was on the recruitment form. No patients or healthcare professionals were contacted without first contacting the researcher. With this method, adequate time and privacy was provided to all potential participants to think if they want to participate in the study and to ask any further questions by email or phone. A web link, identical to the flyer, was used to recruit patients accessing the social networking sites provided by the American Heart Association. A flyer customized to healthcare professionals was posted in public places, such as waiting areas and break rooms at GOH Medical, State of the Heart Cardiology and the American Heart Association. The flyers, both patient and healthcare professional, included a brief description of the study and contact information. The patients and health care workers contacted the researcher directly if they chose to participate in the study. Each study participant received a $10 gift card after they completed the interview. If the participant was interested in participating they were asked to complete an enrollment form, including their contact information. Consent was obtained electronically following the Walden University policy for obtaining electronic signatures. Once they signed the consent form the interview was scheduled.

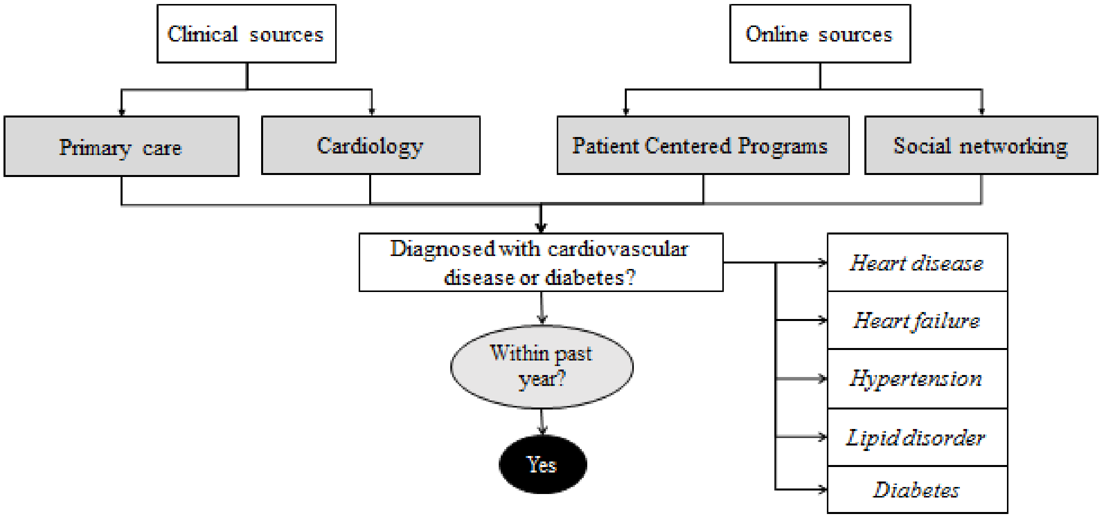

Figure 3. Participant selection process.

The timeframe for this new diagnosis was within the past 12 months because they would not be able to rely on their personal experience, would have a better memory of events, and would be more likely to have had access to technology and digital tools, like a cell phone, smart phone, and computer. A mix of these diagnoses, as well as a mix of age, gender, ethnicity, and level of education was used to determine the selection of patients that resulted in the most information, and of which can result in greater insights in the formulation of the theory.

According to Creswell (2013) 20-30 participants are usually required using grounded theory. It is estimated that 10-15 patients and an additional 10-15 healthcare professionals will be interviewed. Gaining perspective from a broad group is an important part of the theory development. Using theoretical sampling, other perspectives, including care givers and family members, and those who create and design print and digital educational materials may be necessary (Corbin & Strauss, 2015). Using a grounded theory approach, the sample size is ultimately determined by saturation of the data (Patton, 2002). Saturation occurs when no additional information is being obtained in the data collection process (Creswell, 2013). More participants, therefore, may be needed until saturation is achieved.

Instrumentation

The data collection tools in this study are interviews. Two interview protocols have been developed, one for patients, and another for healthcare professionals. The interview protocols were developed by the researcher to answer the research questions.

Procedures for Recruitment, Participation, and Data Collection

Data collection procedures. The primary data collection procedures in this study were interviews of the patients and the healthcare professionals. An interview protocol for participants and healthcare professionals, and developed by the researcher were designed to answer the research questions, including how patients are able to acquire the knowledge and learn the skills necessary to manage their condition. Interviews with the patients were designed to last 45-60 minutes, while interviews with the healthcare professionals were designed to last 30-45 minutes. These protocols are listed in Appendix A and B, and were designed to answer the research questions. The interviews were semi-structured with open ended questions. Although set questions were been predetermined, I allowed the participant to respond in their own words and expand on their response. I redirected, however, if the participant got off track. Following some initial descriptive questions, the key questions asked of the study participants are: (RQ1) Please describe your process for learning how to manage your condition? (RQ2) Are you using technology to assist you in the management of your condition? (RQ3) What is the role of your healthcare professional in learning how to manage your condition? (RQ4) How were the strategies used by your healthcare professional aligned with your process of learning? The participants' responses to these questions were likely to address the source and format of the information. If the responses did not include those areas, I asked these questions as follow up, as indicated in Appendix A. Interviews with healthcare professionals were focused on how health literacy skills are assessed and the instructional plan used to build health literacy skills. If not addressed in the initial response, the use and type of resources used by the healthcare professional were asked, as indicated in Appendix B.

To ensure the validity of the data, each interview was conducted using a conferencing calling system that is recorded. If the interview was done in a face to face manner and audio recording of the interview was made by the researcher. As part of the informed consent, the purpose of the study and the fact that the interview was recorded was reviewed prior to the interview. In addition to the interview and recording, I composed an analytic memo at the end of each interview session (Miles, Huberman, & Saldana, 2014). Interviews with healthcare professionals were conducted in the same format. The interviews with participants and healthcare professionals are based on the conceptual models described by Jordan, Buchbinder, and Osborne (2012), and Edwards et al. (2012), and the principles described in the Health Literacy Toolkit (DeWalt et al., 2010).

The interviews with the healthcare professionals were used to create triangulation of the data, confirming the data generated by the interviews with the participants (Creswell, 2013). Using the constant comparison method and theoretical sampling, as described by Corbin and Strauss (2015), data collection and data analysis occurred simultaneously. Data gathered through a deductive process was validated resulting in inductive elaboration (Corbin & Strauss, 2015). With this technique, the resulting theory is grounded in the data (Glaser and Strauss, 1967).

Data Analysis Plan

Using grounded theory, data collection and analysis occurred simultaneously, using both deduction, validation, and inductive elaboration, leading to a theoretical explanation of the actions and process of building health literacy skills (Corbin & Strauss, 2015). Following each interview an analytic memo was created by the researcher. These memos were used for theoretical sampling, to create and link categories, and to describe the process, and were a source of data that was coded by the researcher (Corbin & Strauss, 2015).

A constant comparison methodology, as described by Strauss and Corbin (2015) was used to generate codes and analyze the data. The coding approach included process and evaluation coding (Miles, Huberman, & Saldana, 2014). Process coding was used to identify observable and conceptual action in the developing of health literacy skills, while evaluation coding was used to evaluate the effectiveness of the sources of information (Miles, Huberman, & Saldana, 2014).

The first step in the coding process used open coding to generate categories and themes, using a line by line technique. From this coding process categories emerged, based on questions of who, what, when, and how, resulting in properties or dimensions (Corbin & Strauss, 2015). The second step in the coding process used axial coding to explain the relationships among the codes (Creswell, 2013). This coding resulted in a description of the core phenomena, actions and process, including causal conditions, strategies, intervening conditions, context, and consequences (Creswell, 2013). This process involved integrating and linking categories through the use of integrative memos and diagrams (Corbin & Strauss, 2015). The final step in the coding process was selective coding, which was used to generate the theory and establish a better understanding of the action and process by identifying the core categories (Creswell, 2013).

The theory emerges from active process of the researcher going beyond the description of the core phenomena (Corbin & Strauss, 2015). The mixed and inconsistent results found in interventional studies may be a clue that the core actions and process are complex, involving more than offered with simplified strategies (Berkman et al., 2011;

Taggart et al., 2012). From this coding process a theoretical explanation is used to explain the process and actions, resulting in a new theory, if one develops, or an updated understanding of an existing theory.

A second researcher coded a sample of the data from the interviews, and memos, to test for intercoder agreement (Creswell, 2013). Discrepant cases were identified in the analytic memo. These cases, however, can enhance the understanding of the patterns that have been established (Patton, 2002).

The recording of each interview was transcribed into a document by the researcher. Names and other identifiable information, however, were removed from the transcript. Data from each interview, including notes, memos, and recordings were entered into the MaxQDA qualitative software program (Verbi Software, 2014).

Table 3

Summary of Data Collection and Analysis Methods

Method	**Description**
Theoretical sampling	Identifying most likely to provide information
Constant comparison	Process of comparing data to emerging categories
Open coding	Initial process of coding data into categories
Axial coding	Process of linking codes and categories
Selective coding	Development of the theory from core phenomena
Analytic memos	Notes written by the researcher linking and explaining concepts and emerging categories

Theoretical saturation	The stage when no new information is emerging from the data

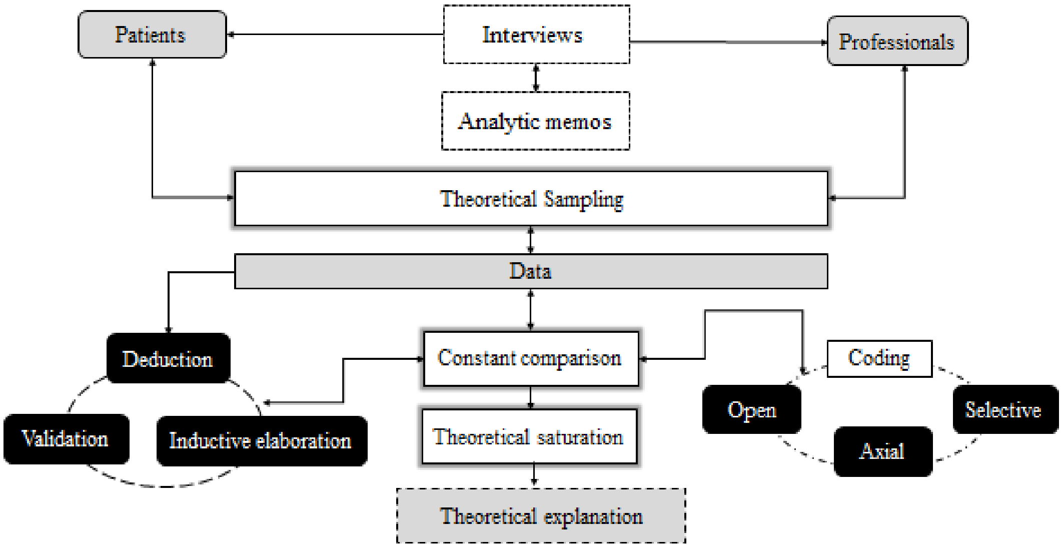

Figure 4. Data collection and analytic methods.

Software tools. Computerized software programs reduce the risk of data loss and overload (Miles, Huberman, & Saldana, 2014). The MaxQDA program was used as the computer assisted qualitative data analysis software (Verbi Software, 2014). This program was selected because it has a student version which is low cost and is the featured qualitative data analysis software in the Corbin and Strauss (2015) text.

Issues of Trustworthiness

Credibility of the qualitative inquiry includes rigorous methods for doing fieldwork that yield high quality data, the credibility of the researcher, and the philosophical belief in the value of qualitative inquiry (Patton, 2002). Strategies to ensure the credibility of this study include the use of multiple methods of data collection, the use of inter-coder agreement, practice in interviewing and coding, and the desire to introduce qualitative methods to a community that is biased towards quantitative methods. Learning to conduct effective interviews included practice exercises described by Janesick (2011). Additionally, the researcher gained practice in coding in projects unrelated to this research study.

While the transferability or external validity of the study is more difficult to establish in qualitative methods, especially if viewed from the lens of the quantitative researcher, generalizations can be extrapolated to consider what is possible. In this respect, individual cases may form the basis for new strategies (Patton, 2002). For example, the belief that health literacy skills cannot be developed in older people with cardiovascular disease can be refuted by the demonstration of one case in which knowledge is gained and skills are developed.

Dependability, the qualitative counterpart to reliability, can be established through the use of multiple methods, triangulation of methods, and inter-coder agreement by having another researcher code a sample of the data (Patton, 2002). Interviewing both patients and healthcare professionals are designed not only to answer the research question, but also can establish triangulation of the data. Confirmability is the qualitative counterpart to objectivity and will be achieved through reflexivity (Patton, 2002). Reflexivity will be established by the researcher becoming more self-aware of their theoretical lens (Patton, 2002).

Ethical Procedures

Appendix A contains the consent form that was used in the study. While the consent form is a written document, it was read to the study participants allowing for questions or clarifications (Soriano, 2013). This consent form included the purpose of the study, the fact that it was voluntary, the risks, instructions on how to complain, and assured anonymity and confidentiality (Soriano, 2013).

Appendix B contains the letter of cooperation from the organizations that were a source of study participants. The cooperating organizations include a medical practice who treats patients with heart disease, heart failure, hypertension, and lipoprotein disorders, metabolic syndrome, and diabetes, a cardiology practice specializing in early detection of cardiovascular disease, as well as preventive and general cardiology, and the American Heart Association patient support network and citizen scientist task force.

Appendix C is the flyer that was used to recruit study participants. To avoid HIPAA violations the potential study participants were not approached directly by the researcher (U.S. Department of Health and Human Services, Office for Civil Rights, 2003). Individuals who were interested in participating in the study were contacted by the researcher directly via phone or email. Once the participant agreed to participate and signed the consent form, the researcher contacted them to schedule the interview. If the potential study participant was recruited through an online source, such as a social network, they were able to complete the enrollment form online or respond to an email with a message that they consent.

The study presented only minimal risk to the study participants. Vulnerable groups were not recruited in this study. There was a possibility, however, that individuals over age 65 chose to participate in the study. The incidence of cardiovascular disease increases with age, and is significantly higher in the over 65 age group, especially the heart failure population (Go et al., 2014). By far, the biggest ethical consideration was the breach of privacy or the inappropriate use of protected health information. While the subjects were informed and asked not to reveal any information that they do not wish to share, it is possible that they inadvertently breached their own privacy or revealed protected health information. Efforts were made by the researcher to strike any such information from their notes or analysis. Data stored in the MaxQDA software system (Verbi Software, 2014) is kept on a secure, password protected computer that can only be accessed by the researcher. A backup of the data is stored in a secure database. The identity of all participants will be protected and individuals are referred to by a code in the analysis. There are no known conflicts of interest. The data collection was conducted outside of the researcher's work environment. Study participants were not in a supervisory or instructional role with the researcher.

Summary

In Chapter 3 the research tradition and methodology were discussed. In this study grounded theory, qualitative methodology, including theoretical sampling, constant comparison, and saturation were used, resulting in a model for how health literacy skills are developed. The study population included patients who have been diagnosed with coronary artery disease, heart failure, hypertension, a lipid disorder, metabolic syndrome, or diabetes within the past 12 months and healthcare professionals. Study participants came from a primary care medical practice, a cardiology practice, the American Heart Association’s patient support network and citizen scientist task force, and social media sites. To avoid HIPAA and other privacy concerns, a flyer was used to recruit patients. Interested participants completed the enrollment form on paper or online, granting the researcher the permission to contact them, provide informed consent, and schedule the interview. The data collection tools include semi-structured interviews of patients and healthcare professionals. Analytic memos were generated following each data collection opportunity. Data analysis includes open coding, axial coding, and selective coding, using procedures described by Corbin and Strauss (2015). Data is stored using the MaxQDA software program (Verbi Software, 2014). Protected health information, or any identifiable information will be removed prior to storage. The participant’s confidentiality was maintained at all times. The results of the data collected using methodological approaches in this chapter will be presented in Chapter 4.

Chapter 4: Results

Introduction

The purpose of this study was to explore the gap in the literature by gaining perspectives of patients and healthcare professionals in the development of health literacy skills in patients who have been diagnosed with cardiovascular disease and diabetes within the past 12 months. The primary research question is how do individuals who have been recently diagnosed with a chronic health condition acquire knowledge and learn skills necessary to manage their condition. Specifically, the research questions include:

RQ1: What are the perspectives of patients and healthcare professionals in the development of health literacy skills in patients who have been recently diagnosed with a cardiovascular disease or diabetes?

RQ2: What are the perspectives of patients and healthcare professionals in the use of new technologies to build health literacy skills?

RQ3: How do healthcare professionals and health educators assess and build health literacy skills in their patients?

RQ4: How are instructional strategies designed to build knowledge and health literacy used by healthcare professionals aligned with the process of learning described by the patients?

In this chapter the setting of the study and demographics of the participants will be described. The data collection procedures will be reviewed. Data analysis will be presented, including the specific codes, categories, and themes that have emerged from the data. Evidence of trustworthiness, including credibility, transferability, dependability, and confirmability of the findings will be discussed. Finally, the results of the study, addressing each research question, and a theoretical explanation will be presented.

Setting

The setting for this study included a primary care and a cardiology medical practice, patient focused programs provided by the American Heart Association, and online sources. Patient focused programs provided by the American Heart Association include the patient support network and the citizen scientist task force.

Patients and healthcare professionals were recruited through a printed invitation that was posted in waiting areas and staff areas. An electronic version of the invitation was posted on the American Heart Association patient support network, an internal employee news blog, and social media sites, including Facebook and Twitter. Patients and healthcare professionals who were interested in participating in the study contacted me through email or phone. After describing the purpose and requirements of the study, if the participant was interested in participating and met the inclusion criteria, an interview time was set and the conference calling instructions were sent via email.

Thirty-four of the thirty-five interviews were conducted through a conference calling system, and one was conducted in person, using a recording device. Each participant was given a $10 gift card following the interview which was sent to them along with a thank you card. After informed consent was obtained, the calls were recorded and transcribed verbatim into a Word document. All identifiable information was removed from the transcript and each participant was given an alpha-numeric code name. Patients began with the letter P and healthcare professionals began with an HP. All audio and document files are stored in the MaxQDA software program and stored on a secure computer.

Demographics

Participants included a broad range of healthcare professionals, representing a wide spectrum of care from the emergency department to health educators (Table 4). All of the healthcare professionals work with patients with cardiovascular disease and diabetes and have an average of 24.4 years of professional experience. The healthcare professionals included direct care givers, such as physicians and nurses, other licensed healthcare professionals that provide both clinical care as well as education, including a pharmacist, physician assistant, and a nurse practitioner, as well as non-licensed professionals who both present and develop health education materials. The physicians included a primary care physician, an emergency medicine physician, and three cardiologists. The roles of the nurses included providing discharge instructions to heart failure and heart attack patients, disease management for patients following discharge, and designing health education materials. The roles of the health educators included health coaching, developing digital materials, and leading an online support network.

The patients also represent a broad range of conditions and ages. Many of the patients had more than one condition and two of the patients were care givers (Table 5). Seven of the patients were recruited from the medical groups, eight were recruited from the American Heart Association patient focused programs, and one was recruited directly from an online source. Patients represented six different states (Texas, Florida, Washington, California, Michigan, and Indiana).

Data Collection

A total of 16 patients and 19 healthcare professionals participated in this study. Data collection was conducted from January 19th through March 18th 2015. Data collection was in the form of interviews. Participants were given the option of an in person interview or a phone interview. Thirty-four of the thirty-five participants chose the phone interview. Once the participants agreed to participate the interview was scheduled. The participants were sent the consent form in advance. The first part of the interview consisted of reviewing the purpose of the study and the elements of the consent form. Participants were reminded that participation was voluntary and that they could stop the interview at any time. Also, it was emphasized that their privacy would be protected and their identity would never be revealed. Participants also were asked to agree to the interview being recorded. Two participants, one patient and one healthcare professional were not able to connect to the conference line, so only notes were taken. All other interviews were recorded by the conference calling system. Immediately following the interview a transcript of the call was made by entering the conversation into a Word document. Once the document was created it was uploaded into the MaxQDA system. Once in the MaxQDA system, the document was coded. Following the coding a memo was created, describing the interview and expanding on ideas that emerged in the interview. The memos were attached to the transcript in MaxQDA.

Characteristics of the healthcare professionals are presented in Table 4. Characteristics of the patients are presented in Table 5. Data was collected in the manner described in Chapter 3 with no variations.

Table 4

Characteristics of Healthcare Professionals

Characteristic	Number of individuals
Male	5
Female	14
Average age	50.4
Age group	
Under 40	4
40-65	13
Over 65	2
Average years of experience	24.4
Profession type	
Physician	5
Nurse	5
Nurse Practitioner	1
Physician Assistant	1
Pharmacist	1
Dietitian	1
Social Worker	1

Medical Assistant	1
Health Educator/Health Coach/Designer	4

Table 5

Characteristics of Patients

Characteristic	Number of individuals
Male	6
Female	10
Average age	55.4
Under 40	2
40-65	10
Over 65	4
High School graduate	9
College graduate	5
Master’s degree	2
Patient type	
Heart attack	4
Heart failure	3
Irregular heart beat	1
High blood pressure	4
Dyslipidemia	4
Diabetes	4

Congenital heart defect	3
Care giver	2

Note. Patients may have more than one condition

Table 6

Details of Healthcare Professionals

ID	Role	Gender	Age	Years
HP1	Primary care physician	Male	54	28
HP2	Social worker	Female	32	10
HP3	Dietitian	Female	57	35
HP4	Nurse	Female	48	25
HP5	Health educator	Female	26	4
HP6	Emergency physician	Male	48	11
HP7	Web Designer/educator	Female	32	2
HP8	Nurse	Female	58	36
HP9	Medical assistant	Female	29	9
HP10	Cardiologist	Male	75	49
HP11	Nurse	Female	58	43
HP12	Educator	Female	44	16
HP13	Nurse practitioner	Female	59	35
HP14	Cardiologist	Male	51	18
HP15	Physician assistant	Female	44	10
HP16	Cardiologist	Male	82	50

HP17	Nurse	Female	53	33
HP18	Health coach	Female	42	15
HP19	Pharmacist	Female	58	34

Table 7

Details of Patients

ID	Condition	Gender	Age	Education
P1	Heart attack	Female	51	Some college
P2	Heart attack	Female	79	College
P3	Dyslipidemia	Female	78	High school
P4	Heart failure, diabetes	Female	58	High school
P5	Diabetes	Male	69	College
P6	Heart attack, diabetes	Male	44	GED
P7	Irregular heart beat	Female	52	College
P8	Hypertension	Male	34	College
P9	Hypertension, diabetes	Male	54	High school
P10	Dyslipidemia, hypertension, diabetes	Female	63	High school
P11	High cholesterol, diabetes	Male	49	High school
P12	Heart failure, pacemaker	Female	41	High school
P13	Heart failure	Female	51	High school
P14	Heart attack	Male	75	Masters
P15	Heart failure – cardiomyopathy	Female	33	High school

P16	Heart disease, diabetes	Female	54	Masters

Table 8

Source of patients

Source	Number
Medical group	7
Patient focused programs	8
Social media	1

Data Analysis

Using the grounded theory methodology described by Corbin and Straus (2015) data analysis consisted of open coding, analytic and methodologic memos, axial coding, selective coding, and diagramming. Using this methodology data analysis and data collection were done concurrently, using a process of deduction, validation, and inductive elaboration (Corbin & Strauss, 2015). Data collection was completed, theoretical saturation was achieved, and data analysis continued into the post data collection period. The objective of the data analysis was to develop a theoretical explanation of how health literacy skills are developed in patients with cardiovascular disease and diabetes.

Open coding

The coding method consisted of three stages, as described by Corbin and Strauss (2015). The first stage was open coding and was inductive and did not use any predetermined codes. Using constant comparison methods, codes were created on the fly as new concepts emerged (Charmaz, 2014). As the coding structure began to emerge, sub codes were added to similar concepts. A total of 566 segments were coded, including 268 patient segments and 298 healthcare professional segments. A total of 70 codes were created resulting in 8 categories. Table 6 includes the 8 categories and the frequency of coded segments for patients and healthcare professionals.

Table 9

Table of Codes and Categories

Categories	Patients	Healthcare professionals
Resources and technology	106	60
Programs and interventions	36	6
Teaching methods	23	88
Influencers	14	5
Emotions	40	37
Behaviors	10	30
Personalized	31	36
Process	8	36

Analytic and methodological memos

Following each interview, a memo was created summarizing the interview and commenting on theoretical concepts. Methodological memos were created to clarify methods, direct theoretical sampling approaches, and define the dimensions and characteristics of the emerging codes. Analytic memos were created to expand on theoretical concepts. A weekly update memo was used to summarize the interviews, methodological, and analytic memos. This weekly update memo began the process of moving concepts from codes to themes and categories.

Axial Coding

The second step in the coding process included using the coding segments of the interviews and the memos to determine the dimensions, context, interactions and relationships among the codes. Axial coding is the process of linking codes and concepts, providing context to the data, including the variation, complexity, integration, and level of abstraction necessary to go beyond a description of the phenomenon to a theoretical explanation. This led to the development of categories and themes, and a description of the core phenomena, actions and process, including causal conditions, strategies, intervening conditions, context, and consequences.

Selective Coding

The final phase of the data analysis process was the development of a unified theoretical explanation of the development of health literacy skills, using selective coding. Theory construction is what sets grounded theory apart from other qualitative methods by moving beyond the description of who and what to an explanation of why and how (Corbin & Strauss, 2015). According to Corbin and Strauss, achieving a theoretical integration of the themes and categories requires a description of the properties, dimensions, density, and variation in the data. The theory formation includes a theoretical integration of the key themes and categories. Techniques used to develop the theory included the use of analytic memos and diagrams to further explain the process of health literacy skill development in patients with cardiovascular disease and diabetes.

Evidence of Trustworthiness

Credibility was assured by following the interview guides and keeping the interview focused on the research questions. Credibility was also established due to the fact that the results were somewhat surprising to the researcher, demonstrating open-mindedness to the findings. Credibility was assured by using scientific rigor by following the process of grounded theory as defined by Corbin and Strauss, (2015). This was important because a target for dissemination of the findings of this study is researchers that are more familiar with quantitative research methods.

Transferability was established by identifying specific cases where a strategy or concept was used to build health literacy skills. HP 17 shared a story of how the teach-back method that she has used as a discharge nurse for heart failure patients was used in an encounter with the patient's daughter in a store. Also, several patients indicated how important the cardiac rehabilitation program was in their process of learning. These examples can be used to determine what is possible in the development of health literacy skills.

Dependability was established by interviewing both healthcare professionals and patients. Transcripts of all of the interviews, as well as codes, categories, and themes, were sent to the chair of the dissertation committee for intercoder agreement. Also, coding was conducted immediately following the transcription by the researcher. The transcript was created by listening to each phrase of the audio recording and typing the word for word response to each question. Transcribing the recording verbatim allowed the researcher another pass at the exact words and phrases that were used.

Conformability was established by becoming more self-aware of their theoretical lens, and this was confirmed through findings that were not expected.

Results

This results section is organized by the four research questions. At the end of this section a unified theoretical explanation of how health literacy skills are developed in patients with a new diagnosis of cardiovascular disease and diabetes is presented.

Research Question 1: What are the perspectives of patients and healthcare professionals in the development of health literacy skills in patients who have been recently diagnosed with a coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes?

The key theme and categories for research question 1 are presented in table 10. This question focuses on how patients learn the knowledge and skills necessary to manage their condition. This research question was asked to both healthcare professionals and patients, and is viewed from the perspective of the patient. These themes and categories are supported by comments from both patients and healthcare professionals.

A consistent theme from both healthcare professionals and patients was the role of social and emotional support in the development of health literacy skills. The response was so consistent that I had to emphasize that I was asking about health literacy, not motivation or compliance. The theme is called “Social support is a learning opportunity.” The categories related to this theme include emotional support, a behavioral approach, and the role of programs.

The clinical setting, both the hospital and the doctor's office, is the setting where the diagnosis is made and early attempts at education are initiated. HP6 is an emergency physician who encounters patients at the moment of diagnosis. According to HP6 the initial process is hierarchical, moving from physical needs, including survival, being able to breathe, and being pain free, to thoughts of "what does this mean for my life". "There are other fish to fry at the moment" and so both healthcare professionals and the patients defer learning about their condition until later (HP6). Once the patient is admitted to the hospital the role of educator shifts from the doctor to the nurse (HP4, HP17). HP4 and HP17 are both nurses who cared for heart attack and heart failure patients in the hospital. Both felt that education should begin early, be provided in smaller bits of information, and should be verified with techniques like teach-back and follow up phone calls.

Emotional support. These early attempts to educate the patient are necessary and ethically responsible. According to several of the patients, however, these attempts were not sufficient in building self-management skills. The primary reason appears to be the emotional state of the patient, including anxiety, depression, or denial. The first step in the development of health literacy skills appears to be an assessment of the emotional state of the patient. HP6, an emergency physician, HP2, a social worker, and HP13, a nurse practitioner all mentioned using the stages of loss as a model for addressing the emotional state of the patient (Kubler Ross, 1969). In the stages of loss, also referred to as stages of grief, or stages of death and dying, patients transition through stages of denial, anger, bargaining, and finally acceptance (Kubler-Ross, 1969).

Emotional state is referred to or inferred by healthcare professionals and patients. From the professional perspective, an assessment of the emotional state of the patient is made. If emotional issues are present the patient may not be able to understand the information presented to them, impacting their ability to make the necessary lifestyle changes. This theme is validated by the healthcare professionals who care for these patients following their acute event. A primary care physician (HP1), social worker (HP2), dietitian (HP3), physician assistant (HP15), and a nurse who provides disease management (HP8) all mentioned the need to address the emotional state of the patient before introducing educational approaches. "If they are overwhelmed they are not listening or hearing" (HP3). "The first factor for everybody is to reduce their stress" (HP11). A cardiologist (HP16) reflected on a patient encounter earlier that day, "You know, this scared the crap out of me, I was so fearful, I did not have any hope. "The dvt paralyzed him emotionally" (HP15).

From the patient point of view, the statement "I was a mess" (P1) meant that their mind was not right and learning was difficult. Emotional state, therefore, means more than depression, or anxiety, it also means level of motivation, readiness for change, self-efficacy, and engagement. If the patient is not in the right state of mind, the strategy is to address the issue and provide social and emotional support. P2, a heart attack survivor said "One of the surprising things was that I was having anxiety, for the first time in my life and I was thinking, what in the hell is this? Because I have never felt anxiety like that". "The heart attack scared the bleep out of me." (P14). "There are times when I have a heart palpitation and it freaks me out" (P7). "It took me a few months because I was in a denial period, the diabetes is new" (P6).

Patients and healthcare professionals alike feel that the best way to address their emotional state is find a social support system. The strategy for building health literacy skills is an interrelated system of emotional support, a behavioral approach, and an instructional approach. Educational methods without support and behavior management do not appear to be very effective.

Virtually every patient made a reference to a support system of some kind. This system included family members and care givers, programs, such as cardiac rehabilitation, diabetes education, or lifestyle management, and support groups. The support system allowed several of the patients to use the experiences of others to develop their own personal experience. For example, P11 mentioned that he talked to other people and would try different things. P12, a heart failure patient said the support groups helped her to learn by getting a chance to talk to other patients who have a shared experience. P14 felt the support of his family was responsible for his being able to stop smoking. P2 emphasized the need to find a physician with a sympathetic ear because "you need all of the support you can get" P2 also came across a newsletter article about a 44 year old jogger who had a heart attack, and that related to her.

From the perspective of the healthcare professionals, the support system is a critical element in addressing the emotions, modifying behavior, and providing a platform for learning.

> I think that when they can share their story there is likely someone else that has had a similar experience, who can chime in and tell their story, and would have that camaraderie and would say, this happened to me, and this is what I did. Or if they are trying a new drug, this is what I did, and I had this specific side effect, and this is what I did to help or improve that side effect. So I think there is some kind of personal connection, and reassurance that there are other people out there going through a similar experience. It is a combination of sharing the story and getting resources from others that makes a difference. HP5

Several of the healthcare providers mentioned including the caregivers, especially spouses. “I did take the time to speak with his wife, so that she would understand” (HP15). HP11 mentioned that many patients have adult children as caregivers who can be an effective means of providing information.

Behavioral approach. Once the emotional state is addressed, the next step is to provide a behavioral strategy focused on increasing motivation and self-efficacy. Again, the most common intervention was the establishment of a social support system. HP4 stated that she uses a behavioral approach, addressing lifestyle changes needed to manage the patient’s health. Similar to addressing the emotional state, social support is a key strategy for implementing behavior change (HP4). Patients described this in a self directed manner. HP1 believed that patients needed to be their own advocate. HP3 began changing dietary habits, while P11 and P15 began long distance running programs. HP1 mentioned being trained in behavioral medicine. Finally, once the emotional state and readiness for change have been addressed, an instructional strategy is implemented.

The theoretical model referred to by many of the healthcare professionals was the transtheoretical model, including readiness for change (Prochaska & DiClemente, 1983).

Instructional methods included internal, external, and social components. The internal component included educational materials and methods provided by the healthcare professional, and included print materials and face to face interactions. The external component included referral to programs or technology platforms. The social component included establishment of a social support system, which included programs, care givers, and support groups. P1, 2, 12, 13, 14, 15, and 16 participated in an online support network. The theoretical model described by the healthcare professionals was Maslow's hierarchy of needs and adult learning theory (Milheim, 2012).

Role of programs. Programs like cardiac rehabilitation, diabetes education, health coaching, and support groups provide a format for behavioral and emotional support. Programs also provide an opportunity for ongoing education, and social support, both in person and online. Perspectives from patients and healthcare providers indicated that these programs are critical in reducing anxiety in patients, allowing learning to occur. Instructional strategies that were perceived to be effective were personalized, interactive, social and relevant.

P1, a heart attack survivor, stated cardiac rehabilitation was important to her success, not only because it helped with the emotional stuff, but also it was where she learned how to manage her condition. P4 was referred to a lifestyle program to learn how to manage her diabetes and blood pressure, but also helped her manage her depression and control negative thoughts due to the comradery of the group. According to HP18, a health coach who works with patients with cardiovascular disease and diabetes, the patients who have gone through cardiac rehabilitation or diabetic education do a much better job of managing their disorder.

The majority of the patients interviewed obtained the information they needed to manage their condition through un-aided, self-directed internet searches. The initial basis for the search is based on the information they received from other sources of influence, including their physician, care giver, friends and family, and the media. These searches usually went much deeper than was intended.

> I take the readings to get a better understanding of my blood sugar to related what I ate to the reading. Now I take it so that I know that I am OK. If I think my blood sugar is high, I will test to see if I am right. The dietitian explained how blood sugar worked, but I really learn by understanding testing with different foods. Nobody told me to do that. P9

Table 10.

Key Themes and Categories for Research Question 1

Key themes	Categories	Selected extract
Social support is a learning opportunity	Emotional support	The support groups help me to learn. The AHA support, there were also camps. The buddy forms and patient forms, you get to talk to other people. When you hear the same thing from multiple forms, it helps you to start to make sense. I learned about studies that had been done, and the results. I would never have known without being connected to those groups. You find out little details that might not be important to the doctor, but helps to explain things. P12.
		So I think there is some kind of personal connection, and reassurance that there are other people out there going through a similar experience. HP5
	Behavioral	A lot of the behavior I observed is expected, and made sense to me. At the same time, I have been impressed by it, because you read so many things that people are just lazy and they don't care about their health, but it was absolutely not the case. It was an older population, every one of them was over 55, and they were all well informed, it seemed like. HP7.
		Understanding what they actually did. I did not really know medically what was going on, so that I was more aware of my choices. I felt at the time like everything was bleak, because I did not know the choices. P2
	Programs	Cardiac rehab had the biggest impact because emotionally, I was a mess, a mess, I mean just don't know how people do it, I didn't even conceptualize that, you know, I didn't die, but I wasn't, I had a lot of fear. P1
		He directed me to the Game of Health. He was able to keep track us and a lot better. It was the camaraderie of the group, people that were losing and not losing and I learned things I forgot I knew. I was depressed myself. Because I would gain weight, I would chastise myself. P4

Research Question 2: What are the perspectives of patients and healthcare professionals in the use of new technologies to build health literacy skills?

The key theme and categories for research question 2 is presented in table 11. The focus of this research question is on the role of digital tools and technology in the development of health literacy skills. This research question was asked to both healthcare professionals and patients, and is viewed from the perspective of the patient. These themes and categories are supported by comments from both patients and healthcare professionals.

When asked how they acquired the knowledge and skills to manage their condition, many patients said they used the internet to obtain information on their condition and how to manage it. The theme in this research question is “Google is a health system.” Categories include a self-directed, personalized experience, the role of digital tools, and new tech confusion.

A self-directed, personalized experience. The majority of patients reported that they get their information through search engines including Google. These searches are primarily self-directed, un-aided, and highly personalized. P10 learned about her diabetes, high blood pressure, and high cholesterol from the internet, and by reading some books. P15 said she uses a search engine and types in key words looking for information on side effects and things to anticipate. “I go online and do my own research” (P13).

They may end up at WebMD, or other professional websites, such as the Mayo Clinic or the American Heart Association, but they start the process in an undirected, unaided manner. The purpose of these searches is to supplement and validate the information they have received, or not received from their healthcare provider. “For health I primarily read websites, like Mayo Clinic or WebMD because they have a good reputation, and I stay away from website sponsored by pharmaceutical companies” (P14). P8 said the primary resource was the doctor, but did go to the internet to look up information on the medications. “I used Google and ended up at WebMD because it was the first on the list … it was a name I had heard before, so there might have been a trust factor” (P8). “I go to the internet to find out what kind of heart attack I had… I use Google and put in key words until I find what I am looking for” (P6).

For the patients, these are simply tools, and do not replace direct interaction with professionals, educators, and other patients. “The internet has some really good stuff, but it is a wonderful and dangerous place” (P1). P9 said his interest in learning more about his condition was piqued by his doctor. He received some information from the doctor, but was interested in more so he went to the internet and found some medical websites that were pretty good. P11 uses a search engine, going one by one until he finds what he is looking for. “I cross reference information with other sites to make sure it is consistent with what others are saying” (P11).

Due to limited time and resources, HP1 and HP6 recommend digital tools and technology for their patients to fill in their educational gaps. HP14, a cardiologist believed some patients go to the internet, while some rely on the doctor, or do nothing. “The ones that go to the internet go to Google” (HP14). This is not always a welcome experience. In HP4’s experience as a heart failure nurse, stated “we work with patients, provide education, and follow up with them on the phone, and they immediately go to the internet or their family members for more information."

According to HP8, a nurse who provided disease management for heart failure patients, technology provides the opportunity for a customizable tool that can support small steps forward and can provide positive reinforcement in a manner that is not possible in the current healthcare system. HP1, a primary care physician believed digital tools will transform how healthcare is delivered.

> So I think the most exciting next step in how this will all occur is with mobile devices, and smart phones that will be the way of the future, but I don't know that right now we have that figured out. I think that the technology that will be developed will work with the individual and identify what has worked or not worked in the past and how they believe people are successful, what they believe is something they are capable of at that moment in their life. It will have a lot of change management technology built into it, which includes intellectual understanding, emotional desire, and practical application of making what is the right thing easier than what you have been doing. HP1

According to HP2, when a patient is diagnosed they would turn to digital tools for more information, and they would look for trustworthy resources. The healthcare professionals rarely recommend specific tools, leaving that decision up to the patient, but will recommend certain websites. The most often mentioned website was WebMD. "A lot of them like WebMD. I actually send them to a website called Fooducate because I am a dietitian and really want them to understand food" (HP3).

The developers of the tools and resources rely on active involvement of the healthcare professions. The health educators and designers do not communicate, interact, or speak the same language as healthcare providers, creating the potential for communication and translation barriers. According to HP7, who designed digital tools for patients, there is a huge barrier between the providers and the designers. "I do not have access to patients, in order to observe them and talk to them about their experience" (HP7). "When we put that information on a mobile device we have to break it down into smaller chunks…do it in under a minute.. And hopefully match the content with their cognitive ability. That is a challenge" (HP7). Another educator, HP12, was responsible for publication of print and digital materials targeting patients with diabetes. "We combine visual, audio, text, and graphics… because when you combine them into a multimedia experience the retention in much higher" (HP12).

Digital tools. It is unclear the role that digital tools and technology play in the development of health literacy skills and corresponding improvement in health. The patients that used apps or wearables, like a Fitbit, use them for fitness and health, not for disease management. A small number of patients used wearables or smart phone apps. Some of the patients mentioned that they had downloaded an app, but did not use it, or it did not work. "I was using a Fitbit until I killed it. I think it needs to be recharged… my trainer just has me write down my information in a log book" (P4). "I do have a fitness app on my phone but I do not follow it" (P11). "I do have an app on my smart phone, but it does not work… I do have a blood pressure machine to keep track of my blood pressure, but it does not work" (P7).

The most common tool was a home blood pressure unit. The information taken at home, however, is rarely shared with the healthcare provider.

Healthcare professionals perceived their role to be that of validator of information. For example, the patient goes out and seeks information, brings it back to the healthcare professional, who sorts out what is accurate and what is not. From the patient’s perspective, the validation goes both ways. They seek validation of the information from their healthcare professional, but they also seek the external information to validate what they have heard from their healthcare professional. The only method the patient has to validate the information they found on the internet is to use a trusted source, like WebMD or the American Heart Association, or visiting medical sites including the Mayo Clinic and Harvard.

New tech confusion and a digital divide. There seems to be some confusion on what is considered new technology. While the interviewer included examples of smart phone apps, wearables, and connected devices, patients cited the internet as the predominant tool. The blood pressure units described by the patients were manual and did not send, sync, or upload information to a database. Also, there is still a digital divide in access and use of digital technology. This confusion extends to healthcare professionals as well as patients. Some of the healthcare professionals recommend new technology opportunities, like an app or wearable. Some only recommend older technologies, including blood pressure cuffs or hand written logs. Finally, some of the healthcare providers did not recommend any new technology.

Several patients had issues with digital sources. “I don’t even have a cell phone” (P2). “I don’t have a computer, only my phone so I prefer face to face” (P4). “I use cable TV. My son gave me an iPad, but I am not computer savvy at all” (P3).

> Oh my goodness, yes, the first blood pressure device I used was a wrist, and it does not work worth a darn. But the doctor gave me a lifesource and it is spot on. So I use that and I really had to learn how to, because I was a little freaked out at first, because I would wake up in the middle of the night freaked out and I would take my blood pressure. P1

Table 11

Key Themes and Categories for Research Question 2

Key themes	Categories	Selected extract
Google is a health system	Self directed/ personal experience	I get most of my information from the internet. I have been misdiagnosed, so I do a lot of my own research. P16. A lot of them turned to journals and really reliable resources, such as the Mayo Clinic, or medical journals. So they were reading what I would consider very high level stuff. The selection of these sources was based on the credibility of the source, and the visibility of the source. So people know about the Mayo Clinic, they know about Harvard Medical. The other place they got information from was friends and family. Some of them would have medical professionals in the family they would turn to, and since they trusted the person, the trusted the information they gave. HP7
	Role of tools	I see such as natural fit, in my experience, when someone was diagnosed they would turn to digital tools for more information. On a day to day routine, where we all engaged digitally, throughout the day, that seemed to be a comfortable form of information, for many age demographics, not all. I would say the need

		for validated instruments, for trustworthy resources, that was always huge. It was not a google search, but a warehouse of vetted, and validated knowledge, similar to going to the heart.org website. Knowing that you have a stamp of approval and thorough science review really does give people comfort as they are taking in all of this information. HP2
		I use google and put in key words until I find what I am looking for. I kind of already know, from my family history what I am looking for and what I need to do. P6
	New tech confusion/ digital divide	I was using a Fitbit until I killed it. P4I don't even have a cell phone. P2

Research Question 3: How do healthcare professionals and health educators assess and build health literacy skills in their patients?

The key theme and categories for research question 3 is presented in table 12. This question focuses on the role of digital tools and technology in the development of health literacy skills. This research question was asked to both healthcare professionals and patients, and is viewed from the perspective of the patient. These themes and categories are supported by comments from both patients and healthcare professionals.

Healthcare professionals assessed health literacy skills in very informal ways. None of the healthcare professionals interviewed used any formal assessment of health literacy. They assess the verbal skills of the patients, including the terms and grammar they use. They also considered the types of questions that the patient asks and how much information is retained from one visit to the next. A few of the healthcare professionals use the teach-back method to determine how well the information has been retained.

The primary method of assessing health literacy skills, however, is based on the results of the patient. Health literacy is based on whether the patient is able to show improvement, or achieve their goals on biometric assessment, including blood pressure, blood glucose, cholesterol, or weight. Several of the healthcare professionals mentioned that they know more could be done, but they are limited by the process, including time and resources, and a lack of a practical way to assess health literacy. Physicians especially felt that it is very difficult to address health literacy, especially in a full-time practice. HP1 believes it is a duty and a challenge in family medicine, especially in a full-time practice to address health literacy, but there is no science to it. HP1 and HP2 both mentioned understanding where the patient is, where they want to be, and meeting them there. HP2 conducts a more formal initial assessment of health literacy, emphasizing medication and a basic understanding of their condition. Also, in a group setting more information is assessed, looking for gaps in knowledge and other hot button issues, such as trust in their doctor (HP2).

According to the results of the study, healthcare professionals developed health literacy skills by first assessing the emotional state and the readiness for change of the patient. Once the emotional state and level of engagement have been addressed, the healthcare professional will initiate an instructional strategy. The level of engagement refers to the patient’s motivation, readiness for change, and willingness to take responsibility and accountability for their behaviors. Attempts to build health literacy skills without first addressing the emotional state and engagement are ineffective, from the perspective of healthcare professionals. This perspective was validated by several patients. HP4 begins by understanding the patient’s history, including family, and support. Once the needs of the patient are identified, HP4 focused on the level of understanding, using reflective listening and teach-back. Listening to the questions the patient is asking is another key to understanding where the patient is (HP9).

Instructional strategies included providing internal resources, external resources, and social support systems. Internal resources included printed materials and face to face, individual or group encounters with a healthcare professional. HP10 is a cardiologist who has been practicing for 49 years and believed it is his responsibility to educate his patients. “I would talk to them, ask them if they understood, and answer their questions. Medicine has changed and much of this has been delegated to nurses. The nurses do a good job, but I still feel it is my obligation” (P10). External resources included recommending a website or a referral to a program, like cardiac rehabilitation, diabetes education, or weight loss. Finally, success of the instructional strategy appeared to hinge on the social support system, which included a care giver, social site, or program that included other patients.

HP2 believed that building health literacy skills involves both internal resources, such as individual treatment, support groups, and counseling, as well as external resources that can be found in the community that is the best fit for the patient. The plan for building health literacy skills should be developed, assessed, and reassessed over time (HP2). HP17 also provided internal and external resources as part of her job discharging patients from the hospital. She began with the basics, including connecting them with their doctor, as well as connecting them with community resources that will best fit their needs, whatever they are (HP17). She started educating the patient as soon as she begins caring for them by giving them little snippets of information, and then uses the teach-back method as a way to assess how well the patient is retaining the information (HP17). HP3 uses a similar strategy by asking more complex questions or giving a scenario to see how they think their way through it. HP19 emphasized the importance of problem solving and trouble shooting. HP2 is a social worker, HP3 is a dietitian, HP17 is a nurse, and HP19 is a pharmacist, representing four different disciplines that use very similar approaches.

Traits

Key traits of instructional strategies perceived to be effective were ones that were personalized, interactive, social, and relevant to the patient. A key trait is relevance. According to HP3 the patients were gathering data and facts and reflecting it back in terms of their life. "After they leave the office they are going out and applying the information and seeking additional information" (HP3). Social support systems, therefore, provided not only the emotional support, but also the educational platform that allowed patients to share and learn from other patients, communicate in an interactive, back and forth exchange, and consisted of information that was relevant to the patient. If the patient is self-directed and engaged they will seek out information on their own, without depending on the provider (HP8). Patients will seek out other patients, not only for social support, but also to learn from their experiences (HP8).

> So it has to be personalized and individualized, so that it is relevant to their lives. They have got to believe that if they engage in this endeavor that they believe that

> there efforts will make a difference in their lives. They have to appreciate it in a way that they feel empowered, and that their efforts are going to make a difference. And then once they do that and they are engaged and motivated, then they have to take responsibility, and how they respond, and are responsible for their actions HP1

Format

Multimedia approaches, provided in small chunks of information, beginning with foundational information, are seen as the best method for building knowledge and skills. Small steps are taken with each encounter, ultimately leading to higher level skills. HP8 started by asking the patients how they absorb information best, and then tries to incorporate the content in a way that matches their preferred learning style. “Most people have been in a learning situation and knows what works best for them, especially if they are anxious and there is new terminology that they have to digest” (HP8).

Integration

Patients attempted to integrate the information they receive in the instructional and support setting with the information they get from their own, self-directed research. Patients validated information by checking with their doctor, and getting confirmation from other sources. Their most trusted source of information is their doctor, yet many mentioned that they get very little information from the doctor.

P8 was diagnosed with borderline hypertension, and began taking a low dose of a blood pressure medication per instructions from his doctor. The doctor talked to him about the medicine and he Googled it to know what to look for (P8). “The medication gave me really bad GI issues….I just stopped taking it. I went in to see my doctor a couple of months later and she said I really needed to tell her about things like that" (P8). P9 learned how sugars work and how it is metabolized in the body from a dietitian who was referred through the doctor.

> Here is the thing, the doctors are really good, but they are overworked and really busy. I always tell people to follow the doctor's orders but you got to be your own advocate. You got to be your own advocate, so I needed to dig, I needed to find, to make an appointment with the doctor even though there was nothing wrong with me and he didn't want me in there, so sit down and talk to me, what is this? You have to be your own advocate. P1

P1 used the doctor to validate information she was hearing from other sources. "You find a way to validate. You correlate with things you already know to be true, or you go ask a doctor, and some of it is common sense" (P1). HP14 agreed with P1 that patients get information from multiple sources and use the doctor as a way to validate what they are hearing. "So we in many cases are used as the appeals court, or if you will, the supreme court, where we have multiple opinions and we make the ruling" (HP14).

The two primary strategies for addressing health literacy were using the teach-back method, and simplifying the message. Rather than simplifying the message, the strategy is to provide the content in small chunks, and taking small steps. Healthcare professionals had no idea whether their efforts to build knowledge and skills in their patients are effective. Even the educators and designers had no data on effectiveness.

By hearing a consistent message, patients are gaining life experiences that can be applied to how they manage their condition. “If they are a newly diagnosed diabetic, I make sure they understand the basic signs and symptoms… we go over practical examples (HP3). As a health coach, HP18 focused on areas that are relevant to the patient. Awareness of the condition gives the patient a frame of reference to judge what is relevant and what is not (HP18).

According to HP6 there are foundational things that need to be learned first before you can learn about other topics, leading to mastery. These foundational skills will allow the patient to progress from point A (foundational) to point B (mastery) (HP7). HP 15 also begins with foundational skills, including key terms, the importance of lifestyle modification, and then, from that knowledge, personalizes it to the patient.

Influencers. The non-physician healthcare professionals deferred and relied on the physician as the primary source of patient education/instruction/leadership and validation. Physicians, however, seemed to be the ones least prepared to provide this instruction, from a training, time, and resources perspective. Even the developers of education and digital tools relied on and prefer active involvement of the healthcare professionals, creating an interesting paradox that the healthcare providers are relying on the technology, while the technology is relying on the healthcare providers.

Nevertheless, doctors appeared to have significant influence over the patients. “If the doctor tells them that this is important, that is a huge driver, and they will keep taking it. They will say, my doctor said this is important, but I have no idea why” (HP19).

Process. With only a few exceptions, the healthcare professionals had virtually no training in educational methods in general, or anything specific to health literacy. All of the healthcare professionals had a good working understanding of health literacy and its health implications. The patients also had a good understanding of their health condition. HP9 was impressed that even in the older population most of the patients are pretty well informed and knowledgeable about their health.

Healthcare professionals were faced with a system that makes education and prevention challenging. HP1 stated that it really depends on how much time he has. If he has only has 7 minutes to get it out, he will focus on what is not working and will focus on 3 things the patient can do. If he has more time, he will focus on how to get the numbers to goal and improved by 20% (HP1). He used an iterative approach, looking for something that is working, "but it is very sloppy, it took a tremendous amount of time, and often I never got there" (HP1). P11, a patient of HP1 learned to understand how to manage his blood sugar my taking readings and looking at his numbers.

Table 12

Key Themes and Categories for Research Question 3

Key themes	Categories	Selected extract
Instructional strategies should be personalized, interactive, social, and relevant	Traits	So it has to be personalized and individualized, so that it is relevant to their lives. I think you have to go to where the person is, and meet them there and find out what works for them, but I think it is going to be more specific and customized. HP1
	Integration	Do I try to give patients very practical examples? I tell them stories, patients remember stories. And it sticks with them. And I give them examples of other patients that

		were successful, and kind of how they thought through things so they can see, ok this is the process. It tells them, it is time to learn. It is so overwhelming. I assess where they are emotionally. If they are overwhelmed, we can't get complicated at all. We need to go over the basics. HP3
	Format	The information I received from my doctor was good, but I was curious to learn more. The print material was helpful, but too general. P8

Research Question 4: How are instructional strategies designed to build knowledge and health literacy used by healthcare professionals aligned with the process of learning described by the patients?

The key theme and categories for research question 4 is presented in Table 13. The focus of this question is on the comparison of instructional strategies of healthcare professionals and the learning preferences of the patients. These themes and categories are supported by comments from both healthcare professionals and patients.

Patients and healthcare professionals were in agreement that the emotional state and the level of engagement must be addressed first. Instructional strategies, therefore, were usually left to the patients who are ready to learn. In this case the instructional strategies of the healthcare professionals seem to match the educational needs of the patients. When the emotional state and/or the level of engagement were not ideal, the strategy was to address the emotional state, including the anxiety or depression, and provide social and emotional support.

The healthcare professional appeared to have significant influence on the patient, and at least for some patients provided validation for information and strategies. There were examples where the information provided by the healthcare professional had a very positive impact.

> I have an example when I was doing my Christmas shopping. I met a lady whom we had cared for her mom about 7 years ago for heart failure. She commended me and all of the nurses for the information the nurses gave not only her mom, but also her. She had a couple of episodes after discharge and she was able to recognize issue early. She was able, 7 years later, and not a healthcare professional, to say, I think my mom is going into fluid overload so I called the doctor and they were able to call in a prescription and get the fluid off, avoiding a hospitalization. She eventually passed, but was able to spend the majority of her time at home. HP17

No patient left behind. It is unclear how the unmotivated/non-engaged patient develops their skills. While it is clear that they are not getting it from healthcare professionals, and in many cases do not actively seek information, nevertheless, they must still be making decisions based on something. The current system, however, is geared to the motivated, engaged patient.

While the most common educational methods used by healthcare professionals were printed materials and face to face interactions, the preferred methods by patients were video and face to face interactions. According to HP12 the majority of patients used Google to learn about their health, but the information they got from their healthcare provider is usually a brochure or pamphlet. HP15 believed that a lot of education happens outside of the clinic setting. “I would refer them on, and of course we would give them pamphlets, but nobody would read them, so I would refer them to a website” (HP15).

> He didn’t seem all concerned that I was bewildered and in denial. I stayed in that condition for months. Now, after having been on the site, I have found that everyone is talking about the new normal. I am very willing to listen to recommendations and give them a try. I am trying to adopt the new normal. Without giving up my exercise program. P2

Several patients and healthcare professionals mentioned the challenges doctors face in providing education in the clinic setting. “All in all, I would say that I learn the least amount from my doctor. They are willing to share information, but I learned more on my own” (P12). “The doctor explained the medications, but not the side effects. I had to figure that out on my own” (P10). “My doctor did not have a diagram of the heart and very little literature… I went to the Mayo Clinic and their resources were amazing” (P16).

While the patients may rely on the physician as the source of information, other disciplines, including health educators and health coaches may be more suited for providing information. “We have a major problem that physicians are busy, and it is our job to be a teacher…I have seen patients 10 years later that have not had any further education” (HP18). “That is concerning me right now. I don’t know that we do a very good job of that (education) and we need to do better to increase understanding and awareness" (HP16). "They are having side effects and don't know what is going on. I don't know that they get much information from the doctor" (HP19).

Healthy distrust. Patients seemed to have a healthy distrust of the information they get from their healthcare providers, and sought external information to validate what they heard from the providers, while the providers had it reversed; that patients sought info and went to the provider for validation. This distrust was rooted in prior experiences of being misdiagnosed, or receiving conflicting information. P2 and P16 both indicated that they had been mis-diagnosed by their healthcare provider. P3 was so skeptical of her physician that she put more trust in homeopathy and information she was getting from a Cable TV program led by a veterinarian.

This healthy distrust may be true of the motivated patients, the ones who were more self-directed, and more willing to participate in this study. Several patients mentioned a lack of trust in the information they were receiving from their doctor. "He wrote out a prescription for a statin, and he was very annoyed when I said I would think about it" (P2). P2 also mentioned feeling pressure from family members to follow the physician's advice, without questioning anything.

Table 13

Key Themes and Categories for Research Question 4

Key themes	Categories	Selected extract
Patients are self-directed learners	No patient left behind	It depends on the condition, but if they are not making changes and are not motivated he does not like to keep them as a patient. We will have them find another doctor. HP9

	Healthy distrust	...question their doctor very closely. If they don't have a sympathetic ear, leave it, because you need all the support you can get. P2

Linking themes and categories

Axial coding was used to link the themes and categories using conditions, actions and interactions, and the consequences. The core phenomena and the first research question looks at how knowledge, health literacy, and self-management skills are developed in patients with cardiovascular disease and diabetes. The remaining research questions, related to digital tools and technology, instructional methods, and the instructional/learning match are described as strategies.

The causal conditions are the diagnosis of cardiovascular disease or diabetes. There appeared to be more emotional issues, such as anxiety in the heart attack survivors compared to patients with hypertension or dyslipidemia, but have not experienced a life threatening event. The education and baseline level of health literacy may be important, but in this study there did not seem to be variability based on the education level of the patient, and all of the participants had fairly good health literacy skills.

Intervening conditions include the emotional state of the patient, like anxiety or depression, their influencers, and their readiness for change. The patient has a diminished ability to process the information they were receiving if they were experiencing anxiety, depression, or denial, according to both patients and healthcare professionals. Likewise, if the patient was unmotivated or not engaged, healthcare professionals perceive educational strategies to be ineffective. Behavioral strategies addressing readiness for change and the hierarchy of needs have been used to motivate, engage, and educate the patient. In both cases finding a support system is perceived by both patients and healthcare professionals to be the key to being able to benefit from instructional strategies. While physicians have a big influence on the patient, there are many other influencers, including care givers, and non-healthcare related individuals, including friends and family, and media personalities.

The context includes the support system of the patient and their access to technology. Virtually all patients and healthcare professionals mentioned, in some way, the role of social and emotional support. Patients mentioned having a difficult time processing information and focusing on their self-management and lifestyle factors until they found their support system. Once they found their support system, whatever it was, they seemed to relax and had a greater ability to focus and learn.

The format of the information varied. The majority of healthcare professionals used printed materials and face to face encounters. The patients preferred self-directed internet searchers and favored face to face encounters and video, or other visual representations.

In this study the healthcare professionals can be divided into three categories: healthcare providers practicing in an acute care setting, including the emergency physician and the nurses who work in a hospital setting; ancillary providers who provide both medical care and education, like the dietitian, nurse practitioner, physician assistant, and social worker; and health educators who are relatively removed from the clinical setting, and focus more on education and support. Using Maslow’s Hierarchy of needs, the acute care givers are more focused on the survival of the patient, while the educators have a longer term, self-actualization focus.

Strategies include a support system, programs and interventions, such as a program or group, a care giver, or an online support network, and an instructional system and teaching methods that are personalized, relevant, and interactive. Support systems included cardiac rehabilitation, diabetes education and lifestyle management programs. Other support systems included online support networks, care givers, health coaches or personal trainers. These programs provided peer support as well as a platform for education. The peer support allowed patients to gain personal experience, through the experiences of others.

The traits of instructional strategies that were perceived to be effective were that they were personalized, interactive, and relevant. This was achieved through self-directed research and interaction with other patients that was tested and validated through results.

The consequences include self-directed learning, improved confidence or self-efficacy, reduced anxiety, and development of knowledge and skills using Maslow’s Hierarchy of Needs (Milheim, 2012). Consequences also included a healthy distrust for the information received from healthcare professionals. This distrust was not so healthy at times. Also, there seems to be a digital divide and confusion about the role and use of digital technology.

The linking of themes and categories is illustrated in Figure 5.

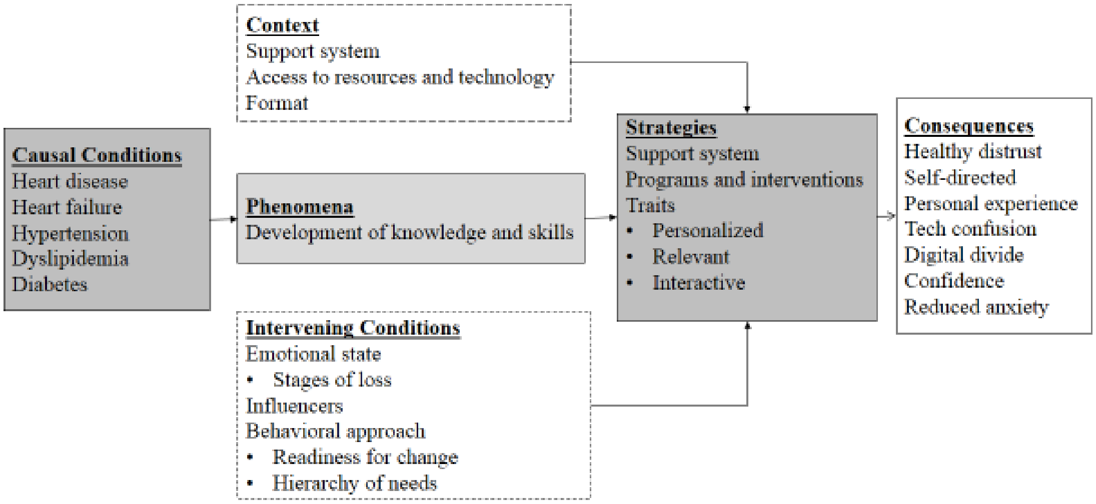

Figure 5. Linking categories.

Theoretical Explanation

The linking of themes and categories from each research question has led to the development of the Health Literacy Instructional Model. The Health Literacy Instructional Model will be explained and explored in more detail in Chapter 5 and is illustrated in Figure 6. The Health Literacy Instructional Model is grounded in the data presented in Chapter 4 and is a theoretical explanation of how health literacy skills are developed in patients with a new diagnosis of cardiovascular disease or diabetes.

Summary

In Chapter 4 the results of this study were presented. The results were presented by the four research questions. To answer the first research question, patients and healthcare professionals were asked how health literacy skills are developed. The theme associated with this research question is the importance of a social support system. To answer the second research question, patients and healthcare professionals were asked how digital tools and technology are used to build health literacy skills. The theme associated with this research question are the use of internet searches as the primary tool. To answer the third research question, participants were asked which strategies are used by healthcare professionals to develop health literacy skills. The primary theme related to this research question was that the most effective strategies are personalized, interactive, social, and relevant. To answer the fourth research question, the instructional strategies of the healthcare professionals were compared to the learning needs of the patients. The main finding of the fourth research question is that healthcare professionals are effective in building skills in patients who have good social and emotional support and who are engaged and motivated, but do not have much to offer patients who are not.

The themes and categories were linked together identifying the context, causal conditions, intervening conditions, strategies, and consequences. This linking strategy was used to form the Health Literacy Instruction Model, which is described in Chapter 5. The discussion of the results described in this chapter, recommendations, and conclusions will be presented in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In this study the gap in the literature related to how knowledge, health literacy, and self-management skills were developed in patients with cardiovascular disease and diabetes was explored. Perspectives from both healthcare professionals and patients were gained from semi-structured interviews. The intent was to go beyond the description of factors related to health literacy to how patients develop the knowledge and skills to manage their condition, how digital tools and technology are utilized, the strategies used by healthcare professionals, and how the strategies used by healthcare professionals match the learning needs of the patients.

In this study a grounded theory approach was used to explore the perspectives of patients who have been diagnosed with coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes within the past 12 months, and the healthcare professionals who treated those patients. The grounded theory process described by Corbin and Strauss (2015) was used to gain a better understanding of the actions and processes of building health literacy skills, leading to a new theory. Grounded theory was selected because it goes beyond a description of the phenomenon of a common experience to a unified theoretical explanation of the process or action (Corbin & Strauss, 2015).

Four themes emerged from the data leading to the health literacy instructional model. The first theme was that social and emotional support is a learning opportunity. Essentially, the support system of the patient was critical in addressing emotional and behavioral challenges, as well as a key component of an instructional strategy. Programs, including cardiac rehabilitation, diabetes self-management, and on-line or in person support groups were perceived by both patients and healthcare professionals to be effective in providing support and building health literacy skills.

The second theme was called "Google is a health system." Patients conduct un-aided internet searches and seek to validate the information they get from their healthcare provider. Other than internet searches, however, it was unclear the role digital tools, like smart phones, apps, wearables and connected devices play in managing health. Patients also appeared to be confused about the definition and role of digital tools, and many were confounded by these tools due to a digital divide. Healthcare professionals acknowledged that patients get information from the internet, and either embrace this by recommending trusted sites, or resist it.

The third theme was that traits of instructional strategies that were perceived to be effective included being personalized, interactive, social, and relevant. The desired format of the educational material was multimedia and provided in small chunks. Patients integrated the information into their own personal experience quickly, and relied on the experiences of other patients to fill in the gaps. Influencers included physicians, and other elements of the support system, including care givers and friends and family. Healthcare professionals were challenged by a system that is not designed for building health literacy.

The fourth theme was that patients were self-directed learners. Patients had a healthy distrust of the information they received from their healthcare providers and sought to validate that information through their own research. Healthcare professionals see themselves as the primary source for validating information patients are receiving from other sources. While some of the patients were doing quite well, and clearly were active participants in their care, it is unclear what resources are available for patients who are not in a good place emotionally, were not engaged, or were not ready to manage their condition. It is unclear, however, how patients who were not self-directed were able to acquire the knowledge and skills necessary to manage their health condition. Themes and categories from each of the four research questions were linked using axial coding, as described by Corbin and Strauss (2015). This led to the identification of the core phenomenon, the context, causal and intervening conditions, strategies, and consequences. The linking and interaction of the themes and categories led to a theoretical explanation of how health literacy skills were developed. For example, social and emotional support, taking a self-directed approach, and focusing on personalized and relevant information crossed into multiple themes.

Identification of these themes and categories led to the development of the health literacy instructional model. The health literacy instructional model included three steps. Step 1 was to provide emotional support for the patient. Step 2 was a behavioral approach addressing readiness for behavior change and self-efficacy. Step 3 was an instructional approach that was personalized, interactive, and relevant. Social and emotional support was a key factor in all three steps.

Interpretation of the Findings

The major finding of this study was the important role of a support system in the development of health literacy skills. While social and emotional support are not emphasized in the national action plan (Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010) and the Health Literacy Toolkit (DeWalt et al., 2012), this finding was not surprising because social support services are utilized more often in other disease states. Huninghake, Dong, Hines, Ablah, and Taylor (2014) reported that more than one-third of cancer patients used support services, and a substantial number of patients not using support services were interested in learning more information.

Health literacy instructional model

A major outcome in this study is the health literacy instructional model, which is shown in Figure 6. The model has three stages. Stage 1 was the assessment of the emotional state. If the emotional state was not good, strategies included addressing the emotional state and providing social and emotional support. If the emotional state is good, stage 2 was an assessment of the readiness for change and engagement in self-management skills. If the patient was not engaged or ready to make lifestyle changes, a behavioral approach, designed to improve motivation and self-efficacy was initiated, along with providing social and emotional support. If the patient was engaged and ready to change behaviors, an instructional approach was initiated in stage 3. This instructional approach includes the establishment of a support system that leveraged technology, and was personalized, interactive, and relevant. The key element that runs across all three stages was the social and emotional support system of the patient. These stages appear to be sequential and hierarchical. For example, going directly to stage 3, without addressing the emotional support or the behavioral approach, was not perceived to be effective. The sequence of addressing the emotional support, then the behavioral approach, and then finally the instructional strategy was perceived to be the most effective. The process of developing health literacy skills also was described by patients and healthcare professionals as having stages, or levels. These stages or levels were described as stages of loss, beginning with high emotions, such as anxiety and depression, and ending with acceptance (Kubler-Ross, 1969). A hierarchical needs process also was described, beginning with physiological and safety needs, and ending with self-efficacy and self-actualization (Milheim, 2012). In both a stages of loss and hierarchy of needs, social and emotional support are key elements.

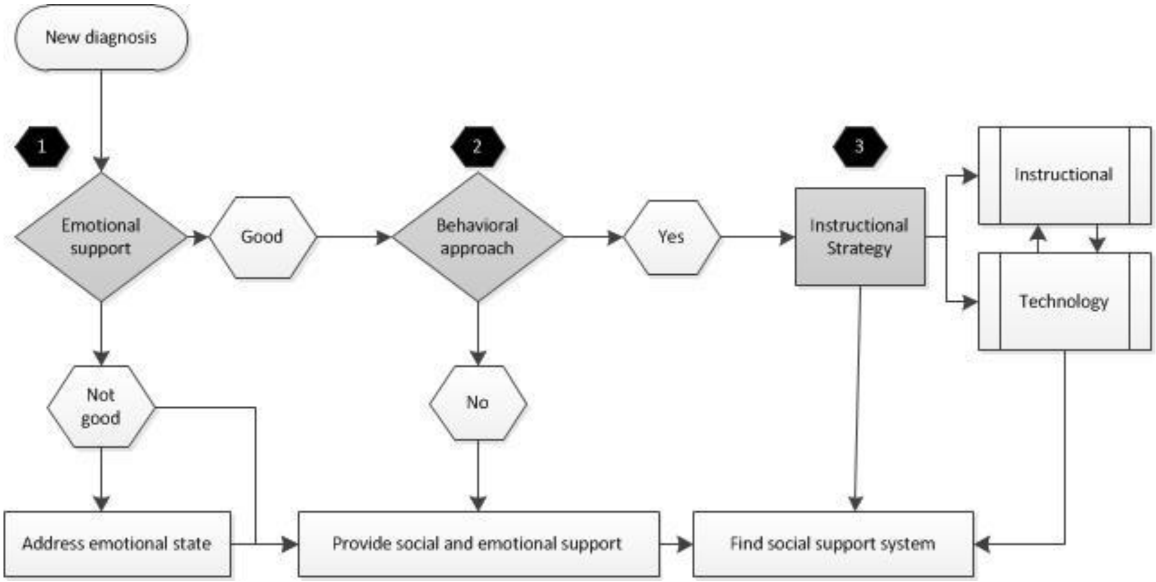

Figure 6. Health literacy instructional model.

The role of social support

The critical element to the health literacy instructional model, therefore, was the social support system. Rather than running in parallel to the instructional model, the support system was actually part of the instructional model. Social and emotional support appeared to be key in three important ways. First, the support system helped to reduce the anxiety of the patient enough that they were now able to absorb the information. P1 mentioned that she was overwhelmed and an emotional mess and it was not until she started to go to cardiac rehabilitation that her anxiety was reduced. Once she found her support system her anxiety was reduced enough that she was able to begin learning how to manage her condition.

Second, the support system was used by patients to quickly establish their personal experience by incorporating the personal experiences of others within the support system. HP1 established a support group for patients with metabolic syndrome, including diabetes, high cholesterol, high blood pressure, and obesity. “The way we have done it in our practice is to have patients teach each other how they overcame challenges in their life and it reinforces what they are doing and how they are doing it” (HP1). P2 was able to relate to other patients through an online support group.

Finally, the support system itself became an educational platform. Several of the patients described the support system or program they were participating in as their source for learning, both through formal channels and through informal interactions with healthcare professionals and other patients. HP2 described how the support system was an opportunity to discuss issues and be a sounding board for their concerns, making the support system far more personalized and interactive than formal channels.

> Having an outlet to discuss it. Having a sounding board with myself as a professional, and we did a lot of group support. Being able to learn from others that were doing the exact same thing, or doing something different, but getting a positive result. See an illustrated view of someone else putting skills into play, and could look at that and determine what made sense to them, for their health, their history, and their needs. We would move from there to support and a lot of additional education, not just on the diagnosis, what else it means. What can we look at with nutrition, with mental health, and additional aspects of physical health, that are all connected. We did a lot of compartmentalizing, breaking it into bits, so the bigger picture did not feel too overwhelming. HP2

HP16, a cardiologist who has run a cardiac rehabilitation program for over 40 years said that patients entered the program, following their cardiac event with a lot of fear. Once they overcame their fear, the next step, according to HP 16 was to focus on their readiness for change. Finally, one on one and group education and exercise sessions were conducted, resulting in a support group. P1 and P6 both stated that they did not begin learning about their condition until they were in cardiac rehabilitation.

P2 and P14 also experienced a heart attack, but did not participate in cardiac rehabilitation. P2 wished she had, but found the Patient Support Network, an online support program provided by the American Heart Association, while P14 found support from his wife. P1, P2, P12, P13, P15, and P16 all participated in the Patient Support Network, which was administered by HP5. HP5 felt the sharing of experiences allowed patients to have a camaraderie with each other, and provided a platform for sharing experiences with each other.

HP1 is a primary care physician who has a large number of patients with diabetes, high blood pressure, and high cholesterol. HP1 stated that the first step was to “get their mind right”, and then to focus on their motivation and engagement. The instructional strategy provided by HP1 is a support group designed to be “highly personalized” and relevant to the patient, and is structured around a gaming conversion (Courtney et al., 2011). P4, P5, P6, and P11 participated in this group program. P4 stated that she participated in the program because it made her more accountable for her behaviors. P4 stated that she was depressed and did not even know it, but when she started participating in the group she started losing weight and feeling better.

Group and peer support was used in the Lifestyle Heart Trial (LHT) (Ornish et al., 1990) and the Stanford Coronary Risk Intervention Project (SCRIP) (Haskell et al., 1994). In the LHT the intervention included exercise, a low fat diet, meditation, and group support (Ornish et al., 1990) This intervention resulted in reductions in episodes of angina and in the size of the coronary lesions, setting the stage for a multicenter trial (Koertge et al., 2003). In the SCRIP, patients were randomized to aggressive risk factor modification or usual care (Haskell et al., 1994). Intervention patients achieved angiographic regression in their coronary arteries and had fewer cardiovascular events than the usual care group (Haskell et al., 1994). Neither the LHT, nor the SCRIP was able to tease out the relative contribution of group support, compared to other factors. Also, neither study measured health literacy. Cardiac rehabilitation programs follow a similar principle of combining multiple behavioral interventions, including exercise training and education, that is conducted in a group format. According to Lefebvre and Bornkessel (2013) there is little research in the impact of social networks as a sole intervention or the use of online social networks compared to real world networks.

There is a link between emotional stress and health literacy and more active participation in self care. In a grounded theory study conducted by Pegner, Ziegert, and Kihlgren (2014) emotional support for elderly patients, provided by nurses, resulted in the patients having an experience in being able to “hand over”, or share with others. The emotional support created a sense of relief that reduced the anxiety levels of the patient enough for them to be active participants in their care. In a quantitative study, Song et al., (2012) found that health literacy was associated with mental distress but not physical distress in men with prostate cancer. Lee, Arozullah, Cho, Crittenden, and Vicencio (2009) found that social support had a positive impact on physical health in patients with high health literacy.

Participation in programs such as cardiac rehabilitation play a role in the development of health literacy skills. Using semi-structured interviews of participants in a pulmonary rehabilitation program, Sadeghi, Brooks, and Goldstein (2012) found that family and peer support, an empathetic patient/provider relationship and better print and teaching materials were perceived by patients and providers to improve health literacy. Cardiac rehabilitation, according to Beatty et al. (2013) provides a format that is patient centered and allows for individual tailoring.

There are reasons why support plays such an important role in the development of health literacy skills. The most common support systems described by the patients included cardiac rehabilitation, diabetes self-management, and online support. These support systems have common elements including the ability to interact directly with a healthcare professional, interaction with other patients, and an opportunity to access educational resources. The reasons that the support system played a role in the development of health literacy skills are illustrated in Figure 7.

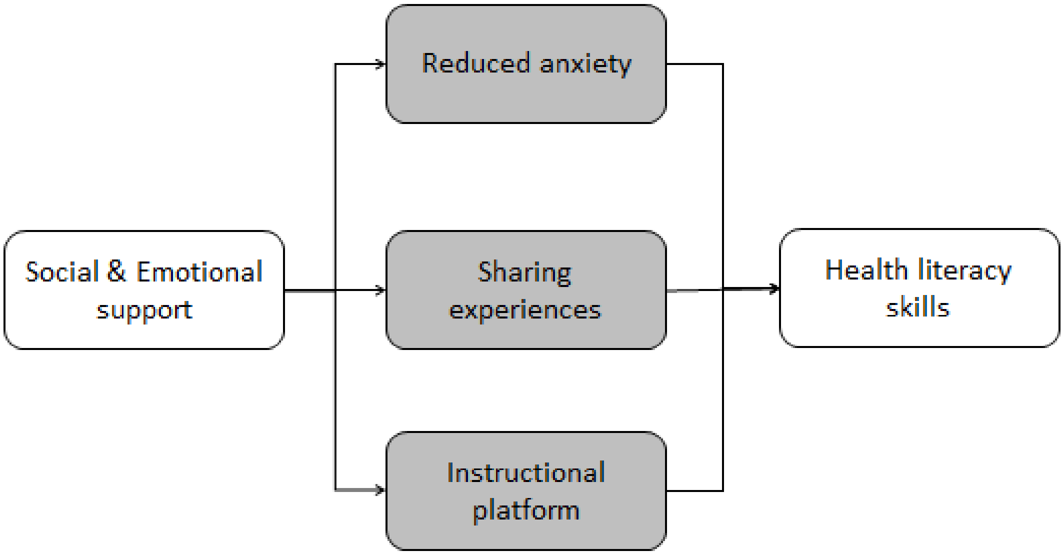

Figure 7. Role of social support in the development of health literacy skills.

Several patients mentioned that the support system, like cardiac rehabilitation, or online support, helped to reduce their anxiety levels enough that they were able to absorb the information that had been presented to them. P1 mentioned being a mess emotionally, P2 stated that she was dealing with anxiety, and P3 said she was depressed. All three patients, referring to a different type of support, cardiac rehabilitation, online support, and a support group, said that the program reduced their anxiety or depression enough that they were able to have a better understanding of their condition. Several of the healthcare professionals referred to the stages of loss, described by Kubler-Ross (1969). Patients also described going through stages of emotions, including anxiety and denial.

The support system also provided for peer support. A key principle of adult learning theory, or andragogy, is that adults learn from their own experiences (Clapper, 2010). Since patients with a new diagnosis do not have their own personal experience to draw from, they seek the experiences of other patients and used those experiences to quickly build their own experience. P11 mentioned using trial and error to learn how his body responded to food, exertion, and stress.

The support systems became a learning platform that was personalized, interactive, social, and relevant. P12 said the online support group helped her to learn by forming relationships with other patients with a shared experience. P6 said he learned a lot in cardiac rehabilitation because he could ask questions. HP1 would start the session by answering questions, making the experience more personalized and relevant.

The role of the support system is consistent with scaffolding, a component of the educational philosophy developed by Vygotsky (Richard-Amato, 2003). The scaffold is a metaphor used to describe the support system necessary for learning. This is also consistent with Gardner's (2002) theory of multiple intelligences, by providing a variety of learning modalities. These modalities included educational materials, peer support, and the ability to interact with a healthcare professional.

Cardiac rehabilitation and online support both provided patients with an opportunity to interact with healthcare professionals and other patients. Tkatch et al., (2010) found that cardiac rehabilitation patients have inner networks of support which were related to better coping efficacy, healthy behaviors, and outcomes. While there were didactic learning opportunities, the patients had the opportunity to ask questions and share experiences with the staff and with the other patients.

The support system, therefore, was the unifying factor of the Health Literacy Instructional Model. As patients progressed through the model, by addressing their emotional state, their readiness for change and self-efficacy, and begin the learning progress, the support system became the scaffolding for the patient. Maslow's hierarchy of needs was mentioned or implied by several patients and healthcare professionals. The hierarchy matched the role of the healthcare professional. Acute care providers, like the emergency physician and critical care nurses, focused on earlier stages of physiologic and safety needs, while educators focused on the later stages of self-esteem and self-actualization (Milheim, 2012). Of note is that the need for relationships is in the middle of the hierarchy, and required in order for higher level needs, including self-actualization to be met (Milheim).

Google is a health system

Despite the increasing utilization of digital tools and technology in patients with cardiovascular disease and diabetes (Lefebvre & Bornkessel, 2013) and promise that these tools bring in the management of these conditions (Beatty et al., 2013), there is little evidence that online tools build health literacy skills (Lang, College, & Maheed, 2011).

In a systematic review of the literature on the impact of behavior change communication on health, Gurman, Rubin, and Roess (2012) found that the results are inconsistent. While many of the interventions reviewed were still in formation, less than half were targeted or tailored to the intended audience (Gurman, Rubin & Roess). Free et al. (2013a), conducted a systematic review of mobile health on behavior change and disease management in consumers. While mobile health technologies, including text messaging are promising, high quality, adequately powered trials are still needed (Free et al.).

Mobile health technologies can be a benefit, not only to patients, but also to healthcare professionals. Free et al., (2013b) conducted a systematic review of the impact of mobile technologies on healthcare service delivery. While the benefits were modest, the benefits of mobile health were consistent (Free et al.). The findings of this study confirm that while these tools show promise, it is unclear how they are used to build health literacy skills. According to HP1 “So I think the most exciting next step in how this will all occur is with mobile devices, and smart phones that will be the way of the future, but I don’t know that right now we have that figured out”. He does not think, however, there is a great source, but the best source is the internet (HP1).

When asked about the use of digital tools and technology patients frequently mentioned the internet as their primary tool. There were limited examples of the use of wearables, apps that had been downloaded to their smart phone, or a connected device to measure health data, such as blood pressure, heart rate, or glucose. The use of glucometers for patients with diabetes, and home blood pressure monitoring was mentioned as adding value. P1, P7, and P11 mentioned that blood pressure monitoring helped them to better understand their body. P7 connected her blood pressure readings to her symptoms. P11 monitored both his blood pressure and blood sugar, but found more value in the blood sugar readings. P10 would “take the readings to get a better understanding of my blood sugar to related what I ate to the reading. P11 used his readings to manage his condition. “I would notice that if I went for a run, I would have better numbers. So I worked it into my routine. I also noticed that if I had a big meal portion, my blood sugar would go through the roof” (P11). P5 mentioned that his insulin pump was helpful in helping him manage his diabetes.

Instructional strategies should be personalized, interactive, social, and relevant

Several examples of strategies to promote health literacy identified in the Health Literacy Toolkit (DeWalt et al., 2012), such as the teach-back methods were mentioned by the healthcare professionals, especially nurses and doctors. The health educators mentioned good oral and written communications as described in the health literacy toolkit and the national action plan to improve health literacy (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010). Patients and healthcare professionals described interventions that are personalized, interactive, social and relevant. These traits are consistent with, but not emphasized in either the Health Literacy Toolkit or the national action plan.

In *Teach to Goal*, Baker et al., (2011) described principles for building health literacy skills in heart failure patients, including providing only information that directly support learning goals, providing information in chucks, confirming understanding, and using plain language. Baker et al. also emphasized the need to develop building blocks of knowledge and to go slower, especially with older patients. Several healthcare professionals mentioned providing information in smaller chunks, or by using small steps. HP3 described the process of taking small bits of information, applying it, and being persistent. Where the perspectives of patients in this study, however, differ from *Teach To Goal,* the Health Literacy Toolkit and national action plan is in their desire for more information, rather than having it rationed by their healthcare provider. Several patients mentioned reading books, medical journals and seeking more information, not less.

Patients are self-directed learners

There is very little in the literature on how the instructional strategies of healthcare providers match the learning needs of the patients. While this question is addressed in this study, there are no clear answers. Koh et al., (2012) described how the process of teaching and learning breaks down in the current system, due to excessive use of medical jargon, and poor written and oral communication on the part of the healthcare professionals and the patients. According to Koh et al. a more health literate patient experience is improved by clear and concise communication, spoken in plain language, allowing the patient to be a more active participant. This experience makes sense, but dependent on the healthcare professional, and is was not the experience described by either the patients, or the healthcare professionals, even under ideal conditions.

The health literate experience described by patients and healthcare professionals in this study was that of a self-directed learner, who is engaged and eager to learn more about how to manage their condition. This is consistent with the description of adult learning by Clapper (2010). According to Clapper, adults are self-directed learners who learn through observation and personal experience. The system, however, appears to breakdown, according to HP1, HP3, HP9, and HP16 when the patient is not self-directed and is not motivated to make necessary changes to their lifestyle.

Healthcare professionals expressed frustration and concern at the process that made it difficult to provide patient education (HP1, HP7, HP16, and HP17). The majority of the patients were not satisfied with the information they received from their healthcare professionals, and sought additional information, primarily from the internet and from other patients. Also, while patient friendly solutions emphasize written communication, the patients in this study preferred oral communication, with the opportunity to ask questions and multimedia resources that are accessed from the internet.

Theoretical model

While other behavioral and educational models apply to the complicated issue of health literacy, the social ecological model remains the primary theoretical framework. The social ecological model was able to tie these other models together in a multi-level approach. In fact, all of these models apply and are interdependent. The social ecological perspective emphasizes this interaction, multiple levels of influence, and that individual’s behavior is shaped by social and environmental factors (National Cancer Institute, 2005). In this context social networks and interpersonal relationships can exist and make an impact at both the individual and community level.

The social ecological model also was a good fit in this study because the healthcare professionals represented a multi-level approach. The physicians, nurses, physician assistant, nurse practitioner, social worker, dietitian, pharmacist and health coaches represented an intrapersonal approach by providing direct care to individuals. The health educators represented an interpersonal approach by providing education and support to groups. The designers of educational materials and digital tools represented a community approach directed at large numbers of individuals.

Limitations of the Study

A limitation of this study is that because of the relatively small sample size, the results may not be generalizable to other groups. Patients and healthcare professionals represented a wide range, meaning that each patient condition and each healthcare profession was represented by only a few participants. With this small sample, the perspectives of the patients and healthcare professionals may have been distorted by the biases of the researcher.

Another limitation of this study is that while health literacy was the topic, it was not quantitatively assessed in the patients. As the measurement of health literacy is a quantitative approach, it is not known how many of the patients would have been classified as having below basic health literacy skills. All of the participants were high school graduates and several of them were college graduates. Based strictly on the patient’s speaking skills, the patients seemed to represent the general population in regards to their health literacy skills. While this study was not designed to focus strictly on patients with low health literacy, it is important to know that patients of all levels of health literacy were represented.

In the NAAL 14% of the population was estimated to have below basic health literacy skills (Kutner et al., 2006). In a sample of 16 participants, therefore, it would be expected that two or three would have below basic health literacy. While this study did not measure health literacy, based strictly on the researcher's perception of their oral communication skills, it is estimated that P6, and P13 had below basic literacy skills.

Recruitment methods made it impossible to target patients who had low health literacy skills. Also, recruitment strategies may have attracted patients who were in a good emotional state and were motivated and engaged in their health. Most of the patients, however, related their experiences of being anxious, depressed, and unmotivated. Recruitment strategies also may have attracted healthcare professionals who were more aware of health literacy as a public health concern. While many of the healthcare professionals did not have a plan for assessing or addressing health literacy, all of them had a good understanding of health literacy and its impact on their patients.

The majority of the participants in both the patient and healthcare professional groups were female and white. Of the 35 participants, 24 were female. Also, 29 of the 35 participants were white.

Recommendations

A major finding in this study was the role of social and emotional support in the development of health literacy skills. In future research the role of social and emotional support in the development of health literacy skills should be investigated. Also, in future research different forms of social and emotional support, like cardiac rehabilitation, support groups, and online social networks that can be used to build knowledge and skills should be studied.

Health literacy instructional strategies at different levels of health literacy should be investigated. This could be done with a mixed methods design that assesses and then groups patients by their health literacy level. Patients also can be grouped by age and ethnicity. All six of the patients who participated in the Patient Support Network were female, so future studies could explore gender differences in the types of instructional strategies.

More research is needed to better understand the role of digital tools and technology. While most of the patients used the internet to search for information, many of the patients were challenged by a digital divide and were confused about how to use these tools. Fox and Dugan (2012) reported that an increasing number of patients with chronic conditions are using digital tools and technology. While some patients used smart phone apps, wearables, and connected devices, it is unclear the role these devices play in how they manage their health. Using the internet to search for information, using a wearable to record physical activity, and using a connected, or disconnected, device to record biometrics have different functions and purpose. While utilization of these tools can be measured through sales and downloads, there is virtually no data on their health impact.

The timing and format of various aspects of the process of building health literacy skills should be studied in future research. Emotional support, behavioral approaches, and instructional strategies all play a role in the prevention and treatment of cardiovascular disease and diabetes. There is no data on the interaction of these three components.

In future research the roles of different types of healthcare professionals should be investigated. Patients were in a different emotional state when they were interacting with the emergency physician and other acute care providers than when they were interacting with the health educators. Different approaches to health literacy should be studied at different levels based on the emotional state, readiness for change, and self-efficacy of the patient.

Many healthcare professionals were confounded by a healthcare system that is not designed to provide education and build health literacy skills. Some expressed frustration at the lack of assessment tools and other best practices that would make it easier for them and their patients. When asked how he assessed health literacy, HP1 said “Pathetically. In my office, we do not have a structured profess.” A recommendation for practice, therefore, is to develop assessment and instructional tools that can be used by healthcare professionals.

Since patients conducted self-directed research, primarily through internet searches, another recommendation for practice is to make it easier for patients to find information from trusted sources. Google Scholar (2015) can be used by healthcare professionals to find scholarly work. A similar, patients oriented tool, might be useful to patients.

Implications

The primary implication for positive social change in this study was the role of social and emotional support in the development of health literacy skills. Strategies for addressing health literacy do not emphasize the development of a support system. A finding of this study is that a support system, such as cardiac rehabilitation, diabetes self-management programs, care givers, support groups, and online social networks, should be a part of an instructional strategy. Greater use of existing support systems, like cardiac rehabilitation, and development of newer support strategies, including online social networks, may result in more opportunities for patients to build their knowledge and skills necessary to manage their health condition.

The use of a support system aligns with recommendations for becoming a more health literate society, as described in the national action plan to Improve Health Literacy (Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010). The Teach-back method was mentioned by two nurses, one physician, and one patient. While one nurse mentioned the need to reduce the use of medical jargon, not a single participant mentioned simplifying that message would have improved their ability to understand the information presented to them by their healthcare professional. In fact, rather than simplifying the message, patients sought more detailed information, including reading books, and going to medical sites. Several healthcare professionals, including HP1, HP3, and HP18 mentioned starting with foundational skills, and taking “small steps” in the development of knowledge and skills. Two of the educators, HP7 and HP12, mentioned considering the reading level of the educational materials.

Another implication of this study could be that for instructional strategies to be effective, the emotional support and the behavioral approach of the patient must be addressed. Instructional strategies should be personalized, interactive, social, and relevant. A practical implication, therefore, is the timing and format of patient education material. For example, discharge instructions provided to the patient in the form of written materials, at a time of high stress, may not be quite the “teachable moment” that it is thought to be.

While there were patients who were self-directed and engaged in their health, it is unclear what, if anything, is available for the un-motivated patient. The two main support systems identified by the patients, cardiac rehabilitation, and online support are both highly underutilized (Balady et al., 2011). Healthcare organizations should make these support systems accessible to all of their patients.

The most common digital tool was the self-directed internet search. Google is considered by patients as a healthcare system. Search engines should make it easier for a patient to find a trusted site that contains credible information. Without such a filter, patients are unable to distinguish credible information. Digital tools, such as apps and web based programs can direct patients to trusted sources. This implication must be done at an organizational/societal level.

There appeared to be a gap between the professionals who provide direct patient care and those who provide education and develop educational resources. The designers of education had very little interaction with patients and other healthcare professionals. The health educators had little or no interaction with the healthcare providers of the patients. More transparency between health educators, designers, and healthcare providers may result in better educational resources and better communication.

The healthcare professionals represented a broad range of disciplines. While the physicians are often considered the "captain of the ship", they also appear to be least equipped to provide instructional strategies. Delegation of these roles to other professionals who have more time, more training in instructional methods, and practice in a less stressful environment should be considered. The physicians, especially, appeared to have no training in educational methods. When asked about his training in educational methods in general, or anything specific to health literacy, P14 paused for over 10 seconds, and then said "no, that's embarrassing." Only one of the 19 healthcare professionals reported any formal training in educational methods.

Conclusion

Cardiovascular disease and diabetes are complex conditions that require a high level of knowledge and skill on the part of the patient in the management of their condition. This level of knowledge and skill is generally referred to as health literacy and includes an understanding of the condition, the ability to manage and manipulate numbers, navigation of the healthcare system, communication with healthcare professionals and the ability to make decisions regarding medical and behavioral strategies. In this study, the actions and processes that led to the development of health literacy skills were investigated from the perspective of both patients with cardiovascular disease and diabetes, and the healthcare professionals who provide medical care and education to these patients.

Four themes emerged from the data. The first theme was that social and emotional support is a key element in the development of health literacy skills. The second theme was that patients develop health literacy skills through self-directed and unaided searches on the internet. The third theme was that the most effective instructional methods are those who are highly personalized, interactive, social, and relevant. The fourth theme was that patients are self-directed learners.

Since grounded theory was used in this study, the theory was also presented. Using grounded theory, these themes and categories led to the development of a health literacy instructional model. This model includes a three step approach. The emotional support of the patient was addressed in Step 1. The behavioral approach to the patient was addressed in Step 2. A personalized, interactive, social, and relevant instructional strategy is addressed in Step 3. Social and emotional support is a common element throughout all three phases of the model.

These findings illustrate the need to provide and identify the social support system of the patient. There is a need to provide information from trusted sources on the internet that can be easily accessed by the patient. Finally, no patient should be left behind in the development of the knowledge and skills necessary to manage chronic diseases such as cardiovascular disease and diabetes.

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Appendix A: Participant Interview Guide

Participant interview questions

Interview setting: Location:____

- ☐ Face to face
- ☐ Phone

Date/time:____/______/____________:____________am/pm

Interviewee:_________Pat Dunn____________Other:__________________________

Q1: What is your age?_______________________________

Q2: What is your gender? Male Female

Q3: Please describe your ethnicity?

Q4: What is the highest level of education you attained? Grade:_______________

Q5: Do you have a chronic health condition

- ☐ Heart disease (heart attack, chest pain, stent, angioplasty, or heart surgery)
- ☐ Heart failure
- ☐ High blood pressure (hypertension)
- ☐ High cholesterol (lipid disorder)
- ☐ Diabetes
- ☐ Other

Q6: When were you diagnosed? Initial date:__________/______/______

Q7: What prior knowledge of your condition did you have?

Q8. (RQ1) Please describe the process of learning this information?

Q8a: What do you do to manage your condition?

(Possible responses: take medications, dietary changes, exercise/activity, behaviors)

Q8b: How did you know to do these things?

Follow up, based on initial response

Q8c: What resources did you use? (Doctor, friends, internet, etc.)

Q8d: How were you directed to those resources (aided, unaided)

Q8e: By whom (physician, friends/family, internet/social networks, books)

Q9: (RQ2) Did you use new technologies, such as a smart phone app, connected health device to track activity, weight, blood pressure, etc., or any other digital resource? If yes, please describe how these technologies helped you to learn how to manage your condition.

Q9a: What was your opinion of those resources? Did they help you better understand how to manage your condition?

Q9b: How did you know the resources that you chose were correct?

Q10: (RQ3) What role did your healthcare professional **or other health educators play in the process of learning how to manage your condition?**

Q10a: What learning methods were used? (Internet, books, other people, etc.)

Q10b: What styles of learning were most effective? (Video, print, audio, face to face, group, etc.)

Q11: (RQ4) How were the instructional strategies used by your healthcare professional**s aligned with your process of learning?**

Q 11a: How did the information that you obtained help you to better manage your condition?

Q11b: How long did it take you to feel confident in the knowledge of the condition?

Q11c: What additional information do you wish you had that would help you to better manage your condition?

Q12: Is there any additional information you would like to share?

Appendix B: Healthcare Professional Interview Protocol

Interview setting: Location:____

☐ Face to face

☐ Phone

Date/time:____/______/_____________:____________am/pm

Interviewee:________Pat Dunn___________Other:__________________________

Q1: What is your age?______________________________

Q2: What is your gender? Male Female

Q3: Please describe your ethnicity?

Q4: What is your role as a healthcare professional? (Physician, nurse, dietician, educator, other)

Q5: How many years have you been a healthcare professional?________________

Q6: Please describe any formal education you have had in education?

Q7: (RQ1) Can you describe the process of learning health literacy skills used by your patients when they are diagnosed with a chronic health condition?

Q7a: Where, or who do they get their information from

Q8: (RQ2) What sources of information, including new technologies, do you use or recommend?

(Books, websites, smart phones, connected devices, other)

Q9: (RQ3) How do you assess the level of knowledge or literacy in your patients?

(Formal, informal)

Q9a: What is the basis of that assessment (language skills, numeracy, navigation, communication, decision making)

Q10: (RQ3) What is you plan for building knowledge and literacy in your patients?

(Philosophy, strategy, approach)

Q10a: Does your plan change depending on the health literacy of the patient?

Q11: (RQ4) How effective do you perceive efforts to build knowledge and literacy are?

Q11a: How do you know?

Q12: Is there any additional information you would like to share?

Additional notes:

Appendix C: Patient Consent Form

You are invited to take part in a research study of the development of health literacy skills in people with chronic health conditions. The researcher is inviting individuals that have been diagnosed with coronary artery disease, heart failure, high blood pressure or diabetes within the past 12 months to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Patrick Dunn, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to better understand how individuals with a new diagnosis of a chronic health condition are able to learn the knowledge and skills necessary to manage their health condition.

Procedures:

If you agree to be in this study, you will be asked to:

Participate in an interview lasting approximately 45-60 minutes

Here are some sample questions:

- How did you learn how to manage this condition?
- What were the sources of information?

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at your location will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as revealing information about how you manage your health. Being in this study would not pose risk to your safety or wellbeing. If you encounter emotional stress due to sharing your experiences involved in learning more about your health condition you can contact the Centers for Disease Control and Prevention at 800-CDC-INFO (800-232-4636).

The benefits of this study may include a better understanding of how health literacy skills are developed, resulting in better strategies and approaches to health literacy by healthcare professionals.

Payment:

In consideration for your participation in this study you will receive a $10 gift card, after the completion of the interview.

Privacy:

To ensure an accurate capture of the information, each interview will be recorded. Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by storing the data on a secure hard drive. Prior to uploading any data all identifiers, including your name, phone number, and email, will be deleted. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via phone at xxxxxx, or email at xxxxxxxxxxx. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is xxxxxxx. Walden University's approval number for this study is **01-14-15-0326016** and it expires on **January 13, 2016**

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, or replying to this email with the words, “I consent”, I understand that I am agreeing to the terms described above.

Printed Name of Participant ______________________________

Date of consent ______________________________

Participant's Signature ______________________________

Researcher's Signature ______________________________

Appendix D: Consent Form Healthcare Professional

You are invited to take part in a research study of the development of health literacy skills in people with chronic health conditions. The researcher is inviting individuals that treat or educate patients that have been diagnosed with coronary artery disease, heart failure, high blood pressure or diabetes within the past 12 months to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Patrick Dunn, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to better understand how individuals with a new diagnosis of a chronic health condition are able to learn the knowledge and skills necessary to manage their health condition.

Procedures:

If you agree to be in this study, you will be asked to:

- Participate in an interview lasting approximately 30-45 minutes, or
- Be observed conducting a one on one, or group educational session

Here are some sample questions:

- How to you assess health literacy skills in the patients you work with?
- How do you build health literacy skills in the patients you work with?

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at your location will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as revealing information about how you communicate with your patients. Being in this study would not pose risk to your safety or wellbeing. If you encounter emotional stress due to sharing your experiences you can contact the Centers for Disease Control and Prevention at 800-CDC-INFO (800-232-4636).

The benefits of this study may include a better understanding of how health literacy skills are developed, resulting in better strategies and approaches to health literacy by healthcare professionals.

Payment:

In consideration for your participation in this study you will receive a $10 gift card, after the completion of the interview.

Privacy:

To ensure an accurate capture of the information, each interview will be recorded. Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by storing the data on a secure hard drive. Prior to uploading any data all identifiers, including your name, phone number, and email, will be deleted. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via phone atxxxxxxxxxxx, or email at xxxxx. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is xxxxxxx. Walden University's approval number for this study is **01-14-15-0326016** and it expires on **January 13, 2016.**

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, or replying to this email with the words, "I consent", I understand that I am agreeing to the terms described above.

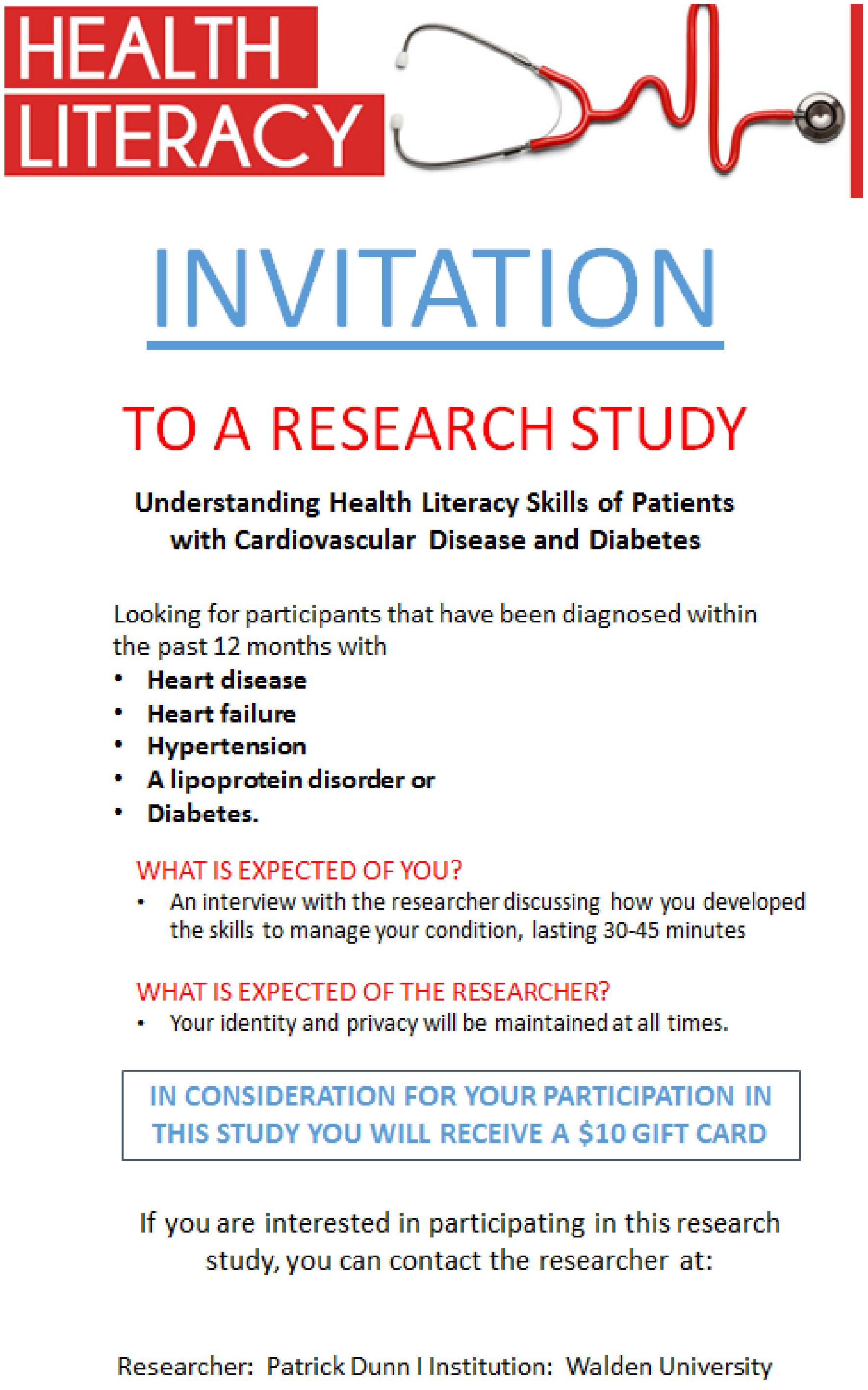
Printed Name of Participant ______________________________

Date of consent ______________________________

Participant's Signature ______________________________

Researcher's Signature ______________________________

Appendix E: Patient Recruitment Flyer



HEALTH
LITERACY

INVITATION

TO A RESEARCH STUDY

Understanding Health Literacy Skills of Patients with Cardiovascular Disease and Diabetes

Looking for participants that have been diagnosed within the past 12 months with

- **Heart disease**
- **Heart failure**
- **Hypertension**
- **A lipoprotein disorder or**
- **Diabetes.**

WHAT IS EXPECTED OF YOU?

- An interview with the researcher discussing how you developed the skills to manage your condition, lasting 30-45 minutes

WHAT IS EXPECTED OF THE RESEARCHER?

- Your identity and privacy will be maintained at all times.

IN CONSIDERATION FOR YOUR PARTICIPATION IN THIS STUDY YOU WILL RECEIVE A $10 GIFT CARD

If you are interested in participating in this research study, you can contact the researcher at:

Researcher: Patrick Dunn I Institution: Walden University

Appendix F: Recruitment Flyer Healthcare Professional

HEALTH LITERACY

INVITATION

TO A RESEARCH STUDY

Understanding Health Literacy Skills of Patients with Cardiovascular Disease and Diabetes

Looking for healthcare professionals that treat or educate patients with:

- **Heart disease**
- **Heart failure**
- **Hypertension**
- **A lipoprotein disorder or**
- **Diabetes.**

WHAT IS EXPECTED OF YOU?

- An interview with the researcher discussing how you assess and build health literacy skills in your patients, lasting 30-45 minutes

WHAT IS EXPECTED OF THE RESEARCHER?

- Your identity and privacy will be maintained at all times.

IN CONSIDERATION FOR YOUR PARTICIPATION IN THIS STUDY YOU WILL RECEIVE A $10 GIFT CARD

If you are interested in participating in this research study, you can contact the researcher at:

Researcher: Patrick Dunn | Institution: Walden University