

Summer 7-1-2017

# Elements Affecting Adoption and Implementation of Health Literacy Initiatives in Healthcare Organizations: A Qualitative Study

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**ELEMENTS AFFECTING ADOPTION AND  
IMPLEMENTATION OF HEALTH LITERACY  
INITIATIVES IN HEALTHCARE ORGANIZATIONS:  
A QUALITATIVE STUDY**

by

**AUDREY C. RIFFENBURGH**

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DISSERTATION

Submitted in Partial Fulfillment of the  
Requirements for the Degree of

**Doctor of Philosophy  
Communication**

**The University of New Mexico  
Albuquerque, New Mexico**

**July, 2017**

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## DEDICATION

I dedicate this dissertation to my late father, Art Riffenburgh. His experiences in healthcare across 15 years with leukemia, emphysema, and throat cancer brought health literacy to my awareness and gave me the passion to make it my work. It's all for you, Dad.

I also dedicate this work to the patients, families, and caregivers who too often feel adrift in the world of healthcare. And finally, I give my dedication and encouragement to all the health literacy change leaders who participated in this study and all the others who are working to advance health literacy in challenging circumstances.

**“Start where you are. Use what you have. Do what you can.”**

—Arthur Ashe

## ACKNOWLEDGEMENTS

I first wish to acknowledge my profound privilege in being one of a tiny percentage of women on this globe that has been able to earn a Ph.D. I do not take this privilege lightly. I vow that I will use this degree to help improve the healthcare system for patients, their loved ones, and the dedicated people who care for them.

I am deeply grateful to my committee members. If I am the humble clay pot, you are the potters. Your input and guidance has shaped, smoothed, and fired my writing and my thinking. Thank you, Dr. Judith McIntosh White for being my Committee Chair. You didn't know me when I returned to UNM after a four year hiatus. Still, you agreed to be my chair. Your wise and practical counsel on the process and my work has been so valuable. Dr. Tamar Ginossar, thank you for your encouragement as I formulated my research focus and for directing me to the D&I literature. Thank you, Dr. Laura Burton for stepping in when Dr. Janet Shiver had to leave the committee. Thank you, too, for all the time and energy you devoted in providing me with your incisive and thorough feedback on my dissertation. And Dr. Lorraine Wallace, thank you for volunteering to be my outside member. You have always shared my passion for health literacy work. As I developed my research plan and thought about what the field needed your input was so helpful in furthering my thinking.

My deepest gratitude goes to my beloved parents who were both alive to cheer me on when I began this journey but who have left this earth since then. I know your hearts are with me. Thank you for always believing I could do it.

And finally, thank you to all my dear friends and mentors who have walked with me. There are many of you. Sue Stableford, thank you! You were my coach, cheerleader, and confidant. You always knew when I needed another card of encouragement.

Thank you, Dr. Marne Austin, friend and spirit sister, your willingness to always help me get through a rough spot kept me going. Dr. Penny Pence, neighbor, friend, and professor, thank you for those hours of guidance, challenges, and affirmation. Emily Lilo, fellow Ph.D. student, you were the one who helped me see that I could resurrect the Ph.D. dream. Thank you for that. Dr. Bhavana Upadhyaya Nissima, wise and strong friend, your wishes for me to cross the stream in joy came true. We will have coffee together again someday, my friend.

I also appreciate the support and help I received from Wendy Mettger, friend and health literacy colleague; Glenn Stark, friend and statistician; the awesome Interlibrary Loan team at UNM; and Doug Weintraub, Senior Academic Advisor at the Office of Graduate Studies, who helps graduate students understand all the rules and forms with a calm and omniscient voice.

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**ABSTRACT**

Nearly nine in ten U.S. adults struggle to navigate and use increasingly complex healthcare organizations as well as the information they provide. However, healthcare organizations are not yet widely addressing the need to make their services and health information easier to navigate, understand, and use. There are many known health literacy approaches that could address this need but few are being utilized.

The purpose of this study was to expand knowledge about the facilitators and barriers to adoption and implementation of health literacy initiatives in healthcare organizations. A rich body of literature on health literacy; organizational change; diffusion of innovations; and adoption, implementation, and dissemination of innovations in healthcare exists. However, there has been little research examining the elements necessary for adoption and implementation of health literacy initiatives in healthcare organizations. Sixteen qualitative interviews with individuals who lead health literacy initiatives in 16 organizations across the U.S. were conducted. Elements of a grounded theory approach were used and data was analyzed using thematic analysis.

The study identified several elements that appear to be facilitators to health literacy adoption and implementation efforts. Many of the elements had already been identified and explored in the broader healthcare literature but four were new. The first element, identified often in the literature, is senior leadership support. Health literacy initiatives in organizations with strong leader support seemed to thrive. Without leadership support, the situation appears very different. Progress was difficult, demoralizing, and slow.

Four elements that emerged as important in health literacy initiatives had not yet been identified in the literature. These include (a) senior leadership's awareness of the importance of health literacy; (b) the health literacy leader's access to meeting with leaders, directors, and managers across the organization; (c) the location of the health literacy office in an area with organization-wide authority; and (d) the use of a structured, strategic approach to plan and carry out change.

Each of these elements is potentially influential in adoption and implementation of other change initiatives in healthcare as in health literacy initiatives. Further research to explore the role of these elements in other initiatives could contribute to the literature and to practical applications. This study makes a theoretical contribution by expanding organizational change theory and theories of adoption and implementation. It makes a practical contribution to the field of health literacy by offering strategies and recommendations that organizations, and the individuals who lead their health literacy efforts, can use to further advance their health literacy initiatives.

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## CHAPTER 1: INTRODUCTION

### Background and Problem

When you need healthcare, it can be hard to know what to do for yourself or your loved ones, especially if you are not familiar with healthcare terminology and concepts or how to use a healthcare system. The level of proficiency required to effectively understand healthcare information and navigate complex healthcare organizations is beyond the knowledge and skills of 88% of U.S. adults, in particular for people with lower educational levels, lower socioeconomic status, and cultural and language barriers (Kutner, Greenberg, Jin, & Paulsen, 2006). As people attempt to obtain medical care, they need to be able to engage with three areas: (a) the organization or system in which they are seeking care, (b) the healthcare providers in that organization, and (c) health information (text-based or delivered orally) the organization provides or which they seek from other sources.

My parents and I, highly-educated healthcare consumers, experienced multiple challenges in all three areas during my father's leukemia and throat cancer diagnoses and treatment. As a result, I became interested in how healthcare organizations could change to communicate more effectively and make their systems easier to use. With my background in adult literacy, I decided to begin working with healthcare organizations to help them communicate more effectively with all people, but particularly with people who are educationally-disadvantaged and/or speak a language other than English at home.

Since I began that work, I have consulted with many organizations in improving communication and system processes that affect patients and families. However, most of these organizations have been able to achieve only small changes. My curiosity and desire to enhance

knowledge about what is required to make organization- or system-wide change in health literacy initiatives are what drove this study.

In this chapter, I provide a historical context for the field of health literacy and for my study's place in the field. I then state the purpose and goals. Next I describe the significance of the study, list the research questions, and define the scope. I conclude with defining the terms I use in this study. Articulating working definitions is necessary for clarity, especially in the field of health literacy where there are multiple definitions and conceptualizations of many concepts.

In the early 2000s, patients' and the public's ability to use health information and services was defined by the Institute of Medicine (IOM) as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 2). In 2006, a national assessment of adult literacy, which contained health-related items, provided the first data on the health literacy skills of U.S. adults. It revealed that only 12% of adults function at a *proficient* level of health literacy in a range of *below basic*, *basic*, *intermediate*, and *proficient* (Kutner et al., 2006). These data show that the majority of U.S. adults lack the health literacy skills to appropriately engage with the current health care system.

People with any level of literacy or education may also have low health literacy due to lack of knowledge about medical concepts or terms, anxiety, illness, effects of medication, and many other causes. However, it is important to note that there are several demographic groups at increased risk of low health literacy: (a) adults living below the poverty level; (b) adults who are ages 65 and older; (c) Black, Hispanic, American Indian/Alaska Native, and multiracial adults; (d) adults who spoke other languages alone or with English before starting school; and (e) adults with low educational attainment (49% of adults who did not complete high school had *below*

*basic* health literacy) (Kutner et al., 2006). Starting with those adults who had completed high school or a GED, average health literacy scores increased with each higher level of education (Kutner et al., 2006). Therefore, it is appropriate to assume that most adults with less than a high school education and/or those who have limited literacy skills are at risk of having the lowest health literacy skills.

Unfortunately, limited functional literacy is also prevalent among U.S. adults (Kutner, Greenberg, & Baer, 2005). Forty-three percent of U.S. adults function at the *basic* or *below basic* levels for prose literacy in a range of *below basic*, *basic*, *intermediate*, and *proficient*. Further, 44% function at the *intermediate* level, and only 13% function at the *proficient* level for prose. Another source claims that half of U.S. adults function at or below the 8<sup>th</sup> grade reading level (Doak, Doak, & Root, 1996).

Limited literacy creates barriers for people who need to use the healthcare system to obtain information and care. If text-based information demands a higher level of literacy than patients possess, they will struggle to understand. If patients do not understand the information they are given, they are unable to apply it to make appropriate health decisions which can lead to poor health outcomes. Much text-based information is written at a higher literacy level than the average U.S. adult possesses. There is abundant research—well over 800 peer-reviewed studies—documenting the mismatch in the literacy demands of health information and the literacy skills of U.S. adults (Rudd, 2007). Studies have shown that health materials are usually written at levels requiring skills far above the abilities of average high school graduates (Nielsen-Bohlman et al., 2004; Rudd, 2010).

Moreover, nearly 100 studies document a relationship between limited functional literacy skills and a variety of adverse health outcomes, including (a) greater risk of hospitalization, (b)

lower medication adherence, and (c) less knowledge of self-care guidelines for chronic conditions such as asthma (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Rudd, Anderson, Oppenheimer, & Nath, 2007). The above statistics call the healthcare community to better address the mismatch between (a) demands of understanding and using health information and services and (b) the functional and health literacy skills of the U.S. public. If healthcare organizations address this significant mismatch, the health literacy challenge can be solved and the public can experience better health (Rudd, 2010).

There has been an increasing awareness of health literacy and the challenges of low health literacy among healthcare professionals and many healthcare organizations in the past decade (DeWalt et al., 2011). For many years the primary emphasis in research in the emerging field was on identifying individuals' health knowledge, skills, and attitudes and the relationships between individuals' literacy skills and health outcomes. However, there was an underlying implication that it is the individual's responsibility to become more health literate in order to manage the demands of the complex healthcare system.

In the last several years, however, there has been a trend in the field to consider the responsibility of both healthcare professionals and healthcare organizations as the "other side of the coin" in health literacy. Despite healthcare professionals' responsibility for clear and effective communication, they do not routinely use health literacy practices (Castro, Wilson, Wang, & Schillinger, 2007; Coleman, Hudson, & Maine, 2013; Schwartzberg, Cowett, VanGeest, & Wolf, 2007).

In addition to the healthcare professionals' role, there is a growing acknowledgement of healthcare organizations' responsibility to redesign their communications and systems to become more accessible to patients and their loved ones through increasing the level of implementation

of health literacy practices (Parker, 2009; U.S. Department of Health and Human Services, 2010). A description of the qualities of organizations that are effectively addressing this systemic challenge was outlined in the *Ten Attributes of Health Literate Healthcare Organizations* (Brach et al., 2012). In this document a “health literate organization” is described as an organization that makes it “easier for people to navigate, understand, and use information and services to take care of their health” (Brach et al., 2012, p. 1). (The ten attributes are listed in the literature review.)

The study and practice of becoming a health literate healthcare organization has recently become known as *organizational health literacy*. Another document which calls for improved organizational health literacy is the *National Action Plan to Improve Health Literacy* (U.S. Department of Health and Human Services, 2010) which outlines seven goals for the nation. Three of the goals relate to the need for healthcare system redesign or increased dissemination and implementation of health literacy practices.

Despite these calls to change; the availability of more than 20 resources containing guidelines, standards, and tools, some available for over a decade; and widespread awareness of the challenges healthcare organizations present to patients and their loved ones, change has not come readily. The healthcare community has yet to widely embrace the necessary organizational changes in order to communicate effectively with patients, families, and the public (Institute of Medicine, 2013a). Donald Berwick (2003), former Administrator of the Centers for Medicare and Medicaid Services, stated, “In health care, invention is hard, but dissemination is even harder” (p. 1970). Only recently are healthcare organizations beginning to integrate health literacy into their quality improvement, cost containment, or patient engagement agendas (Koh et al., 2012). There is much to learn about how to overcome the barriers to integrating health

literacy into healthcare organizations. This present study seeks to identify the factors that facilitate successful adoption and implementation which may be helpful in assisting other healthcare organizations in making this change.

While a great deal of research has been done over many years concerning dissemination and implementation in other areas of healthcare and medicine, there has been little research examining the factors involved in dissemination, adoption, and implementation of the attributes of health literate organizations (Institute of Medicine, 2013b). The IOM is charged with advising the federal government on, and examining matters related to, the public's health (Institute of Medicine, 2013b). In 2012, the authors of the new Institute of Medicine (IOM) document on the attributes of health literate healthcare organizations recognized the need for specific guidance and an impetus for organizations to move toward embracing the attributes (Brach et al., 2012).

A year later, the IOM Health Literacy Roundtable convened a workshop on the topic. The IOM Health Literacy Roundtable convenes workshops of experts and key informants to foster dialogue and discussion to advance the field of health literacy. In 2013, it convened a workshop on a topic it deemed important to discuss and advance—organizational health literacy (Institute of Medicine, 2013b), suggesting a knowledge gap in this area. The workshop was convened specifically to examine what is known about implementation of the attributes through (a) discussing implementation, (b) sharing tools, and (c) creating a network of health literacy implementers (Institute of Medicine, 2013b). The few articles in the literature addressing this topic are discussed in the literature review.

This study is important to further explore strategies healthcare organizations have used to disseminate information about health literacy, promote its adoption, and advance its

implementation. This study contributes to filling the knowledge gap by investigating what has been employed in this quest.

### **Purpose of the Study**

The purpose of the present study is to understand the experiences and perceptions of individuals charged with advancing health literacy in healthcare organizations in order to expand knowledge about the adoption and implementation of health literacy initiatives. I conducted a qualitative study in which I interviewed people who are, or have been, in charge of advancing a health literacy initiative in a healthcare organization or system.

I sought to identify facilitators and barriers, communication strategies, and processes through which change occurs in beginning and building health literacy initiatives. This study makes a theoretical contribution by expanding organizational change theory and theories of diffusion of innovations relative to implementing healthcare initiatives and, in particular, health literacy initiatives. It makes a practical contribution to the field of health literacy by offering recommendations the individuals in charge of health literacy can use to further advance their initiatives.

### **Significance of the Study**

Understanding between healthcare professionals and patients is a critical component of effective healthcare (Dreger & Trembeck, 2002; Paasche-Orlow & Wolf, 2007; Williams, Davis, Parker, & Weiss, 2002). Health literacy is a cross-cutting issue which influences many areas already being addressed in healthcare settings, including the major challenges of quality of care, patient safety, health outcomes, costs of care, and health equity (Abrams, Kurtz-Rossi, Riffenburgh, & Savage, 2014; Adams & Corrigan, 2003; Isham, 2009).

Addressing health literacy is critical to the health of our nation. The fact that 88% of the U.S. adult population lacks the level of proficiency required to use and navigate healthcare systems and organizations (Kutner et al., 2006) suggest there is a need to reduce the complexity and demands of the systems and organizations. This calls for a new level of attention and commitment to addressing health literacy in healthcare organizations and systems.

The health literacy field should now devote significant resources to determine what strategies and methods are effective in bringing health literacy initiatives to fruition in healthcare organizations. There are a limited number of health literacy implementation-related articles in the literature (DeWalt et al., 2011; Shoemaker, Staub-DeLong, Wasserman, & Spranca, 2013) and the Institute of Medicine's summary of the workshop it convened on health literacy implementation (Institute of Medicine, 2013b). However, no clear guidelines or a logic model for implementing health literacy initiatives exists in the literature.

Yet health literacy is at a tipping point, and could be moved to the mainstream in healthcare because of recent federal legislation such the Affordable Care Act (*Patient Protection and Affordable Care Act. Public Law 111-148. Title IV, x4207, USC HR, 3590, 2010.*, n.d.), recent federal policies such as the National Action Plan for Health Literacy (U.S. Department of Health and Human Services, 2010) and the existing knowledge base (Koh et al., 2012). Evidence-based health literacy practices have been identified, so the task at hand was to explore the methods that have been used to create support, obtain commitment, and enlist resources for implementing health literacy changes in healthcare organizations. This study contributes to the literature in this area by identifying many of the facilitators and barriers of creating support, obtaining commitment, and enlisting resources for health literacy.

### **Research Questions**

The goal of this study is to understand the experiences and perspectives of individuals charged with advancing health literacy in a healthcare organization. The research questions that drive this study are:

**RQ1:** How do participants describe the facilitators to adoption and implementation of health literacy initiatives in their organizations?

**RQ2:** How do participants describe the barriers to adoption and implementation of health literacy initiatives in their organizations?

**RQ3:** How do participants communicate with administrative leaders and healthcare providers at all levels to build support for health literacy activities?

**RQ4:** What models and methods for making organizational change are evident in participants' reports of efforts to implement health literacy activities?

### **Scope of the Study**

This study addresses the development of health literacy initiatives only in the context of healthcare organizations and healthcare systems. That is to say, the study looks only at organizations that provide medical care. These include free-standing hospitals that may have primary care clinics in the hospital and/or in the community; hospitals and medical centers affiliated with a medical school; and networks of hospitals and other care facilities under the auspices of one health system.

Medical settings such as nursing homes, hospice care facilities (unless part of a healthcare organization), urgent care clinics, or free-standing "minute" clinics are not included in the scope of this study. Neither are public health organizations or programs promoting health literacy in non-medical contexts included. A second delineation in the scope of this study regards

the stages of organizational change. The focus is on (a) the adoption or innovation initiation phase and (b) the implementation phase.

### **Definition of Terms**

In this section, I discuss the meanings of terminology I use in the study. Within academia and across disciplines there exists a multiplicity of definitions and conceptualizations, making articulation of working definitions necessary for clarity. I begin with the broader terms of the fields I study.

*Dissemination* refers to specific, planned strategies and activities using pre-determined channels designed to spread innovations or interventions to specific audiences (Rabin, Brownson, Haire-joshu, Kreuter, & Weaver, 2008). Depending on the approach or model one is using, *dissemination* can occur (a) before the decision to adopt an innovation or (b) after implementation of an innovation has occurred and the innovation is spreading to a new audience or organization.

*Adoption* is the decision and commitment to put an innovation into use, but does not include the implementation phase (Rogers, 2003). The decision usually occurs after exposure to dissemination efforts to spread information about the innovation or intervention.

*Implementation* occurs when a new idea or practice is actually put into use (Rogers, 2003). Implementation science is the study of the factors involved in integrating scientifically-proven research findings into routine use in healthcare programs and practices (Colditz, 2012).

*Health literacy* was first viewed as an individual's set of skills and knowledge and defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, para. 7). In this study, health literacy refers to the above set of skills specifically in

relation to medically-oriented organizations, such as hospitals, rather than public health departments. One could say that *health literacy* could be interchanged with *medical literacy* in this study, at least in reference to individuals' skills.

*Organizational health literacy* and *health literate healthcare organization* both refer to an organization's ability to make it "easier for people to navigate, understand, and use information and services to take care of their health" (Brach et al., 2012, p. 1). This occurs when organizations redesign and/or add new information delivery systems, practices, processes, internal structures, and policies to create an organization that actively supports patients' health literacy (Brach et al., 2012).

*Organization* refers to "a stable system of individuals who work together to achieve common goals...through a pattern of regularized human relationships...with a relatively high degree of structure that is imposed on communication patterns" (Rogers, 2003, p. 404).

Health literacy *initiatives, activities, strategies, and practices* relate to various phases or approaches to implementing health literacy change or improving the health literacy of patients. In this study, a health literacy initiative refers to a broad effort to address health literacy challenges in a multi-pronged approach over time. Under the umbrella of an initiative there may be a single project or activity in the early stages followed by multiple projects or activities as the initiative grows. Various strategies could be used in the projects or activities within the entire initiative. For example, an initiative might develop a marketing plan for health literacy as a strategy for helping people understand its importance. Another part of an initiative might be a project to use Plan-Do-Study-Act (PDSA) cycles and small tests of change with implementing *teach back*, a health literacy practice, in one clinic. In this case, PDSA cycles are a strategy for structuring change efforts and teach back is a practice to improve the health literacy of patients.

*Plain language* refers to communication (oral or text-based) which provides information the audience needs and wants, is easy to understand after being read or heard once, and is easy to use. Plain language print materials are usually written at about 7<sup>th</sup> to 8<sup>th</sup> grade level. Print materials written at 6<sup>th</sup> grade level or below are usually called *low literacy*.

*Clear health communication* refers to effective and easily understood communication among the health care system, the health care providers and other employees, and individual patients and their loved ones. Clear health communication with patients and their loved ones is usually based on the principles of *plain language*.

*Health literacy change leaders* refers to the individuals in charge of advancing health literacy initiatives in their organization. This term also refers to individuals who may not be officially charged with health literacy work but work on it on their own either with the knowledge of leaders or “under the radar.”

*C-Suite leaders* refers to leaders whose titles begin with *Chief* such as Chief Executive Officer (CEO), Chief Operating Officer (COO), or Chief Nursing Officer (CNO)..

*Senior leaders* is a term I use to identify a larger category of leaders that includes C-Suite leaders, the Board of Directors, and the next level or two just below C-suite leaders in the organizational hierarchy, e.g., Senior Vice Presidents and Executive Directors. Each organization has a somewhat unique organizational chart but often-used titles are listed above.

*Primary care* refers to general care for non-critical conditions like flu or a sprained back. It is often provided by physicians, physicians’ assistants, or nurse practitioners.

### **Summary**

In summary, there is a well-documented and substantial mismatch between the demands and complexity of healthcare organizations and the knowledge and skills of the majority of people

who need to use these organizations for their medical care. The challenges of interfacing effectively with healthcare organizations are greater for certain populations, but the vast majority of adults living in the U.S. struggle to navigate healthcare systems. There is much that can be done to make healthcare organizations and information easier for patients, consumers, and communities to understand and use but few of the practices known to be useful are being implemented across the country.

This study explores the facilitators and barriers in implementing health literacy initiatives and practices that are being used to advance organizational change toward becoming health literate healthcare organizations. In the next chapter, I describe and discuss various aspects of the relevant literature on health literacy, organizational structure and change theories, dissemination and implementation science, and what is known in the literature about facilitators and barriers of change in healthcare and health literacy.

## CHAPTER 2: LITERATURE REVIEW

Moving newly-discovered scientific advances, whether disease treatments or the reengineering of a process in health services, into everyday clinical practice has long been known to be very difficult (Colditz, 2012). Bowen and colleagues observed, “Our previous 30 years have taught us that dissemination does not just happen if we wait for it. New information is often needed to make it happen. Let’s consider this a call to action to gather the new information in support of making it happen” (2009, p. 483). This study gathers and explicates new information needed to expand the use of health literacy principles and activities in healthcare.

The theoretical and practical goals of this study are to expand knowledge of the facilitators and barriers to organizational change in adopting and implementing health literacy initiatives. This study confirms many aspects of what was already documented in the literature and also identifies new aspects of organizational change involved in health literacy initiatives. This knowledge can now be used to provide recommendations which can guide and assist health literacy change leaders to move the health literacy agenda forward in their organizations.

The objectives of this chapter are (a) to review the salient literature and theories on the challenges of implementing change in healthcare organizations; and (b) consider ways this study can contribute to existing knowledge, and professional practice, in addressing the facilitators and barriers to adoption and implementation of health literacy initiatives. There are large bodies of literature on theories of organization, dissemination, and implementation; theories on diffusing new ideas and innovations of all types; models of organizational change; and the many factors that facilitate and obstruct all of the above. However, surprisingly, organizational change and restructuring in the hospital sector is often occurring without research and evidence on how it should best be done (Lansisalmi, 2006). Moreover, there is little literature which explores the

facilitators and barriers relative to launching and implementing health literacy initiatives. This study informs and further advances knowledge in that area.

Existing theory provides the sensitizing concepts to guide my analysis, interpretation, and conclusions. Key concepts in my research questions include facilitators and barriers to adoption and implementation, how models for organizational change impact adoption and implementation efforts, and how support for interventions is generated at the individual and organizational levels. Therefore, the literature review describes theories and relevant studies which use the concepts, where possible, in relation to healthcare settings.

### **Philosophical Foundations**

In this section, I consider my ontological, epistemological, and axiological positions. My ontological position is social constructionism. In this perspective, people make sense of and understand their social worlds through interactions with others (Leeds-Hurwitz, 2009). Through communication with others, people co-construct their view of themselves and each other. Through the same process they co-construct and re-construct their social reality.

These communication processes create norms and conventions—the structures of our relationships with others as well as social entities such as organizations and institutions—which become our social worlds (Littlejohn & Foss, 2011). Within those social worlds, in the structures we have created, we learn and recognize the rules that govern what we must do or cannot do (Pearce, 2007). In ongoing iterative cycles of interactions we are continuously co-constructing, shaping, and changing our social worlds even as they shape us by influencing our behaviors.

In healthcare organizations, an example of the processes of social construction is through the verbal communication between employees in mid-management level positions and leaders such as the chief executive officer (CEO) or chief nursing officer (CNO). This level of leadership

is often referred to as the *C-Suite leaders*. When a C-suite leader talks to the director of primary care, for example, the communication creates and reinforces their social world and the boundaries of their relationship as they both participate in using prescribed patterns of communication between people at those levels in a hierarchical organization. The director will certainly know about the importance of following the chain of command through her past experience, hearing stories from others in the organization, and perhaps explicit training when joining the organization. She and the C-suite leader both know the rules and (usually) choose to communicate within them. This implicit agreement and habitual repetition of the patterns of communication reify and reinforce the rules of their interactions.

Through this process the socially-constructed conventions of communication can become perceived as objective features of their realities. This crystallization of the conventions is clear in healthcare organizations. The hierarchical structures and rules of communication are rigid and strongly enforced, thus can appear to be objective characteristics of the organization when they are, in fact, socially-constructed and are simply being reinforced by repeated communicative acts between and among the leadership and employees of the organization.

My epistemological position is subjectivist. I believe knowledge is not separate from the knower as an objective truth. Rather, knowledge is relative and comes through experiencing a specific event or context. I believe knowledge about a particular social world can best be discovered through the experiences of the people who inhabit the social world, engage in the communicative patterns of that world, and reify the communicative structures of their world, knowingly or not. These patterns of communication create the culture of the organization (Hall, 1959); therefore, through communication, people create and are simultaneously created by culture.

Knowledge can be discovered when the researcher works inside the social world of the participants. In this subjectivist view, knowledge is understood only when the researcher works directly with the people in the situation or organization being studied (Burrell & Morgan, 1979). By investigating the social world through interviewing those who inhabit it, I gained contextualized knowledge from those who socially-construct the reality and who live within the framework of the reified reality of the healthcare world.

My axiological position embraces the belief that our values should inform and inspire our scholarship. My experiences in healthcare as a patient, family member of a patient with a learning disability, friend of a patient with economic and educational disadvantages, and an employee of a healthcare system have all developed my scholarship interests, personal commitment to my field of study, and my values regarding its importance. My values include a belief in social justice and health equity, and those principles inform and animate my current inquiry. As an interpretivist, I value relational communication, since I assume reality to be relationally/socially constructed and seek to understand the intersubjective experiences and voices of individuals, particularly related to their interactions and struggles with healthcare organizations and healthcare information.

### **Theoretical Framework**

I assume an interpretivist approach to this study of health literacy initiatives in healthcare organizations. The interpretivist paradigm is primarily concerned with obtaining deep understandings of communicative meanings and conventions which apply in specific contexts (Baxter & Babbie, 2004; Creswell, 2009; Lindlof & Taylor, 2011). Interpretivism is concerned with understanding the realities and experiences of the people being studied, in particular discovering the web of meanings embedded in the social realities of those individuals (Baxter &

Babbie, 2004). I am interested in the lived experiences of people who are responsible for, or have been responsible for, the health literacy activities or initiatives in the healthcare organizations in which they work or worked.

Healthcare professionals are situated in and participate in creating webs of meaning constituted by the communicative interactions among all the people in the healthcare organizations in which they work. Healthcare organizations' webs of meaning are embedded in hierarchies and histories (Lyndon, 2008). These organizations' multiple hierarchies, and the norms that guide how people behave within them, are created and co-created in iterative cycles of interactions which constrain the behaviors of the people who create them.

For example, historically, physicians have been given positions of greater authority in the medical hierarchy than nurses (Thomas, Sexton, & Helmreich, 2003), and this difference in position in the hierarchy has created a prescribed pattern of communication between physicians and nurses which both enables and constrains their interactions (Lyndon, 2008; Tang, Chan, Zhou, & Liaw, 2013; Vazirani, Hays, & Martin, 2005). Similarly, an employee in charge of health literacy in a hospital most likely occupies a different place in the organizational hierarchy than a senior leader. If the person in charge of health literacy interventions understands the senior leader's world, webs of meaning, and patterns of communication, presumably, he or she can tailor messages with greater effectiveness to garner support for health literacy activities.

To understand the social realities of health literacy change leaders' experiences in advancing health literacy initiatives, I used semi-structured interviews to explore, with the interviewees, their subjective realities and experiences within the web of meanings in their organizations. Each organization provided a unique context but one which also has commonalities with the other participating healthcare organizations. All healthcare organizations

are governed by the same external forces, such as accreditation requirements (The Joint Commission, 2016); the financial realities of unreimbursed costs (Kocher & Adashi, 2011); and cultural characteristics such as hierarchical structures which may dictate communication behavior among leaders, physicians, mid-level providers, and other employees (Lyndon, 2008). Although the data and findings of the present study specifically illuminate the facilitators and barriers related to implementation of health literacy initiatives, the common cultural elements of hierarchy, governmental policies, accreditation requirements, and a quickly changing healthcare environment suggest that the findings may provide useful strategies for other healthcare organizations to consider.

In the following section, I review the literature in several key areas that provide theoretical grounding and contextual background for this study. First, to set the context, I look at concepts in health literacy and organizational health literacy. Next, I examine organizational theories developed by Karl Weick, Max Weber, and Peter Drucker. Following this, I provide an overview of four theories of organizational change which have been used in healthcare: (a) Diffusion of Innovations, (b) the Model for Improvement, (c) Kotter's Eight-Step Process, and (d) Lewin's Three-Stage Model of Change. Finally, I briefly describe the overarching field of dissemination and implementation research and document research on facilitators and barriers to organizational change in healthcare.

### **Health Literacy**

The definition of health literacy, proposed by the Institute of Medicine (IOM) in 2004, is "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Nielsen-Bohlman et al., 2004, p. 2). This is the definition for individual health literacy I use in my work.

Many of the early health literacy studies in the literature documented the mismatch between the literacy demands of print materials used in healthcare and the literacy abilities of U.S. adults. Many studies have shown that health-related information is usually written at levels requiring skills far above the abilities of average high school graduates (Nielsen-Bohlman et al., 2004; Rudd, 2010). This mismatch is critical to address because limited literacy is prevalent in the U.S. (Kutner et al., 2005). Forty-three percent of U.S. adults function at the *basic* or *below basic* levels for prose literacy in a range of *below basic*, *basic*, *intermediate*, and *proficient*. Further, 44% function at the *intermediate* level for prose and only 13% function at the *proficient* level for prose (Kutner et al., 2005). Another source claims that half of U.S. adults function at or below the 8<sup>th</sup> grade reading level (Doak et al., 1996).

Adults with limited functional literacy skills struggle to read and understand printed health information and are at risk of having low health literacy as described above. Moreover, nearly 100 studies document a relationship between limited literacy skills and a variety of adverse health outcomes (Dewalt et al., 2004; Rudd et al., 2007). There are many interventions that could reduce the negative impact of low literacy on patients' understanding of health information and use of health services, including improving access to more reader-friendly health information and helping patients understand how to move from knowledge to action (Nielsen-Bohlman et al., 2004).

In 2006, the National Assessment of Adult Literacy (NAAL), the first assessment of adults' literacy skills to include health-related items, revealed the status of U.S. adults' health literacy knowledge and skills compared to the demands of the healthcare system. The report revealed that only 12% of adults function in the *proficient* level for health literacy which is considered the level required to successfully navigate and use the healthcare system (Kutner et

al., 2006). In addition, more than a third of adults function in the *below basic* or *basic* health literacy levels. These data indicate that the *majority* of U.S. adults lack the health literacy skills to appropriately engage with the current health care system, *even those with well-developed functional literacy skills*.

The NAAL data on health literacy also identified specific demographic groups at risk of having lower than average health literacy skills:

- adults living below the poverty level;
- adults who are ages 65 and older;
- Black, Hispanic, American Indian/Alaska Native, and multiracial adults;
- adults who spoke other languages alone or with English before starting school; and
- adults with low educational attainment (Kutner et al., 2006).

The racial and ethnic minority groups at higher-than-average risk of low health literacy are also the groups at highest risk of experiencing health disparities (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010). Links between low health literacy and racial disparities in health outcomes have been well documented (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Nielsen-Bohlman et al., 2004).

Health literacy cuts across many areas in healthcare settings, including the major challenges of quality of care, patient safety, health outcomes, health equity, and costs of care (Abrams et al., 2014; Adams & Corrigan, 2003; Isham, 2009). Links between low health literacy and patient safety, high medical costs, higher rates of hospitalization, poorer knowledge of recommended health behaviors, poorer health outcomes, and possibly lower adherence to medical instructions have been well documented (Berkman et al., 2011; Nielsen-Bohlman et al., 2004).

Health literacy's link to quality of care is illustrated by its inclusion in three of six aims in the report, *Crossing the Quality Chasm* (Institute of Medicine, 2001): patient safety, patient-centered care, and equitable treatment. But only recently are healthcare organizations beginning to integrate health literacy into their quality improvement agendas (Koh et al., 2012).

Patient safety is at risk if there is a lack of attention to health literacy and/or cultural competence. Another Institute of Medicine report, *To Err is Human* (Kohn, Corrigan, & Donaldson, 2000), identifies several examples of problems that can result if health literacy and cultural competence are not addressed, including medication errors, failure to obtain truly informed consent, and failure to get accurate medical and health histories. Patient safety may also be compromised by health literacy-related challenges such as poor knowledge of health conditions and lower use of preventive services (Kohn et al., 2000).

### **Organizational Health Literacy**

Today's health care systems and organizations are increasingly complex and are making greater demands on consumers than ever before. Consumers are expected to take more responsibility in caring for their chronic diseases; are assumed to be capable of seeking, finding, and using health information to make lifestyle changes on their own; are expected to understand their rights and responsibilities and give informed consent; and are often asked to choose their own treatment from several options (The Joint Commission, 2007).

Increasingly, the healthcare community is recognizing that health literacy is the interface between individuals' knowledge and skills and the demands and complexity of healthcare organizations (Adams & Corrigan, 2003; Baker, 2006). Healthcare organizations must address systemic barriers to patients' access and use of the system (Parker, 2009; Rudd, 2007) and

healthcare providers must address the areas in which they are not currently meeting patients' communication needs.

Despite healthcare professionals' responsibility for clear and effective communication, they do not routinely use health literacy practices (Castro et al., 2007; Coleman et al., 2013; Schwartzberg et al., 2007). Moreover, physicians often do not communicate health information in a way that patients with lower health literacy can understand (Davis, Williams, Branch, & Green, 2000; Lindau, Tomori, McCarville, & Bennett, 2001; National Work Group on Literacy and Health, 1998). Studies also show that clinicians are often unaware of the gap between their ways of communicating information and patients' processes of remembering, comprehending, and making meaning of that information (Doak, Doak, Friedell, & Meade, 1998; Williams et al., 2002).

In addition to the changes needed by healthcare providers, "...system changes are needed to better align health care demands with the public's skills and abilities" (Institute of Medicine, 2013b, p. 1). If 88% of U.S. adults lack the health literacy proficiency to access and use the healthcare system (Kutner et al., 2006), it is evident that healthcare systems and organizations have a responsibility to redesign themselves, and their ways of interacting with patients, to be more accessible to the people they exist to serve. Much is known about the strategies healthcare organizations can use to more effectively reach their audiences with understandable health information (both in print and oral delivery) and supportive services for using the healthcare system. This study attempts to identify and understand some of the reasons those strategies are not more widely used.

In 2012, the IOM published a new document outlining the ten attributes of *health literate healthcare organizations*, a new term in the field. Health literate healthcare organizations, and

*organizational health literacy*, both refer to “health care organizations that make it easier for people to navigate, understand, and use information and services to take care of their health” (Brach et al., 2012, p. 1). This occurs when organizations redesign and/or add to their policies, processes, communications, internal structures, and physical environment to improve access to and quality of care. The ten attributes identified by the Institute of Medicine are listed here:

“A health literate health care organization:

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services. (Brach et al., 2012, p. 3)”

Many mandates require organizations to address certain health literacy barriers. For example, both The Joint Commission accreditation standards on communication and the Office of Minority Health's Culturally and Linguistically Appropriate Services (CLAS) Standards call for healthcare organizations and professionals to provide culturally and linguistically appropriate care (Office of Minority Health, 2001; The Joint Commission, 2007), of which health literacy is a part.

In addition to mandates, there are documents and reports which call for system changes. The U.S. Office of Disease Prevention and Health Promotion published *The National Action Plan to Improve Health Literacy* (U.S. Department of Health and Human Services, 2010), which provides a vision and seven goals to address health literacy. Three of the goals relate to the need for healthcare system redesign or increased dissemination and implementation of health literacy practices.

Another example of the awareness of healthcare organizations' role comes from a discussion paper published by the National Academy of Medicine (previously the Institute of Medicine) which calls for an expanded definition of health literacy (Pleasant et al., 2016). The first added component of the expanded definition calls for considering system demands and complexities in addition to individuals' skills (Pleasant et al., 2016). Examples of these demands and complexities are (a) the process of obtaining prior approval through an insurance agency before scheduling a diagnostic test, (b) challenges in physically navigating a medical campus, and (c) understanding and carrying out the processes to check in for an appointment when there is no person to greet patients, but only signs, clipboards, and a box in which to drop a slip of paper with key information written correctly on it.

In addition to the mandates and calls for action, there are at least 20 resources providing guidelines, standards, and tools for organizations to more effectively reach their audiences. Some of these resources have been available for over a decade. The resources come from a variety of sources ranging from a comprehensive guidebook on organizational change (Abrams et al., 2014) published by a multistate healthcare system to guidance from federal agencies and private organizations.

Many U.S. federal government agencies have produced guidance on these topics (Brach et al., 2012; Brega et al., 2015; Centers for Disease Control and Prevention, 2010; Institute of Medicine, 2013b; McGee, 2012; National Cancer Institute, 1999; U.S. Department of Health and Human Services, 2010). Private organizations and accrediting agencies which have produced guidance on these topics include the American Medical Association (2007); The Joint Commission, the accrediting agency for healthcare organizations (2007); and the National Quality Forum (2010).

In addition to all the above, there is a new proposed model of health literate care (see *Appendix A*) which is based on the well-established chronic care model (Koh, Brach, Harris, & Parchman, 2013). For health care organizations adopting the model, “health literacy would...become an organizational value infused into all aspects of planning and operations” (Koh et al., 2013, p. 357).

Despite the mandates, calls, expanded definitions, 20 resources, and a new model, innovations to address the challenge of meeting patients’ communication, system navigation, and access needs are slow in coming. Further, there is little research available on implementation of interventions related to the attributes of health literate healthcare organizations (Institute of Medicine, 2013b).

At this time, there is no clear evidence on what is needed to bring health literacy into the mainstream in healthcare organizations. Little is known about the organizational influences and processes that impact acceptance of, support for, and implementation of health literacy initiatives. More research is needed to identify facilitators and barriers to health literacy initiatives. The present study identified what methods have created support, obtained commitment, and enlisted resources for implementing health literacy changes within healthcare organizations.

Research is needed to (a) determine where and how health literacy strategies have been adopted and implemented successfully, (b) identify key factors in adoption and implementation, and (c) communicate the successful strategies to the health literacy field to support the adoption of health literacy across the U.S. and beyond. The present study addressed this need by identifying elements that affect the adoption and implementation decisions and processes to provide guidance for organizations who want to integrate health literacy into their systems.

The purpose of the study is to learn about the experiences of health literacy practitioners' experiences with the facilitators and barriers of adoption and implementation of health literacy initiatives. Facilitators and barriers to health literacy initiatives have not yet been described well in the literature. Little is known about the organizational factors and processes that influence acceptance of and support for health literacy initiatives.

### **Organizational Theory**

In this section, I outline the basic tenets of three scholars whose work is foundational in organizational theory: Max Weber, Karl Weick, and Peter Drucker. I then look at healthcare organizations in relation to these theories and their implications for health literacy initiatives and the health literacy change leaders, the individuals charged with implementing them.

**Max Weber**

Weber's theory of bureaucratic organizations uses a machine metaphor to describe organizations which are specialized, standardized, and predictable. Like machines, organizations operate using (a) specialization of functions, (b) standardization of parts which can easily be replaced (including humans), and (c) predictability in rules that govern how the organization operates (Miller, 2006). Despite this rigid metaphor and view of bureaucracies as immutable, I look at them from a social constructionist lens. Healthcare bureaucracies may operate as if they are established and solid, but they are continually constructed, re-constructed, and reinforced by the communication, interactions, and behaviors of the people who inhabit them.

There are many conventions for communication and behavior in healthcare which depend on shared assumptions of their importance. Employees usually act in specified ways because they assume that is expected and appropriate. They may choose to respect the conventions and rules (when they are aware of them). When they do not follow the conventions, they will usually be quickly informed in an interaction with their supervisor and instructed to change their behavior. The employee's response can further reinforce the understanding of the convention or, perhaps, question it. If the convention is challenged and re-examined, it may be changed by the interactions and communications around the challenge, thus socially-constructing a new convention in the bureaucracy.

Weber's theory outlines the features of bureaucracy, which he saw as a form of the "ideal" organization. He cites the following qualities (among others) as critical to the fully developed bureaucracy: (a) precision, (b) speed, (c) prescribed roles, (d) unambiguity, (e) knowledge of the rules and the documents which codify them, (f) strict subordination, and (g) reduction of material and personal costs (Weber, 1968). Weber does not explicitly address

communication processes as part of the organization; however, it is hard to see how any of the functions of bureaucracies could be accomplished without it.

Weber (1968) believed that organizations ought to be governed by well-defined vertical hierarchies where the lower offices are subordinate to the higher offices. In these hierarchies, communication should be limited to up or down the vertical hierarchy. The positions in the hierarchy are governed by clear division of labor and specialization of functions. Those at the top of the hierarchy are the decision-makers and have the most power. The management of the organization should be based upon a comprehensive set of rules codified in the organization's written documents. However, the rules often create barriers to the organization being flexible enough to meet the needs of individuals.

A healthcare example of the rules serving as barriers is a requirement for patients to have an MRI before they can book an appointment with a spine specialist. Not all patients need an MRI for a doctor to obtain an accurate diagnosis. The patients who do not necessarily need an MRI are not allowed to book an appointment until, and if, they obtain an MRI, often at a cost of many hundreds of dollars. Given the cost, some patients may decide not to be seen at all or may take their business elsewhere. None of these outcomes work well for the patient, and the latter two do not work well for the organization. However, the rule is the rule, and the employees who book appointments are not empowered to override it. However, if the patient chooses to protest the application of the rule and it is changed as a result, the patient would have participated in socially-constructing a new convention in the bureaucracy. These kinds of challenges and changes may be uncommon because so many people see bureaucracies as immutable.

One of Weber's most important concepts is the idea that organizations should have a system of authority, power, and discipline. Weber describes one of the types of authority in

bureaucracies as rational-legal. It relies on rationality, rules, and the expertise of individuals in power (Miller, 2006). It is the most impersonal of the types of authority. It is this type of authority which supports a policy or rule like the MRI requirement. It seems to be rational and is based on the knowledge and expertise of the system administrators who established the rule. However, it is very impersonal and does not allow for exceptions to meet patients' needs.

Despite Weber's description of bureaucracies as the ideal form of organization, he also identified some potential disadvantages. As elucidated by Clegg (1990), Weber predicted that modernity would bring the discipline of bureaucracy into every corner of life, and organizations would become an inescapable part of the future. Weber described this encroachment of bureaucracy as the "iron cage." In the iron cage, "humanity will become ever more captive in the thrall and bondage of technical perfection" (Clegg, 1990, p. 30). In healthcare, the rules, policies, processes, forms, and guidelines for behavior can indeed become like an "iron cage."

Healthcare organizations exhibit many aspects of Weber's definition and descriptions of bureaucracy (Alaszewski, 1995). They are replete with embedded hierarchies (Lyndon, 2008) that support, prescribe, and/or impact the actions of employees at all levels. They have explicit objectives specified in official documents. Efforts to meet those objectives are led by administrators such as chief executive officers and executive directors. They are comprised of vertical hierarchies with communication channels often limited to one's supervisor and one's subordinates; well-defined authority and power positions; and documented rules and policies that govern many activities of the organization. I now move to an examination of Weick's view of organizing and communication.

**Karl Weick**

Karl Weick defined organizing (rather than organizations) as the process of resolving differences in interpretations of the same event (which he calls *equivocality*) in a communication environment (which he labels an *enacted environment*) by means of communicative processes (Weick, 1995). In using the word *organizing* (a verb) rather than *organization* (a noun), Weick made a significant shift in the dominant view of organizations. This change in terminology indicated his belief that organizing and communicating are intertwined processes that occur continuously and reinforce each other (Weick, 1995). This is quite different from the classical view of organizations as bureaucratic, highly controlled, and impersonal (Weber, 1930). The primary concepts of Weick's theory are explained further below.

*Equivocality* refers to multiple plausible perspectives or interpretations of the same event. For example, in a healthcare setting, a physician may ask a patient at the end of an appointment, "Do you have any questions?" The patient may be unsure if she is truly being invited to ask her questions. She could think (a) the doctor doesn't really want her to ask anything, (b) the doctor is willing to answer a quick question, or (c) the doctor would be willing to answer her questions fully.

*Enacted environment* refers to an information and communication environment (rather than a physical environment) in which people enact with the communication environment. In trying to discern the nature of an equivocal situation, a person may notice a specific part of the environment and react to it which then will impact the person's experience of the environment. A person's actions create the constraints as well as the possibilities in their future interactions (Weick, 1995). In the example of the patient, she would likely decide by engaging in what Weick calls *sensemaking* (1995).

*Sensemaking* is a key concept in Weick's theory of organizing. In organizations, employees make sense of the organization, its decisions, policies, communication, and their place in it. Sensemaking is not something we do alone. Weick (1995) explains that our decisions in sensemaking are influenced by our conscious or unconscious beliefs about how our actions might affect and be seen by others. He calls this the "implied, imagined presence of others" (Weick, 1995, p. 40). The patient who is not sure about asking her questions might imagine the presence of her sister and wonder to herself, "What would my sister say I should do in this situation?"

Sensemaking relative to an equivocal event involves a method of selection in which we call upon several different processes to help us decide on our interpretation (Miller, 2006; Weick, 1995). These are called *assembly rules* and *communication cycles*. Assembly rules are routine procedures, or "recipes," which can help people make sense of a situation. We can predict that what happens routinely, and has occurred in the past, is likely to occur again. The standard structure of doctor/patient interactions during a medical appointment (Cole & Bird, 2013) would constitute a set of assembly rules.

In the example of the patient wondering whether she should ask questions of her doctor, to make sense of the situation she will likely rely on assembly rules, if she has been to that doctor in the past. Her understanding of the situation will be influenced by her memory of past encounters (with this doctor and others), her beliefs about how others' might view her behavior, her confidence to formulate a question, etc.

In information environments that change quickly and in which there is unfamiliar information, and therefore, high equivocality, *communication cycles* are used in lieu of assembly rules. Communication cycles are conversations in which members of the organizational

environment discuss and react to new information in efforts to reduce the equivocality and make sense of the situation (Miller, 2006; Weick, 1995). In the example of the patient, if someone knocks on the door of the examination room just after her doctor asks if she has any questions that could change the context and meaning of the question quite quickly. She might notice that the physician stands up and has his hand on the doorknob. If she is a confident patient, she may (a) ask the physician directly if he can now answer a question or two or if he needs leave, and (b) point out she notices his hand is on the doorknob. This line of conversation would constitute a communication cycle.

After the sensemaking phase is completed and people have developed their interpretations and expectations through assembly rules and communication cycles, a template of those interpretations and expectations can be mentally stored for future use. Weick (1979) calls this process *retention*. To continue with the example of the patient who is unsure about asking a question, her past experiences with the physician will have created the template of expectations which she has retained in her memory. Her decision to ask a question will be determined by her retained template of the meaning in the environment of the visit.

Weick's model of organizing describes many aspects of communication and interactions in healthcare organizations. The national healthcare environment changes rapidly and healthcare organizations must often change in response which can create equivocality in the enacted environment that engages people in sensemaking processes. The following example of the organizing communication that could occur between a senior leader and a health literacy change leader exemplifies a possible situation to which Weick's model applies.

In this example there is a difference between a health literacy change leader's and a senior leader's interpretation of the best way to address new payment guidelines which penalize

hospitals for preventable readmissions of certain patients. The senior leader may feel the need to address it with the most expeditious strategy while the health literacy change leader may want to make changes in the process of educating patients before discharge. This latter approach could take a bit longer to show results but would be a patient-centered approach. The health literacy change leader may envision the implied presence and voice of the leader as communicating a lack of care about patients. The senior leader may envision the health literacy leader's perspective as naïve and not understanding the fiscal realities.

This equivocality could be resolved by both people engaging in a communication cycle to discuss their perspectives and resolve the different perspectives. The fluid and iterative nature of Weick's model is quite different from the traditional model of bureaucratic organizations but it applies to many of the communication processes which take place to make sense of the bureaucracy. It also serves as an interface between the bureaucratic structure in healthcare organizations and the more flexible part of these organizations as described by Peter Drucker. I now explicate Drucker's contribution to organizational theory as it relate to the structure of healthcare organizations.

### **Peter Drucker**

Drucker's view of organizations moves beyond the classical bureaucracy wherein decisions are made by top management. He acknowledges that top management must have the final say but also that delegating certain decisions is critical if the organization's workforce is to be productive and satisfied. He describes the business enterprise as an "organization of professionals of highly specialized knowledge exercising autonomous, responsible judgement" (Drucker, 2011, p. 126). There is no central bureaucracy in Drucker's model; instead, he advocates semi-autonomous units within the organization (1988). Drucker's view was that each

person in the organization should participate in developing and be committed to the overall mission and goals of the organization (1954).

Drucker described four fundamentals of communication that represented what the communication field had learned to that point (2011):

- 1) communication is perception,
- 2) communication is expectations,
- 3) communication is involvement, and
- 4) communication and information are different and interdependent.

*Perception* refers to the idea that the receiver of a communication text is the person who makes it into communication rather than simply information. The sender can send out a communication text but that act is not communication unless a receiver perceives it and understands it. This is relevant to healthcare in terms of communicating with patients and remembering that the healthcare provider's experience is usually vastly different from the patient's. This means, for example, that a patient who has never learned the dangers of cholesterol can be more easily taught if the sender can use a metaphor such as, "Cholesterol in your arteries is like sludge in your pipes" to bring the information closer to the experience of the patient.

*Expectations* create the framework or window through which we see, hear, and understand. Mostly, humans see and hear what they expect to. The unexpected may be resented, ignored, or not received at all. The human mind vigorously resists "any attempts to make it 'change its mind,' that is, to perceive what it does not expect to perceive (Drucker, 2011, p. 8). In order to change a mind, there must be "a 'shock of alienation' for an 'awakening' that breaks

through the recipient's expectations and forces him [sic] to realize that the unexpected is happening" (Drucker, 2011, p. 9).

This principle could be very helpful to health literacy change leaders. First, they must learn what their intended audiences would expect to hear about health literacy. If the change leaders need to deliver a message about the need for different approaches to communicating, they need to know how to provide the shock in a believable manner. Perhaps they need incontrovertible data or dramatic stories of patients' poor care experiences, preferably from their own organization.

Drucker's concept of *involvement* is based on the claim that all communication makes demands on people, requiring them to be involved and to "become somebody, do something, believe something" (2011, p. 11). He also claims that all communication is propaganda in that the communicator wants to get something across. People who receive too much information that is perceived as propaganda begin to disbelieve everything. Everything is "considered a demand and is resisted, resented, and in effect not heard at all" (Drucker, 2011, p. 11). By and large, there can be no meaningful communication unless it fits the receiver's aspirations and values.

This principle is critical for any change-effort leader to keep in mind. In healthcare, there are many forces and pressures healthcare leaders and managers need to attend to and manage. Examples of these demands include mandatory requirements to use a variety of performance and safety indicators (Stefl & Bontempo, 2008). These multiple demands may end up being ignored because they require too much involvement and change. In this climate, bringing about health literacy change should possibly be delayed until other initiatives and their demands have eased or been completed.

Drucker also pointed out that *communication and information* are different but interdependent. Information is nothing more than impersonal data with no meaning until it has been communicated in a personal and meaningful way. Too much information can overload the receiver and become less meaningful, perhaps contrary to the communicator's intent.

In summary, the theories of Weber, Weick, and Drucker each speak to aspects of healthcare organizations—the process of organizing, their structure, their communications, and their ways of making sense of the external and internal demands on healthcare today. Health literacy change leaders may be more effective in their efforts if they understand the principles proposed by these early theorists. This study revealed much about the bureaucratic structure of healthcare organizations, the existence of a co-existing less bureaucratic system of semi-autonomous units, and the organizing processes such as sensemaking and communication cycles that act as a cohesive force between the bureaucracy and the semi-autonomous system as described below.

### **Structure of Healthcare Organizations**

I now discuss briefly some aspects of healthcare related to these theories. First, it is important to understand that healthcare organizations are situated in a social, political, and economic context that is fast-paced, high-pressure, and quickly-changing. “Managers and leaders strive to balance competing, shifting and irreconcilable demands from a wide range of stakeholders—and do so while under close public scrutiny” (Walshe & Smith, 2011, p. 4). Perhaps some of the challenges in healthcare today can be explained or informed by considering two intertwined aspects of healthcare organizations—the bureaucratic infrastructure that supports patient care and the semi-autonomous professional practice structure that delivers patient care.

In healthcare organizations, two distinct but intertwined systems appear to operate simultaneously. One is the Weberian bureaucratic infrastructure that supports patient care, i.e., manages and maintains systems which need to be run with precision, reliability, and standardized accuracy, such as booking appointments, collecting payments from insurance companies, and getting diagnostic information from the laboratory. The functions of the organization that must be conducted to ensure patient safety or compliance with accreditation requirements or mandates from external organizations may require the authority structure, standardization, procedures, policies, and rules characterized in Weberian bureaucratic structure. For example, rules are critically important when a performance gap could cause death or disability for a patient.

The other system is more flexible (similar to what Drucker described as semi-autonomous units) comprised of functions and professional practice involved in delivering patient care. In their professional practice of delivering care, healthcare professionals rely on knowledge gained in their educational programs, their experience treating patients, information from journals (Rycroft-Malone, Fontenla, Bick, & Seers, 2008), and their conversations with colleagues, rather than rigid bureaucratic rules.

Patient care is rarely straightforward or predictable, so healthcare providers need to have latitude in their decision-making rather than standardized protocols (Rycroft-Malone et al., 2008). Alaszewski (1995), in discussing Weber's work as it relates to healthcare, pointed out that professional practice cannot be reduced to rule-bound decision-making since it is based on special professional insight and knowledge. In fact, professional practice is specifically characterized by autonomy. Alaszewski (1995) further explained that the doctor-patient relationship is both private and personal, and therefore, medical decisions are insulated from organizational control.

Miller (2006) expands Thompson's concept of the "technical core" (1967), an area of the organization that must be protected from environmental interruptions by bureaucratic means. She identifies the doctor-patient interaction in the exam room as a technical core activity of healthcare. Interestingly, one could say this technical core is buffered from bureaucratic rules, as well as environmental interruptions, by the rules enforced by the actions and communication of receptionists, nurses, and others in the socially-constructed context.

The areas of delivering patient care which involve the services of highly-trained professionals such as physicians need to be managed differently. Walshe and Smith (2011) state that it makes no sense to manage highly-intelligent clinicians in ways that conflict with their self-image as autonomous professionals. Rather than managing from the bureaucratic structure, relationships with these professionals require negotiation and persuasion to gain agreement (Walshe & Smith, 2011).

There are likely many places where the two systems—the bureaucratic infrastructure and the autonomous, professional practice insulated from the bureaucracy—are in tension or even collide. We see examples of this tension in a movement to introduce standardized care protocols in various aspects of medicine. The traditional model of patient care lacks coordination of processes which should be in place to assure efficient, quality care (Walshe & Smith, 2011). This traditional model is increasingly being seen as potentially unsafe, unreliable, and error-prone (McDonald, Waring, Harrison, Walshe, & Boaden, 2005).

In recent years, more healthcare organizations are using standardized treatment plans and clinical guidelines to provide more structure to the caregiving process (Mittman, 2012; Walshe & Smith, 2011). Typically, nurses advocate standardization and see it as part of professionalism, while doctors reject written rules, preferring to adhere to what they see as unwritten rules about

professional and acceptable behavior (McDonald et al., 2005). Perhaps nurses identify more closely with the more bureaucratic system because nurses (other than nurse practitioners) are not part of the professional practice system since they are not allowed to diagnose and prescribe. Instead, they have essentially served to buffer the healthcare professionals from the bureaucracy. The successful implementation of guidelines depends on balancing standardization and decision-making autonomy (Rycroft-Malone et al., 2008), i.e., managing the tension between the two systems.

Weick's concepts of organizing and communicating as intertwined continuous processes that reinforce each other and his sensemaking assembly rules and communication cycles may be seen as crucial processes in enabling the dual systems, the systems that support care or deliver care, to co-exist and work together. For example, it may be that physicians and administrative leaders come from such different sets of assumptions about organizing, authority, freedom in decision-making, and much more, that to effectively work together they need to engage in communication cycles to establish and re-establish assembly rules more frequently than people who work in the same side of the dual systems.

### **Applications to Health Literacy Initiatives**

The theories outlined above can deepen our understanding of some of the challenges health literacy change leaders encounter in bringing about change. Almost everything these change leaders ask of individuals in a healthcare organization will require changing rules, roles, and responsibilities in the bureaucratic systems of the organization. In the more flexible professional-based systems, making health literacy changes will require conducting communication cycles, installing new assembly rules, and changing the "technical core" described by Miller (2006), as people work to change their styles of communication with

patients. For example, asking healthcare providers to add the teach back strategy to their office visits with patients (their technical core) may be seen as reaching into a sacrosanct space.

Another example of changes required is illustrated by the challenge of revising a patient consent form for office-based procedures to be more understandable and to improve certitude of informed consent. Many steps would be required to achieve this. The steps would include engaging with the bureaucratic part of the system to obtain (a) approval to begin, (b) resources to revise and redesign the form, (c) approval by the legal department and many department heads, (d) health literacy staff's time to speak to various stakeholders about the form, (e) health literacy staff's time to test the form with patients, and (f) ultimately, a mandate from top leadership that the new form and new process will be used.

The steps also might include engaging with the professional-based parts of the system to obtain (a) at least one champion who can assist in promoting the new form, (b) input from representatives of the healthcare providers on the changes made, (c) agreement to changes in the form, (d) agreement to changes in the consent process to reflect the intentions and recommended use of the new form (i.e., using teach back to confirm understanding), and (e) cooperation of healthcare providers and staff in using the form. Completion of these many steps and tasks would require the interest and cooperation of many other people in multiple places in the organization. This study identifies some of the inherent structural barriers and other challenges such as lack of leadership support and adequate resources health literacy change leaders face in trying to coordinate efforts that require the participation of multiple people with different understandings of and commitment to health literacy.

### **Organizational Change Theories**

Theories, models, and frameworks on organizational change can serve as maps to guide change leaders' efforts. Research on organizational change provides information on what has resulted when various theories were implemented. That said, it is important to note that (a) some research does not cite the use of a theory and (b) there is not an abundance of literature related to the application of change management theories in healthcare organizations (Antwi & Kale, 2014; Varkey & Antonio, 2010). This gap in the literature further justifies the need for the present study. The study findings contribute to understanding how organizational change models are and are not used and their use affects the advancement of health literacy initiatives.

Below, I describe four models of change which I have chosen because they are being used in healthcare organizations (Berwick, 1998; Cohn et al., 2009; Harting et al., 2005; Peter et al., 2015; Shirey, 2013; Sutherland, 2013): (a) Diffusion of Innovations, (b) the Model for Improvement, (c) Kotter's Eight-Step Model, and (d) Lewin's Three-Step Model. These models are known to be relevant to healthcare settings and to address features of change which are of interest in this study. Knowledge of the theories informed my coding, analysis, and interpretation, as well as the development of recommendations for future practice in organizations that are trying to build health literacy initiatives.

#### **Diffusion of Innovations**

The first theory I describe is the Diffusion of Innovations (DoI) theory (Rogers, 2003). This theory is important to the study of adoption and implementation of health literacy initiatives because it is one of the most comprehensive theories of change and it has been used and studied extensively in healthcare settings (Berwick, 1998; Carlford, Lindberg, Bendtsen, Nilsen, & Andersson, 2010; Greenhalgh, Robert, & Bate, 2008). Unlike any of the other theories of

innovation implementation or organizational change, it provides a rich description of the adoption process and, therefore, may be particularly relevant for health literacy change leaders. In this study, I focused on the processes involved when an innovation is adopted and implemented. I do not address the theory as it applies to sustainability or post-implementation dissemination of an innovation.

The definition of diffusion of innovation is “the process by which an innovation is communicated through certain channels over time among the members of a social system” (Rogers, 2003, p. 5). An innovation is defined as “an idea, practice, or object that is perceived as new by an individual or another unit of adoption” (Rogers, 2003, p. xx). The diffusion of an innovation is a social process in which people share information and opinions about innovations, often seeking information from their peer network (Rogers, 2003), similar to Weick’s communication cycles. When new ideas or practices are diffused and adopted, social change occurs. Seen through the lens of social constructionism, the adoption phase of the Diffusion of Innovations is a socially constructed process as it is driven by communication among individuals in the system and their peers, especially those who influence others through their role as opinion leaders in the peer network.

**Main concepts.** Three of the main concepts of the theory describe factors which affect implementation of an innovation: the attributes of an innovation, characteristics of different potential adopters or user groups in the social system, and the communication among peers and peer networks (Rogers, 2003). Before describing those factors, however, I look at the individual and organizational factors involved in the process of making a decision to adopt or reject an innovation.

**Innovation-decision process of individuals.** This theory outlines a process individuals go through in deciding whether to adopt an innovation. Rogers (2003) calls this the innovation-decision process and outlines its five stages: knowledge, persuasion, decision, implementation, and confirmation. The stages represent a sequential series of choices over time that can move the individual to the decision to adopt or reject the innovation. Rogers (2003) points out that individuals within an organization may go through the individual innovation-decision process before deciding to become an adopter, an opinion leader, or a champion.

**Innovation process of organizations.** The organizational innovation process consists of two overarching sets of activities: *initiation* and *implementation*. The initiation stage constitutes the innovation-decision process for organizations. Initiation refers to (a) gathering the data, (b) thinking through the options, (c) deciding to adopt (or not), and (d) planning for the adoption.

**Perceived attributes of innovations.** Rogers (2003) found that the characteristics of innovations, or rather individuals' perception of the innovation, contribute to how quickly the innovation is adopted. According to this theory, there are five specific perceived attributes of an innovation which influence the rate of its spread. The five perceived attributes of the innovation account for from 49 to 87 percent of the variation in rates of adoption. They are relative advantage, compatibility, complexity, trialability, and observability. Relative advantage refers to an innovation being relatively better than the current practice. Compatibility refers to the ease in which the innovation can be integrated into current practice—the amount of change that would be required to use it. Complexity, trialability, and observability refer to how difficult an innovation is to use, how easily it can be tried, and whether it can be observed. Of the five attributes, relative advantage and compatibility were found to be the most influential.

**Adopter categories and characteristics.** Rogers' (2003) theory describes five categories of adopters and groups them according to their rate of adoption of an innovation: innovators, early adopters, early majority, late majority, and laggards. Individuals in each of these categories have different adopter characteristics such as (a) socioeconomic and social status, (b) personality variables, and (c) communication behaviors such as social participation and information-seeking tendencies.

**Communication channels.** A main precept of Diffusion of Innovations theory is that "interpersonal communication with near peers about an innovation drives the diffusion process" (Rogers, 2003, p. 342). A communication channel is the pathway in which a message moves from the sender to the receiver. Rogers (2003) describes two main aspects of communication channels which influence diffusion (a) the type of channel, i.e., mass media or interpersonal and (b) the sources, i.e., local sources vs. more widespread, non-local sources.

The Diffusion of Innovations theory contributes many elements to the analysis in this study because of its emphasis on the adoption decision process and the early implementation phases. One of its weaknesses, however, is its individual-blame bias. Its focus on individuals as adopters does not fully acknowledge the importance of organizational factors in innovation. Organizational context greatly influences individual action. Another possible weakness of the theory may be the lack of a specific, detailed process overarching framework for planning and integrating health literacy-related innovations.

### **The Model for Improvement and Plan-Do-Study-Act (PDSA) Cycles**

As with Diffusion of Innovations, The Model for Improvement is important to the study of adoption and implementation of health literacy initiatives because it is one of the most comprehensive theories of change and improvement. It has been used extensively in healthcare

settings since the 1990s (Cifuentes, Brega, Barnard, & Mabachi, 2015; “Institute for Healthcare Improvement: History,” 2016; Langley, Nolan, Nolan, Norman, & Provost, 1996; Nielsen, Rutherford, & J., 2009; Scholten, 2012).

The Model for Improvement is based on the “science of improvement” and is comprised primarily of three key questions and the PDSA cycle (Langley et al., 1996). The Model begins with the three key questions:

- 1) What are we trying to accomplish?
- 2) How will we know that a change is an improvement?
- 3) What changes can we make that will result in improvement?

After the questions have been answered, the Model moves to the PDSA cycle. Langley et al. (1996) recommend using the PDSA cycle as the framework for small tests of change. The PDSA provides the specific, detailed framework for testing and integrating innovations which is lacking in the Diffusion of Innovations theory. The cycle’s four elements are sequential and are often cycled through multiple times. The Plan-Do-Study-Act cycle is sometimes used to answer one or more of the three questions when the current knowledge is not adequate to answer them all. The components of the cycle are:

- 1) *Plan*: State objectives of the cycle, make predictions, and develop a plan to carry out the cycle (who, what, where, when).
- 2) *Do*: Carry out the test, document problems, and begin analysis of the data.
- 3) *Study*: Complete the analysis of the data, compare data to predictions, and summarize what was learned.
- 4) *Act*: Decide what changes are to be made and what the next cycle will be (Langley et al., 1996).

The Model assumes that leaders in the organization will initiate the change, but applying the elements requires the participation of everyone involved in the change. “The effective leader must understand that the road to improvement passes through change and that one efficient way to change is to learn from the actions we ourselves take” (Berwick, 1996, p. 622). One of the key elements of the Model for Improvement is the democratic and participatory process of those who will be affected by the change asking the three questions and carrying out the PDSA. Engaging the people who will use the change in its design and testing can result in less resistance since the participants are creating the change (Donnellon, 2014; Langley et al., 1996).

Successful implementation of the Model for Improvement requires learning how to ask the questions, carry out the PDSA cycle, and understand how people interact with each other and with the system (Langley et al., 1996). Combined, those elements are the framework for any change. Yet it is important to remember that “not all change is improvement, but all improvement is change” (Berwick, 1996, p. 622).

Strengths of the Model for Improvement are its explicit framework for testing and integrating innovations (a form of re-invention in Rogers’ terminology), its focus on learning the knowledge and skills of the science of improvement, and its attention to the organizational side of implementation. A weakness is the lack of attention to an adoption decision phase which is covered well in Diffusion of Innovations. These two theories complement each other and may be useful at different levels. However, they are both quite massive in their detail and may be difficult for a busy health literacy change leader to grasp in terms of where to start and how to create an overall plan for the initiative.

### **Kotter's Eight-Step Model for Leading Change**

Kotter's model identifies key factors in change but is not as broad and inclusive as the Diffusion of Innovations theory. Still, it may lend itself well to health literacy change initiatives in this study because it can address the challenges of making change in healthcare and provides overarching guidance and principles for addressing them. Moreover, it has been used extensively in healthcare organizations (Arshida, 2012; Battilana & Casciaro, 2012; Scholten, 2012; The National Academy of Sciences, 2016).

John Kotter (1996) outlined eight steps in the organizational change process based on decades of work with hundreds of organizations. In 1996, he described the process as sequential and stated that no step should be skipped. He also recommended that each step be done completely before moving on to the next. The steps, and salient features of each, are outlined here.

1) *Create a sense of urgency.* According to Kotter, it is critical to begin a change effort by helping the people involved see the need for the change and the importance of speed. "Sufficient urgency around a strategically rational and emotionally exciting opportunity is the bedrock upon which all else is built" (Kotter, 2012, p. 54). Without a sense of urgency which engages the heart, people will typically resist an initiative that comes from higher levels (Kotter, 1996).

Complacency can be caused by the lack of a visible crisis and the human ability to be in denial about a problem. Creating urgency can be enhanced by discussing potential threats and problems more openly, setting outrageous and possibly unrealistic goals, and creating a crisis that gets people's attention. In a health literacy initiative, talking about the experience of a patient who was harmed because of a misunderstanding would possibly build some urgency, particularly if there was a threat of legal action.

2) *Create a coalition.* Kotter points out that change is very difficult in organizations; therefore, it requires a powerful force to keep it going. His recommendation to create that force is to gather a coalition of supporters—powerful people from various areas of the organization who can bring influential job titles, status, expertise, political importance, and leadership skills. The change leader should encourage and facilitate their role as champions of the change. This type of coalition can be a powerful force to bring pressure on key leaders who need to provide their support in order for the initiative to move forward.

3) *Develop a vision and a strategy.* Having a vision, an image of the future an organization is striving for, is essential in change processes (Kotter, 1996). It can accomplish three key things: clarify the direction of change, motivate people to start changing in the right direction, and help make sure the actions of those involved are coordinated efficiently. Kotter says when developing the vision, it is essential to include everyone on the coalition, take the needed time, and work to engage both people's heads and hearts in order to arrive at an effective vision.

4) *Communicate the vision.* When the vision is completed, it is essential to ensure everyone involved in the change understands its goals and direction. However, this is easier said than done. Kotter (1996) estimates that less than 1% of an organization's communication to employees is about the vision. He outlines key elements to help in communicating an organization's vision. These include keeping it simple (no jargon), using metaphors, presenting it often in many venues, allowing interaction with employees about the vision, and ensuring leadership sets an example of following the vision's recommended behavior.

5) *Empower employees by removing obstacles.* By "empower," Kotter means to help more people become more powerful. He advises that change cannot happen unless many people help to achieve it. Employees must feel that they have power to contribute to the change or they will

not engage. The barriers to the change must be removed to allow people to participate.

Addressing the barriers might include making structural changes, providing training, aligning the organization's systems with the vision, and dealing with supervisors who don't support the change.

6) *Generate short-term wins.* Major change can take a very long time. It is critical to celebrate the short-term wins. Early successes can contribute to the long-term success of the change effort. These early successes can provide the needed evidence, build support, and keep momentum going. One strategy for generating short-term wins is to identify and prioritize “low-hanging fruit,” changes that will be easy to attain (Kotter, 1995).

7) *Produce more change and don't let up.* Celebrating and recognizing short-term wins is important, but an organization must be careful not to send the message that the hard work is over. Many forces can derail a change effort before it is embedded in the culture of the organization. Moreover, resistance is never completely gone and celebrating short-term wins can give resisters an opportunity to declare a premature victory, which can be disastrous. If change leaders ease up before the change is complete, momentum is easily lost (Kotter, 2012).

8) *Anchoring new approaches in the culture.* “In the final analysis, change sticks when it becomes ‘the way we do things around here,’ when it seeps into the bloodstream of the corporate body” (Kotter, 1995, p. 67). Seeping into the bloodstream would mean changing the organization's culture. If a change is not compatible with an organization's culture—its behavioral norms and shared values—regression will always be a threat.

This type of culture change is extremely difficult and, therefore, Kotter believes it cannot happen at the beginning of the process, only as the last phase. It can only occur if the results of

the change are clearly superior to the old ways. Changing the culture also requires talking explicitly and often about the superiority of the new practices.

In this study, the data describe how some health literacy change leaders are using various aspects of this model. Some change leaders have (unknowingly) been working to create a sense of urgency in the patient stories and statistics they present to decision makers. Health literacy change leaders have created, or benefitted from, task forces, work groups, or teams of champions which serve as the guiding coalition, although these groups do not typically include enough needed powerful people with high status positions. No one talked about developing an official vision for the initiative but they did try valiantly to communicate their own vision for the initiative in some of the ways they communicated about health literacy.

Kotter's model provides general guidance on the process of change, unlike DoI and The Model for Improvement which tend to give more detail about the discrete features and processes of adoption and implementation. Kotter's model has much to offer health literacy change leaders as a strategic framework. Moreover, it can be expanded by several of the strategies that emerged in the data.

### **Lewin's Three-Step Model**

Lewin (1947) noted that change was often short-lived and that group behavior easily returned to the previous norms. His concern for a more permanent change led to his development of the three-step model. According to Schein (1988), Lewin was the father of theories of behavioral science and planned change. Burnes (2004) noted that Lewin's work was the most prominent theory in change management for over 40 years. Burnes (2004) also cited Lewin's (1947) definition of the three steps for a successful change initiative.

**Step 1: Unfreeze**—Lewin believed that human behavior is at relatively stable equilibrium and is influenced by multiple driving and restraining forces. Before change can occur, Lewin believed the equilibrium must be disturbed, old behavior discarded, and new behavior put in place. Expanding on Lewin's ideas, Schein (1996) described three processes necessary for unfreezing: (a) proving the status quo is not acceptable or correct, (b) causing guilt or survival anxiety, and (c) ensuring psychological safety. Schein says the last step is essential because, "if we admit to ourselves and others that something is wrong or imperfect, we will lose our effectiveness, our self-esteem, and maybe even our identity" (Schein, 1996, p. 29), and therefore, the new behaviors will not be used.

**Step 2: Change**—Lewin believed change is an iterative process which can help individuals and groups move from unacceptable behaviors to acceptable behavior. He pointed out that change is not permanent and must be reinforced to be sustained.

**Step 3: Refreeze**—This step strives to re-stabilize an individual or group to make sure the new behaviors are embedded and sustained. Lewin believed that change is only possible if the new behaviors are congruent with the social environment of the learner. Therefore, he saw change as a group activity.

When Lewin created the three-step model, he never intended for it to stand alone. It was designed to be integrated with three other concepts of planned change: field theory, group dynamics, and action research (Burnes, 2004). Salient concepts from these other elements of his work are outlined below.

*Field theory* refers to an understanding of individuals' behavior as a function of the group environment, or field, in which they are engaged. Lewin (1947) stated that changes in the field were necessary precursors to changes in individual behavior. He believed that if it were possible

to identify the forces changing the field, it would then be possible to understand why individuals and groups act as they do. Overall, Lewin saw change as a slow process but also acknowledged that at times, such as during a crisis, certain forces could move quickly.

*Group dynamics* came from Lewin's investigations into the processes and forces involved in changing group behavior. Group dynamics argues that the group, rather than individuals, should be the focus of change. Lewin (1947) explained that it is not useful to try to change individual behavior because it is constrained by the norms of the group. Instead, the focus of change should be on group norms, roles, and socialization processes (Schein, 1988). Lewin (1947) also noted that it was not adequate to understand and change group dynamics, but that it was also necessary to provide a process where members of the group could be engaged in changing their own behavior. This concept led Lewin to develop action research and the three-step model of change (Burnes, 2004).

*Action research* specifies that change is a group process and that those who will be affected by the change must participate and collaborate in the change process (Lewin, 1947). Action research refers to a process which allows groups to examine three concepts: change requires action; one must analyze the options for action in a situation correctly; and to be successful, individuals, groups, or organizations must have a 'felt-need'. This refers to a realization that change is needed. Without a 'felt-need' change is likely to be very difficult.

Lewin's Three-Step model is similar to Kotter's in that it provides a larger context view but few specifics for actual implementation of a given innovation. The three steps are comparable to the content of Kotter's Eight Steps, but Lewin's additional concepts of planned change provide important reminders as a backdrop to innovation efforts. Field theory speaks to the organizational context in which healthcare innovation takes place. Group dynamics

recognizes the importance of understanding that individuals cannot act alone and that groups should be the first target of change efforts. Similar to Drucker's views of involving employees, action research exhorts us to involve those who will be affected by a change, or asked to implement it, in the change process. Being involved can help them understand the problem and develop the essential 'felt-need'. Lewin's three steps and additional three concepts provide excellent reminders of aspects to integrate in adoption and implementation efforts and acted as sensitizing concepts.

The four models and theories of change outlined above are being used in healthcare to varying degrees (Berwick, 1998; Cohn et al., 2009; Harting et al., 2005; Peter et al., 2015; Shirey, 2013; Sutherland, 2013). I described key elements of (a) Diffusion of Innovations, (b) the Model for Improvement, (c) Kotter's Eight-Step Model, and (d) Lewin's Three-Step Model. Aspects of each were found in the data and are referenced in the findings. I now describe the findings in the literature of the field of dissemination and implementation research. This field studies many of the same aspects of implementation and change processed based in the above theories and models but is based in the science of moving new medical discoveries from the research "bench" to direct patient care.

### **Dissemination and Implementation Research in Healthcare**

Dissemination and implementation research (D&I) seeks to improve quality of care through creating systemic changes and facilitating behavior change among healthcare providers and patients (Woolf, 2008). Implementation science focuses on integrating research into practice or moving research from "bench to bedside" (Colditz, 2012). Healthcare has provided rich and diverse settings and foci for research in implementation science. Like the broader field of D&I,

healthcare research also faces many challenges, from lack of consensus on terms and concepts to lack of available relevant theory (Mittman, 2012).

A challenge in this area of inquiry is the lack of standardized terminology (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). There are many different terms used, with varying meanings attached. The field itself has several different names including *dissemination and implementation science*, *translational research*, and *clinical and translational science*.

In this study, I use the terms *dissemination*, *adoption*, and *implementation*. Dissemination refers to the specific, planned activities to expose select audiences to an innovation (a) before the decision to adopt it or (b) after it has been implemented and wider spread is desired (Rabin et al., 2008). I use *dissemination* to refer to early activities that are part of the adoption decision process rather than activities that occur after implementation. *Adoption* refers to the decision to “make full use of an innovation” (Rogers, 2003, p. 21). The decision usually occurs after exposure to dissemination efforts. *Implementation* occurs when a new idea or practice is actually put into use (Rogers, 2003). The goal of studying implementation is examine the barriers to putting a new practice in place (Colditz, 2012).

It is widely known that implementation and organizational change is difficult (Colditz, 2012). An often quoted statistic in D&I research claims that it takes 17 years to translate 14% of medical research into care that benefits patients (Balas & Boren, 2000). It is also recognized that knowledge transfer is not enough for change to occur. Organizational and system functions, as well as individual behavior, both must change for adoption and implementation to occur.

D&I research has been conducted in a variety of health fields from health promotion to patient safety, with some overlaps with healthcare quality improvement research (Mittman, 2012). No single theory or approach has been identified as most effective in organizational

implementation research, although dozens have been developed and reviewed. Tabak and colleagues (2012) reviewed 61 models for use in research studies, organized along the continuum of dissemination to implementation. Each has strengths and weaknesses and would be suitable for different situations.

Using a model in D&I research makes a study more likely to be successful (Tabak et al., 2012). The models reviewed were designed for research, but it would also be helpful to assess whether a model is designed to guide D&I interventions, evaluate them, or both guide and evaluate them (Tabak et al., 2012). Barriers to addressing the identified gaps in D&I research include ongoing debates about the role of theory in implementation science, although there are many theories and models being used, and more are being developed and proposed, as discussed above.

Rogers' Diffusion of Innovations is one of the major theories being used in implementation research, and it provides rich descriptive information on the many characteristics of innovations that correlate with change and implementation. Much of the research using Diffusion of Innovations is descriptive rather than experimental and thus, "rests on a narrow foundation of inference and extrapolation" (Berwick, 2003, p. 1973). D&I research using other theories has been experimental and has provided useful information on the facilitators and barriers. Research using other theories of organizational change as outlined above has also identified various factors in the adoption and implementation of innovations in healthcare.

In this study, the focus is on the adoption decision process and the early phase of implementation. This process involves (a) dissemination of information about an innovation to a specific audience, (b) an organization's or system's decision to adopt the innovation, and (c) the steps to implement the innovation (Rabin et al., 2008). Therefore, the next section discusses only

factors related to those activities, i.e., it does not cover factors in sustaining or disseminating implementation.

### **Facilitators and Barriers to Organizational Change in Healthcare**

Much of the research in D&I identifies facilitators of and barriers to adoption and implementation but often does not identify an underlying theory or model for change. In this section, I identify many of the factors of adoption and implementation that may not be specific to any particular theory of change but are found in the organizational change or D&I literature related to healthcare. Since there is little research about implementation in health literacy initiatives, I rely on the literature on implementing healthcare initiatives of non-health-literacy innovations at this point. Later, I outline some of the facilitators and barriers to health literacy initiatives that have been identified. This study contributes additional information on the several of the factors found in the literature and described below.

I have listed many of the most commonly identified and most critical facilitators and barriers in the literature, all of which informed the data analysis phase, but this is not an exhaustive list. This study (a) confirmed the influence of many of these influences, (b) added dimensions or new depth to a few of them, and (c) added new facilitators and barriers which had not been identified.

I organize the facilitators and barriers into the following four categories: (a) the system or organization (e.g., policies, funding, and leadership); (b) the individuals (e.g., staff buy-in and cooperation); (c) the innovation (e.g., perceived complexity and observability); and (d) the process of adoption or implementation (e.g., the speed of implementation). Below I delineate the facilitators and barriers identified in the literature that are relevant to the present study, organizing them into the above conceptual categories.

**Organization/System Level**

**Leadership support.** Leadership support is one of the most cited factors in success or failure of initiatives. Support for change from both top level leaders and staff was crucial for implementation of hospital-based information technology systems at Veterans Administration hospitals (Spetz, Burgess, & Phibbs, 2012). Harting and colleagues (2005) evaluated factors in implementing a health counseling intervention and found that a key physician who provided leadership focus and served as a champion was able to support stronger efforts by the project leader. A study examining training of mental health workers to provide health promotion and support to clients showed that implementation was facilitated by buy-in and commitment from agency leaders (K. Davis, Swarbrick, Krzos, Ruppert, & O'Neill, 2015).

**Mandates and requirements.** An Institute of Medicine workshop summary on implementation in genomic medicine showed that institutional leaders found that success in implementing new practices was more likely if systems and policies that mandated compliance were present (Addie, Olson, & Beachy, 2016). A study on implementation of clinical practice guidelines in nursing homes reported that when there is limited staff time, the only factor that seemed to impact the adoption of the guidelines was mandated use at the corporate or state level (Colón-Emeric et al., 2007).

**Competing agendas and change fatigue.** When local governmental units attempted to implement a new planning process, Bryson and Roering (2000) observed that external events and crises frequently distracted participants' attention and led to information overload as the participants were forced to deal with the external demands. The events and crises represented competing and conflicting priorities from outside the organization. Organizations can also create

conflicting priorities internally if they simultaneously implement multiple change processes. This can lead to change fatigue, burnout, and apathy (Perlman, 2011).

In a study on implementing screening for substance abuse in primary care clinics, alignment with other organizational priorities (cost of care and quality improvement) was important (Rahm et al., 2014). The innovation needed to be shown to be cost-effective and effective in primary care clinics to address concerns of both physicians and nurses.

**Allocation of adequate resources.** In a study of implementation of hospital-based information technology systems in Veterans Administration hospitals, lack of resources for equipment and infrastructure (e.g., computer hardware, mobile carts, and patient wristbands) was problematic. In addition, needed resources for additional staff during the learning phase of implementation were challenges in several locations (Spetz et al., 2012).

**Time to implement.** Nurses and physicians mandated to implement hospital-based information technology systems in Veterans Administration hospitals were concerned about time pressures in adding a new system (Spetz et al., 2012). Similarly, Colon-Emeric and colleagues (2007) found that concerns about inadequate staffing and accompanying time pressures contributed to the lack of implementation of clinical practice guidelines in nursing homes. And in a study of implementing screening for substance abuse in primary care clinics, physician time to conduct the screening was seen as a barrier (Rahm et al., 2014).

**Balancing daily operational work with improvement efforts.** Graban (2009) discusses the challenge of balancing the responsibilities of daily operational duties employees must do with improvement efforts they are being asked to add. “The challenge of balancing stability and change is a key task for management...” (Meyer & Stensaker, 2006, p. 14). This challenge is also supported in other literature (Scholten, 2012).

## **Individual Level**

**Effective champions.** Champions were critical to adoption decision and initiation in diffusing telehealth services in Australia, and their work was a critical precursor to clinician willingness to use the services (Wade, Elliott, & Hiller, 2014). In this study, the role of champions was primarily relationship-building and providing information to legitimate the innovation.

**Clinician and staff acceptance.** Acceptance by clinicians or the staff who must use the innovation is critical. In a study of telehealth acceptance, Wade and colleagues (2014) found clinician acceptance (willingness to use) to be the key factor in implementation. This acceptance is distinct from acting as a champion for the innovation. Champions were critical in the adoption of the innovation.

**Resistance to change.** A disruptive event is sometimes needed, or at least useful, to stimulate innovation. However, people are programmed to "focus on, harvest, and protect existing practices" (Van de Ven, 1986, p. 591) and are, therefore, likely to resist innovation. Resistance by nurses and physicians to implementing hospital-based information technology systems in Veterans Administration hospitals was noted by Spetz and colleagues (2012) and was attributed to time pressures and fear of using new techniques. Another study of technology acceptance, computerized drug/drug interaction alerts, noted clinicians' resistance and attributed it to the automation of decision-making threatening clinicians' autonomy (Zheng et al., 2011).

**Concerns about clinical judgement being replaced.** A study of implementation barriers to clinical practice guidelines in nursing homes identified concerns that mandatory guidelines and checklists remove healthcare providers' autonomy and reduce the ability to provide individualized, patient-centered care (Colón-Emeric et al., 2007). Moreover, as

mentioned above, the automation of decision-making was met with resistance because it was perceived as threatening clinicians' autonomy (Zheng et al., 2011).

### **Innovation Characteristics**

As with many studies in D&I research and decades of research on the Diffusion of Innovations theory, studies in healthcare identified perceptions and features of the innovation as critical.

**Perceptions and features of the innovation.** Rogers' theory of Diffusion of Innovations identified relative advantage, compatibility, complexity, trialability, and observability as the key attributes of innovations, with relative advantage and compatibility being the most influential (Rogers, 2003). A Swedish study on the adoption of innovations in primary care found that key factors in implementation were (a) perceptions of the need for it, (b) advantages of using it, and (c) its compatibility with existing routines and processes (Carlford et al., 2010). Unfamiliarity with the innovation could cause anxiety and resistance. Therefore, training should emphasize the beneficial attributes and ensure that potential adopters understand that tailoring the innovation is appropriate (Colón-Emeric et al., 2007).

**Re-inventing the innovation.** In order to be acceptable to a healthcare organization, innovations may need to be simple and can often be successfully re-invented to become simpler. This change enhances ease of implementation as would be predicted by the factor of complexity in Diffusion of Innovations (Rogers, 2003). It can also enhance sustainability if modification makes the innovation more site-specific (Barnett, Vasileiou, Djemil, Brooks, & Young, 2011). Berwick (2003) describes a hospital that changed a complicated 30-page clinical practice guideline and still met their goal. By using only the two simple changes with the highest leverage, they were able to reach their goal of an 80% reduction of pressure sores in vulnerable

patients. Moreover, a simpler innovation can be easier to try than a complex innovation so the factor of trialability would facilitate adoption of a simpler, re-invented innovation (Rogers, 2003).

**Robustness of evidence.** Fitzgerald et al. explored the role of certain forms of knowledge (such as evidence and science) in the process of adoption and diffusion and found that “robust, scientific evidence is not, of itself, sufficient to ensure diffusion” (2002, p. 1437). Their case studies clearly demonstrated the ambiguous and contested nature of scientific knowledge. On the other hand, evidence was seen as a powerful source from which innovators could build their arguments and persuasive efforts to promote the innovation. Hard, numerical evidence was considered vital, especially when the innovation was led by non-medical staff (Barnett et al., 2011).

### **Elements of Change Processes**

**Perceptions of change.** In a Swedish study on the adoption of innovations in primary care perceptions of change were important (Carlfjord et al., 2010). Too much change was seen to create reluctance for more change. The timing of change in relation to other ongoing changes in the organization was also key.

**Implementation strategy.** Carlfjord and colleagues (2010) also cited an explicit implementation strategy as important in positive opinions toward the innovations. Being informed about the details of implementation was most likely helpful in people being able to envision how the innovation would impact them (Rogers, 2003).

**Flexibility of implementation timeline.** In the study of implementing hospital-based information technology systems in Veterans Administration hospitals, flexible implementation timelines and the ability to implement unit by unit were helpful. In contrast, in the sites where

the timeline was short and inflexible, staff were more likely to struggle and feel pressured and implementation was more difficult (Spetz et al., 2012). In a related study in Sweden, too much change at once created resistance to more change (Carlfjord et al., 2010).

### **Potential Facilitators and Barriers in Health Literacy**

The facilitators and barriers to adopting and implementing health literacy initiatives have not yet been well documented. Only a handful of studies provide insights into these challenges in any way, but none was designed specifically to examine adoption or implementation of health literacy strategies or initiatives. One study examined factors involving ways to improve patient safety and informed consent (Wu, Nishimi, Page-Lopez, & Kizer, 2005). Another evaluated the extent of use of health literacy practices in underserved clinics (Barrett, Puryear, & Westpheling, 2008).

A third explored aspects of the business and clinical impacts of screening patients for low health literacy (Welch, VanGeest, & Caskey, 2011). A fourth study reviewed the process of developing and testing the use of a health literacy tool designed to help primary care practices address health literacy. In testing the toolkit, the study did identify and list barriers to implementation of the toolkit (DeWalt et al., 2011). Last, one study investigated factors influencing adoption and implementation but only of a tool for assessing a pharmacy's health literacy practices (Shoemaker et al., 2013).

The above studies are descriptive, atheoretical, and not designed specifically to test the organizational change factors required for adoption or implementation of health literacy strategies or initiatives. The present study is designed to explore and identify organizational elements and change processes specifically related to adoption or implementation of health literacy strategies or initiatives, and thus, will contribute to this body of literature.

The above studies, while not specific to health literacy, do provide rich insights and descriptions of some factors related to implementation of health literacy. The factors gleaned from these studies are described below. I also include information from a salient U.S. Health and Human Services document, Institute of Medicine reports and workshop summaries, the hospital accrediting agency (The Joint Commission), and a few policy papers.

Below I delineate possible facilitators and barriers of health literacy implementation as identified in the existing limited literature, organizing them into the same conceptual categories as above. These served as sensitizing concepts in the present study.

### **Organization/System Level**

**Executive-level leaders.** Federal policy analysts who outlined a national plan to advance health literacy suggest that executive-level leaders in healthcare organizations could create an organizational climate that promotes and supports health literacy by providing leadership, allocating resources, creating policies, setting goals, and enforcing accountability for performance measures (U.S. Department of Health and Human Services, 2010). In addition, health literacy researchers suggest that leaders need to assign responsibility for health literacy and provide funding for health literacy activities (Parker, 2009).

However, leaders at executive levels experience many barriers. Healthcare organizations are very complex and involve many players and stakeholders (Plsek & Greenhalgh, 2001; Sales, Smith, Curran, & Kochevar, 2006). There are dozens of agendas competing for leaderships' attention and time pressures are often acute (Scheck McAlearney, 2006). Monetary resources are being threatened and lost, putting increasing pressure on leaders, healthcare providers, and staff (Kocher & Adashi, 2011; Wick et al., 2011). Aspects of patient safety and quality of care, e.g., reducing hospital acquired infections, must be tracked and reported and can bring financial

penalties if progress is inadequate (Koh, Brach, Harris, & Parchman, 2013; The Joint Commission, 2015; Wick et al., 2011). Regarding increasing regulatory demands and resource challenges, the CEO of UNM Hospital often said, “We need to do more, better, with less!” (S. McKernan, personal communication, March 13, 2014).

Nonetheless, leadership is critical to the success of health literacy initiatives. A study to understand the factors influencing the adoption and implementation of a tool to assess pharmacies’ health literacy practices identified leadership support as a key factor in both the adoption and implementation of the tool (Shoemaker et al., 2013). In a National Quality Forum implementation report on improving patient safety through changes in informed consent, provider attitudes illustrated a need for leaders at all levels to develop strategies to improve awareness of, and create a culture that addresses, health literacy and communication challenges to enhance provider buy-in (Wu et al., 2005).

Another aspect of leadership support involves clarifying the importance of addressing health literacy and identifying the roles of people who should be addressing health literacy and communication challenges in the organization. The implementation report on improving patient safety and informed consent recommends that leaders clarify who is responsible for which aspects of ensuring effective communication and hold them accountable for ensuring patient understanding (Wu et al., 2005).

Similarly, leadership is viewed as responsible for setting a climate that expects health literacy to be addressed. In a study conducted to identify health literacy practices used in healthcare settings across the U.S., facility administrators and clinicians identified barriers to implementing health literacy practices including (a) staff’s lack of recognition that health literacy was a priority, (b) inadequate resources, and (c) inadequate time. Clinicians described

organizational barriers such as the need for institutionalized policies and operational barriers such as the lack of funding as limiting their use of health literacy practices. They saw administrative leaders as responsible for, and uniquely qualified to, remove barriers and require health literacy practices in the facility (Barrett et al., 2008).

**Organization-level policies.** In 2004, the seminal book on the emerging field of health literacy noted the lack of organization-level policies on health literacy in healthcare organizations (Nielsen-Bohlman et al., 2004) and noted that health literacy activities seemed to be based on the interest and determination of a few people who frequently are not policy makers within their organizations. In addition, the authors believed that increased awareness and activities related to health literacy tended to spread anecdotally rather than as a result of policy. Of interest here as well is that only eight of 61 D&I models for research reviewed addressed policy activities (Tabak et al., 2012).

Discussion on the international health literacy discussion list, the lack of information on organization-level policies in the literature, and the author's personal experience suggest that these policies are still lacking in most healthcare organizations. The literature on health literacy policy focuses primarily on national policy (Institute of Medicine, 2013a; Koh et al., 2012; Vernon, Trujillo, Rosenbaum, & Debuono, 2007). Organization-level policies requiring (a) clear, plain language communication in text-based and oral information, even with informed consent for surgeries; (b) assessing patient comprehension; (c) creating reader-friendly print information; or (d) other health literacy strategies appear to be rare in healthcare organizations. This present study seeks to identify some of the factors contributing to the creation, adoption, and implementation of policies on health literacy practices in healthcare organizations.

**Resources.** Fully integrating health literacy into a healthcare system requires resources. For example, developing new documents, revising existing documents, and creating and maintaining archival and periodic review systems all require resources such as outside expertise and/or training and time for internal staff. There may also be a need for technical assistance if no one in the organization has health literacy knowledge and skills.

In the study mentioned above that was conducted to identify health literacy practices used in healthcare settings across the U.S., lack of additional financial resources was seen as a barrier (Barrett et al., 2008). The study report, however, pointed out that health literacy practices can be implemented in many ways without requiring financial resources and are usually worth the modest cost (Barrett et al., 2008). Perhaps administrators' and clinicians' concerns about financial resources are more of a barrier.

The resources to provide support and technical assistance for making change are also essential. In a study to understand the factors influencing the adoption and implementation of a tool to assess pharmacies' health literacy practices, support from colleagues or colleges of pharmacy was identified as a facilitator to implementation (Shoemaker et al., 2013).

**Time.** In addition to the resources of funding, training, and outside expertise mentioned above, time is an important resource. It is important to adjust resources to allow clinicians more time to apply the new skills in their practice. For example, in clinical encounters, an additional two to five minutes of time was required to tailor communication to patients' health literacy level and check for comprehension (Welch et al., 2011). And in a study conducted to identify health literacy practices used in healthcare settings across the U.S., clinicians identified lack of time as a barrier to using health literacy practices (Barrett et al., 2008).

On a larger scale, a study describing the development and testing of a health literacy resource for primary care practices described that implementation took longer than anticipated and that time was a barrier in the implementation of the prototype toolkit (DeWalt et al., 2011). In contrast, however, Schillinger and colleagues (2003) determined that a health literacy practice, teach back, did not require more time after providers learned to be more efficient in their teaching and also in using the method. In the present study time did not emerge as a key facilitator or barrier.

### **Individual Level**

**Training and professional development.** In many organizations, health professionals do not understand health literacy issues (Kelly & Haidet, 2007; Macabasco-O'Connell & Fry-Bowers, 2011). Addressing the lack of understanding calls for resources for offering professional development and training as well as additional time for professionals to learn new communication techniques such as teach back, a specific strategy for confirming patient comprehension of information given verbally (Davis, Swarbrick, Krzos, Ruppert, & O'Neill, 2015; U.S. Department of Health and Human Services, 2010).

After being trained, physicians tended to revert to the behaviors they used before attending the professional development sessions indicating a need for resources to provide refresher training (Welch et al., 2011). Indeed, training alone cannot bring about behavior change. A follow-up coaching and consultation model is critical to support healthcare professionals in making changes in their practice, particularly changes to the technical core of their practice, the provider-patient interaction (Davis et al., 2015).

In an implementation report on improving patient safety through changes in informed consent, the lack of awareness among healthcare providers of health literacy challenges, especially for English-speaking patients, illustrated a need for a “major educational campaign...to

raise provider awareness...” (Wu et al., 2005, p. ix). In addition, this study identified a structured, formalized training in using teach back and in communicating more clearly with patients as one of the most critical needs for successful implementation.

In a study conducted to identify health literacy practices used in healthcare settings across the U.S., facility administrators and clinicians identified barriers to implementing health literacy practices. They cited the belief among providers and staff that low health literacy is not a problem or is low-priority as one of the biggest barriers, indicating a need for professional development and training (Barrett et al., 2008).

These findings indicate a need for additional training and professional development opportunities about various aspects of health literacy across every level of healthcare organizations and on both systems in their infrastructures, i.e., the people who support patient care and those who provide patient care.

**Staffing challenges.** A study to understand the factors influencing the adoption and implementation of a tool to assess pharmacies’ health literacy practices identified presence or lack of qualified staff (pharmacists or pharmacy residents) to oversee the use of the tool as a factor in implementation (Shoemaker et al., 2013). Shoemaker and colleagues also found that lack of staff time to use the tool was a barrier to implementation.

**Effective champions and promoters.** A study to understand the factors influencing the adoption and implementation of a tool to assess pharmacies’ health literacy practices identified a champion for the change as a key variable in adoption (Shoemaker et al., 2013). In addition, a study testing the implementation of a health literacy toolkit for primary care clinics learned that without a team of people to champion and lead the implementation plan, change was not likely (DeWalt et al., 2011).

**Knowledge of organizational change and implementation.** Health literacy change leaders may face challenges because of knowledge gaps with regard to organizational change models and strategies for promoting adoption and implementation of new initiatives (DeWalt et al., 2011). They may also find that the resources, guidelines, and tools available to help with adoption and implementation are not specific enough for quick application and ease of use (DeWalt et al., 2011). Without specific knowledge and easy-to-use tools, busy change leaders may find it challenging to direct a change process while also addressing the need to raise awareness, revise documents, develop policies, and the many other tasks involved in health literacy initiatives (DeWalt et al., 2011).

**Health literacy change leaders.** While the research does not address this topic directly, there is research on the impact on individuals of being in the role of innovator. “The innovators often assume a rather stressful role, questioning the existing organizational practices and rocking the boat, and consequently, meet with a lot of resistance” (Lansisalmi, 2006, p. 71). Moreover, making change in healthcare organizations can be quite political (May, Mort, Williams, Mair, & Gask, 2003). These factors may cause political disputes and emotional distress (Lansisalmi, 2006). If they do not have the support of leaders, innovators may become stressed, discouraged, and/or leave the organization (Lansisalmi, 2006).

### **Innovation Characteristics**

**Perceptions and features of the innovation.** As with many studies in D&I research, as well as decades of research using Rogers’ Diffusion of Innovations theory, health literacy studies identified perceptions and features of the innovation as critical. In a study to understand the factors influencing the adoption and implementation of a tool to assess pharmacies’ health literacy practices, the relative advantage, compatibility, and complexity of the tools were key

variables in the adoption decision (Shoemaker et al., 2013). In the same study, the adaptability of the tool was identified as a facilitator to implementation (Shoemaker et al., 2013).

An implementation report on improving patient safety and informed consent identified providers' negative perceptions of the costs, time burden, and value of the use of teach back as barriers to adoption (Wu et al., 2005). A study reporting on the development and testing of a health literacy resource for primary care practices described factors affecting the implementation of the prototype toolkit in the test clinics. Testing showed that practices will implement tools that are easy and quick to use (DeWalt et al., 2011).

### **Summary**

The objectives of this chapter were to (a) review the salient literature and theories on implementing change in healthcare organizations and (b) consider ways this study can contribute to existing knowledge and professional practice in addressing the facilitators and barriers to adoption and implementation of health literacy initiatives in healthcare organizations. Both researchers and practitioners acknowledge that there is a need for organizational change to enhance the implementation of health literacy initiatives. However, there is not yet a body of literature documenting facilitators and barriers or models for advancing health literacy initiatives.

Some healthcare and health literacy research has contributed to knowledge of facilitators and barriers to implementation of health literacy activities but not organization-wide initiatives. In addition, there has been much descriptive research on attempts at organizational change in the broader healthcare field, but many of those studies have been atheoretical. Further, some healthcare organizations in the U.S. are already addressing health literacy but mostly without a model, theory, or framework for organizational change. This study addresses the need for more

knowledge by exploring the facilitators and barriers encountered in efforts to implement health literacy initiatives in healthcare organizations.

The literature on facilitators and barriers to organizational change, innovation adoption, and health literacy implementation, identified the following influences known to impact these processes in healthcare organizations and in some health literacy-related activities. Influential elements related to organizations and individuals include (a) leadership support at multiple levels, (b) external mandates and internal policies, (c) resources (i.e., financial, staff, time), (d) presence of champions, (e) training and professional development, and (f) resistance. The literature also identified the following key factors related to innovations: (a) perceptions of the need to use it, (b) the advantages of using it, (c) its compatibility with existing processes, and (d) its adaptability.

These elements from the literature served as sensitizing concepts in both the data collection and data analysis. Sensitizing concepts are broad concepts or terms which can spark the researcher's thinking about a topic and alert the researcher to patterns and nuances which may arise in the data (van den Hoonaard, 1997). Sensitizing concepts are discussed further in the methods chapter.

The review showed there is a gap in the literature in relation to influences affecting adoption and implementation in health literacy initiatives. The literature also shows there is a gap between theory and praxis in efforts to implement health literacy initiatives and in implementation efforts in healthcare, in general. This study addresses a gap in the literature by providing insights into elements of adoption and implementation that have not been documented in the past.

It contributes to closing the gap between theory and practice by identifying that (a) many healthcare organizations working to adopt and implement health literacy initiatives are not using a formal model or framework to guide their efforts, and (b) there are elements affecting adoption and implementation in practice that can be added to various theories and models for change to enhance their applicability in general, but specifically in health literacy efforts. New information is often needed to make adoption and implementation occur (2009). This study identified new information by confirming that most facilitators and barriers present in the literature were also present in the participating organizations, and by identifying four new elements that were of particular importance to advancing health literacy initiatives in the study organizations.

## **CHAPTER 3: METHODS**

In this chapter, I describe the rationale for my methodological choices, the research design, the researcher's role, legitimation in the present study, the participants, data collection, and data analysis.

### **Methodological Rationale**

The interpretivist perspective guides this study. Qualitative methods are an excellent fit for an interpretive paradigm, because they serve to investigate and understand meanings rather than predict or identify causal relationships. Qualitative methods are also useful when issues or constructs are not yet known or well-defined because there is little earlier research. Because there is little research about facilitators and barriers to adoption and implementation of health literacy initiatives into healthcare organizations (Institute of Medicine, 2013b), it was most appropriate to use qualitative methods to uncover the foundational constructs that comprise the challenges of adoption and implementation.

### **Research Design**

#### **Qualitative Methods**

Adoption and implementation are processes that cannot be observed directly or easily. Interviews are useful in cases such as this, because they make it possible to learn about processes that are not easily observed (Lindlof & Taylor, 2011). I used individual, semi-structured interviews to explore the participants' experiences of adoption and implementation of health literacy initiatives. Interviews can be conducted with little structure, a great deal of structure, or somewhere in between. The semi-structured interview format I utilized is midway in this range of formats. I chose this particular format because it allows for fluidity and changes in the process as the interview evolves and it allowed me to achieve two goals. One goal was to learn about

participants' perspectives and experience around several key elements of adoption and implementation that had been identified in the literature and which I had identified through my personal experience as a health literacy consultant and a health literacy change leader. The other goal was to also stay open to new concepts and elements that might emerge in the interviews since a researcher never knows what she does not know. The format of using some structured questions, and probe questions that were more open, elicited information on the key topics but also allowed the participants to bring up additional elements not covered by the initial questions.

### **The Researcher's Role, Ethical Considerations, and Reflexivity**

The role of the researcher should, ethically, be considered and revealed. I now identify some factors related to my role in this research. In addition to being a researcher and student, I am a health literacy practitioner with over twenty years of experience in the field. This fact impacts my research in two ways. First, my experience and knowledge of the field created my interest in and commitment to this area of inquiry but also place me in a position in which the participants may have seen me as an expert. Having this status in their eyes had the potential to influence what they shared since they may have wanted to answer as they thought I would expect or save face if they had been struggling with something they thought I would know how to handle. Second, I am known in the health literacy field and have long-term relationships with many other health literacy professionals. This may have contributed to my entry into organizations which may not have otherwise been as accessible to me.

In addition to being a researcher and practitioner, I am also aware of my positionality as a consumer of healthcare and a family member and friend of many others whom I have accompanied in their journeys in healthcare. Because of these multiple roles, there exists an ethical imperative for me to be committed to reflexivity in my research, i.e., be attentive to how

my experience, interests, assumptions, biases, and preconceptions might affect my research practice (Charmaz, 2014).

The three areas in which I engaged in purposeful reflexivity are the development of the interview guide, my interactions with the participants, and my analysis of the data. I describe each below. First, I was diligent in my reflexivity as I created my interview guide. I was careful to word questions in a neutral, non-leading way, thinking carefully about whether my own assumptions, perspectives, and biases influenced the guide. I requested feedback on these topics from my committee member who is a health literacy researcher, as well as from two health literacy practitioner colleagues. None of the reviewers reported concerns about the neutrality of the questions.

Second, I needed to be attentive to my interactions with the participants, especially during interviews. I worked for three years in an equivalent position as those I interviewed, so I entered the interview space with knowledge, assumptions, and memories of some exciting and some frustrating experiences. I was careful not to share too much of my experience—only enough to build rapport but not so much as to redirect or create reticence in my participants if their experiences were different from mine.

As the interviews were transcribed, I read and listened to them with particular attention to my responses and questions. I discovered that I would often ask questions to clarify or to encourage more sharing. I also discovered that I would share a story of a similar experience I had, especially if the participant had described an experience that had been difficult for him or her. I wanted to encourage and validate their sharing and to shift their possible perspective of me from an expert who knew how to handle all the challenges to a person who had struggled with similar challenges when in the position of health literacy change leader. When I would reveal

that I had also struggled in my former position, my story seemed to help participants share more freely.

At first, I judged myself as having talked too much in a few interviews. Then I revisited the feminist perspective on interviews. Feminist methodology encourages interviews to be more like conversations with friends, and encourages the researcher to provide both “focused attention... and non-judgmental validation of their experiences” (Bloom, 1998, p. 20). I found that I was often giving both the focused attention and the validation of their experiences when the interview briefly took on a more conversational feel. The participants would continue to share, sometimes commenting on the experience I had shared. In addition, many of the participants were very passionate about their experiences. It facilitated our relationship and communication when I would exclaim, “Oh, I know exactly what you mean! I struggled with that, too.” I conclude that moving into a more feminist type of interview at times was often beneficial to building rapport as well as gaining key information.

Third, I was careful in my analysis of the data so that, as much as possible, I did not read my experience and biases into the coding. As a health literacy consultant, a health literacy change leader, a patient, and a caregiver and advocate for many family members and friends, I have learned of, and experienced, many events and situations in which patients did not receive quality care. As a result, I am aware I have developed some negative assumptions about the way systems work, motivations for decisions, the actions of people in leadership, and the attitudes and communication skills of healthcare providers. I have also developed many positive assumptions about people’s dedication, the hard work of some key leaders, the excellent communication skills of some healthcare providers, etc. but I acknowledge that the negative

assumptions carry more negative emotional valence for me. Thus, they had the distinct possibility of influencing my work as a researcher.

As I analyzed my data, I knew I needed to be very reflexive as I proceeded. In coding, I stayed close to the data, creating new codes only as the themes emerged from the data. I also discussed my findings with a health literacy colleague (not one of the participants) who has worked with hospitals and health systems on organizational change. I sought her perspective to help guard against known and unknown biases about health literacy implementation in my findings and conclusions. I asked her to address whether she believed my findings and conclusions are credible and consistent with her knowledge of the field. She affirmed that she found them to be.

### **Legitimation in Qualitative Research**

In qualitative research, validity is related to the quality of the study and how it is carried out and the term *validity* is often replaced by *legitimation*. In qualitative research, the main concern is whether the researcher accurately and fully captured and described the experiences of the interviewees (Onwuegbuzie & Johnson, 2008). The quality of this study was assured by following standard practices for qualitative research. In addition, I used the following measures to address legitimation.

To address internal legitimation with the qualitative interviews, I sent the interview guide to Dr. Wallace, the committee member who specializes in health literacy, and to two health literacy colleagues with years of experience with healthcare organizations and asked them to provide feedback on whether they believe the questions were credible, appropriate, and relevant. I received responses indicating the questions met those three criteria well. The responses also included a few suggestions for clarifying wording which I integrated when appropriate.

I also conducted peer debriefing which is a review by a person in the field who is well-versed in the phenomenon being investigated (Lincoln & Guba, 1985). The peer can provide support, make observations about gaps, and challenge the researcher's assumptions and interpretations. The peer reviewer with whom I shared my findings and conclusions is a health literacy expert with nearly 30 years' experience in the field who has worked extensively with hospitals and health systems across the country. Much of that work was in helping those organizations adopt and implement various health literacy activities or best practices, so she is very familiar with the related challenges healthcare organizations face as well as the challenges health literacy change leaders experience. This external expert provided valuable feedback and interpretations, challenged me to explain some of my assumptions, and helped me expand my thinking in a few areas by asking probing and insightful questions.

In addition, I shared some of my findings and conclusions with a friend who is a professor in education. She works with school systems as they adopt and integrate new practices, processes, and education for staff—all mandated by federal and state guidelines, similar to the kinds of forces for change healthcare organizations experience. As someone unfamiliar with healthcare systems, but well-versed in the requirements of making change in large educational systems, her questions and observations were very helpful. They required me to step back and take a broader view of my field as I explained to her why I had concluded certain things. We vigorously debated various points which enhanced my thinking as I stood my ground, or discovered I could not.

The strength of qualitative research is its ability to identify previously unknown findings. My reflexivity and expert checks helped guard against researcher bias and allowed me to discover previously undocumented and unknown aspects of implementation processes.

## **Participants**

### **Selecting and Contacting the Sample**

The goal of sampling for this study was to find cases that would help define and richly describe the phenomenon of implementing health literacy initiatives in healthcare organizations and systems in order to build understanding of the facilitators and barriers involved. The initial purposive sample was comprised of people and organizations whom I knew, or knew of, working to implement health literacy initiatives or activities. I also identified two people who had posted questions or comments on the international health literacy discussion list related to issues of implementation relevant to my study. Through those sampling approaches, I identified 30 people who had recently worked or were currently working in organizations known to be addressing health literacy.

I then evaluated the organizations on the list for diversity with regard to characteristics such as size, populations served, and location. I wanted to determine if I needed to identify additional potential participants whose organizations would contribute to the diversity. Among those 30, however, there was a good deal of diversity in their organizations so I worked from that initial list. I created a smaller list of 15-18 people whose organizations offered the best diversity and contacted 15 of them initially. I had prior collegial relationships with five people on that list. I had personally met three of them and had spoken by phone with the other two. Every individual I invited from that smaller list agreed to participate and did so.

Seventeen interviews were conducted sharing data on 16 different organizations. Sixteen health literacy change leaders were interviewed. Once transcribed, the interview data equaled 402 double-spaced pages and 142,775 words. One participant was interviewed twice, discussing each of the two organizations in which that person has been, or is, the health literacy change

leader. Another participant was interviewed twice because additional information about the health literacy initiative in the organization had emerged. Another interview was with two participants, both of whom worked in the same organization as co-leaders of the health literacy initiative.

Next is a summary of the personal demographic information disclosed by the 16 participants. (One participant did not provide demographic information. The few items of information I gleaned from the interview are included here. Therefore, at times, the totals in the table do not match.) I report the demographic information here but with some lack of detail to preserve confidentiality. Fifteen of the 16 participants were female. Henceforth, I use feminine pronouns to refer to health literacy change leaders.

Table 1. Participant Demographic Information

Sex	Age Range	Education Levels	Type of Education	Time in HL Job	Level of Job	Position Before HL (or still doing with HL duties)
F=15 M=1	26-39=4 40-60=9 61 or over =2	Bachelor=4 Master=8 Doctoral=3	Anthropology, business administration, marketing, healthcare administration, healthcare finance, library science, medical writing, medicine (md), nursing, public administration, public health, quality improvement, sociology	<1 yr = 1 1-2 yrs = 6 3-4 yrs = 3 5-10 yrs = 4 >10 yrs = 2	Part of duties = 4 Coordinator = 1 Director or Manager = 7 Senior Director or Vice President = 4	Clinical (RN, MD), communication, health education, healthcare administration or management, library science, marketing, public health, research, social work, writing

I now describe the participating organizations. The community of health literacy professionals and the organizations known to be addressing health literacy in the U.S. are both relatively small groups, so in the interest of confidentiality, I provide only general information about the 16 participating organizations. I do not correlate the participants' information with the

organizations' information because doing so would enable the possibility of guessing the identity of the participants and/or the organizations in several cases.

Most of the organizations represented are large, multi-state systems, but there were also mid-sized organizations and systems, as well as single hospitals. The participants represented organizations and systems from across the United States: the west coast, eastern seaboard, and states in the south, west, and mid-west areas of the country. They are diverse in terms of serving urban, suburban, and/or rural areas. They are also diverse in the racial/ethnic populations they serve. Some see primarily Caucasian populations, some see a majority of Caucasian patients but significant percentages of African Americans and/or Hispanics/Latinos, and others see a very diverse range of racial/ethnic populations. Most organizations see adult and pediatric patients, but two provide only pediatric care.

Organizations varied in their health literacy staff levels as well. In five organizations there is either (a) one person who has permission to devote only a few hours a week to health literacy or (b) a group of employees who volunteer additional time working on health literacy without formal responsibility. In seven organizations, at least one full-time person, and sometimes a second part- or full-time person, is responsible for health literacy. In the remaining four organizations, three or more people work full-time on health literacy. The length of time organizations have been addressing health literacy ranged from less than a year to more than a decade.

The size of the sample was determined by the point of saturation of the concepts and categories (Charmaz, 2014). Even before the last interview, after collecting data on 14 organizations, there appeared to be no new significant unique codes or themes emerging. I conducted two more interviews to be certain I had an adequate sample and that no new concepts

of themes were emerging. When it was clear the data was redundant, and I had identified the most salient themes (Creswell, 2015), I stopped data collection.

### **Protection of Human Subjects**

Approval for this study was obtained from University of New Mexico's main campus Institutional Review Board (IRB) office. No personally identifiable data of participants was collected or archived. The IRB-approved consent information was e-mailed to the interviewees before the interview. Before we began the interview I answered any questions about the study, obtained a verbal affirmation of their willingness to participate, and obtained their verbal consent to be audiotaped. No one refused to be audiotaped but two interviewees asked that the audio recording be deleted when the transcription was completed. Both recordings were deleted and I notified the participants by e-mail when I had done so.

I provided the audio files to the transcriptionist who then transcribed them in Word documents. Neither the names of the participants nor their organizations were used in correspondence with the transcriptionist. Only an assigned participant number and date of the interview were in the audio file names. For confidentiality, the transcriptionist did not include names of people or organizations mentioned in the interviews in the transcripts. Phrases such as "her supervisor" or "X hospital" were used. To represent a person whose name was mentioned, an initial, other than the correct initial, was used. The transcriptionist did not transcribe personal conversations unrelated to the research which occasionally transpired at the end of interviews when the interviewee and I had a prior relationship. After sending the transcripts to me, and confirming my receipt, the transcriptionist deleted the audio files from her system.

### **Data Collection**

This study used semi-structured interviews. The rationale for using qualitative interviews, as described above, was based on the purpose of the study and the state of the field. The purpose of the study was to learn about the experiences of health literacy practitioners' experiences with the facilitators and barriers of adoption and implementation of health literacy initiatives.

Facilitators and barriers to health literacy initiatives have not yet been described well in the literature.

### **Preparing the Interview Guide**

For the semi-structured interviews, I created an initial interview guide, which incorporated the research questions as a general framework. The interview guide was intended to guide the conversation enough to answer the research questions but also be open enough for new areas of inquiry to emerge. Interview guides provide a flexible approach wherein a list of questions can be asked in different ways of different participants. The researcher can omit questions, add questions, or improvise new ones during the interview (Lindlof & Taylor, 2011).

This flexible format works well for participants who have a wide variation in their experience and expertise, as those in this study. The researcher can adapt the order and content of the questions to better suit the participant (Lindlof & Taylor, 2011). I changed the order of the questions occasionally, as the conversation flowed from topic to topic. In addition, new concepts or foci that arose in the interviews informed some of my probe questions in future interviews. I also customized the interview guides occasionally by adding questions related to information gained or omitted from the demographic forms which I felt was essential for understanding the participants' contexts. Semi-structured interviews allowed me to obtain information on similar

topics and themes for some degree of comparability, while also exploring interviewees' unique perceptions and experiences. Thus, this method is an excellent fit for the purpose of this study.

After conducting the first three interviews, I reflected on the efficacy of the guide in gathering data that answered the research questions, uncovered new concepts, and could be completed within the timeframe participants were able to allot for the phone call. The guide was functioning well in all areas so I proceeded with a few adaptations as noted above and a few further adaptations over the course of the other interviews.

### **Preparing for the Interviews**

After identifying the participants, we corresponded by e-mail to set up telephone appointments at their convenience. After the appointments were arranged, I sent them each a confirmation e-mail along with the consent information and a document asking for some demographic information.

In order to be well-informed about the organizations for each interview, I reviewed each organization's website and conducted a web search to find any other relevant public documents about the organizations (Charmaz, 2014). Being knowledgeable about the organizations enabled me to be more fluent in discussing and understanding the organizations' contexts.

### **Conducting the Interviews**

The interviews were conducted by phone since the participants were all in other states. Before beginning each interview, I confirmed that they had read the consent form and that they consented for the interview to be audio recorded.

Semi-structured interviews are meant to be a "gently-guided, one-sided conversation" (Charmaz, 2014, p. 56). However, at times, the interviews became more of a conversation as I responded to participants' comments and disclosed some of my experiences to build rapport. I

was careful not to share as much as would be appropriate in a normal conversation and would return to the approach of asking open-ended, non-judgmental questions (Charmaz, 2014); practicing active listening (Lindlof & Taylor, 2011); encouraging in-depth responses by using probe questions (Charmaz, 2014; Lindlof & Taylor, 2011); and expressing gratitude for their participation (Charmaz, 2014).

The relationship between the interviewer and the interviewees is one of the most critical aspects of qualitative interviews and sets the stage for authentic and accurate data collection (Kvale, 1996). To build the relationship, during the process of recruiting interviewees, I disclosed that I had been a health literacy change leader. This seemed to build rapport and engender trust, perhaps because participants saw that I was familiar with the challenges they face. The fact that they knew of this common experience helped us establish an interdependent relationship and co-create an account of their experiences in the context of their healthcare organizations (Mertens, 2008). Whenever I shared that I had struggled with a similar challenge, participants seemed interested to hear that my experience had also been difficult at times.

### **Data Analysis**

#### **Elements of Grounded Theory**

The analysis phase of the present study used elements of a grounded theory approach. Grounded theory is a method to inductively analyze data for themes and patterns that emerge from the data that can then be developed into theories (Charmaz, 2014; Glaser & Strauss, 1967). Charmaz (2014) delineates the following hallmarks of grounded theory. In grounded theory, the data collection and analysis occur at the same time, and the researcher moves iteratively between them. The researcher inductively develops new concepts and categories based on what is found in the data by moving from the specific, particular findings to more general patterns. The

researcher also assumes and acknowledges that findings are only an interpretation of what was researched, not a representation of the reality. In grounded theory, the focus is on developing new categories and developing a theory (Charmaz, 2014; Mills, Bonner, & Francis, 2006).

I conceive of this study as using some elements of grounded theory for two reasons. First, I used semi-structured interviews. Traditional grounded theory recommends the researcher avoid looking at the literature on the topic to be researched and go into data collection as open as possible. However, an evolved grounded theory (Strauss & Corbin, 1998) allows for the literature and the researcher's insight to be interwoven throughout the process. I chose to use semi-structured interviews because the literature, and my insights and experience from the field, identified some key concepts I wanted to ensure were explored and explicated. So rather than use solely open-ended questions, I provided some structure with the questions in the interview guide while staying open to new information and concepts that might emerge.

Second, I describe this study as using elements of grounded theory because my primary goal was to understand more about a specific phenomenon as described, interpreted, and experienced by the participants rather than necessarily to construct a theory. Charmaz (2014) points out that grounded theory can be adapted to solve a variety of problems regardless of whether the goal is theory development.

I used applied thematic analysis methods in this study. Like grounded theory, applied thematic analysis entails careful examination of the data, identification of themes, and iterative comparing of emerging themes (Guest, MacQueen, & Namey, 2012). The focus of thematic analysis, however, is not necessarily theory development (Guest et al., 2012). Its primary goal is to describe and understand. While I was open to a new theory or model to emerge, the data suggest there are theories and models of organizational change which are effective in health

literacy initiatives, but they are not being widely used. With further consideration and research, a new theory may emerge.

**Sensitizing concepts.** In the data analysis, concepts from the literature review as well as my own prior knowledge and guiding interests, provided points of departure (Charmaz, 2014) and served as sensitizing concepts as I noted and created categories for the emerging concepts. Sensitizing concepts are broad concepts or terms which can spark the researcher's thinking about a topic (van den Hoonaard, 1997). They provide a place to start our inquiry and create a loose framework for our guiding interests (Charmaz, 2014).

Sensitizing concepts are useful in qualitative research as they alert the researcher to patterns or processes which may appear in the data. They can heighten the researcher's awareness and perceptions of what arises in the data and can influence the complexity and nuances the researcher perceives (van den Hoonaard, 1997). Sensitizing concepts can be used in both the data collection and data analysis. Literature on the topic of the study provided sensitizing concepts as did my perspectives and knowledge.

### **Coding and Analysis Process**

The interviews were transcribed during both the data collection and analysis phases. The transcription process began after three interviews were completed, so I could adapt the interview guide to engage with emerging themes, where indicated. After each interview, I recorded notes about anything I noticed. I wrote the notes either on the interview guide itself or in a journal. As the transcripts were completed and returned to me as Word documents, I listened to the interviews again and edited the transcripts for accuracy. The transcriptionist was not familiar with some of the specialized vocabulary participants used so I needed to add or correct the text at times. Immediately after that step, when the content was fresh in my mind, I read through the

transcripts again and pre-coded by highlighting passages that appeared significant and quotes that were good exemplars of the concept being described (Charmaz, 2014; Saldaña, 2009).

I was not sure if I wanted to do the analysis manually or with a computer-assisted qualitative data analysis software. Initially, I had selected a bound paper notebook which I planned to use as (a) a journal for analytic memos and (b) a *codebook*. Analytic memos are recorded as a researcher reflects on his or her relationship to the participants or the phenomenon being studied, the study's research questions, codes and their definitions, emerging categories, and more (Saldaña, 2009). A codebook is used to record codes created by the researcher, the code descriptions, and an example of data which represents each code (Braun, Mokuau, Hunt, & Gotay, 2002; Guest et al., 2012; Saldaña, 2009). As I worked in the paper journal for the first three interviews, I realized it was more time consuming to write everything by hand than to type it. In addition, I tried coding and sorting of the first three interviews' transcripts but determined it was also too time intensive and did not suit my work style well.

I decided to move from those methods to electronic methods. At that point, I began keeping my analytic memos in a Word document created for that purpose and I purchased NVivo, a computer-assisted qualitative data analysis software for the coding and analysis steps. I then began creating, defining, and describing codes in NVivo's codebook function and I loaded the transcripts into NVivo as they were edited and the pre-coding was completed. I moved the names and descriptions of the codes I had created when analyzing the first three manually-coded interviews from the paper codebook into NVivo.

These codes created initial *nodes* in NVivo. In NVivo's terminology, nodes are containers for the codes that represent themes or concepts. I think of them as buckets in which to put related data for later analysis. Then one by one, I continued coding in NVivo, highlighting

and assigning nodes (or codes) to paragraphs, and sometimes sentences, with words that represented the phenomenon participants were describing. Each time I created a new node, I would add the name and description to the NVivo codebook. Sub-categories can be added to each code level forming *child* nodes beneath it. When I created child nodes, I added their names and descriptions to the codebook.

Creating child nodes was important as I began to differentiate the dimensions of larger categories. Being able to include detailed descriptions for each node was critical because I could record the finer delineations and aspects of the concept at each level. As I coded, I returned repeatedly to these descriptions to further refine my conceptualizations of the emerging categories and themes and their relationships to each other. Below is the legend for the top level nodes that emerged. A list with all the child nodes added and a more detailed description of each node is in *Appendix C*. Below I also include images of all of the nodes and child nodes as they appear in NVivo.

**Legend for Top Level Codes** (see *Appendix C* for detail on all codes)

- ACCESSUP—access to leaders above their level
- ADVICE,QUAL—advice, qualifications
- AWAREBEG—beginning awareness of health literacy
- BLDSUPP—building support for health literacy
- CHAMPS—champions, opinion leaders
- CONSPERSP,INPUT—consumer perspectives, input
- CULTCOMP,D&I—cultural competence, diversity and inclusion
- DEVELHL—development of the health literacy initiative
- EMBED\_SUSTAINABILITY—embedding, sustainability, hard-wiring

- EVIDPROG—evidence of progress
- EXPLAIN\_HL—explanations of health literacy
- EXTOUTREACH—external outreach beyond the organization
- GREATQUOTES—great quotes by health literacy change leaders
- HISTORY—history, what set the stage for health literacy
- HLACTVTS—health literacy activities
- HLCLCHAR—health literacy change leaders’ characteristics
- HLCLEXP—health literacy change leaders’ description of their experiences
- HLCLHIRING—getting the health literacy change leader into the position
- LANGACCESS—access to healthcare by non-English speaking patients
- LDRBARRS—leadership barriers
- LDRSUPP—leadership support
- LOCHLPGM—the location of the health literacy program in the organization
- METAPHOR—metaphors used to describe health literacy work
- ORG\_CULT, HIERARCHY—organizational culture, hierarchy, structure
- ORG\_ASSESS—organizational assessments related to health literacy
- ORG\_BARRS—organizational barriers
- ORG\_FACILIT—organizational facilitators
- ORG\_SYSTEM DESCRIP from DEMO—organization or system descriptors from the demographic forms
- ORGMODEL\_CHANGE STRATS—organizational model or change strategies used
- PHYSICIANS MISC—miscellaneous info regarding physicians
- PRVPERSP—providers’ perspectives

- PTEDUC\_HOs,DSCHINSTRUC—patient education, handouts, discharge instructions
- RESIST—resistance to health literacy
- STRUHL—structure(s) that support health literacy in the org, e.g., Task Forces, staff
- VISION—health literacy change leaders’ visions for health literacy in their organizations

I used three coding methods described by Saldaña (2009) during this process: structural, descriptive, and simultaneous. Structural coding is a method in which the researcher assigns a term or phrase to a section of data that relates to a specific research question or to questions in a semi-structured interview guide (MacQueen, McLellan-Lemal, Bartholow, & Milstein, 2008). An example is the code BLDSUPP, for “building support,” for health literacy which relates to research question three.

I also used descriptive coding which is applying a descriptive word or phrase to the topic of data. Turner (1994) describes this method as creating the basic vocabulary to form categories for later analysis. It worked well for concepts that emerged which were unrelated to a specific research question or were related to the two broad questions about facilitators and barriers. Those questions were so broad that there were many smaller, discrete categories to explore with descriptive coding. An example is the code ACCESSUP, for “access to leaders above their level,” which emerged as both a facilitator and a barrier rather than specifically under one research question.

Last, I used simultaneous coding which refers to the process of coding a section of the data with more than one code. This occurred relatively frequently as the nodes were emerging and being developed. At times, I was unsure what code to use so I used more than one. In some cases, this was due to my indecision, but more often it was due to the existence of additional relevant topics that needed to be coded. An example is AWAREBEG, for “beginning awareness”

of health literacy. The awareness of health literacy was related to, and revealed in, data also coded as leadership support, organizational assessment, and the features of the developing health literacy initiative. One can easily see how these topics are interrelated. C-suite leaders' awareness of literacy is the foundation of their support and the ensuing development of an initiative. In some organizations, an organizational assessment was used to create the beginning awareness of health literacy challenges in the organization.

As I coded, I used the constant comparison method, a key concept in grounded theory (Glaser & Strauss, 1967). The basic rule for this method is “while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category” (Glaser & Strauss, 1967, p. 106). This comparison process involves comparing data within interviews and across interviews (Charmaz, 2014). Comparing incident to incident leads the researcher to compare the emerging conceptualization of earlier coded incidents or lines (Charmaz, 2014).

NVivo was an invaluable tool for this process as I was able to quickly switch between looking at all the incidents of a node in one interview to a list of all text coded with the same term in all of the other interviews. This allowed me to refine my nodes as I discovered items in a node that did not fit with all the others. I created new nodes or recoded that data to a more appropriate node. For a table of the nodes showing under which research question(s), if any, they fall, see Appendix C.

In this process, I found the memoing function of NVivo to be difficult and time-consuming. So I developed a process where I would call up all the data under a node I wanted to compare again, copy and paste it into Word, and then add notes and comments in that document. I saved those documents for future reference and came back to them repeatedly as I compared

and confirmed my coding and my reflexive thoughts on the nodes and other concepts I was noticing and thinking about. I continued to record memos regarding my observations, questions, assumptions, relationships among various themes and components which were emerging, and ideas for further research. Those documents were also instrumental in moving through the next phase of coding.

The next phase was “focused” coding in which a researcher uses significant and frequently used codes to “sift, sort, synthesize and analyze large amounts of data” (Charmaz, 2014, p. 138). Focused coding moves a researcher into a more focused and conceptual analysis of the data and enables a move in a theoretical direction (Charmaz, 2014). I continued to use the constant comparison process in focused coding as I examined and compared my codes to emerging concepts in the data, what was found in the literature, and my knowledge of the field.

Through this process I began to identify overarching themes and processes. Initially, as I moved into this phase, I began by using three criteria: (a) recurrence which denotes the same thread of meaning found at least twice, (b) repetition which denotes the repeated use of a word or phrase, and (c) forcefulness which denotes changes in voice inflection or volume and the use of pauses (Owen, 1984). I began by looking at the number of references to each node and the number of sources in which they were found, reasoning that those mentioned more often were likely to be dominant themes.

I quickly realized that using the number of *references* and *sources* had to be carefully applied. *Reference* refers to the number of times a node appears in a single transcript. *Source* refers to the transcript of an interview. NVivo reports the number of sources in which a node was mentioned as well as the number of times a node was mentioned in each of those sources. So a researcher could look at the totals and assess the total mentions of any given nodes and

mistakenly assume that shows its importance. However, I discovered that in the present study, some nodes were mentioned more often than others simply because they were the subject of an explicit question I asked. Other nodes, which were mentioned fewer times, but emerged from more open-ended parts of the interview, could be considerably more important. For example, I asked an explicit question about the use of formal models for organizational change so the node for that topic had 66 references from 16 sources.

In contrast, the node for the importance of relationships as an organizational facilitator had only 25 references in nine sources. These numbers did not mean that organizational models were twice or three times more significant than relationships. Relationships emerged spontaneously in response to the broader question, “What has made it easier for you to move the health literacy initiative forward?” Therefore, nine recurrences in 16 interviews indicate that relationships are very important. After I realized this, I selectively looked at the number of references and sources for nodes and gave them less weight in my thinking.

I categorized the findings under the same organizational structure and topics that had emerged in the literature review to be sure I knew which categories in my data were unique in that they did not fit in a category already defined in the literature. Then I was able to use those general categories and the new categories to further my analysis. I used NVivo’s visual mapping tools to advance my thinking through examining the categories and their relationships. I created multiple iterations of mind maps, concept maps, and flow charts of the findings related to processes of awareness, adoption, and implementation. These diagrams helped me examine the interplay of the conditions, consequences, and actions (Mills et al., 2006; Strauss & Corbin, 1990) of change processes around health literacy implementation.

I also created several iterations of mind maps which showed the knowledge and skills health literacy change leaders need to have or acquire to be most effective in their positions. Unfortunately, the mapping functions in NVivo create images which cannot be enlarged and moved into a Word document very effectively. The type is generally so small it is difficult to read. Nonetheless, images of the both (a) the mind map of the knowledge and skills needed by health literacy change leaders and (b) a sample working version of a concept map on the adoption and implementation process are duplicated in *Appendices D* and *E*. It is possible to see the overall structure and number of components.

In my multiple reviews and reexaminations of the various nodes and emerging iterations of diagrams, I was able to test my inferences and conclusions. A breakthrough emerged when I created a concept map of the process of adoption and implementation and then examined each organization's path to determine if the map was accurate. I discovered it applied to only about half of the organizations. I diagrammed a new process map with the differentiating aspects for the organizations that did not fit the first diagram. The result of comparing the two and testing the fit for all the organizations led to the development of a theory of two main paths of advancement for health literacy initiatives.

After having this insight, and identifying the overarching models of the two major pathways of health literacy initiatives, I compared the components to the literature. New aspects of adoption and implementation which had not been examined in the literature emerged. These new aspects, such as the importance of the location of the new initiative's office in an organization, contribute new dimensions or further develop aspects of other models and theories.

### Summary

In this chapter, I discussed my rationale for using qualitative methods. I reflected on the researcher's role, my ethical stance, and my reflexivity. I described the ways in which I addressed the challenges of legitimation. Then I described the participants and organizations in as much detail as possible while preserving their confidentiality. I explained the data collection methods and described in detail my coding and analysis process which included using Nvivo, a computer-assisted qualitative data analysis software.

In the next chapter, I briefly revisit the problem the study seeks to address, the participants' profiles and information about the organizations. I then take a closer look at the participants and the emotional component of their experiences in health literacy work, including the use of a metaphor based on a quote from a participant. I then move to the key findings arranged by research question and list three additional findings that are not specific to a single research question.

## CHAPTER 4: FINDINGS

### Introduction

The purpose of the present study is to understand the experiences and perceptions of individuals charged with advancing health literacy in healthcare organizations in order to expand knowledge about the adoption and implementation of health literacy initiatives. In the literature, multiple individual- and organizational-level elements affecting adoption and implementation of various types of change initiatives in healthcare were identified. Data I collected revealed many of the same elements as well as some elements which were specific to health literacy work and had not previously been identified and explicated.

In this chapter, I provide a brief recap of the participants' and their organizations' characteristics. I make some observations about the participants, describe some of the emotional content of their stories, and offer a metaphor for their experiences. Next, I describe the findings related to each research questions and then present new findings which were not specific to a particular research question. I close with a chapter summary.

### The Participants and Organizations

Seventeen interviews were conducted which collected data on 16 different organizations. Sixteen individuals participated in interviews. I use pseudonyms to protect the participants' confidentiality as I describe and quote them in this document. About half of the participants were between the ages of 40 and 60. About a quarter were between the ages of 26 and 39, and the rest were over age 60. About a quarter had a bachelor's degree, about half had a master's degree, and about a quarter had a doctoral degree. Their academic training and the positions in which they were employed before moving into health literacy were very diverse and none included formal training in health literacy. About half of the participants had been in their positions for one to

four years, about a quarter for five to ten years, and the others less than a year or more than ten. Three-quarters of the participants were in full-time health literacy positions, ranging from coordinator level to vice president.

The organizations represented the west coast, eastern seaboard, and states in the south, west, and mid-west areas of the United States. They are diverse in terms of size; whether they serve urban, suburban, and/or rural areas; the populations they serve; their health literacy staffing levels; and the length of time they have been addressing health literacy.

Generally, about half of the participants portrayed their organization as having strong leadership support for health literacy. Several participants indicated they feel this support is crucial for their initiatives. The other half of participants portrayed their organization as lacking adequate leadership support for health literacy. These participants often reported frustration and discouragement about the lack of growth in their initiatives.

### **Participants' Willingness to Participate and their Level of Commitment**

An unexpected finding emerged during the recruitment process. As I contacted people to invite them to participate, I was surprised by their eagerness to be interviewed, in almost all cases. A few needed clarification about (a) whether they were the right person to interview or (b) certain aspects of confidentiality. When these questions were addressed, they were enthusiastic about participating.

Perhaps the openness to participate was based in my prior collegial relationship with some of the participants. Also, I informed everyone in advance that I had worked in a position similar to theirs. This may have engendered trust as well as a willingness to participate. However, lack of a prior relationship did not seem to exclude participation in any way. Every person I approached, with whom I did not have a prior relationship, also agreed quite easily.

Of the 16 interviewees, nine were the only person in their organization who had specific responsibility for advancing health literacy. As one of those who is the sole person responsible for health literacy, Pearl expressed a sentiment that indicates the feeling of isolation she sometimes feels, "...this is a shot in the arm, really, and I truly feel so less alone. I can't tell you what a gift it was to take part in your research here and chat with you." This finding may indicate that struggle and feelings of isolation are a common experience among the participants, particularly those who are the sole person leading health literacy efforts.

As I learned from the participants about their struggles and triumphs in leading health literacy initiatives, I was struck by the level of passion, care, and commitment to health literacy they exhibited. It is evident, however, that the deeper commitment which fuels their health literacy work is really about making the lives of patients and their loved ones easier and healthier. The spoken or unspoken goal of each participant seemed to be to ease patients' journeys through challenges and experiences in the healthcare system. Nolan, for example, who runs a large and successful initiative, described an encounter he had with an elderly patient. His voice had a catch in it, revealing his emotion, as he talked about wanting to help her get back home with her grandkids. He recounted,

I always tell a story about a lady...who touched me and drove my work to this day. And so what I learned from her was...it has nothing to do with readmissions...it's about giving her quality days of life. So she is not in the hospital every two weeks...she is playing with her grandkids. It's about *that!*

Pearl, a health literacy change leader in a large, multi-hospital health system, was committed to her work as a result of her own experiences as a patient with a chronic health condition. She used a particularly poignant metaphor for her efforts. She described her deep and

ongoing frustration as the health literacy change leader as feeling like she was “digging a tunnel with a tablespoon.” She illustrated many barriers throughout her time as the health literacy change leader and felt that she had been unable to ease the way for patients. (She left her position because of lack of progress and an unmanageable workload.) I expand her apt metaphor to describe an organizing principle for my findings.

### **Pearl’s Metaphor**

The tunnel represents the path of advancing health literacy in an organization. Pearl’s statement that she is digging a tunnel may mean she feels like she is working in a narrow, dark space which is potentially unstable. Moreover, it is underground rather than visible to others in the organization. Using a tablespoon may reflect the feeling that she has completely ineffectual tools to do her job. The barriers to advancing health literacy can be seen as rocks and roots that need to be navigated in order to proceed.

Using the digging metaphor, I identify two different situations in which health literacy change leaders generally seem to find themselves. Those in situations with little perceived leadership support could be seen as having been given only a tablespoon for their digging. Those in situations with strong perceived leadership support could be seen as having been given a backhoe for their digging. A backhoe can do the job faster, on a bigger scale, and is much more visible than a tablespoon scratching away in an underground tunnel. Each situation can lead to different outcomes for health literacy and a very different experience for the change leaders. In the present study, I use the terms *Path One* and *Path Two* to describe these two different scenarios for health literacy initiatives. Path One organizations have the metaphorical backhoe and Path Two organizations have the metaphorical tablespoon. More detailed descriptions of these organizational profiles can be found in Chapter Five.

### Research Questions

In the literature review I examined adoption and implementation of various types of change initiatives in the broader healthcare field. I also reviewed the handful of health literacy studies that were not specifically on the topic of adoption and implementation but whose findings shed light on these processes nonetheless. These bodies of literature identified multiple elements affecting adoption and implementation processes. The study participants' stories echoed many of the same elements and these are outlined in this chapter. There were a few elements in the literature review that did not emerge as significant in the present study. These were primarily related to the characteristics of innovations and the elements of change processes.

In addition to the findings mentioned above, there were several new elements that emerged in the present study that are (a) not mentioned in the literature, (b) mentioned by only one study, or (c) only alluded to in one or more studies. The elements are (a) the source of the initial awareness of health literacy; (b) the location of the health literacy initiative in the organization; (c) the existence of staff, an interdisciplinary team and champions to guide the initiative; (d) access to senior leaders, directors and managers; (e) health literacy change leaders' personal commitment, experience, and knowledge; (f) the impact of hierarchies; (g) strategies for communicating about health literacy to build support; and (h) participants' willingness to participate in the study. These are all described below.

In this chapter, I choose to focus primarily on the findings that are most relevant to health literacy initiatives' change efforts. I describe these key findings for each research question, and I also describe three findings not related to a specific question. The themes are illustrated by quotes from the participants. The following table is a summary of the findings in an abbreviated form. The relevant findings and quotes from the table are repeated under each research question.

**Table 2. Main Findings and Participant Quotes**

<b>Research Question 1: Facilitators to adoption and implementation</b>
<p>Initial awareness of health literacy is key but often occurs randomly  <i>We stumbled upon the concept...It was like a thunderbolt from on high.</i></p> <p>Leadership support is crucial for building awareness and support  <i>It's funny how much mileage you can get out of a policy.</i></p> <p>Location of health literacy in an area with organization-wide reach enhances employee buy-in  <i>Being in Patient Experience lets us move fluidly across the continuum.</i></p> <p>Adequate staffing is necessary for an initiative's advancement and staff retention  <i>We long have yearned for a...full time position that would be leading this.</i></p> <p>An interdisciplinary team and champions to guide initiative enhance influence and buy-in  <i>Through our interdisciplinary work groups...we get cross organizational buy in.</i></p> <p>Access to senior leaders is crucial for building awareness and support  <i>I scheduled meetings with all the key leaders within the organization.</i></p>
<b>Research Question 2: Barriers to adoption and implementation</b>
<p>Lack of leadership support blocked awareness, support, and growth  <i>This is not fluff, this is really as important all the other things we're doing.</i></p> <p>Location of health literacy in area without wide reach thwarts buy-in  <i>If it belongs to everybody, it often belongs to nobody.</i></p> <p>Inadequate staffing hinders initiative's advancement and staff retention  <i>And, gosh I was drowning in work</i></p> <p>Lack of a team of champions to guide and help with initiative decreases influence  <i>If it wasn't just the two of us, what would life look like?</i></p> <p>Lack of access to leaders is a significant barrier to awareness, support, growth  <i>I couldn't talk to anyone without [my boss] being there</i></p> <p>Health literacy change leaders' experiences, background did not equip them well  <i>I had no idea what health literacy was...but I was asked to lead the project.</i></p>
<b>Research Question 3: Communication to build support for health literacy activities</b>
<p>Linking health literacy to other initiatives is commonly used and very effective  <i>Oh, this fits right in with our work to improve HCAHPS.</i></p> <p>Cost and return on investment is helpful but lacks strong data as evidence  <i>So now there is a monetary incentive to look at...communication.</i></p> <p>Presenting general health literacy statistics increases awareness and understanding  <i>The data that show it's a problem which was rich then, even richer now.</i></p> <p>Stories about patients' and consumers' experiences are powerful and engage the heart  <i>...case studies in front of senior leaders and clinicians is an 'aha' moment.</i></p>
<b>Research Question 4: Models and methods for making organizational change</b>
<p>The Model for Improvement and PDSA cycles were most commonly used formal models  <i>So yeah, we use PDSA cycles for almost everything we do.</i></p> <p>Informal models and strategies in health literacy efforts were also common  <i>Someone will bring it forward and there will be a discussion [with leadership].</i></p>

### Research Question 1

The first research question is, “How do participants describe the facilitators to adoption and implementation of health literacy initiatives in their organizations and systems?”

**Table 3. Research Question 1: Facilitators to Adoption and Implementation**

Initial awareness of health literacy is key but often occurs randomly <i>We stumbled upon the concept...It was like a thunderbolt from on high.</i>
Leadership support is crucial for building awareness and support <i>It's funny how much mileage you can get out of a policy.</i>
Location of health literacy in an area with organization-wide reach enhances employee buy-in <i>Being in Patient Experience lets us move fluidly across the continuum.</i>
Adequate staffing is necessary for an initiative's advancement and staff retention <i>We long have yearned for a...full time position that would be leading this.</i>
An interdisciplinary team of champions to guide initiative enhance influence and buy-in <i>Through our interdisciplinary work groups...we get cross organizational buy in.</i>
Access to senior leaders is crucial for building awareness and support <i>I scheduled meetings with all the key leaders within the organization.</i>

### Initial Awareness of Health Literacy

Being aware of health literacy and its implications is a necessary precursor to establishing a health literacy initiative. However, in many organizations, health professionals do not know about or understand health literacy issues (Kelly & Haidet, 2007; Macabasco-O'Connell & Fry-Bowers, 2011). Consequently, it is important to examine the ways in which awareness of health literacy developed and how it impacted the nascent health literacy activities in organizations.

The health literacy initiatives in the participating organizations began through a variety of factors. The initiatives started when someone, usually a leader at some level, became aware of health literacy as a challenge, a solution, and/or a field and then told others about it. In the early stages of innovation adoption, the Innovation-Decision Process is utilized (Rogers, 2003). The first stage of the process is *knowledge* and this stage begins when an individual is exposed to the existence of an innovation. Simply learning that an innovation exists can produce a perceived

need (Rogers, 2003). Awareness and perceived need are the first steps in moving toward adoption.

Two health literacy change leaders depicted their early exposure to health literacy as coming from outside their own organization. One had heard about it from someone in another organization and had seen videos about it at a meeting of a state medical society. The other worked in an organization which received a grant from an external agency to address health literacy.

The other participants expressed that their organizations' awareness came from internal conditions such as a need, an assessment, or recognition of a problem. An example is the internal need to reduce hospital readmission rates for certain conditions after Medicare reimbursement was withdrawn for them. Similarly, another participant cited their patient education director's perception that they needed to coordinate and standardize patient education throughout their system. A large system recognized it needed to address several trends in healthcare so it conducted focused research with patients, families, providers, staff, and others to find out what people expected from a healthcare system. Their consumers identified many areas which the organization distilled into four sectors, one of which was health literacy.

An example of the health literacy change leader recognizing a problem comes from a relatively small system with several hospitals and medical centers. Farah describes their awakening to the concept of health literacy. She traces their thinking,

And then we were seeing content from physicians who were writing at *like 25th grade level* and thinking to ourselves, '*I don't understand this, so I wonder if other people understand this.*' ...we stumbled upon the concept of health literacy...It was like a thunderbolt from on high.

Another participant, Katie, used the same wording, “I was working on a diversity program...and I completely stumbled on health literacy and plain language.”

Clearly, there is no standard way in which healthcare professionals are being exposed to health literacy concepts. However, once they are exposed to it they can begin to see its potential. If they are in positions of leadership, they can use their power and influence to launch a viable and effective health literacy initiative. Nolan, who is based in a large multi-state healthcare system, gives an example by describing the convergence of leaders who launched a significant system-wide health literacy initiative in his system: (a) the Chief Medical Officer of one of their large hospitals, (b) the President of the Medical Group, (c) the Chief Experience Officer, and (d) the directors of education for patients, nurses, and staff.

Interestingly, the participants who recounted organizational awareness coming through a senior leader also portrayed their organization as having strong leadership support. The organizations in which awareness came through the health literacy change leader (who was not also a senior leader) were portrayed as having moderate to weak leadership support. This suggests that having a senior leader become aware of health literacy brings more power, authority, and resources to the effort. If the person who is now the health literacy change leader was the primary person who became aware of health literacy and the benefits of addressing it, that person would have needed to share her awareness with someone in leadership before leaders took action.

### **Leadership Support**

In the literature and in the data from this study, leadership support was defined as any number of the following actions taken by leaders, usually at the senior or executive level (Davis et al., 2015; Harting et al., 2005; Langley et al., 2009; Spetz et al., 2012): (a) designating the

initiative as a key strategic priority; (b) designating an executive sponsor to lead and facilitate the effort; (c) making it clear that support of the initiative by other leaders and by staff is an expectation; (d) establishing and enforcing policies that support the initiative; (e) allocating resources for an office, dedicated full-time staff to lead the day-to-day operations, and the staff's professional development; (f) allowing staff the time to test and implement new strategies; (g) facilitating, and when necessary, mandating training attendance and, then, compliance with new behaviors. Unfortunately, health literacy support is often dependent on the interest and dedication of just a few people (Nielsen-Bohlman et al., 2004) who may not have the positional authority to take these kinds of actions.

Leaders who take many or most of the above actions can be seen as providing the metaphorical backhoe. In this study, senior leaders' support for health literacy was perceived as the primary factor in the success of initiatives. In the eight organizations and systems which were perceived by participants as enjoying strong leadership support of health literacy, participants reported more health literacy activities than were reported in the eight organizations and systems which were perceived as lacking leadership support. Participants reported support in the following areas: (a) policies and strategic priorities, (b) allocation of resources, (c) mandated champions and representatives, and (d) mandated training and accountability.

**Policies and strategic priorities.** Leaders can set policy themselves, charge others with creating them, support existing policies, and mandate that they be followed. For example, in one organization, the CEO mandated the policy (providing the metaphorical backhoe) and the health literacy change leader collaborated with the clinical operations and medical affairs leadership to create it. Seven participants reported their organization had no health literacy policies in place or did not mention policies at all, two participants reported their organization has a few health

literacy policies in place, and seven participants reported their organization had multiple or comprehensive health literacy policies in place. All of the organizations that reported having multiple or comprehensive policies in place were Path One (“backhoe”) organizations.

Health literacy policies, in the participating organizations that had them, were reported to address many areas of operations including (a) the development and review of printed materials for patients (including guidelines on using readability formulas and a required reading level), (b) the processes for ensuring informed consent, (c) required training for newly hired employees and annual competency training for all employees, (d) guidelines for translation and interpretation, and (e) guidelines for oral patient education, e.g., requiring plain language and the use of teach back to check for comprehension. Some organizations had only one or two policies on health literacy and others had several. Sheila, the health literacy change leader in a single hospital which serves patients from a multi-state region, reported the most comprehensive health literacy policy. Her organization’s health literacy policy (a) provides guidance on assessing patients’ and families’ learning needs; (b) identifies best practices for patient education, including the use of teach back; (c) instructs on documenting patient education; and (d) describes the process of developing internally-produced educational materials.

When a policy is established, it delivers an expectation that the staff to whom it applies will comply with it. Health literacy change leaders described how they can gain traction and emphasize the importance of a health literacy activity or an organizational change by invoking the policy. Farah depicted the power policies carry,

...it’s funny how much mileage you can get out of a policy as soon as you start tossing around terms like ‘wanna bring this into compliance with our policy’ and ‘here is how we will help you do that.’

Organizational or system-level leaders and boards can also set up expectations by using strategic priorities instead of, or in addition to, policies. Health literacy change leaders have also invoked strategic priorities for ensuring compliance with a policy. Carol, who was leading the system-wide rollout of a new health literacy activity, would occasionally encounter resistance in which a clinic or practice would say they were too busy to do the required project at that time. Carol recounted how helpful it was to be able to refer to the board's strategic priority whenever she would get push back. She said, "It's mostly carrot but when you have the board behind you, you have a little bit of stick..." She would say to the people who were resisting, "Well, I hear that you are busy. And this is a strategic priority. It's endorsed by the board. This is what the expectation is. Are you telling me your practice is so busy that I need to go to your VP and get an exception for you?" She reports their responses were usually, "Oh no, we're good!" This kind of accountability is not possible without leadership support.

**Allocation of resources.** Some participants reported that leaders supported health literacy initiatives by allocating funds for document revisions and development of new documents for patients, allowing champions and those who serve on time-consuming committees some release time from other duties to work on health literacy, and making sure there is adequate staffing for the health literacy initiative. Getting funding for staff can be challenging since health literacy is not yet seen as a necessary position or priority in many healthcare organizations. Leaders may have to be creative to establish health literacy positions. Sheila relates how her position was funded, "There were two librarian positions and the senior librarian was retiring...They reclassified that position and turned it into Health Literacy Manager."

**Mandated champions and representatives.** At time, leaders who want to create a team, a network of trainers, or a learning collaborative of people who will add health literacy to their

work mandate that champions or representatives from different areas be designated to serve.

When I asked how it works to have them mandated rather than volunteer, Carol pointed out that using champions is a model her organization has used for a long time. It is an established part of the culture, she explains, “So having it be a [strategic priority] and an expectation that you will send a trainer, that worked. And...having these extra roles in our area is not unusual ...you know it’s the champion thing..”

**Mandated training and accountability.** The first step in getting people to support health literacy is for them to understand it. Training can be critical since health literacy is still not a well-known concept in healthcare. Participants from five organizations reported their leaders had mandated training in health literacy awareness for newly hired employees. One organization required their entire workforce be trained in using teach back and plain language. Another organization mandated that a specified percentage of the staff in designated units attend training during a certain time period.

These training mandates are perceived by participants as a good first step in spreading awareness. If people don’t know the basics of the issue or any strategies for addressing it, nothing happens. However, in many cases, training was the only intervention and impact was very limited. Without the organizational supports such as extra time to learn and implement new behaviors or systems for compliance and accountability to encourage and ensure use of health literacy principles, progress was described as being hindered. Carol’s organization exemplified this challenge. She imparted, “So it was rolled out simply as an educational measure. No follow up steps, no true accountability...And then [four years later]...they did a survey to see...what they had retained...And the results came back... ‘No we don't really use it’.”

**Summary.** The importance of having the support of many leaders in an organization, especially senior “C-suite” leaders, was portrayed as critical. Marcy beautifully summarizes this perspective,

[You] need a senior leader to say, ‘This is not just the flavor of the month...This is a major part of our core values, the way we plan to do business.’ If you wanna make a huge change...obviously the more it is elevated, the more resources we will have, the more attention will be paid to it, and the more accountability...

### **Location of Health Literacy in the Organizational Structure**

Participants described a great variety of locations in organizations and systems into which health literacy initiatives have been placed. Some locations appear to act as a facilitator and some act as barriers. The many factors involved in determining whether location was a facilitator or barriers are discussed below.

Many initiatives have been moved from one location or reporting structure to another once or more. Jamie, a consumer librarian whose health literacy duties are only a small part of her job, explained, “It began as part of safety, but was recently moved as there has been a reorganization within the hospital of governing departments. And it actually doesn’t report to anyone at this time.”

Participants reported their health literacy programs or initiatives are, or have been, placed under or in these 18 different departments and areas in their organizational structures: Patient Education; Patient Experience; Patient Engagement; Quality; Safety; Risk; Clinical Improvement; Care Coordination; Nurse Practice; Nursing Education; Population Health; Marketing, Communications or Community/Public Relations; Diversity and Inclusion; Organizational Development; Graduate Medical Education; and Home Care/Hospice. This

diversity in location is apparently not uncommon in the field. Alice, one of the participants who reached out to other health literacy leaders in her area, explained,

I have reached out to other hospitals in our area to form a consortium...And what has been really interesting is it was hard to find people!...[in one hospital] they sit within Rehabilitation Science. Crazy, right? We sat in Population Health. Others are scattered through different departments. So it is hard to find people like us.

Eight participants perceived that their current placement in the organizational structure works well. In all eight of those organizations, health literacy was located in an organization- or system-wide department, and all eight were Path One organizations with strong leadership support.

Two participants described their current placement as working well but used language like “for here” indicating they may not really have felt it was working. Rather they may have felt it was as effective as they thought it could be. In one of these two organizations, health literacy was in an organization-wide area but was not working on any organization-wide projects. In the other of these two organizations, health literacy was in a narrow, siloed area—nursing education. Both of these participants were in Path Two organizations with little leadership support.

Two participants perceived that their current location suffices but it was better in a previous placement. Both are currently in narrow, siloed areas but were previously under organization-wide offices. One of these participants was in a Path One organization and one in a Path Two organization.

Finally, four participants perceived that their current placement does not work well and that it needs to be moved to a new location. Two of these four are in Population Health, an area that can have organization-wide influence. Despite this, their health literacy work does not enjoy

that status. The other two were in siloed areas. All four were in Path Two organizations. In summary, it appears that organizations in which health literacy is placed in an area with organization- or system-wide authority and reach tend to have more effective health literacy initiatives than organizations in which it is placed in a narrower area without wide reach.

One participant believed it is important to have the initiative be its own designated department. Pearl, who led the effort in a huge healthcare system, described how things changed after her work was elevated to a department level, “Suddenly people could see this is a real thing and the system was aligned to put some money into it.” (Later the situation changed drastically for Pearl when the initiative was moved.)

There were several different themes in participants’ explanations for the effectiveness of the locations. First, participants described their perception of how the location of the initiative communicates who it governs or to whom it applies. For example, many believe if it is placed in a clinical area such as nursing, people who are not nurses perceive it does not apply to them. If it is placed in a non-clinical area such as risk management or legal, the clinical staff perceive that it does not apply to them. However, if it is placed in an area that has authority across the entire organization or system it is perceived as applying to everyone.

Many participants said they believe it needs to be in an area that has reach and authority across the entire system so that people throughout the organization will perceive that it applies to all departments and all employees. For example, Carol, whose health literacy work is located under Patient Experience, said,

Patient Experience works across all the various care locations in our system. If health literacy lived in one department, it might be perceived as something unique to that area

and wouldn't be as effective system wide. Being located in Patient Experience allows us to move fluidly across the continuum.

A second theme also related to perceptions. However, it looked at perceptions about positional power and authority rather than employee perceptions of the applicability of the health literacy initiative to them or their department. If health literacy were placed near the top of the organizational structure or chart, or the health literacy leader reported to someone who was near the top, participants perceived that was helpful to the effort. This perception held regardless of whether the effort was in an area with cross-system reach. Nellie, whose initiative was placed in an area without authority across the system, explained, "...it worked very well as the Senior Vice President of [her area's] office reported directly to the President and CEO of the health system. We had visibility, buy in and a 'seat at the table' so to speak."

Participants viewed other aspects of the placement as important, as well. For example, Alice talked about stakeholders and Marcy cited traction as important. Alice explained, "I think...you're not gonna find "a" place where it sits nationally. It goes back to... 'What is the best way for you to position yourself with stakeholders?' That's where it needs to live." And Marcy said, "It needs to go wherever it...is likely to get traction."

Health literacy leaders believed that it is important to figure out how to advance health literacy regardless of where they find themselves. Nolan, who has worked as a health literacy change leader in more than one organization, says he just makes his case wherever his office is placed. He concedes that where you report, which indicates where the initiative is placed, can influence access to different areas. If someone reports to a lower level manager, they are less likely to have access to directors above their level. However, he sees the primary task as focusing the message on what is relevant to whomever you are speaking. He said, "Yes, maybe I'm

coming out of the Office of Patient Experience, but I am talking about readmission rates, length of stay, HCAHPS scores, cost of care.” (These are all issues which are addressed in many different areas of a healthcare organization, from finance to patient satisfaction.) His advice is to first understand your organization and the potential impact of health literacy changes on the various areas and people.

### **Staffing and Structure of the Health Literacy Initiative**

In addition to the location of the initiative, the people who work on the initiative are seen as critical to its success. In most cases, the participants were the employees who were charged with leading the health literacy initiatives. Most of them also had other people helping them in their work.

**Staffing.** The staffing for the initiatives in the participating organizations varies. Adequate staffing was not a strong factor in the literature but it certainly is pertinent in health literacy initiatives. Five of the participating organizations had only a person who had been asked, or allowed, to spend a small percentage of their time on health literacy, in addition to their other duties. Seven organizations had one or two people dedicated to health literacy activities. If there were two people, one was assigned full-time to health literacy and the other was either full-time or part-time. The largest four organizations had three or more people dedicated to health literacy, mostly full-time. The organizations with the most staff, and the highest level of reported leadership support, were also those whose health literacy change leaders described multiple streams of activities occurring in their initiatives.

**Networks of other people.** Another feature of health literacy initiatives was the networks of people who worked with the health literacy change leaders to advance health literacy. Only one study in the literature mentioned the importance of a supporting team to lead the

implementation effort (DeWalt et al., 2011). In the participating organizations, there were typically people who served on work groups, councils, task forces, or other groups of this type. Whether mandated or volunteering, the presence of these networks of dedicated people was an important facilitator.

The groups varied in their composition and function. Groups with advisory functions were typically senior leadership groups whose members advocated for and monitored health literacy work with mechanisms such as quarterly reports from the health literacy change leader. These leaders were usually people whose C-suite leaders had assigned them to serve as a link to the health literacy initiative or who were deeply committed to health literacy and spoke often as champions.

Workers and champions “on the ground” who were empowered to develop the health literacy initiative were the other commonly mentioned people. These people came from many different levels and settings including management, or direct patient care, on hospital floors or in ambulatory clinics. For example, a supervisor on a hospital floor can serve as a local champion (formally or informally) and facilitate health literacy as a priority for her team. Some of these people had reportedly been mandated to serve but others volunteered.

Typically, these individuals (a) informally raised awareness among their networks, (b) formally presented to groups, (c) led PDSA cycles for health literacy change, (d) were available to help brainstorm solutions to health-literacy-related problems in their areas, and/or (e) served as team leaders. In the organizations which use officially-designated champions to keep different issues visible, the people who serve on the committees or groups described above also commonly served as official champions for health literacy.

Carrie describes some of the people in her organization who volunteer on a committee that addresses patient education materials. She said with some amusement, "...it's so funny, everybody is *so passionate* about a single word. We would have arguments over little words...So I am grateful we have lot of support and a lot of people that are really into it."

Interdisciplinary groups and individual champions which represented many levels and areas of the organization were perceived as effective and important. Having representatives with interest, knowledge, and/or authority in a variety of areas in the organization contributed to different perspectives and cross-organizational buy in. In the organizations perceived as having strong leadership support, it was not unusual to see representation from diverse system-wide divisions such as Patient Experience, Quality Improvement, Finance and Billing, Communications, Spiritual Resources, Legal/Risk Management, Diversity and Inclusion, Facilities, and Nursing. There was also often representation from various service lines, e.g., cardiology, pediatrics, oncology, or emergency services.

When Sheila was hired for her health literacy position, one of the things she did after coming to understand the organizational chart, was to create a steering committee for her initiative. She details how she constructed it,

...it was important to me that it was interdisciplinary, that we had doctors *and* nurses *and* ancillary services, as well as our Patient/Family Experience Director, people from a lot of different areas who could...weigh in.

**Established relationships.** Another organizational influence which was perceived as very important was the relationships, partnerships, and networks among people in the organization. People who are considered competent in their area of expertise, are socially approachable and available, and adhere to the norms of the organization often influence others in

the organization in a role Rogers (2003) calls opinion leaders. The data show some of the participants were likely enacting that role and it was beneficial to the initiative. The importance of relationships did not appear in the dissemination and implementation literature. This aspect of adoption and implementation may be uniquely important in health literacy initiatives, perhaps because of the need to work across so many areas of the organization. Having relationships and being known in multiple areas may enhance the acceptability of health literacy as an innovation.

Some health literacy change leaders had been in their organization for a period of years, and some had been in a variety of roles over those years. Those earlier activities meant that a good cross-section of people in the organization had personal relationships with, and were familiar with the work of, the participants. Their history within the organization was perceived as playing a strong facilitative role. Nellie shared what people said to her after she left her health literacy position and someone else had taken over, “I have heard that, ‘Oh, it’s not the same because you’re not the voice. People knew you, knew your passion, people knew your knowledge, they trusted you’.”

Similarly, some participants who had not been in their organizations for a long time believed they received benefits if their supervisors were those well-known people. Their supervisors could open doors, and hearts. Alice perceived that her director was able to do this for her,

She has been here for 14 years so she was able to create pathways that allowed me to move to the right forum as quickly as I did...She had a really good relationship with her senior team...she [said]...we need to get this in front of senior leadership. So she created that pathway...

Many participants perceived the level of trust and respect they enjoyed in the organization and

the presence of established relationships as critical to their ability to access key leaders whose support they needed.

### **Access to Leaders**

Access to leaders emerged as a key facilitator to moving health literacy initiatives forward. There are many levels of leadership to which health literacy change leaders described needing access. These include the senior leader and administrative level usually comprised of “C-suite” leaders (those whose position titles begin with Chief, such as Chief Executive Officer or Chief Nurse Executive), vice presidents, executive directors, and department heads. The next level of leaders to whom access is important is comprised of unit directors (usually a hospital floor), clinic directors (usually off-site ambulatory clinics), program managers, nurse managers on floors or in clinics, and other administrative and programmatic leaders. Another level or category of people to whom access is perceived as important is those who lead or participate in key committees, councils, and shared governance groups.

Without access to these leaders, a health literacy change leader’s ability to advance the initiative can be quite limited. Access is needed in order to be allowed to (a) present information about health literacy to raise awareness and understanding of its importance, (b) meet with leaders individually to educate them and gain support for policies and activities, (c) attend leadership meetings, and (d) serve on key committees to bring a health literacy perspective.

There were several elements which health literacy change leaders believe enhanced their access to leadership in their organizations. Reporting to someone at a relatively high level in the organization, having a champion or sponsor at that level, or working at that level herself, appeared to set the stage for greater access to others at that same level. Sheila’s experience exemplifies the benefits of having a supervisor in senior leadership as she recounts how her

supervisor helped her obtain access to many different leaders, "...I do think it was facilitated by my direct supervisor, who is a VP, who has worked here for 35 years and knows all of them well."

Having a champion or sponsor who is a clinical person, especially a physician, was also seen as helpful. Nellie describes her perception of the impact of her supervisor being a physician as well as working in a senior position. Her supervisor "...was a physician. She reported directly to K. who was the President and CEO of the health system. So that put us in a very strategic place and we had a seat at the table." Two participants spoke of the benefits of having a champion who was a nurse. Again, having a clinical person advocating for health literacy was thought to be very helpful.

Another aspect, mentioned by two participants, was being given permission, time, and access to meet one-on-one with leaders across many departments and levels. Sheila's supervisor provided the time and connections for her to meet with administrators and leaders. She paints a picture of moving freely at those higher levels, "I was kind of freed up to really, I did lots of meet and greets during that time. I scheduled meetings with all the key leaders within the organization—nursing leadership on all the patient floors within the institution, our Chief Patient Safety and Quality Officer, and so on."

One participant also identified the influence of results from health literacy activities already underway. Nolan made clear how his results got leadership's attention as he chronicled his sudden increased access to leaders after a successful initiative, "And we took off and we just went. I mean, suddenly I am in front of Medical Exec committees and the different departments. Everything is rolling."

Last, one participant believed that she gained access because she spoke from her position as a patient. Pearl, who has a lifelong chronic health condition, talked about frequently being invited to speak,

...that podium time came from word of mouth. The reason...I was not shy about the fact that I do this work *because* I am a patient, and I did not understand my own care and that the way we are caring for our patients and communicating with them *is hurting them*.

### **Summary**

According to participants, there are several facilitators to advancing health literacy initiatives. These may be unique to health literacy initiatives and perhaps to other initiatives that are similar in that the content area is not broadly known or thought to be important, e.g., patient- and family-centered care.

The first five facilitators are (a) awareness of health literacy entering the organization via a senior leader, (b) senior leadership support, (c) a location that offers organization-wide reach, (d) existence of at least a full-time position dedicated to health literacy, and (e) access to leaders, directors, and managers throughout the organization. Executive leaders' awareness of health literacy must precede their support.

When the decision to adopt and support health literacy has been made, there are many ways leaders can facilitate the advancement of the initiative, including assigning it to an organization-wide location, providing adequate staffing, and ensuring the health literacy leader has access to meeting with and presenting to leaders and managers throughout the organization. All the study organizations in which executive leaders supported the initiative were Path One organizations. The data suggests that senior leadership support determines that the health literacy initiative will advance on Path One.

## Research Question 2

The second research question is, “How do participants describe the barriers to adoption and implementation of health literacy initiatives in their organizations?”

**Table 4. Research Question 2: Barriers to Adoption and Implementation**

Lack of leadership support blocked awareness, support, and growth <i>This is not fluff; this is really as important all the other things we're doing.</i>
Location of health literacy in area without wide reach thwarts buy-in <i>If it belongs to everybody, it often belongs to nobody.</i>
Inadequate staffing hinders initiative's advancement and staff retention <i>And, gosh I was drowning in work</i>
Lack of a team of champions to guide and help with initiative decreases influence <i>If it wasn't just the two of us, what would life look like?</i>
Lack of access to leaders is a significant barrier to awareness, support, growth <i>I couldn't talk to anyone without [my boss] being there</i>
Health literacy change leaders' experiences, background did not equip them well <i>I had no idea what health literacy was...but I was asked to lead the project.</i>

The tunnel metaphor is useful here as we look at the many perceived barriers described by participants. Again, the tunnel can represent the development of a health literacy initiative in an organization. The barriers can be seen as rocks and roots in the tunnel that need to be navigated in order to proceed.

### Lack of Leadership Support

As one might expect, the lack of leadership support was a metaphorical boulder as having strong support was a graveled path. Participants identified multiple ways they perceived that leaders either blocked support or simply did not provide it. Organizations with little leadership support were described as having few streams of activity occurring in their initiatives. They also tended to have health literacy change leaders who expressed frustration and demoralization about their work. Pearl, whose frustration led to her metaphor of digging a tunnel with a tablespoon, reflected on her organization, “The #1 attribute of a health literate organization is that leadership

piece. We didn't have that at the top...and so it was a bottom-up endeavor...I was like the tiny little seed that blew in like a weed." Other participants commented on not having leadership support. Carol's belief was, "You really have to use an improvement model—like be chartered...Without that I don't know how you could do it." (Charters are issued by senior leaders and are seen as mandates for action throughout an organization.)

**Perceptions of health literacy.** The first step in being able to provide support for any new initiative or innovation is to understand what it is, how it works, to whom it could apply, and its potential benefits and impact. Unfortunately, health professionals often do not understand health literacy issues (Kelly & Haidet, 2007; Macabasco-O'Connell & Fry-Bowers, 2011; Wu et al., 2005). Moreover, some providers and staff believe that low health literacy is not a problem or is a low-priority (Barrett et al., 2008). This is disappointing since providers and staff have more direct contact with patients than administrators so they might be expected to have a greater understanding of the difficulties patients have with health information and services.

Several participants identified the challenge of getting leadership to understand the characteristics of health literacy. They observed what they viewed as a lack of awareness, but also a negative and condescending perception of health literacy as unimportant. Nellie remembered her early work in which she would try to get leaders on board, "I would say we need to have a department, an office for this. This is not fluff, this is really as important as all these other things we are doing." A second participant also mentioned the word "fluff" being used and a third participant said there was "eye rolling" at the term health literacy in her organization. These perceptions of lack of support went along with change leaders' expressions of discouragement.

Lacking understanding of an innovation's importance was perceived as leading to a lack of commitment to it. Jamie explained how health literacy somehow made it onto her organization's official strategic plan but there was, "...no strategic plan for how are we going to *actually* incorporate it, *how* are we going to further this in the organization...[it was] just 'Check,' we got it on the strategic plan." Other participants thought the same lack of understanding and commitment was exhibited when health literacy was on a meeting agenda but would get moved to the next meeting repeatedly because other agenda items were always seen as a higher priority.

Alice believes one of leadership's reasons for not supporting, or for blocking, health literacy is not wanting to change the status quo and being unwilling to allow for innovative activities. She traced some of her contentious experience this way,

They wanna keep the status quo because change is scary...I'm innovative, right? I'm not used to working like this. Not everybody has been receptive. I've had a couple of smack downs...you put your big girl panties on...I rarely back down.

**Policies.** Some senior leaders provide support by establishing policies. The policies were in a variety of areas, from a process for reviewing internally-produced patient education materials to mandates that healthcare providers use teach back and record that they have done so in the electronic health record. However, most leaders were described as not establishing or supporting these types of policies.

In a few cases, senior leaders vested health literacy change leaders with the authority to develop policies themselves and bring them forward to leadership venues for review. Nellie was one of these rare cases. She was empowered to create policies as she reports here, "I changed policy at the hospital, and developed a process around vetting materials, educating, and doing

classes and training volunteers.” However, she was an executive director and a nurse in addition to being the health literacy change leader. Her position as a senior leader, rather than her role as a health literacy change leader, may have vested her with the authority to create policy.

**Lack of authority.** Most participants’ senior leaders did not give their health literacy change leader the authority to mandate certain changes. An example would be to allow the health literacy leader to set standards for oral communication with patients such as the use of plain language and teach back. But as Farah lamented, “...we don't have the power to say everybody in this hospital will learn how to use teach back and then be monitored to make sure we are meeting our goals.” This lack of authority was the norm in the participants’ organizations.

**Lack of financial resources.** In today’s healthcare environment, financial resources for health literacy can be scarce (Barrett et al., 2008). Participants reported lack of funding as the cause of inadequate staffing levels and slow replacement of vacant positions in health literacy initiatives. Funding for health literacy activities in many organizations was observed to be non-existent or very limited. Jamie illustrated this scenario, “Some of our struggle is that we don't have a budget. We have no funding for our committee and for the work. And when we made signs, we pretty much paid for all the stuff ourselves, out of our own personal money.” Participants also cited lack of professional development funds for attending health literacy conferences or trainings as a barrier to their effectiveness.

**Summary.** Leaders set an example of how seriously the organization is taking health literacy, and in so doing, show others the level of priority they need to give it. Overall the lack of leadership support, and in some cases the condescension of leaders, was perceived as having profound negative effects on the progress of some health literacy initiatives. Metaphorically, the

leaders were showing the low priority they give to digging the tunnel as they provide only a tablespoon for the task.

Lack of leadership support also appeared to have profound negative effects on health literacy change leaders' experiences and perceptions. As mentioned above in discussing facilitators of health literacy, participants who perceived little leadership support were quite negative. They used phrases like, "hands are tied," "we don't have a voice," and "it will never be important enough." When leadership support is absent, employees may perceive health literacy as unimportant, an attitude that create resistance to cooperating with health literacy change leaders. Perhaps this barrier also negatively affects the participants' level of satisfaction.

### **Location of Health Literacy in the Organizational Structure**

The location of the health literacy initiative in the organizational structure can be a facilitator or a barrier to its adoption and implementation. I now discuss the findings related to several aspects of the location of health literacy initiatives which can present barriers.

Several participants reported the health literacy initiative in their organization had been moved to a different location since it began because there is no place in the organization is it seen to logically fit. This lack of a sense of where it belongs can add to the confusion about who needs to pay attention to it and over whom it has authority. Nellie, a health literacy change leader with many years of experience in a large system, proposed that "if it belongs to everybody, it often belongs to nobody." This can create a perception of health literacy as not being "owned" by anyone which is to say it is not important to the organization. Thus, this perception can become a barrier to attention and engagement in health literacy work.

For the research question on facilitators, participants describe their belief that it was important to be in a department or area which had organization- or system-wide reach rather than

being situated under a specific area, such as nursing. When health literacy initiatives were placed under a specific area, people in the organization who do not work in that area reportedly often perceive that health literacy does not apply to them. Therefore, being placed in an area without organization-wide reach was seen as a barrier.

The lack of an office or a full-time staff person dedicated to health literacy is a related perceived barrier. For example, if the initiative is led by someone who primarily works in an office dedicated to another topical area (such as a medical library), this seemed to restrict the progress of the health literacy work. Moreover, a part-time or full-time staff person is often the only staff person charged with advancing the health literacy initiative so they can feel isolated.

There does not seem to be an emerging best practice yet for the most effective location for a health literacy initiative. Until there is a recognition in the field of the best location, this confusion over where it should be located will most likely continue to be a barrier.

### **Staffing and Structure of the Health Literacy Initiative**

Having less than a full-time person responsible for advancing the health literacy initiative was believed to be a barrier, even in small hospitals. Organizations which had less than one full-time employee devoted to health literacy were more likely to be described as lacking leadership support and their health literacy change leaders were more likely to feel frustrated. Kelly, who along with her other duties, has been charged with advancing health literacy in her organization, described, with resignation in her voice, the lack of interest she often hears from her organizational leaders. She described their typical response to health literacy as, “I would say that it’s usually, ‘This is really great. I am so glad you are doing it. Have a great time’.” Holly, who volunteers her time to help Kelly with health literacy work, talked of her desire for the future, “I think what would be awesome would be a full-time employee... Someone whose sole

job is that, not one of, one piece of their job. I think we are a big enough system to be able to have that and support that!...Until we have that FTE we can't have the operational plan.”

Even with one or multiple full-time employees dedicated to health literacy, however, staffing issues could still be a barrier depending on the size of the organization or system and the expectations placed on the health literacy employees. When Pearl moved from doing health literacy work on her own time to raise awareness of the issue in the organization into a full-time health literacy position in the huge system, she talked about struggling with workload and unrealistic expectations. She described her situation, “...and before I knew it, I had 50,000 employees, 5,000 physicians, over 20 hospitals, and it goes on and on—all of whom were free to call me as a health literacy resource.... And, gosh I was *drowning* in work...”

### **Lack of Access to Leaders**

Limited access to meeting with or presenting to senior leaders appeared in the data as a perceived barrier. Being able to access the people who have the power to make the initiative go forward was seen as profoundly important. By way of review, it is important to have access to various levels of leadership so the health literacy change leaders are able to (a) present information about health literacy to groups, (b) meet with leaders individually to gain support or permission for policies and activities, (c) attend leadership meetings, and (d) serve on key committees at high levels. Limited access to leaders makes it difficult to communicate the relevance of health literacy, show how it can impact other ongoing initiatives, or provide a forum for requesting resources.

Kelly made apparent the difficulties in gaining access to address leaders. She described how she was allowed to address senior leaders only twice in about four years,

...I think it was 2011 or 2012, we talked with the CNO [Chief Nursing Officer]... She asked us to then bring it to Senior Exec Ops which we did... So that was the first time we presented...And then we followed up last summer, about a year ago, with a presentation to system leadership.

For another participant, gaining access to present to leaders at any level had been impossible. Instead of trying to get on the agenda at meetings, Jamie and her Health Literacy Task Force decided to create a video about health literacy. She said, "It is our hope that it will really gain the attention of senior leadership so that maybe they will be more receptive to talking about actually creating a role for at least one person..." When I asked her if she had the access to take it out to senior leadership when it was finished, she responded tentatively about even getting permission to take it to leadership at a level considerably lower than senior leaders. She explained, "I'm gonna ask for permission to do so. Let's see if I receive permission to go to the site leadership meeting and present it." (Site leadership is typically multiple levels down the organizational hierarchy from senior leadership.) Lacking a forum to share important information about health literacy was seen as blocking the efforts to move the initiative forward.

Jamie's situation also illustrated an access barrier she experienced because she is not a clinician. Her co-lead in the health literacy initiative is a clinical person and she had to step in when Jamie was not allowed access to two committees. Jamie, who is a medical librarian, lamented,

Our HCAHPS Champion Committee, I was asked to participate on, and Betsy does that for me. And our Patient Experience Committee, I was asked to participate on, and Betsy does *that* for me. So Betsy is able to do so as a clinical educator. She can address health literacy...where I cannot.

Jamie recently shared with me that she left her position and is moving to a different organization where she is looking forward to working on health literacy part time.

The last access barrier which was described was that of not understanding the culture of accessing leaders and knowing the appropriate etiquette once in the company of those leaders. Sheila described how she didn't realize that in setting up meetings with leaders, she needed to email the leaders' assistants, not the leader. Even knowing that, her next barrier was to figure out who their assistants were. And finally, when she found herself in a leadership meeting, she had to learn the appropriate behaviors. With a little chagrin, she reported, "And sometimes, you don't know the rules like the guests don't sit *at* the table, they sit in the back." She had taken a seat at the table and had then been told she could not sit there.

### **Other Organizational Barriers**

**Time challenges.** Half of participants mentioned time constraints as a barrier to implementing or engaging with health literacy activities. Both their own time constraints and the constraints other employees face were mentioned. The general theme was expressed well by Janet, "...another barrier is everybody has got so much on their agenda. Everybody is so busy...people are always so overwhelmed with one more thing to do, especially in primary care. They cannot take on *one more thing!*" Nolan represented time challenges as an issue of capacity, "Probably the largest barrier was capacity...Because if you think of it, when was the last time something was taken off a nurse's desk or a provider's desk? It doesn't happen."

**Competing agendas and multiple priorities.** When employees had competing agendas to attend to and multiple priorities to juggle, health literacy activities were often reported to come to a standstill. There were several organizations which were, or had recently been, working on implementing an electronic health record (EHR). The health literacy change leaders recognized

that their agenda had to go on hold for a year or more until the rollout of the electronic health record was completed. Implementing an EHR is so demanding that little else, besides direct patient care, can be sustained. Similarly, if employees were engaged in initiatives that related to reimbursement or accreditation, for example, health literacy had to take a back seat.

**Physician resistance.** The last organizational challenge significant enough to include in this document is perceived resistance toward health literacy from physicians. As mentioned earlier, there is a commonly found organizational structure which creates problems for health literacy change leaders trying to work with physicians. In the majority of organizations and systems, physicians are not employed by the hospital, organization, or system in which they provide care. Typically, there is a medical group, a separate legal entity which employs physicians, bills for their services, and often provides professional development opportunities. This structure means that hospital leaders and administrators are not vested with the authority or power to supervise physicians' work, cannot dictate physician behavior with patients (e.g., using teach back), cannot insist they attend training that all employees are mandated to attend, and cannot set performance goals for the physicians. (All employees in a healthcare system have performance goals, and specified training, which they must complete each year.)

Against this backdrop, participants described hearing a common belief among physicians that their communication skills with patients are "just fine" and that they do not need help in that area. Participants report that physicians are invited to attend health literacy presentations and trainings on a variety of topics, including communication and teach back, but seldom attend. Farah pointed out that, like all other employees, she is, "...supposed to name my goals, what tactics I am going to use to get there, and what the measures are." She is convinced that physicians, and others who do direct patient care, should have a mandated communication goal

but she reveals the clinician response to this idea, "...that has just been greeted with such hostility. I don't understand it at all."

Health literacy change leaders, like hospital leaders and administrators, are not in a position to address patient/physician communication in any way because of this organizational barrier. This structure, which provides a place of protection to physicians, was perceived as enhancing their resistance to any changes in their patterns of practice.

### **Health Literacy Change Leaders' Experiences and Background**

Some participants' descriptions of their negative experiences in organizations with little perceived leadership support exemplify their frustrations. Yet, they face different types of barriers as well. Being in a new position, leading an as-yet-undefined initiative, is challenging. So finding one's own way in the new position can be difficult.

Part of the difficulty many participants faced upon entering their health literacy positions was their reported lack of knowledge, training, and experience in health literacy. Health care professionals, providers, and staff in many organizations do not understand health literacy or do not perceive it as a problem (Barrett et al., 2008; Kelly & Haidet, 2007; Macabasco-O'Connell & Fry-Bowers, 2011; Wu et al., 2005) so it is understandable that a newly-appointed health literacy change leader would have had little exposure to it. Moreover, participants reported having a wide variety of educational backgrounds. Their degrees were in the following 13 areas: Anthropology, Business Administration, Marketing and Public Relations, Healthcare Administration, Healthcare Finance, Library Science, Medical Writing, Medicine, Nursing, Public Administration, Public Health, Quality Improvement, and Sociology. So it is not surprising that a newly-appointed health literacy change leader would need additional information to be effective.

The learning curve for health literacy change leaders can be very steep, given that there is no clear formal route to learn about health literacy. Many health literacy change leaders come into their positions with little to no formal preparation on the subject matter—health literacy, patient/provider communication, plain language, teach back, materials development, editing, readability, graphic design and layout, or other subject matter content which is critical to health literacy efforts. Carrie described her start, “I had no idea what health literacy was at that time but I was asked to lead the project...” Participants reported that most of their knowledge about health literacy came from a variety of short learning opportunities such as learning circles, a breakout session at a medical librarian chapter meeting, a 2-3 day health literacy training, a health literacy conference, self-tutorials on the web, health literacy blogs, consultants’ websites, and the health literacy discussion list.

Another challenge change leaders may experience is their lack of knowledge about organizational change models and strategies for promoting adoption and implementation of new initiatives (DeWalt et al., 2011). Only four participants reported having any formal training or professional development in organizational change, the science of improvement (e.g., Plan-Do-Study-Act cycles as used in The Model for Improvement), quality or process improvement, implementation and dissemination (e.g., Diffusion of Innovations theory), or project management.

Moreover, unless they had worked in their organization in another management or leadership position, they may have also needed to learn the organizational chart; how their organization operates; what communication channels are available; how system-wide change is made; the politics of support; how to get time with leaders; who their stakeholders are and the stakeholders’ priorities and needs; what committees and groups they need to approach for

support or permission; the difference between entities such as a guidance council, a workgroup, a task force, an advisory group, etc.; and which people and entities are key to their work.

Additionally, because many healthcare organizations have different definitions for terms like patient engagement, patient experience, and patient activation, health literacy change leaders would have needed to learn how their organization defines and conceptualizes these issues. They would also need to know if the organization is addressing the issues in ways that health literacy strategies could support.

Sheila remembers how lucky she was to have been given 90 days to learn about the organization, “Because I was not just starting a new program but new to the organization, it ended up being a really crucial piece of getting off on the right foot. I mean I could have started doing something not really understanding the culture of the organization...so, I had the opportunity to do research, to meet people, to learn about what was already going on.”

Another perceived barrier in the data was clinical employees’ attitudes toward health literacy leaders. Participants who were not trained as healthcare providers or nurses reported not being accepted or not taken seriously because they lacked a clinical background. This perception of not being respected for their knowledge was difficult for them.

In particular, participants reported feeling frustrated and disrespected when they were perceived to lack credibility in creating or revising medical information for patients. Internal clients of the health literacy initiatives’ reader-friendly document services often asked how participants could do the job without medical training. Farah’s argument to them was, “You need me. I am the one person on your team who understands what it’s like to *not* understand you!”

The last potential barrier relates to the context in which many health literacy change leaders find themselves. Of the 16 interviewees, nine were the only person in their organization

who had specific responsibility for advancing health literacy. As one of those who is the sole person responsible for health literacy, Pearl expressed a sentiment that indicates the feeling of isolation she sometimes has, “I just can’t tell you...I truly feel so less alone...to take part in your research here and chat with you.” This points to the possibility that isolation and feelings of being alone, disrespected, and not supported can be barriers to progress as well as negative influences on the well-being of the health literacy change leaders.

### **Summary**

Related to the facilitators discussed above, many of the same factors operate as barriers to advancing health literacy initiatives if they are lacking. Most of them have not been identified in the literature. This again suggests these barriers may be unique to health literacy initiatives and to others that are similar. The first four barriers are (a) absence of leadership support, (b) a location that lacks organization-wide reach, (c) less than a full-time person dedicated to health literacy, and (d) lack of access to leaders. The presence of even one or two of the barriers discussed above may determine that the organization proceeds on Path Two. In particular, the lack of leadership support appears to be the determining factor for the initiative’s advancement or lack thereof.

The health literacy change leaders also experienced many challenges due to their lack of knowledge and skills in a variety of topic areas related to their job responsibilities. The expectations of the health literacy change leaders’ positions require knowledge of a broad range of diverse topic areas including (a) health literacy, e.g., reader-friendly materials design, (b) organizational change, quality or process improvement, and project management, (c) strategic planning, (d) strategic communication, and (e) the inner workings of their organization, e.g., the organizational chart, communication channels, and how system-wide change is made. Other

barriers for some of the health literacy change leaders were the perceived lower status of being a non-clinician and the isolation of being the only person working on health literacy.

### Research Question 3

The third research question is, “How do participants communicate with administrative leaders and healthcare providers at all levels to gain support for health literacy activities?”

**Table 5. Research Question 3: Communication to Build Support for Health Literacy**

<p>Linking health literacy to other initiatives is commonly used and very effective <i>Oh, this fits right in with our work to improve HCAHPS.</i></p> <p>Cost and return on investment is helpful but lacks strong data as evidence <i>So now there is a monetary incentive to look at...communication.</i></p> <p>Presenting general health literacy statistics increases awareness and understanding <i>The data that show it's a problem which was rich then, even richer now.</i></p> <p>Stories about patients' and consumers' experiences are powerful and engage the heart <i>...case studies in front of senior leaders and clinicians is an 'aha' moment.</i></p>
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Participants described using multiple approaches to get the attention and support of leaders and healthcare providers with varying levels of success. Having strong leadership support already in place was perceived as a facilitator, but for those who had little to no leadership support, it almost seems that they were “stabbing in the dark.” Not surprisingly, many did not know how to approach this task.

The majority of the participants had little to no training in the basic concepts and content of the health literacy field and little to no background in marketing or selling. Many of them were unfamiliar with the processes for approaching or accessing leaders. Moreover, most were unfamiliar with the processes for making change in their organization and may, or may not, have a supervisor who could help. Therefore, not knowing the “who, what, where, when, and how” of presenting and selling a new concept was described as a challenge for many participants. Despite these constraints, they were often able to make at least some progress.

There were a few approaches which participants reported using quite commonly and several others used by only a few participants. Here I describe each of them (except those used by only 1-2 people), listing them in order of the frequency they were mentioned.

### **Linking Health Literacy to Other Initiatives**

This strategy was reported to be the most commonly used, with ten of the 16 participants describing it. Participants used three apt metaphors for linking to other initiatives: “carpool,” “piggy-back,” and “hitch your wagon.” There were many different initiatives to which participants reported trying to link health literacy. Most of them were organization- or system-wide priorities. The 13 initiatives to which participants attempted to link health literacy were patient safety, patient experience, patient engagement, patient outcomes, quality improvement, health equity, population health, patient satisfaction scores (to address financial incentives and penalties), reducing hospital readmissions (to address financial penalties), length of stay in the hospital, cost of care, linguistic and cultural barriers, and cultural diversity.

There were some smaller efforts underway which were specific to one area or service line. These included linking to shared decision making, medication non-adherence, opioid safety, and finding ways to encourage patients to share accountability for their health outcomes. Marcy outlined how she sees linking to other initiatives can be effective,

... you may be able to align resources that are related, not officially designated as health literacy but, ‘Oh, this fits right in with our work to improve HCAHPS...’ And those resources are there because of other external drivers and priorities, and regulations...it becomes important to...align with those other drivers.

Lack of access to leadership was seen as a barrier to linking to other initiatives. Many health literacy change leaders reported lacking access to situations where discussions about

broader issues in the organization occur, and lacking access to those who are responsible for addressing them. In these cases, the logistics of communicating how health literacy can support other initiatives was experienced as a barrier.

### **Cost and Return on Investment**

Many of the initiatives above are powered by a need to address financial incentives or penalties from external influences, such as changes in Medicare reimbursement for hospital readmissions. Thus, it is not surprising that eight participants reported using cost and return on investment data as the second most commonly used approach for communicating about health literacy. In fact, the most frequent use of this approach was to link it with the cost aspects of the initiatives discussed above, e.g., showing the cost savings health literacy strategies could bring to the efforts to reduce readmissions.

However, participants described the lack of actual cost data as a barrier to this approach. Three participants mentioned needing specific numbers or percentages they were unable to obtain. Most participants who used cost and return on investment, instead, would simply refer to the fact that there would be a cost saving. For example, they might point out that a readmission could be avoided if teach back was used at hospital discharge, even if they did not know the typical cost of an unreimbursed readmission.

### **Presenting General Health Literacy Statistics**

Seven participants reported presenting data on the health literacy of U.S. adults, looking at age, race/ethnicity, income levels, education levels, the impact of low health literacy on health outcomes, etc. Participants would apply that data to the local patient population. This information was often included in basic, initial presentations and discussions about health literacy.

A barrier in this approach was healthcare professionals who did not appear to believe the data was correct; who claimed the data did not apply to their patient population for a variety of reasons; or who believed their communication styles were effective enough that health literacy challenges were non-existent in their practice. Another barrier participants observed was the healthcare providers' belief that the national data simply did not hold for their locale. In these cases, participants used stories of local patient experiences (when they could obtain a story) and believed they were useful.

### **Stories about Patients' and Consumers' Experiences**

Six participants reported using this approach to help others understand the importance of health literacy. Stories were thought to be crucial in helping others understand the reality of limited health literacy and its dynamic nature as a state vs. a trait. Participants saw local stories about patients' and consumers' experiences as particularly effective and they were obtained in two ways. First, patients and/or their loved ones gave information directly. Second, patient or consumer experiences and stories were reported by employees of the organization who had either observed or been told about an event.

Three participants portrayed ways in which the voices of patients from the organization or consumers in the community served by the organization were obtained directly. In one case, the health literacy team conducted a navigation tracer, a process wherein adult literacy learners from the community were invited to come in to give feedback on signage to the hospital. Another organization invited patients and adult literacy learners to review print materials which were in development. And in a third, the participant talked about her own experience as a patient. Pearl stated the importance of a patient perspective, "...there is only one thing health systems value more than ROI and that is when patients talk."

The other tactic for obtaining stories was indirectly, from employees who had observed or been told stories about patient experiences or from clinicians who shared about their own experiences as patients or parents of a patient. One participant was allowed significant time to observe patient/provider interactions in her organization as part of her orientation to the position. She described her perceived success in presenting her findings to leaders, “When you put these case studies in front of senior leaders and clinicians it’s an ‘aha’ moment for them. They get it...it’s probably the best strategic way that we’re going to continue to get buy-in even in these precarious economic times.”

A nurse in Carol’s organization told her a particularly poignant story about a very educated patient who misunderstood how to administer his medication. Carol described how this story provided a powerful “aha” moment for leaders and clinicians in her organizations. The story engaged them because they don’t expect this kind of misunderstanding to occur with an educated person. She describes a man in his forties who had just been diagnosed with diabetes and was learning to inject himself with insulin in his abdomen. She recounts,

...he was a mechanical engineer. He got his instructions. And he came back a week later because he had this one swollen area that was really tender. And he came in and talked to the nurse and she said, "Okay, show me what you’ve been doing?" He [drew up the insulin] and did everything right. Then he says, “I put it in and I rotate the site.” And he literally rotated the needle at the site! Because “rotate the site” to him meant “rotate the *needle* at the site.” It didn’t mean, put the needle in different locations so you don’t get one big giant bruise.

Another participant spoke about the power of sharing stories she has been told by clinicians,

...we give examples of physicians that are on our team, when one of their children got sick and the doctor tried to talk to them in doctor speak and they were like, 'No, no, no. I want you to talk to me like I know nothing because I am freaking out right now.'

### **Showing Progress and Results**

Six participants recounted how they showed progress and positive results in some of their ongoing health literacy efforts to build support for future efforts. This is consistent with the step of celebrating successes in Kotter's 8-Step model (1996, 2012) but none of the participants mentioned using this model in their health literacy work. Presenting results which had the desired outcome can also show how the new way is an improvement, not just a change. This illustrates Rogers' (2003) principle of relative advantage, one of the two most influential of his five attributes of innovations.

Showing good results also proves that the new way can be integrated into the current structure, illustrating compatibility, the other of the two most influential of Rogers' (2003) five attributes of innovations. Sharing progress and results was thought to help people to whom participants were presenting see a concrete example of a health literacy strategy. Sharing progress may have been helpful because it enhanced people's ability to envision what health literacy strategies look like, how they might fit in with the current way of doing things, and what they can contribute. Emilia described how she applied this approach,

...we revised our patient registration form just because our old version was difficult to read...And after we modified that...the number of patients returning the form incomplete...was a lot fewer. So I think just seeing those kinds of immediate benefits helps to get...leadership on board, and also staff on board.

### Other Strategies

There were multiple other approaches to communicating about health literacy employed by a few participants. If an approach was used by more than two but fewer than six people, it is listed here. First, I want to foreground a strategy that was reported by only two participants but which I believe is worthy of note. This strategy is to spend time meeting with and listening to people at all levels in the organization. The purpose of this *listening tour*, as one participant called it, was to learn the priorities, challenges, needs, motivations, and successes of as many people as possible to gain a deep understanding of their experiences of their day-to-day work lives.

After listening and learning, the participants were then equipped to use the new information in future discussions and presentations by framing how health literacy can diminish challenges and support what the staff care about most. One of the participants who used this strategy described using a *heart-head-heart* approach, meaning to speak first and last to the heart and provide the data in the middle. The heart-head-heart approach is made possible by the information gained in listening carefully to staff.

The same participant suggests telling patient stories and also engaging the audience in remembering what motivated them to go into healthcare in the beginning—to remind them of their *why* as a way of engaging the heart. This heart and head approach is one of Kotter's (2012) five principles of managing the guiding coalition, the creation of which is one of the eight steps in his model for change.

The other approaches, used by one or two participants, were all supported by the Diffusion of Innovations' theory and its principles on communicating through interpersonal communication channels to inform others about the attributes of innovations (Rogers, 2003). The

approaches were (a) sharing how health literacy strategies could improve patient/provider communication which illustrates the use of relative advantage, (b) talking about health literacy widely and repeatedly which illustrates the use of interpersonal communication channels, and (c) explaining how health literacy can ease clinicians' everyday work rather than add a burden which illustrates the use of compatibility, complexity, and relative advantage.

### **Customizing Messages**

Several participants mentioned customizing their messaging to their audience's priorities and needs. Sheila elaborates on her process for doing this,

We always...adapt the message or the presentation to the audience. So if I am talking to the Chief Patient Safety Quality Officer, we're gonna talk about...why health literacy is important for that, for keeping families and patients safe....So I think the message has to change depending on who you're talking to.

Customizing like this is only possible, of course, if the health literacy change leader has knowledge of the priorities, challenges, needs, motivations, and successes of those to whom she is presenting (perhaps gained through a listening tour); has access to necessary data, e.g., patient satisfaction scores to present; and has access to communicating with or presenting to the appropriate leaders.

### **Summary**

Health literacy change leaders are using a wide variety of communication messages and approaches to raise awareness of and build support for their initiatives. One strategy in particular was described by three participants as very powerful—telling stories about patients' experiences and misunderstandings. Participants believed this strategy was effective and powerful because it engaged the hearts of the listeners and reminded many of them of their original reasons for going

into healthcare. Strategies that engage the heart were highly recommended. Tailoring the messaging for the specific audience was also recommended.

Strategies for choosing an approach and an overall plan for marketing health literacy were not mentioned in the data. This suggests that a planned marketing approach and strategies tailored to the organization's and audiences' priorities might be helpful over the "scattershot" method most health literacy leaders seem to be using. Perhaps recruiting someone from the organization's marketing and public relations office as a health literacy champion would be appropriate.

#### **Research Question 4**

The last research question is, "What models and methods for making organizational change are evident in participants' reports of efforts to implement health literacy activities?"

#### **Table 6. Research Question 4: Models/Methods for Making Organizational Change**

The Model for Improvement and PDSA cycles were the most commonly used formal models  
*So yeah, we use PDSA cycles for almost everything we do.*

Informal models and strategies in health literacy efforts were also common  
*Someone will bring it forward and there will be a discussion [with leadership].*

Going into the study, I was aware of several formal models for change I had identified in the literature review and that I had been exposed to through working in healthcare for over 20 years. I realized during the data collection that few participants were using formal, explicit, named models for change. A few participants asked for clarification when I asked the interview question about models for change. Giving examples of some models' names did not appear to be very helpful.

As I reflected on this, I realized that my definition of a model for change was not the same as many of the participants' definitions, if they had a definition. I realized that asking about

their organization's model was not getting at the deeper processes of change. If they were not familiar with a formal model, I often asked how change happens in their organization or how they were working to bring about health literacy changes.

In my analysis, I enlarged my perspective and was attentive to their understandings and practices of making change in their organizations. I listened for implicit, perhaps subterranean, avenues and processes participants were using. I also looked for how participants came to know about any implicit avenues and the protocols for using them. As an example, going "up the chain of command" in a hierarchical organization is certainly an avenue for change but it may not be explicitly codified in written documents. Another example might be learning that a change management office exists and is available to help staff plan an approach for their change project.

In response to the question about the use of models for change in their organization, six of the 16 participants did not know of any or were unsure. For example, Alice showed uncertainty, "...this is way out of my realm of expertise. But I will tell you what I *think*... developing change is positioned within our vision and our values." Alice's way of thinking about, and planning change, at the level of her initiative, was to conduct research within her organization to provide evidence of the current practice. She had observed dozens of patient/provider interactions over a year to obtain qualitative data. She was in the process of writing a report using the data to justify her plan for the health literacy initiative. However, she did not describe her research as a plan for making change.

Nine of the 16 participants reported that their organization used a formal model for making change in at least some areas. Seven participants named Lean and Lean Six Sigma as a formal model which was being used in various areas of the organization but not in their health

literacy initiative. Carol articulated aspects of the formal model used in the organization and one of its methodologies in great detail,

The LEAN methodology utilizes the A3 form of communication. So it is a technique used where... it includes things like what is the background, current conditions, goals, analyses, recommendations, and the plan.

Holly talked about her organization's use of Lean Six Sigma, "...more formally we teach Green Belt Lean Six Sigma training and we will use that as a model for change." There were no organizations using Lean or Lean Six Sigma in their health literacy work.

Only five of the 16 participants reported using a formal model for organizational change in their health literacy work. In health literacy, three participants use the Model for Improvement (two of those also use learning collaboratives as a part of that model), one uses learning collaboratives without the Model for Improvement, and one uses Kotter's Eight-Step Model. No one reported using the Diffusion of Innovations or Lewin's Three-Step Model in their broader organization or their health literacy work. All organizations described by the participants as using a formal model for change and/or PDSA cycles were Path One organizations. Only one Path One organization used solely informal or implicit processes.

Twelve participants described other strategies and approaches for making change. None were explicit models. Interestingly, many of these strategies which were described as approaches for change could instead be seen as strategies for building support and many of them were mentioned in the section of the interviews on that topic.

The most commonly used was a form of "going up the chain of command" and was usually focused on obtaining permission or approval for an activity rather than explicit support such as resources, policies, or mandates. Participants' approaches in this area included (a) asking

one's supervisor for permission to do an activity, (b) presenting to a group such as a council or committee that was vested with the authority to give permission, and (c) presenting to groups of leaders to obtain permission and support, when the health literacy leaders had access to meeting with those leaders. Other approaches included (a) conducting pre- and post-testing using a health literacy strategy, (b) piloting a strategy at the unit level without leadership permission and then showing results to leaders, (c) presenting to leaders on how health literacy can support other ongoing initiatives in the organization, (d) building relationships across the organization to build support for change, and (e) finding and working with the Change Management office staff.

### **The Model for Improvement's PDSA Cycles**

Thirteen participants' reported using at least one of the Model for Improvement's three elements: (a) three key questions, (b) PDSA cycles, and/or (c) learning collaboratives in their health literacy efforts and/or in other areas of their organization. The Model for Improvement involves many methods beyond PDSA cycles and learning collaboratives (Langley et al., 2009) but no others were explicitly mentioned by participants. Participants from three organizations described using the three questions, the PDSA cycle, and learning collaboratives. Two of the three were based in large multi-state systems and one was in a single hospital. All three were Path One organizations.

Eight participants reported using PDSA cycles in their health literacy work. Marcy explained how the organizational culture of improvement science enhanced her initiative, "One of the things that made it easier, I think, was they had already established a strong culture of using improvement science, using the Model for Improvement." Some health literacy change leaders reported learning the PDSA method from someone inside the organization, often quality improvement or process improvement professionals.

### **Learning Collaboratives**

In three of the largest systems represented in the study, teams comprised of at least one representative from each hospital within the system were created. These teams are often called learning collaboratives and are designed to test and implement changes that can be hardwired into the system. Learning collaboratives originated in the Model for Improvement but only one system mentioned the Model in relation to their collaboratives. Collaboratives can work well whether or not they are used with the Model for Improvement. (Only two of these three organizations used PDSA cycles and the learning collaboratives.)

In health literacy learning collaboratives, the representatives are charged with driving health literacy change in their own hospital. Each hospital typically addresses the same general challenge but is encouraged to design and test its own ideas for changes. The members of the collaborative compare their work and results during monthly phone calls, bringing what they learn to the system level. Marcy described her organization's use of health literacy learning collaboratives this way,

There were multiple other learning collaboratives going on. So there was a pretty broad awareness...about this structure. So when the call went out that each hospital needed to designate a lead...that was not foreign to them. The learning collaborative structure provided a way to make those folks mini-experts pretty quickly.

### **Kotter's Eight-Step Model**

Kotter's Model was mentioned by one participant, Emilia, who described its successful use across her organization, "We are definitely looking at an adapted version of Kotter's model, the eight steps for organization change...since 2013, that's been our framework and kind of how

we maintain and continue to advance any changes.” She also uses Kotter’s Model in her health literacy work. Her organization was a Path One organization as well.

### **Informal Models and Strategies Used in Health Literacy Efforts**

In some organizations, decisions about change reportedly occur through certain avenues and processes used to access leaders who make decisions. Carrie, who works in a small, free-standing hospital, is in the only Path One organization that does not use a formal model. Carrie described her organization’s process this way,

It depends on what the change is and who it affects, which route it goes basically. So if it’s a change to nursing, we don’t have to go through all of the VPs that don’t have anything to do with nursing. So we just bring it up that channel with our Chief Nurse Exec and make those changes there. If it is something that affects the whole house, then it is brought through to our Management Operations meeting...

Nolan reported working with members of a change management office who helped him develop strategies for using the appropriate avenues to access leaders who make decisions. This was an informal process he initiated but his organization also uses learning collaboratives.

Another reported process for change was using a task force to assess an organizational need and decide whether and how to address it. Carol described this process and how it was used in the early development of her health literacy initiative,

The Health Literacy Task Force is charged with researching health literacy. See if, “Is this a problem? Is there something we can do about it? What do you recommend?”...

Their results are, “Yes, we think we can do this system-wide. Let’s put together a learning collaborative...and let’s see what traction we get from that.”... So it has moved from taskforce to learning collaborative.

Participants described additional strategies used to drive change for health literacy including (a) conducting pilot testing of health literacy activities at the unit level without senior leadership permission, knowledge, or explicit support; (b) doing pre- and post-tests; and (c) carrying out the steps in the Health Literacy Universal Precautions Toolkit.

### **Summary**

In summary, participants described formal and informal models and processes for driving change in their organization and in their health literacy initiatives. Four health literacy change leaders reported using (a) all of the aspects of the Model for Improvement—the three questions, the PDSA cycles, and learning collaboratives or (b) Kotter’s Eight-Step Model. All four were Path One organizations. Twelve participants described using only PDSA cycles, only informal processes, or combining PDSAs with informal processes in their health literacy work. Five of those organizations were on Path One and seven were on Path Two.

Another way to summarize these findings is (a) all of the organizations that used a formal model for change were on Path One and (b) less than half of the organizations that did not use a formal model were on Path One. This suggests that using a formal organizational change model (which provides an explicit structure and plan) as a framework for advancing health literacy initiatives would be beneficial to healthcare organizations.

### **Findings Not Related to a Specific Research Question**

#### **Healthcare Organizations as Bureaucracies**

Weber’s bureaucracy theory describes the structure, operations, and functions of healthcare organizations very well (Alaszewski, 1995). In a bureaucracy, many rules and norms guide the interactions across the system of authority, power, and discipline (Weber, 1968). Employees usually share assumptions about this socially-constructed reality and agree to abide

by its conventions. Aspects of bureaucracies which affect health literacy change leaders include the clear division of labor, prescribed roles, the vertical hierarchy of power and authority which restricts communication to strictly up or down, and the norms used in communicating in the hierarchy. Through all these aspects, healthcare organizations' hierarchies (Lyndon, 2008) enable and constrain behaviors and actions of employees at all levels as they participate in upholding the socially-constructed understandings and conventions.

Participants experienced this phenomenon in a variety of ways. When health literacy initiatives were placed in a location in the hierarchy that employees felt did not have authority over them, they felt like they didn't have to pay attention to it. When participants were not allowed to talk to or present to leaders at different levels, they were being affected by the system of authority, the vertical nature of the hierarchy, and the rules of communication within it. Alice disclosed her frustration in not being allowed to present at Grand Rounds and concluded, "Because when you work within the system, the power domain can really set up barriers that are almost impossible to get through."

When a participant's supervisor paved the way to meet with other leaders, the supervisor used her position and power in the vertical hierarchy. When a participant did not know the rules for making an appointment with a high level leader, she faced the bureaucratic rules and norms. When a participant was able to state that a senior leader has made something a priority and that there are written policies to mandate compliance with it, she was effectively invoking the power and authority of the top of the hierarchy. And when a participant was treated as having a lower status and questionable skill in the eyes of clinicians because she did not come from the same specialized background, the bureaucratic privileging of specialization of functions, clear division of labor, and prescribed roles were being applied.

It is interesting to note that physicians are generally not subject to the healthcare organizations' or systems' bureaucratic and hierarchical structure since they are often not employed by the organization or system. Physicians are usually employed by a separate organization even as they practice within the organization or system. This socially-constructed and reinforced arrangement impacts health literacy change leaders in that they have no power or authority to even talk with physicians about their interactions with patients. One participant mentioned offering assistance and she was surprised she was allowed to provide it. The others who mentioned physicians spoke of resistance and of the inability to get them to attend trainings. This structure makes it difficult to engage physicians in health literacy unless a physician learns about it, becomes dedicated to it, and shares his or her commitment to it as an opinion leader among near peers (Rogers, 2003). If this occurs, it could enhance the likelihood that others in the organization will pay attention to health literacy.

### **Health Literacy Change Leaders' Passion and Personal Connection**

An important finding relates to health literacy change leaders' experiences and emotions in relation to leadership support. The way participants described their experiences leading the initiatives seems to reflect the level of leadership support they perceived having. Participants who perceived high levels of leadership support, used words and phrases like, "great fun," "rewarding," "enjoyed," "loved it," "very lucky," and "feel grateful" to describe their experiences. Participants who perceived having a moderate amount of support usually framed their experiences with somewhat positive language but focused more on the ways in which they hoped to grow, had grown, or were being strong. They used words and phrases like, "big learning curve," "figuring it out," "long way to go," "learning a lot," "taking risks" and putting her "big girl panties on" to stand up to resistance. Participants who perceived they had little

leadership support were quite negative and several sounded hopeless. They used words and phrases like, “struggle,” “it will never be a priority,” “frustration,” “our hands are tied,” “setbacks,” “running into resistance,” “we don’t have a voice,” and “it will never be important enough.” Leadership support levels appeared to be directly related to the health literacy leaders’ emotional investment and morale. With low leadership support, the health literacy leaders were often deeply discouraged and demoralized which can profoundly impact the advancement of the health literacy initiative.

Having positive experiences in their positions was reported to promote positive emotions and hopeful expectations for the future and may, therefore, be facilitators of adoption and implementation of health literacy initiatives. Having difficult and frustrating experiences because of the lack of appropriate support of leaders appeared to cause health literacy change leaders to become discouraged and even leave the organization (Lansisalmi, 2006). In talking about her months of work trying to get health literacy moved to a more appropriate location in her system, Pearl lamented,

I tried to position it as, “Let’s let health literacy take off and we can bring the other pieces along”...But the decision was made to go the opposite direction. So I resigned. It was a disappointment for me. Mostly I was disappointed on behalf of the patients who could have benefitted from that.

When innovators in healthcare organizations are engaged in the work of making change, they can experience a good deal of stress (Anderson, De Dreu, & Nijstad, 2004; Lansisalmi, 2006; May et al., 2003). Therefore, change leaders’ emotional state and perception of the strength of leadership support can also function as a barrier to adoption and implementation.

The data suggest that the health literacy change leaders' drive and commitment may also be a related facilitator of advancing health literacy. Many participants shared stories of feeling called or having a sense of passion and purpose in their work. Carrie shared her view on this, "Because it is thought of as a fluff subject by so many, if you don't have someone who is passionate about it to really change that, it's not gonna go very far." Participants who mentioned their passion and drive for health literacy were from organizations which enjoyed strong leadership support as well as those with less leadership support. They were in organizations with vital and active health literacy initiatives as well as those with struggling initiatives but their descriptions of the passion, drive, and commitment were framed differently, depending on the level of leadership support in their organization. This is a significant finding, pointing toward the impact of leadership support levels.

Participants in organizations with strong leader support and thriving health literacy initiatives described being driven to do their work by a deep sense of personal commitment. Those in organizations with little leader support and a struggling initiative described their deep personal commitment as the force that enabled them to come to work each day. But where does that passion originate? For some participants, it comes from their own, or family members', experiences in the medical system. Pearl, who has a chronic disease that requires day-to-day management, described the day she read an article which impacted her deeply,

It was the day I realized...this was something that affects individuals far more severely than I ever encountered from not understanding what I was being told... A young woman...lost her life to [the disease Pearl has] unnecessarily. Her story appeared in the Wall Street Journal...her doctor said she died of a failing health system, not the disease...that is the day I decided to go to grad school [so I could change the system].

Nolan also shared a story about what makes him passionate about his health literacy work,

...My boss said something about my passion...and he said, 'Passion equals change.' And that's the key...I always tell a story about a lady...who touched me and drives my work to this day. [With a catch in his voice] What I learned from her was it's not about readmissions...it's about giving her quality of life... So she's not in the hospital every two weeks. She's playing with her grandkids. It's about *that*.

The drive and passion that result from these personal experiences seem to act as facilitators. Participants who struggled in their work may have developed a coping mechanism and path to motivation in making it personal. Putting a face or a story with the reason for the cause and their struggle provides the deep connection to own the struggle in a very personal way.

### Summary

In this chapter, I briefly reviewed the purpose of the study, information about the participants and their organizations, and described the findings from the participants' stories. The findings explicated participants' experiences with the topics in the research questions: (a) the facilitators and barriers to adoption and implementation of health literacy initiatives, (b) the ways in which participants communicate about and build support for health literacy, and (c) the formal and informal uses of models and internal processes for making organizational change to advance their health literacy initiatives. The chapter closes with a description of three findings that do not fall under any of the research questions. Many components of adoption and implementation described in the literature were found in the present study as well as some components that had not yet been identified or explicitly examined in the literature.

In Chapter 5, I discuss the key findings, important themes that emerged, and recommendations for theory and praxis to advance health literacy adoption and implementation.

## CHAPTER 5: DISCUSSION AND CONCLUSIONS

This study sought to understand the experiences and perceptions of individuals charged with advancing health literacy in healthcare organizations. Sixteen qualitative interviews were conducted with individuals representing 16 healthcare organizations and systems across the United States. I learned a great deal from the participants and their compelling stories. The data derived from the rich sharing in the interviews gave witness to the participants' commitment, compassion, tenacity, and creativity in the face of sometimes very challenging circumstances. The data suggest there are many concepts and strategies that can be applied in health literacy efforts to advance the initiative and to ease the implementation journey for health literacy change leaders. I explore these concepts and strategies in this chapter.

The present study's findings situate the experiences of the individuals in charge of health literacy initiatives in the extant literature on organizational theory and organizational change theory. The findings are consistent with the majority of results of other studies in the adoption and implementation literature in healthcare, and in addition, reveal some unique aspects of organizational change in health literacy work.

In this chapter I provide a review of the problem and the research questions. Next I discuss the findings relative to three organizational theories and aspects of four organizational change theories and also include implications for praxis. Subsequently, I describe the unique findings of adoption and implementation of health literacy initiatives, a conclusion related to structured approaches to change, and a new concept which can be added to organizational change theories. I then share personal reflections, study limitations, and recommendations for further research. I close with a summary of organizational elements critical for success and a list of recommended actions for health literacy change leaders.

### **Review of Problem and Research Questions**

The problem this study addresses is the slow progress of adoption and implementation of health literacy activities in healthcare organizations. The low health literacy of individuals juxtaposed with the demands of using healthcare organizations in the United States create barriers to effective and safe healthcare for 88% of U.S. adults (Kutner et al., 2006). This gap has created a growing acknowledgement of healthcare organizations' responsibility to (a) redesign their systems to be more accessible to patients and (b) implement more health literacy practices in communicating with patients (Parker, 2009; U.S. Department of Health and Human Services, 2010). Despite widespread awareness of the responsibilities of healthcare organizations to address this challenge, the healthcare community has not widely embraced the needed organizational changes (Institute of Medicine, 2013a).

The goal of this study is to understand the experiences and perspectives of individuals charged with advancing health literacy in a healthcare organization to expand knowledge of health literacy adoption and implementation. The research questions that drive this study are:

**RQ1:** How do participants describe the facilitators to adoption and implementation of health literacy initiatives in their organizations?

**RQ2:** How do participants describe the barriers to adoption and implementation of health literacy initiatives in their organizations?

**RQ3:** How do participants communicate with administrative leaders and healthcare providers at all levels to build support for health literacy activities?

**RQ4:** What models and methods for making organizational change are evident in participants' reports of efforts to implement health literacy activities?

The findings answered the above questions and revealed additional information on the processes involved in adoption and implementation of health literacy initiatives. I now discuss the findings relative to three organizational theories that I explored in the literature review.

### **Organizational Theories**

This study confirmed many aspects of organizational theories described by Weber, Weick, and Drucker. These theories each speak to aspects of healthcare organizations—their bureaucratic structures, processes of organizing, communications, and ways of making sense of the external and internal demands on healthcare organizations. The present study offers insights into the ways these theories impact health literacy efforts. Health literacy change leaders who learn about the principles offered by these theorists may be more effective in their change efforts. In this section I discuss the ways in which the participants in the present study experience aspects of organizational theories posed by Weber, Weick, and Drucker and then outline implications and recommendations for health literacy change leaders related to these theories and the structures and processes they describe.

**Weber's theory.** Participants' stories in this study confirmed (a) the bureaucratic nature of their organizations, (b) the existence of multiple hierarchies, and (c) the ways in which the hierarchies enable and constrain their activities and ability to communicate within the organization. The bureaucratic structure can constrain processes of change because the established rules, and the people who create them, can be very rigid. Moreover, the people governed by the rules often reify them and may be uncooperative with changes posed by health literacy change leaders if it is believed the change violates any rules or norms. Changing processes in the system is possible, but it can be very challenging because of the rigidity and size of long-established bureaucracies in healthcare organizations and employees' belief that

bureaucracies are immutable. Re-constructing norms, rules, processes, and communication avenues can create challenging barriers to change for health literacy leaders. Obtaining explicit support from senior leaders, if possible, can help address employees' reluctance to adopt change for fear of violating rules.

Health literacy change leaders find themselves situated in the heart of multiple hierarchies within their bureaucratic organizations. Participants are subject to, and must work within and across, many of the multiple hierarchies. When multiple hierarchies exist there is often tension as various sources of authority compete for power in decisions that are made with conflicting criteria and priorities. Health literacy change leaders need to learn how to effectively work with people in all the hierarchies and bring people from various hierarchies together to work on health literacy activities.

Hierarchies can enable quick, efficient, top-down communication which carries great authority because of its source. If this communication channel is used to express explicit support of top leadership for health literacy, it can be extremely powerful. When employees across the organization hear that executive level leaders have made health literacy a strategic priority or have mandated organizational changes to address health literacy, the employees understand quickly that it is important to the organization and that they must pay attention. When possible, health literacy leaders should work to obtain such explicit communications to the entire organization from their executive leaders.

A bureaucratic, hierarchical structure can also constrain communication. It limits communication both up and down the hierarchical levels with strict rules about who can meet with, talk to, or present to whom. These communication limits present challenges for enacting change since change does not happen without communication. Neither does awareness increase

without exposure to health literacy through communication. Health literacy change leaders need to work with key leaders and other supporters to enhance communication flow with people in the organization to which they do not have direct access. This may involve champions strategically communicating with people in their sphere of influence to raise awareness of health literacy and to get access to key leaders for the health literacy change leader.

I now move to discussing Weick's and Drucker's theories of organizations and how they interact with the Weberian bureaucratic structure in healthcare organizations. The study findings suggest that processes and concepts from both of these theories operate within, interact with, and contribute to changes in the bureaucratic structures of healthcare organizations.

**Weick's theory of organizing.** Weick describes organizing and communicating as intertwined processes that occur in a communication environment, such as a hospital's internal communication network. Health literacy change leaders would benefit greatly from being aware of the assembly rules of the people they invite to participate in health literacy activities, especially in relation to implementation of prior initiatives. The health literacy leader may want to ask employees at a variety of levels about previous initiatives so she can better understand their potential attitudes and expectations toward the health literacy initiative. For example, in one organization, employees were aware of prior initiatives that had not been well implemented and were eventually discontinued. Their past experience caused them to approach the health literacy changes with lack of attention or commitment because they believed it would also just go away if they ignored it long enough.

Health literacy leaders may also find it useful to think about, and ask about, the communication cycles in which employees discuss health literacy as they work to make sense of it and its impact on them. She might also want to hold open discussion sessions where employees

can come and talk about health literacy, ask their questions, and hear what others are saying. If the health literacy leader has identified champions, or knows of stories of success other people can describe, she might benefit from having those people attend the open sessions to contribute their voices to the communication cycles and, possibly, the establishment of new assembly rules.

**Drucker's theory.** Drucker describes how people's perceptions of information are filtered through pre-existing expectations (2011). If new information does not fit into our expectations, the unexpected may be resented, ignored, or not received at all (Drucker, 2011). Some participants described how healthcare providers in their organization seemed to resent, and often ignored, information about health literacy. This was especially frustrating for health literacy leaders. Perhaps what is needed, as Drucker (2011) believes, is a shocking awakening that forces a person to recognize that the unexpected is, indeed, occurring. True stories of patient misunderstandings and avoidable harm to patients, especially if they occur in the local organization, could be appropriate to provide this type of awakening.

Health literacy change leaders would benefit from extensive use of patient stories to engage the heart and the head to shock skeptical people with the facts. Therefore, change leaders should devote significant resources to (a) recording all health-literacy-related stories of which they are informed, (b) ask their support network (e.g., work groups, champions) to request stories from the people with whom they work, and (c) ensure the stories are reported back to them. She might also set up an anonymous way for employees to share stories and create a way to recognize and reward people who share stories publicly. Finally, she could ask to observe patient/provider interactions (promising strict confidentiality) to obtain stories on her own.

In communication, everything is seen by the receiver as a demand for involvement which is often resisted, resented, and unheard (Drucker, 2011), particularly if it does not fit with the

receiver's aspirations and values. If health literacy change leaders listen to people in their organizations, as described fully below in the section on listening tours, they can discover the aspirations and values of the people they wish to engage. They can then customize their messages to make them more personal and compelling.

To ensure that communications fit with the receivers' aspirations and values, health literacy change leaders can talk about health literacy with others using a "heart-head-heart" approach. This means to first engage the listener's heart by focusing on what they value, then provide the data to engage the head in logic and reason, and then return to a heart-based message, perhaps reminding them to "return to why," remember their reason for choosing their field of work in the beginning.

**The dual systems.** As described in Chapter Two in the section "Structure of Healthcare Organizations," there appear to be two distinct intertwined systems co-existing in healthcare organizations. One is the Weberian hierarchical, administrative system that supports patient care. The second is the more flexible, professional practice system, described by Drucker as semi-autonomous units of professionals (1988), that provides patient care.

In most healthcare organizations, these separate and less structured semi-autonomous units employ and support physicians and other licensed healthcare providers. In these common arrangements, physicians work *in* hospitals but not *for* them. Thus, these separate physician-created structures, often called *medical groups*, insulate healthcare providers from much of the power and authority in the bureaucracies in which they practice.

Physicians often use their professional judgement to take actions inside the organization. At times, these actions may be inconsistent with rules or policies of the organization, thus causing tension and conflict between the organization and the physician and/or medical group. In

health literacy work, physicians can block or ignore something that a policy in the organization stipulates such as a mandate to provide plain language materials for patients and families.

These two systems must co-exist because they each rely on and need the other. Yet, their differences may cause them to experience tension, power struggles, and conflict as they strive to work together to support and provide patient care. Physicians and administrative leaders come from such different sets of assumptions about organizing, authority, freedom in decision-making, and much more, that to effectively work together they may need to engage in communication cycles to establish and re-establish assembly rules more frequently than people who work in the same side of the dual systems.

Weick's continuous and reinforcing processes of organizing, communicating, sensemaking, and enacting communication cycles may be powerful and crucial processes that enable the dual systems to co-exist and work together. The continuous and fluid cycles of communicating to reduce equivocality and make sense of potentially contentious situations can serve as the glue that provides cohesion to these two very different systems.

### **Implications for Health Literacy Change Leaders**

The health literacy change leaders in this study find themselves situated in the middle of multiple systems and forces that are at times at odds with each other. In the organizations in which health literacy received strong support from senior leaders, the health literacy leader was more easily able to negotiate the challenging landscapes of multiple hierarchies.

These change leaders must negotiate the primary overarching hierarchy of their organization, which may or may not be the hierarchy to which they report. They must also negotiate multiple hierarchies within the overall organization. This means they must learn about, and become skilled at, working with a variety of norms, rules, processes, and communication

avenues while keeping in mind the politics, personalities, and egos of everyone they need to engage. When they are allowed, they meet with, present to, and work on projects with people up and down multiple hierarchies and power structures in their organization, sometimes without understanding the relationships each hierarchy has with the others. At times, they also need to cross over to the medical group side of the organization to meet with or present to physicians. Further, some of their work may entail going into patient care areas to work with unit and floor managers, as well as nurses, on projects related to direct patient care.

They can also find themselves with the need to bring people from different hierarchies together to support and implement health literacy activities. In addition, they may need to bring in physicians from the medical group to work with other areas. The challenges can be multiplied if the health literacy leader has not been given the authority to ensure that people adopt new behaviors and that the initiative succeeds.

An example of this type of project, one that involves many areas, is the implementation, or roll out, of a mandatory teach back initiative. Some of the administrative tasks of organizing training and creating a system for tracking and accountability must be done by one area. The training itself is likely delivered by people in another area. Healthcare providers, nurses, and employees across the organization's unit that provide care must be involved as they learn and apply the new skills.

Another challenge is the fact that health literacy change leaders are disrupting hierarchies as they meet with, and present to, people above their level in the hierarchy. When someone at a lower level seeks the time and attention of the people above her, this behavior goes against the rules and norms of the bureaucracy. Her behavior challenges the socially-constructed system to change and adapt to her requests and audacity. Moreover, she will be encouraging others to

challenge the established processes, communicate with their peers, and try new practices to better meet patient needs. These can be risky behaviors in a rigid bureaucracy.

Disrupting the hierarchy can, indeed, be a dangerous endeavor if the challenges create an impression that the disruptor is too impertinent. A few participants spoke of their willingness to challenge leadership, which I identify as disrupting the hierarchies. These brave participants appeared to be aware that they were breaking rules and norms even if they did not see it as a larger act of disruption to the hierarchy. They all knew they needed to tread lightly.

The skills to build support and acceptance among the many constituencies may not be part of a health literacy leader's skill set when she embarks on the job. Moreover, she will likely be challenged by lack of knowledge of (a) the inner workings of the bureaucracy, (b) the organization's approval and change processes, (c) the systems for rolling out change initiatives, (d) the independent nature of healthcare providers' medical groups, and (e) much more.

It would behoove health literacy change leaders to identify the people in the organization who understand all of the above areas and recruit mentors from within that group to teach them the politics and processes necessary to make systemic change. In addition, they would benefit from identifying all appropriate training opportunities to learn more about their own organization's inner workings.

In the subsequent sections of this chapter, I examine several aspects of two contrasting paths to developing health literacy initiatives revealed in the voices and stories of the participants: one path where there is a strong will to effect change and the other without the adequate will to effect change. I then identify and describe four unique aspects of adoption and implementation this study revealed which are not found in the literature, including some

challenges health literacy change leaders may experience with regard to bringing the required skills to the change process.

In the following sections, I discuss the need for a more strategic approach to change and I offer a new component that could be added to three organizational change models to be of particular benefit in health literacy adoption and implementation. Then I cover personal reflections on what I have learned and how it relates to my own experience as a health literacy change leader. Last, I discuss the limitations of the study and directions for future research.

### **Paths to Developing Health Literacy Initiatives**

The literature on organizational change in healthcare shows that executive-level leaders in healthcare organizations could create a climate that promotes health literacy by providing strong leadership support, identifying health literacy as a strategic priority, setting goals, allocating resources, creating policies, and establishing systems for performance measures. Three factors found in the present study, but not in the literature, advance our understanding of other influences that can create a climate to promote health literacy: (a) senior leadership's awareness of health literacy; (b) the health literacy change leaders' access to meet with and present to leaders and managers at all levels; and (c) the location in which the health literacy initiative is placed in the organization. These three factors are discussed later.

The above organizational changes for promoting health literacy, like any other improvement effort, can only be successful if (a) the will and (b) the skill to make it happen exist (Langley et al., 2009). The will must be present at a high enough leadership level in the organizational hierarchy to effect change. Additionally, the skills and knowledge required to make the change for improvement must be present in the health literacy change leader. I now

describe the two contrasting paths to developing health literacy initiatives: one with a strong will for change and the other without the will for change.

The data in this study suggest that there are two paths along which health literacy initiatives generally seem to evolve. Organizations on the first path enjoy strong, high-level leadership support and the initiative advances well with many streams of health literacy activities occurring in the organization. Organizations on the second path have little to moderate leadership support, not necessarily at a high level, and the initiative does not advance well or easily as evidenced by few streams of health literacy activities occurring.

As discussed in the findings, Pearl, one of the participants in an organization on the second path, described her experience as the health literacy change leader using a metaphor of digging a tunnel with a tablespoon. This metaphor represents the hopelessness and frustration Pearl experienced working in an organization in which she could make little progress. Perhaps her use of the metaphor indicates her frustration with having ineffectual tools, the feeling of working underground, and the discouragement of making virtually no progress in relation to the magnitude of the job.

I extend this metaphor to describe the very different experience of other participants. In contrast to the metaphorical tablespoon Pearl was using, health literacy change leaders in organizations with strong leadership support could be seen as having been given a metaphorical backhoe as their tool for digging. The backhoe could represent a highly-effective tool which digs a large, visible trench, providing easy progress in relation to the magnitude of the job.

Organizations on the first path, those with strong leadership support, represent the organizations using a backhoe in the tunnel-digging metaphor. I use the descriptor *Path One* for this type of organization. Organizations on the second path, those with little to moderate support,

represent the organization using a tablespoon in the tunnel-digging metaphor. I use the descriptor *Path Two* for this type of organization.

Which path an organization takes seems to be determined early on by the presence or absence of engaged senior leadership support, an influence reinforced by many theories of organizational change (Kotter, 1996, 2012; Langley et al., 2009; Rogers, 2003). The Institute of Medicine's list of attributes of a health literate organization declares the first attribute is having leadership that makes health literacy an essential component of the organization's mission and operations (Brach et al., 2012). I now describe some of the key characteristics of organizations on both paths.

### **The First Path**

The health literacy initiatives which were advancing well were typically in Path One organizations, i.e., those that had strong, engaged leadership support. The first step in the development of this setting is for a leader to be exposed to health literacy and to become aware that it is an issue that needs to be addressed in the organization. About half of all organizations in the study had learned about health literacy when a senior leader became aware of it and brought it into the organization. The health literacy initiatives in these organizations were described as advancing well. As we saw in the findings, there were a variety of avenues through which leaders learned about health literacy. For review, these avenues included hearing about it from people in other healthcare organizations, seeing the American Medical Association health literacy videos, and internal recognition of a need or problem such as reducing readmission rates or better integrating patient education across the system.

After becoming aware of the challenges related to health literacy, a top leader in a Path One organization usually uses his or her interpersonal communication networks to obtain support

for the cause from other leaders. This process is described in the authority innovation-decision process (Rogers, 2003). The group of leaders decides to address health literacy and then authorizes a cascade of events which unfolds through the action and direction of one or more senior leaders (Kotter, 1996; Langley et al., 2009; Rogers, 2003). These events usually include making an explicit commitment to health literacy by embedding it in the organization's mission, values, and strategic plan. The senior leader also assigns an executive sponsor to oversee the initiative. The sponsor has responsibility and authority to provide leadership, report to the board, communicate about the importance of clear communication to other leaders, and to provide access to other leaders for the health literacy change leader (Langley et al., 2009).

Other actions by the senior leader(s) might include assembling an interdisciplinary team of leaders at various levels who serve as a guiding coalition, communicating widely to promote and bring attention to health literacy, designating resources, reminding staff that engaging in interventions is an expectation, creating a project charter, setting policies, and possibly mandating compliance in some activities such as attending training (Langley et al., 2009). The executive sponsor and the group of senior leaders then decide where to place the office and staff who will be dedicated to health literacy, often placing them in an organization-wide department. They establish and fill a position for a health literacy change leader who is likely the person to serve as project manager to oversee day-to-day operations under the guidance of, and with support of, the executive sponsor and guiding coalition.

The next phase is led by the newly-assigned or hired health literacy change leader. This individual typically presents on health literacy to leaders and groups of other employees, works closely with the guiding coalition, and identifies people who want to (a) be on the coalition, (b) serve as champions, or (c) try Plan-Do-Study-Act (PDSA) cycles. The people who engage in

conducting PDSAs determine what to try and discover what works, a process that aligns with Kotter's step of removing barriers and empowering people to participate in the change (1996). The people who engage in PDSAs are participating in Rogers' Stages of Innovation Process in Organizations when they implement and then redefine and adapt the innovation (Rogers, 2003). These successes can turn skeptics into champions.

All of the above actions, metaphorically, provide the backhoe to dig a path for health literacy. The overall result of this path, or some version thereof, is a strong, active health literacy program with a good base of support. There are many health literacy interventions and activities occurring, and progress evolves, is celebrated, and embedded into standard processes. Another result of this model is a happy, fulfilled health literacy change leader who speaks positively about her work.

### **The Second Path**

In contrast to the above, the health literacy initiatives which were advancing more slowly and less broadly were typically in Path Two organizations, i.e., those that had little to moderate senior leadership awareness and support. About half of all the organizations in the study had learned about health literacy because an individual inside the organization who was not a senior leader began to talk about it in the organization. Those individuals either noticed problems with patient communication and learned those issues were a part of the health literacy field, stumbled onto health literacy in some aspect of their work, or knew about health literacy when they came into the organization. Often these individuals eventually became the health literacy change leader.

In these Path Two organizations, there was enough leadership support to either (a) give the person who was concerned about health literacy permission to spend part of her time working

on it, or (b) create a new part-time or full-time health literacy position, often for the person who had raised the issue. However, the person allowed to, or charged with, addressing health literacy was seldom perceived as leading a change effort. Instead, these individuals tended to be seen as project managers or simply as editors to revise the organization's documents. They were usually not given explicit access to other senior leaders, directors, managers, or other decision-makers. In Path Two organizations, the location of the health literacy staff person tended to be in the area in which they were already working (e.g., the library) or in an area which did not have organization-wide reach and sometimes had little to do with health literacy (e.g., home care and hospice).

In these organizations, the leader who authorizes health literacy work often seems to let the health literacy change leader do whatever she thinks is best. The senior leader may be busy with other demands, and possibly has such divided attention, that he or she has not been able to think about what the change leader will actually need to do to address health literacy.

In Path Two organizations, the senior leaders typically do not (a) make an explicit commitment to health literacy, (b) create a strategic initiative, (c) assign an executive sponsor, (d) open access to other leaders, (e) create a guiding coalition, (f) set policies, or (g) mandate activities. They may have too many competing demands, limited resources to allocate, little attention for new initiatives, and no awareness that their actions on the above items are needed. They also may not realize the health literacy change leader will need to

- create her own guiding coalition and find her own champions;
- find a way to raise health literacy awareness with other leaders through various communication channels despite hierarchical access barriers;
- develop ideas for programs to address health literacy;

- find people to try new activities with no incentive for them to do so; and
- fill all of the following roles: spokesperson and advocate for health literacy, project manager, subject matter expert, trainer and presenter, editor, writer, graphic designer for print materials, and more.

Moreover, the senior leaders may not yet have a clear understanding of the importance and potential impact of health literacy since they were, after all, not the person who brought it to the organization's attention. They may have only a vague understanding of health literacy as something that should be addressed in some way. In this context, it is understandable that they would not be driven to take the above actions which could make the health literacy change leader's work more achievable. In this situation, the health literacy leader is asked to take on many roles for which she has little background, support, or resources.

All of the above actions, metaphorically, provide only a tablespoon as the tool to dig a path, an underground tunnel, for health literacy. The overall result of Path Two, or some version thereof, is a weak and struggling health literacy program, usually with a small base of support. There are a few health literacy interventions and activities occurring, progress evolves slowly, and it is not likely to be embedded into standard processes.

Another result of this path is often a frustrated health literacy change leader who speaks negatively about her work. Advancing health literacy in Path Two organizations will not be easy and may occur at an excruciatingly slow pace. The health literacy change leaders need to find strategies for coping such as focusing on their personal connection to the cause. They also will need to dig deeply inside to find creative ways to work from within the context that encloses and constrains them.

Clearly, there is a different result depending on the general path on which an organization proceeds. The literature shows that leadership support is critical for progress in any new initiative (K. Davis et al., 2015; Harting et al., 2005; Spetz et al., 2012). With strong leadership support, health literacy initiatives are often equipped with the power of being declared a strategic priority, given adequate staff and funding, supported in establishing policies, and fortified by a team of champions. Without leadership support, the situation is very different. Progress is difficult, often demoralizing, and slow.

Leadership support appears to be the key factor in determining which path a health literacy initiative takes. Therefore, it is imperative to look closely at various ways leadership actions affect health literacy initiative adoption and implementation. Below I describe and discuss four unique aspects of health literacy initiative adoption and implementation not found in the literature. These aspects influence, or are influenced by, leadership support.

#### **Unique Findings of Adoption and Implementation in this Study**

While several studies in the healthcare and health literacy literature confirmed the central role of leadership support in organizational change (K. Davis et al., 2015; Harting et al., 2005; Spetz et al., 2012), they did not identify four unique findings that emerged in the present study. The data from this study contributes to knowledge of adoption and implementation of health literacy initiatives by identifying these previously unmentioned factors. These factors are (a) senior leadership's awareness of health literacy, (b) the health literacy change leader's access to leadership, (c) the location of the health literacy initiative, and (d) the multiple challenges faced by the change agent—the health literacy change leaders. I now discuss these unique findings and recommendations for praxis.

### **Leadership Awareness**

In order to provide support for health literacy, senior leaders must be aware of it, understand its implications, and see its strategies as useful in meeting organizational priorities. Without senior leaders' awareness, progress will be hindered greatly. However, leaders' attention is pulled in many directions in today's healthcare context of multiple priorities, acute time pressures, and shrinking resources (Kocher & Adashi, 2011; Scheck McAlearney, 2006; Wick et al., 2011). Moreover, health literacy is a somewhat abstract concept that is hard to define briefly and is not easy to visualize in practice.

Unfortunately, it seems common that many senior leaders lack exposure to, and an awareness of, what health literacy is and what it means to patients, how poorly most healthcare organizations are meeting the guidelines for becoming health literate, and how health literacy activities can help meet the objectives of other initiatives. Awareness will not expand beyond the leader or leaders who authorized addressing health literacy unless they use their interpersonal communication channels to inform their peers and other leaders. They also need to provide the health literacy change leader with access to directors, managers, supervisors, and staff at all levels. She will then be able to communicate about health literacy across the organization and continue to broaden awareness.

In a Path Two organization, the senior leader who simply allowed a health literacy change leader to begin addressing health literacy is not likely to promote it to his or her peers. In this situation, the health literacy change leader will need to take a larger role in raising awareness among senior leaders. This can be difficult because the person who allowed her health literacy work has usually not provided access for her to meet with or present to the other senior leaders. Other challenges she may face are (a) her own lack of a complete understanding of health

literacy and how to explain it, and (b) her lack of presentation and persuasion skills likely to be effective with the top leaders in the organization. These, and other, personal challenges for health literacy change leaders are discussed more below.

**Conclusion and recommendation for praxis.** Lack of awareness of health literacy is one of the biggest barriers to health literacy initiatives, and increasing awareness has its own barriers. More action is needed to spread awareness of health literacy in healthcare. I believe those of us who know the importance of health literacy should explore ways to increase exposure to, and raise awareness of, health literacy nationwide particularly among senior healthcare leaders. Healthcare professionals, who are passionate about health literacy but work in other healthcare specialties such as hospital administration, quality improvement, and patient safety, can help advance health literacy by talking with colleagues in their specialized fields. Senior leaders in Path One organizations with vibrant health literacy initiatives can talk to colleagues and present at conferences in their field. Health literacy specialists can seek opportunities to present at conferences, and write articles for trade publications, in related healthcare fields. Federal agencies can explore avenues to spread health literacy awareness beyond their current reach.

### **Access to Leaders**

The second unique finding in the study is the unexpected difficulties some health literacy change leaders experienced in being allowed to meet with or present to leaders at a variety of levels. Leadership access and attention are valuable commodities in healthcare organizations. If the senior leader who authorized the health literacy work does not arrange access to the other leaders by making it clear they should meet with the change leader or by ensuring she is on their

meeting agendas, her hands are tied. This phenomenon was seen primarily in Path Two organizations, i.e., those without strong senior leadership support for health literacy.

Not only does lack of access to leaders affect the change leader's ability to increase awareness but it blocks the ability to get started with health literacy activities that could themselves increase awareness. For example, there may be a few staff who are willing to work with the health literacy change leader to test the use of teach back, but they need permission. If the health literacy person cannot meet with their leader, there can be no permission.

**Conclusion and recommendation for praxis.** The health literacy change leader can meet with her supervisor and outline the impact of not having access to the people she needs to engage. Perhaps the leader who promoted or allowed health literacy is simply unaware of the lack of access to others. The health literacy change leader can ask that her supervisor request explicit actions from that leader. Those actions could be to (a) invite her to speak at some executive level meetings, (b) announce to other leaders that they should be ready to meet with the health literacy person, and (c) instruct others to allow time on the agenda of their group meetings. If this is not successful, the change leader can ask her supervisor to reach out to appropriate others and request those actions. If that is also unsuccessful, the health literacy change leader might find someone else at her supervisor's level that supports health literacy and ask for help in creating routes to access other leaders.

### **Location of Health Literacy Initiatives**

There is no mention in the literature of the location of a new initiative as a facilitator or barrier. Therefore, this third unique finding reveals a new aspect of adoption and implementation of change initiatives, in general. This finding relates to leadership support in that leaders determine where a new initiative is placed. Leaders in Path One organizations usually ensure the

initiative's programs are placed in an appropriate location and this becomes a facilitator. In Path Two organizations, the initiatives are often placed in locations without organization-wide reach, e.g., nursing or patient education. This can create a perception that only the people in that area need to pay attention to the activities of the health literacy office and this perception can become a barrier. Removing barriers to implementation, which can include barriers in organizational structure (Kotter, 1995), is one of the steps in Kotter's Eight-Step Model.

In the present study, the location of the initiative's office and staff was crucial to the way in which it was perceived throughout the organization. Additionally, how it was perceived by the leader likely determined its placement. Perhaps health literacy offices' placements were affected by senior leaders' perceptions of whether the potential benefits fit with organizational problems (Rogers, 2003). Since health literacy is still an unfamiliar body of knowledge to many leaders, their perceptions of the best location for the initiative may have been affected by incomplete knowledge. If they didn't understand what health literacy is and the benefits of the strategies to address it, they may not have been able to see where it would best fit. Later, as their understanding of health literacy grew, perhaps from the experiences of employees who were piloting health literacy best practices, leaders' perceptions of where it fit best might have changed. This could explain why the initiatives were moved to different, although not always more appropriate, locations in some organizations.

**Conclusion and recommendation for praxis.** Health literacy change leaders and their supporters need to advocate strongly for the health literacy initiative's office and staff to be located in an area with organization- or system-wide authority and reach. Being appropriately located can remove barriers related to organizational structure (Kotter, 1995). Not having a generally-agreed-upon location for health literacy initiatives in healthcare lessens their impact.

As with the patient experience movement which is becoming more commonly found in healthcare organizations, health literacy may take more years to become widely-understood as a concept that touches everything and should, therefore, be in an organization-wide location.

### **Challenges Faced by Health Literacy Change Leaders**

About half of the health literacy change leaders who said they work in organizations with little to moderate leadership support described their work as difficult. Their depictions of their experiences in leading health literacy were more negative than the depictions of health literacy leaders in organizations with strong leadership support. There appear to be several reasons for the negative and difficult experiences these participants in Path Two organizations reported. Here I outline some of the unique challenges that exist for all health literacy change leaders but which may be especially difficult for those with little to moderate leadership support.

**Challenges of leading change in a bureaucratic organization.** The actions of health literacy change leaders are both enabled and constrained within the bureaucratic structure of their organization (Lyndon, 2008). As health literacy change leaders navigate their way in the bureaucracy, they need to unearth and learn how to use the forces which enable and constrain their work. The task of unearthing the unspoken rules of such actions as where to sit in a meeting with the leaders can be nearly impossible. In those cases, trial and error are the trick and, as Sheila learned when she sat in the wrong place, the learning can be uncomfortable.

Health literacy change leaders must work within the bureaucratic structure while concurrently asking others to examine assumptions, administrative and technical processes, and communicative practices between patients and the people and documents in the structure. Working to engage people in the social interactions and communication required to reconstruct aspects of the rigid, but socially-constructed bureaucracy, can be difficult and taxing. Being in

the role of innovator can be stressful on individuals who question existing organizational practices (Anderson et al., 2004). Moreover, making change in a healthcare organization can be very political and, therefore, emotionally stressful (Lansisalmi, 2006; May et al., 2003). Without the material and emotional support of senior leaders, health literacy change leaders may become stressed, discouraged, and/or leave the organization (Lansisalmi, 2006).

**Isolation and need for networking.** Without nation-wide data, it is impossible to know how many organizations have created positions to address health literacy. However, one can look at the number of people subscribed to the health literacy listserv and the number who attend health literacy conferences. The international listserv has about 1,600 subscribers and the health literacy conferences in the U.S. usually attract 200-300 attendees. These are relatively low numbers considering the American Hospital Association reports there are more than 5,500 hospitals in the U.S. I also reflect on my experience in the field and many conversations with colleagues and people who work in healthcare but not in health literacy. These things all point toward there being relatively few full-time health literacy positions across the country.

It can be hard for health literacy leaders to find people in similar positions in other organizations for professional networking, support, and the sharing of approaches that have been successful. Moreover, many of those who lead health literacy initiatives are the only person charged with advancing health literacy in their organization. While they may have teams, champions, and others to help, there is no one else in the organization in a similar position with whom they can compare notes. In contrast, in healthcare organizations there are many people who serve as the director at an ambulatory clinic, for example. Others in the same role throughout the organization might have similar challenges. They could talk to each other for

mutual support and learning. Health literacy change leaders would not have that luxury and, therefore, may experience feelings of isolation.

I believe the feelings of isolation and frustration when lacking success in their work speak to their willingness to talk with me as described in the findings. Perhaps this eagerness to talk about their work comes from the fact that many of them are the sole person responsible for health literacy in their organization. I believe a chance to “talk shop” with another health literacy professional was appealing as evidenced by Pearl calling our conversation a gift. This also speaks to the challenges of working in healthcare organizations when one is trying to advance an initiative whose importance is not yet widely known or embraced.

***Conclusion and recommendation for praxis.*** Health literacy change leaders could benefit from networking with others who have knowledge of their struggles and are in similar situations. It may be helpful for them to find health literacy leaders in other healthcare organizations for shared learning and support. In addition, those who work in the health literacy field could develop more ways to support and connect change leaders to each other across states, regions, and the country.

Also, it would be productive to have a national health literacy conference focused specifically on the needs of those who are working to implement health literacy initiatives in healthcare organizations. Perhaps one of the federal agencies that work in health literacy, e.g., Agency for Healthcare Research and Quality or the Centers for Disease Control and Prevention, could convene such a conference. They have set out health literacy goals for healthcare organizations and listed the attributes of health literate organizations but provide little guidance on how to achieve them. The guidance in the documents can make it sound simple to achieve the

goals but some participants describe being stymied and frustrated in their attempts to get the goals and attributes on their organization's agenda.

**Health literacy change leaders' backgrounds vs. their diverse job responsibilities.**

Participants' reported having a wide variety of educational backgrounds. Their degrees were in the following areas: anthropology, business administration, marketing and public relations, healthcare administration, healthcare finance, library science, medical writing, medicine, nursing, public administration, public health, quality improvement, and sociology. Of course, each of the above degree programs could contribute to some aspects of a health literacy job but would not adequately equip the person for the breadth of their duties in a health literacy position.

Given the demands and wide diversity of the role and tasks health literacy change leaders reported doing, a formal training program would need to be quite comprehensive. Participants reported carrying out many different tasks including

- leading an organization-wide initiative (sometimes doing the tasks normally done by an executive sponsor);
- selling health literacy as an important and useful subject to a variety of audiences;
- implementing organizational change models and strategies, e.g., helping staff use PDSA cycles to assess the best work flow for using teach back;
- developing and delivering content for presentations to leaders and for professional development for employees;
- developing and revising forms and informational material for patients; and
- consulting with employees on various aspects of health literacy, health communication, and patient/provider communication.

Health literacy change leaders may have a steep learning curve in at least a few topics. The sheer volume of content, in such diverse areas, which health literacy change leaders need to know, might seem staggering. In addition, many are not aware of some of the content they could benefit from knowing.

There are four primary overarching categories of knowledge and skills health literacy change leaders need: (a) health literacy, (b) development and delivery of presentations and training programs, (c) internal structure and culture of the organization and the external forces that influence it, and (d) organizational change, diffusion, and process/quality improvement. Health literacy includes its epidemiology, principles of plain language and clear communication, patient/provider communication, developing and revising reader-friendly materials and forms, language and literacy acquisition, involving patients in providing feedback and assistance, health disparities, and health inequity. A second category is development and delivery of presentations and training programs which includes adult learning principles, speaking skills, curriculum development, instructional systems design, technology used in delivering training, and the organization's system for tracking employee attendance and progress in training programs.

The third category is the internal structure and culture of the organization and the external forces which demand its attention. This includes the codified and uncodified rules and norms of the bureaucracy; the rules for navigating the vertical leadership communication network as well as communication across the organization; how decisions are made; finding stakeholders and learning about their needs and priorities; and understanding the external mandates, regulations, and accreditation requirements that affect the organization. The last category is organizational change which includes models, theories, and processes of organizational change; theories of

diffusion of innovations, adoption, and implementation; and principles of quality and process improvement.

*Conclusions and recommendation for praxis.* A helpful resource for health literacy change leaders might be a framework or curriculum which lists all the knowledge and skills a health literacy change leader might find helpful. There is one such list in development at this time. The Institute for Healthcare Advancement, a national leader in health literacy, sponsored a Job Task Analysis Task Force in 2016 to identify the basic knowledge and skills health literacy professionals need. When it is finalized, it might be useful for health literacy change leaders who would like to know of areas in which increasing their knowledge might be helpful to them. This could be accompanied by a list of resources for learning more in each area.

**Knowledge of organizational change and implementation.** Health literacy change leaders need to lead change efforts and participate in improvement projects as a central part of their jobs but the literature and data from the present study suggest they lack knowledge about models for change and quality improvement techniques (DeWalt et al., 2011). Without the knowledge and skills to use processes and tools for change and improvement, busy health literacy change leaders may find it challenging to direct a change project while also addressing the need to raise awareness, develop policies, revise documents, and the many other tasks involved in health literacy initiatives (DeWalt et al., 2011).

All of the organizations that used a formal model for change were on Path One and less than half of the organizations that did not use a formal model were on Path One. This suggests that using a formal organizational change model (which provides an explicit structure and plan) as a framework for advancing health literacy initiatives would be beneficial to healthcare organizations. These findings reveal a general disconnect between theory and praxis. Health

literacy change leaders could benefit greatly from knowing more about formal organizational change models, in general, and, in particular, their own organization's change model(s) and/or informal paths for change.

***Conclusions and recommendation for praxis.*** One of the most important changes health literacy change leaders can make is to address the disconnect between theory and praxis by delving into the area of organizational change and quality improvement models and techniques. They can benefit from starting their exploration by first looking at the need for a more strategic approach to their initiatives' development. The use of a formal model itself may not be the most crucial factor but rather the structured and strategic thinking and planning it creates. Adopting any framework for a more strategic approach may be sufficient to usher in great change. I elaborate on this in the next section. Here I continue with some recommendations for health literacy change leaders to learn more about (a) their organization's models for change and (b) organizational and quality improvement models, in general.

Health literacy change leaders may benefit from exploring their organization's offices of quality, change management, quality improvement, process improvement, and/or professional development to determine if the organization uses a formal model for change. If so, the change leaders might want to ask if there are training sources or mentoring support available.

If there is no formal model being used, they could try to find someone who can mentor them in identifying the informal processes for change. They may also want to find the leaders of other initiatives such as becoming a *Baby-Friendly* or a *Magnet* hospital and ask how their initiatives were spread in the organization. These people could serve as informants on successful processes.

Health literacy change leaders, particularly those without strong leadership support, may want to learn about Kotter's Model on their own as an overall framework for approaching their initiative. It may help them and their guiding coalition think through the processes they could use to move forward without fully-engaged leaders (Kotter, 1995, 2012).

If the organization uses the Model for Improvement, health literacy change leaders may want to find the people in the organization who are trained in using PDSA cycles, ask for help in learning, and then start by finding someone to help them do a small PDSA (Langley et al., 2009). They may also want to read *The Improvement Guide* (either edition). They may also consider starting an internal learning collaborative of people who are willing to try PDSAs for health literacy in their area. Sharing their findings about using PDSAs, as well as the results of the PDSAs themselves, could be beneficial to everyone.

### **New Approaches Suggested by a Broader View of Models and Change**

Given the study's findings relative to organizational change models and the disconnect between theory and praxis, I did not envision a new model for health literacy adoption and implementation being necessary or productive. There are already organizational change models and quality improvement frameworks that work well. The four organizations that use formal, explicit models for change in their health literacy work were the Path One organizations with the most progress in advancing their health literacy. These findings suggest that applying existing models like the Model for Improvement and Kotter's Eight-Step Model are sufficient and beneficial in ushering in health literacy changes.

However, at least one Path One organization used only informal methods for change, so a formal model is not necessarily the critical component. Rather than the model itself, I suggest the

critical component is an explicit, strategic, and structured approach to the larger change process that is being attempted in health literacy initiatives.

The Model for Improvement and LEAN are examples of strategic and structured approaches used for many types of change in healthcare. They use tools like charters and change packages (written statements of the aim of the change and the implementation). For example, a change package usually outlines (a) the problem, (b) the reason it needs to be addressed or assessed, (c) the leaders who endorse and/or mandate the changes, (d) the goals of the change package, (e) a plan and timeline for addressing it, (f) who will do which piece of the plan, and more. Going through the process of creating a strategic approach such as a charter or change package may require a great deal of work in collaboration with multiple people and departments in several of the multiple hierarchies in the organization. I suggest it is the process of thinking through, developing, and engaging in communication cycles about the initiative that is the critical component.

This process will be difficult and likely less-fully developed, if strong leadership support is lacking. Path Two organizations may struggle to create a full change package but can still benefit from engaging in an explicit process of developing a strategic approach and a master plan.

To provide structure for developing a strategic plan, health literacy change leaders could use the Model for Improvement, Kotter's Model, elements of Diffusion of Innovations, and/or Lewin's processes singly, or in combination. For example, beginning with Kotter's Model as a larger framework (with the addition of the listening tour discussed in detail in the next section) would provide the guidance for an overarching strategic plan. The Model for Improvement's three questions could serve as prompts for the first phase of identifying the aim of the initiative.

Applying information about the attributes of innovations from the Diffusion of Innovations theory could contribute to determining how to frame the problem as well as how to decide which activities might be easiest to address first. Keeping aspects of Lewin's steps and processes in mind can also inform the development of the plan.

Regardless of whether health literacy change leaders use a formal model as the foundation for their strategic plan, the point is that a strategic approach is crucial. Having a solid, well-developed strategic plan, and then working to carry it out, may be a way to enhance health literacy advancement in both Path One and Path Two organizations that currently lack a strategic approach.

In developing a charter, change package, or another type of explicit strategic plan, it may be helpful to learn from the experiences of another organization's health literacy efforts. Becoming familiar with a successful organization's journey could provide a framework for others to adapt and adopt. The utility of examining the successes, challenges, and lessons learned by another organization cannot be understated. Knowledge of various aspects of the other organization's journey can provide guidance, structure, and ideas for a strategic plan. In the "Isolation and need for networking" section above on health literacy change leaders' challenges, I outline several recommendations for enhancing ways for health literacy leaders to connect with and learn from each other.

In addition, there is a guidebook available that was written specifically to provide an example from a healthcare system that has been successful in adopting, implementing, and embedding health literacy awareness and activities throughout multiple hospitals and clinics in its multi-state system (Abrams et al., 2014). This guidebook is available as a free pdf file on the

internet, yet none of the participants in the study mentioned using it. This suggests wider distribution of the guidebook would be helpful to health literacy change leaders.

### **A New Step for Organizational Change Models in Health Literacy**

This study contributes a potentially powerful new step to organizational change models and theory. Perhaps some version of this step is assumed in change models but I believe it needs to be explicitly featured as a key addition to theory and praxis. This step is what one participant called a *listening tour*. It can be seen as an exploration or discovery step where the goal is to listen and learn.

Two participants, both from Path One organizations, reported using this strategy extensively. Both individuals were new to their organization and their health literacy position. They both spent two to three months conducting their listening tour before beginning any health literacy activities. In one case, the participant was allowed the time and access to meet with over 100 people at all levels of the large system. In the other case, the participant was directed to meet primarily with C-suite leaders, vice presidents, and executive directors.

In both cases, the health literacy change leader's supervisor, a senior level executive, communicated to other leaders and to employees that they would be contacted by the new health literacy leader in the coming weeks. The supervisors made it clear they supported these meetings and they expected cooperation. The supervisors' explicit communication that they expect cooperation created a crucial path of access to the other leaders and employees for the health literacy change leaders. Normally, when someone lower in the organizational hierarchy requests to meet with executive leaders, this upward communication disrupts the hierarchy and the communication rules of the bureaucracy, and there may be resistance from the people who are accustomed to one-way downward communication.

A listening tour is designed to learn about the priorities, challenges, needs, motivations, and successes of the people who work in the organization as well as the organization itself. This knowledge can provide a health literacy leader with a great deal of rich information which can be used in many settings in the future. A listening tour can be most beneficial if done as the first step in introducing an initiative but could also be helpful if done later in the adoption or implementation process.

### **Benefits of a Listening Tour**

Regardless of whether a health literacy leader finds herself in a Path One or Path Two organization, an essential step is to learn what matters most to the people who work in the organization. By meeting with as many people in the organization as time and access allow, and by listening and being curious, a health literacy leader can learn a great deal. Whether she conducts a listening tour as she first starts in her health literacy position, or later, she has a tremendous amount to gain through this strategy.

Such an approach offers many benefits to (a) the change leader, (b) the health literacy initiative, and (c) the organization. The health literacy change leader can learn about the organizational structure, culture, norms, rules, and politics; the employees' priorities, needs, challenges, and successes; the opportunities for health literacy to be useful; and strategic ways to frame health literacy for discussion and presentations later.

The two participants, Sheila and Nolan, shared extensively about their experience with listening tours and described them as crucial to their future work. Sheila, who works in a single hospital that serves patients from several states, remembered how her meetings helped her understand the organization,

...I scheduled meetings with all the key leaders...[that's] when I was starting to understand the culture of the organization, where the strengths were, and where the opportunities were for my program...Because I was new to the organization, it ended up being a really crucial piece of getting off on the right foot.

Nolan, who works in a large healthcare system with several hospitals, described how his listening tour helped him frame his communication back to the employees later,

...it helped me understand, 'How did this fit into a busy person's day?' 'Why would it be important to them and the system?' ...That allowed me then to resonate back to the group..., 'These are the things...I'm thinking about solving. What do you think about that?'

The listening tour will naturally raise awareness of the initiative, and perhaps curiosity about it, by virtue of people meeting face-to-face with the new change leader and hearing about health literacy. Listening may also build goodwill and buy-in for the initiative by demonstrating that the health literacy change leader is willing to be a learner. In addition, in the course of those conversations it would be natural for some information about the change leader's background, passion for health literacy, and goals for the initiative to arise. Subsequently, if key people who have met with the change leader decide she is likeable, credible, trustworthy, and potentially helpful with some of their daily challenges, they are likely to share those impressions through their interpersonal communication networks.

Neither of the models reportedly being used in participating organizations' health literacy initiatives (Kotter's Eight-Step Model and the Model for Improvement), nor any others I reviewed, explicitly include this strategy. The listening tour strategy can make a theoretical contribution to the two models currently being used in health literacy. In addition, it can

contribute a new dimension to the Diffusion of Innovations theory, also covered in the literature review. I now discuss the listening tour's contributions and uses as an additional element in these three models.

### **The Listening Tour and Kotter's Eight-Step Model**

The listening tour strategy could be fruitful if added to Kotter's Eight-Step model. Such a tour could support and enhance the first three steps of the model, so ideally it would be conducted before any of the three steps are begun. Kotter's first step is to establish a sense of urgency which begins by helping people see the need for a change and the importance of speed in addressing it (Kotter, 1995, 1996, 2012). A listening tour could raise awareness of a need for health literacy simply through people becoming aware of its existence as an innovation (Rogers, 2003). But perhaps more importantly, the listening tour can equip the health literacy change leader with the information she needs to frame health literacy in meetings and presentations later in such a way as to create the urgency.

Kotter's second step is to create a guiding coalition, a group of powerful, influential, diverse supporters who can become champions for the initiative (Kotter, 1995, 1996, 2012). The change leader will be meeting many people in the tour and will learn who is already interested in health literacy. She will be better equipped to assemble her guiding coalition, which is especially important if she is in a Path Two organization where the senior leader has not designated a team to help her.

Kotter's third step in the model is to develop a vision for the change that would serve to motivate people. The vision must engage the heads as well as the hearts before people will decide to join the effort (Kotter, 1995, 1996, 2012). After a listening tour, the change leader will be more familiar with the topics people care deeply about and can incorporate those in early

versions of the vision and the strategic plan as she begins to work with her coalition to develop and refine them.

The benefits of adding a listening tour before embarking on Kotter's steps are many. This step should be considered by health literacy change leaders at any point in developing their initiative but particularly early on.

### **The Listening Tour and the Model for Improvement**

The Model for Improvement consists of three key questions and the Plan-Do-Study-Act (PDSA) cycle (Langley et al., 1996). The three key questions are (a) "What are we trying to accomplish?", (b) "How will we know that a change is an improvement?", and (c) "What changes can we make that will result in improvement?" After the questions are considered and answered, the next step is to plan and carry out a small test of change using the PDSA cycle (Langley et al., 1996). The cycle's four elements are sequential and are often cycled through multiple times for each change project. A health literacy example might be one physician assistant testing the use of teach back with one patient each day for a month to discover how well it fits with the clinic workflow, if it works, and what unanticipated problems might arise.

The Model assumes that organizational leaders will initiate the overall change process, but answering the questions and running PDSA cycles requires the participation of everyone involved in the change. This democratic and participatory process is a key part of the Model and can result in less resistance since the participants are creating the change (Donnellon, 2014; Langley et al., 1996; Lewin, 1946, 1947). Successful implementation of the Model for Improvement requires learning how to ask the questions, carry out the PDSA cycle, and understand the interactions among the people involved and the system in which they are creating change (Langley et al., 1996).

A listening tour by the health literacy change leader can be instrumental in discovering the kinds of questions being asked in the organization, what small tests of change and PDSA cycles are being used, how widely the model is being used, and how the people involved feel about it. This can contribute to understanding the problems that are being addressed as well as the inner workings of the local change processes being used to address them.

Hearing about this often-used model for change in a listening tour can also help the health literacy change leader understand the overarching model for change and how change is seen in the organization. Having this knowledge can provide the health literacy change leaders with invaluable insights for creating the strategic plan for implementing health literacy processes and activities in the organization.

### **The Listening Tour and Diffusion of Innovations**

In applying the Diffusion of Innovations' theory (Rogers, 2003), there are several ways the listening tour can be of benefit. One way is related to interpersonal communication networks of near peers, one of the key elements of the Diffusion of Innovations theory (Rogers, 2003) mentioned above. As the health literacy leader meets with people to listen to their concerns, those people are likely to then tell others what they think of her. In this way they will be serving as opinion leaders in the interpersonal communication networks.

The second way a listening tour can be of benefit is related to empathy, a characteristic of the change agent (Rogers, 2003). A change agent's empathy is positively related to his or her success in convincing others to adopt the innovation. After a listening tour, a health literacy change leader—the change agent—will know more about the challenges and daily work lives of the people in the organization and may have developed a greater sense of empathy for the people she hopes to engage. This could enhance her ability to relate to and communicate with them.

A third way a listening tour can benefit relates to the innovation-decision process which is applicable to both individuals and organizations. The initial stage of the process, gaining knowledge by learning about the innovation, begins when an individual is exposed to the existence of an innovation. Rogers (2003) theorizes that a need for the innovation can be created by simply learning that a new idea or process exists. During the listening tour, while meeting with individuals, the change leader would primarily be listening to the other person's perspectives. However, during the process of setting up the meeting, health literacy would be briefly discussed to explain the reason for meeting. Even this small exposure could provide at least a bit of new knowledge about the existence of health literacy to the person with whom the health literacy leader is meeting.

A fourth way a listening tour can be useful relates to the five perceived attributes of innovations: (a) relative advantage, (b) compatibility, (c) complexity, (d) trialability, and (e) observability. Using the information gleaned in a listening tour, a health literacy change leader may be able to speak explicitly to how the innovation, a new health literacy activity, provides relative advantage, is compatible with existing processes and workflow, is easy to use and try, and/or is observable.

For example, she may have learned during her listening tour that nurses are often frustrated that patients don't comply with medical instructions. So later, when she talks to nurses about teach back, she can focus on the attribute of relative advantage by explaining how it can improve patient understanding and compliance. Moreover, she can focus on observability and complexity by demonstrating its use. In this way, she uses what she learned by featuring the key attributes in ways that address the concerns of the nurses.

**Summary.** In summary, conducting an extensive listening tour soon after starting as a new health literacy change leader, especially if she is also new to the organization, could set the stage for a successful future for the initiative. Health literacy change leaders who are not allowed to take the time for a listening tour, or do not choose to do so, are missing an opportunity to build a foundation of understanding and empathy for their initiatives. Moreover, this strategy will work well in any initiative for organizational change for many of the reasons outlined above and perhaps many others. It is my hope that more organizations will begin to include this step.

### **Personal Reflections**

Through the process of conducting this study, I have grown both personally and professionally. The study was motivated by two things. First, I have been moved by my observations of the difficulties in implementing health literacy initiatives that I have witnessed through my work with clients and colleagues in the field. Second, my work is informed by my own experience as a health literacy change leader, but also as a patient with a significant health challenge and a family caregiver of two terminally-ill parents who have passed on. Like the health literacy change leaders in this study, it is deeply personal for me as I remember my parents' and my journeys.

I am deeply motivated to continue doing what I can to improve the ways in which healthcare and health communication is delivered and practiced. I believe there are too many patients and families who experience confusion, fear, and inadequate care because health literacy is not being addressed in their healthcare organizations. I came to the study with knowledge and experience which I could bring to bear but which also meant I had to be careful to manage my bias in the study. I discuss my reflexivity in Chapter Three.

I resonated with much of what the participants communicated about their experiences. I have a much better understanding of the dynamics present in my work when I was a health literacy change leader and I now see several things I would do differently. Hearing participants' stories has shown me that I was fortunate in some aspects of my experience as a health literacy change leader and not so fortunate in others.

I learned about myself, my former organization, and the situations of other colleagues in health literacy as I reflected on what I was hearing. I come away from the study having learned so much from the stories of the participants—many principles and strategies which I can apply to any future positions I may have and which I can impart to clients as a health literacy consultant.

Hearing the stories of my participants' journeys deepened my compassion and respect for health literacy change leaders. I was inspired, but not surprised, by their passion for their work. I was also impressed with their patience and tenacity. I was reminded that change takes time. Many of them overcame barriers and frustrations that could have caused them to give up, but they persisted. Their commitment to easing the journeys of patients and their families was uplifting. These characteristics are particularly remarkable in light of the fact that most of them had little formal training in health literacy and other areas they needed to master to be effective. They just kept going. The things I learned from them will inform my future professional work and my personal journey. My admiration and respect for them all are immense and I am grateful for their willingness to share their successes and struggles with such openness, clarity, and grace.

### **Limitations**

The present study has several limitations. I begin with limitations of the sample. This study illuminates the experiences and perspectives of the participants. Applicability to other populations must be considered cautiously, however, the strong saturation of findings suggests

the usefulness of these findings for exploring health literacy implementation in other organizations.

The goal of qualitative, or purposive, sampling is to select cases based on a specific purpose rather than for randomness (Teddlie & Yu, 2008). The purpose of the present study was to obtain rich, detailed accounts using the voices of participants (Baxter & Babbie, 2004). Therefore, the purpose of the sampling was to locate specific cases which could provide those rich accounts to answer the research questions.

The purposive, typical case sampling (Teddlie & Yu, 2008) was designed to locate organizations that represented the larger group of all healthcare organizations in the United States that are currently in the process of adopting or implementing activities to advance a health literacy initiative or program. One limitation of the sample is that it may not have, in fact, been representative of all organizations that fit the description above. For example, I identified two primary types of organizations which I call Path One and Path Two. There may be (a) other types of organizations or (b) organizations that have characteristics of both paths which could be seen as outliers. Interviewing someone in an outlier organization, e.g., one in which there was little leadership support and the health literacy initiative was, nonetheless, advancing quickly and easily, would be an informative deviant case to explore.

Another limitation is that I interviewed only one person from each organization (with the exception of one organization in which two people who work closely wanted to join the interview). This offered only one lens through which to view the organization's health literacy work. However, the breadth and diversity of the participants and these findings provide a useful lens for exploring and understanding this issue in other organizations. A quantitative survey and an in-depth case study approach could both be fruitful in future research.

Additionally, all of the interviews were conducted by phone and audio-recorded which eliminated the visual and non-verbal cues inherent in face-to-face communication. Overall, though, the conversations flowed easily and naturally and did not seem to suffer from lack of visual cues.

Another limitation, as with any interview-based research, is the willingness of participants to answer honestly. Participants were assured I would protect their privacy throughout the research, including in the write-up of the findings. Two participants were particularly concerned about the recordings (interestingly, not the transcriptions) saying the health literacy field is a small world. Both requested that I delete the audio recording right after the transcription was completed. I consented, of course, and to reassure them, I sent them each an e-mail confirmation when I had deleted the audio file after transcription. Being assured the audio recording would not be kept long-term probably contributed to their comfort and honesty in their responses. No other participants mentioned confidentiality concerns. Neither did any participant express hesitation in the interviews which might have indicated reluctance to discuss a particular topic.

Last, the data was collected from self-reported recall of participants' experiences and perceptions of events, intentions, etc. When looking back, our recall is not always completely accurate (Rogers, 2003). Still, as Rogers points out, the significance of the issue or innovation to the participant affects recall. The issue seemed very important to all the participants, several of whom mentioned their passion for health literacy.

While there are limitations to the present study, the findings on adoption and implementation of health literacy initiatives are useful in providing new information which can

be examined in future research and can be applied to assist healthcare organizations and health literacy change leaders advance health literacy initiatives.

### **Directions for Future Research**

Multiple different directions of future research could contribute to the understanding of how health literacy programs are adopted and implemented. First, the results of the interviews could be used to construct a quantitative survey which could be administered nationally. The survey could clarify and expand on the elements and constructs identified in the interviews. In addition, the quantitative data from a larger sample could increase the knowledge base about the implementation of health literacy in the United States.

More research on the ways in which leaders of healthcare organizations have been exposed to health literacy would be beneficial because senior leaders' awareness and understanding of health literacy appears to be crucial to adoption and implementation. In addition, research into the media and channels these leaders use to stay current with the external healthcare environment could provide guidance in designing approaches to raise awareness among senior leaders nationally.

Research into the change models and strategies used in other hospital-wide initiatives could contribute to organizational change theory, Diffusion of Innovations theory, and the literature in dissemination and implementation. In particular, examining the adoption decision processes for initiatives which, like health literacy, are not mandated by external forces, could be especially informative. For example, certification as a *Baby-Friendly Hospital* is a journey with organization-wide impact. Similar to health literacy, the decision to start the journey is not federally-mandated and must be made by each organization. The process begins with the decision to adopt, then moves to the adoption process, and subsequently moves into

implementation across the organization. Examining such other initiatives' adoption and implementation might uncover new approaches that could be used in health literacy.

Another line of research which could benefit health literacy would be investigating how some organizations use a strategic approach in planning the adoption and implementation of their health literacy initiatives. It might be fruitful to examine the specific processes and tools they may have drawn from models of organizational change, change management, adoption, implementation, and diffusion of innovations theories. Disseminating information on the tools and processes could be widely beneficial.

### **Key Findings and Recommendations for Action**

I now close with a summary of the critical elements for successful implementation of a health literacy initiative and a list of key recommended actions for health literacy change leaders.

#### **Organizational Elements Critical for Success**

The data in the present study, as well as the literature, suggest that health literacy initiatives are much more likely to thrive when the elements below are present. While health literacy change leaders are rarely in control of these organizational elements, it would behoove them to do everything within their power to facilitate the establishment of these elements in their organization.

- Senior leaders are aware of health literacy's importance and impact.
- The health literacy initiative has been given formal recognition and support, e.g., senior leaders designate it as a strategic priority, appoint an executive sponsor, allocate resources, and establish policies.
- Senior leaders place health literacy in a location on the organizational chart that has organization-wide reach and authority.

- Health literacy change leaders are vested with the authority to meet with and present to leaders at all levels as well as most decision-making bodies.
- The organization uses a strategic and structured process for change and this process is used in the health literacy initiative.
- Health literacy is linked to, and supports, other strategic initiatives and organizational objectives, such as efforts to reduce readmissions.

### **Recommended Action Steps for Health Literacy Change Leaders**

Depending on which of the above elements for success are present, the following recommended actions will vary in the ease with which they can be carried out.

- Conduct a listening tour as early as possible in undertaking a health literacy initiative.
- Find quality training and professional development activities as early as you can. Start with learning about health literacy and the role of organizational change in addressing it.
- Find a mentor who can initiate you into the organization's culture, norms, internal politics, communication vehicles, and change model and/or processes.
- Carry out a baseline assessment of health literacy activities in the organization. Track and assess progress measures regularly. Re-assess every 3-4 years.
- Build alliances and recruit champions for health literacy at all levels and across disciplines in your organization.
- To promote awareness and support of health literacy:
  - Link health literacy to other initiatives, e.g., reducing hospital readmissions for unreimbursed conditions and/or improving patient safety.
  - Illustrate the ways in which health literacy can provide cost savings and increase return on investments.

- Provide statistics on the scope of low health literacy in U.S. adults and the role of organizations in changing the statistics.
- Reveal stories of less-than-ideal patient experiences and results of, or potential results of, misunderstandings (in your organization, where possible) to engage the audience’s hearts. Bracket statistics with stories—remember the “Heart-Head-Heart” approach.
- Use attributes from Diffusion of Innovations theory, especially, featuring health literacy attributes that offer relative advantage and compatibility.
- Show how health literacy activities can mitigate legal risk and enhance compliance with regulatory and accreditation requirements.
- Build your skills for leading change.
  - Identify and research your organization’s change model and processes.
  - Learn how to do a Plan-Do-Study-Act cycle and begin one with clinical collaborators.
  - Recruit a mentor—someone who knows the organizational change model and processes and the strategic planning process in your organization.
- Build a network of health literacy change leaders working in other organizations for mutual support and to learn what others are doing that may benefit you.
- Bring in external health literacy expertise for guidance in strategic planning, presentations, training, resources, and other technical assistance.

### **Summary**

This study explored many elements that affect the advancement of health literacy initiatives. While there is much yet to learn and explore, the voices of the participants resonated

with and confirmed many findings from the literature. Understanding the broader influences that are common in implementation research and practice may encourage health literacy change leaders and equip them, and their organizations' senior leaders, to better support health literacy efforts.

Through the participants' stories, I was also able to identify new concepts and dimensions that can refine and expand various aspects of several models for organizational change in healthcare. Some of the new concepts may be unique to health literacy efforts, but other organizational change researchers and practitioners may benefit from applying the findings in other healthcare settings.

I learned that effective and useful theories and models for organizational change in health literacy exist and appear to be crucial in health literacy implementation. I believe, however, that the models themselves are not the crucial factor as much as the need for an explicit, strategic, and structured approach to the larger change process. The use of a formal model or an explicit strategic approach can be expanded into more organizations, with attention to the new factors of (a) improving leadership awareness, (b) providing health literacy change leaders with better access to leaders at all levels, (c) attempting to have the health literacy initiative in an area with organization-wide reach, and (d) conducting a listening tour.

I yearn for health literacy leaders, their peers, and the leaders above them in the hierarchy to explore and become more familiar with the benefits of organizational theories, models of change, and an explicit strategic approach in developing a change plan. An increased awareness of the existing theories, models, and strategic planning resources could lead to more structure and the use of explicit tools and strategies that were shown in this study to advance health literacy.

This study also identified several factors related to the experience, perspectives, and backgrounds of the participants. My hope is that learning explicitly about the impact of (a) working in a bureaucratic organization, (b) the need for support and networking, and (c) lacking the training and background needed for a health literacy position, will assist health literacy change leaders in understanding their experiences.

Further, the voices and stories of the participants showed great passion, dedication, and concern for patients and families who must journey through the maze of healthcare. Along with passion, the frustration, disillusionment, and isolation of some of the participants are real and powerful. My respect and compassion for these tenacious and bold leaders has grown through this study. I am grateful for their willingness to share as this study would not have been possible without them. For reciprocity and to express my gratitude, I will develop an executive summary version of the findings and will disseminate it to each of the participants in the coming months.

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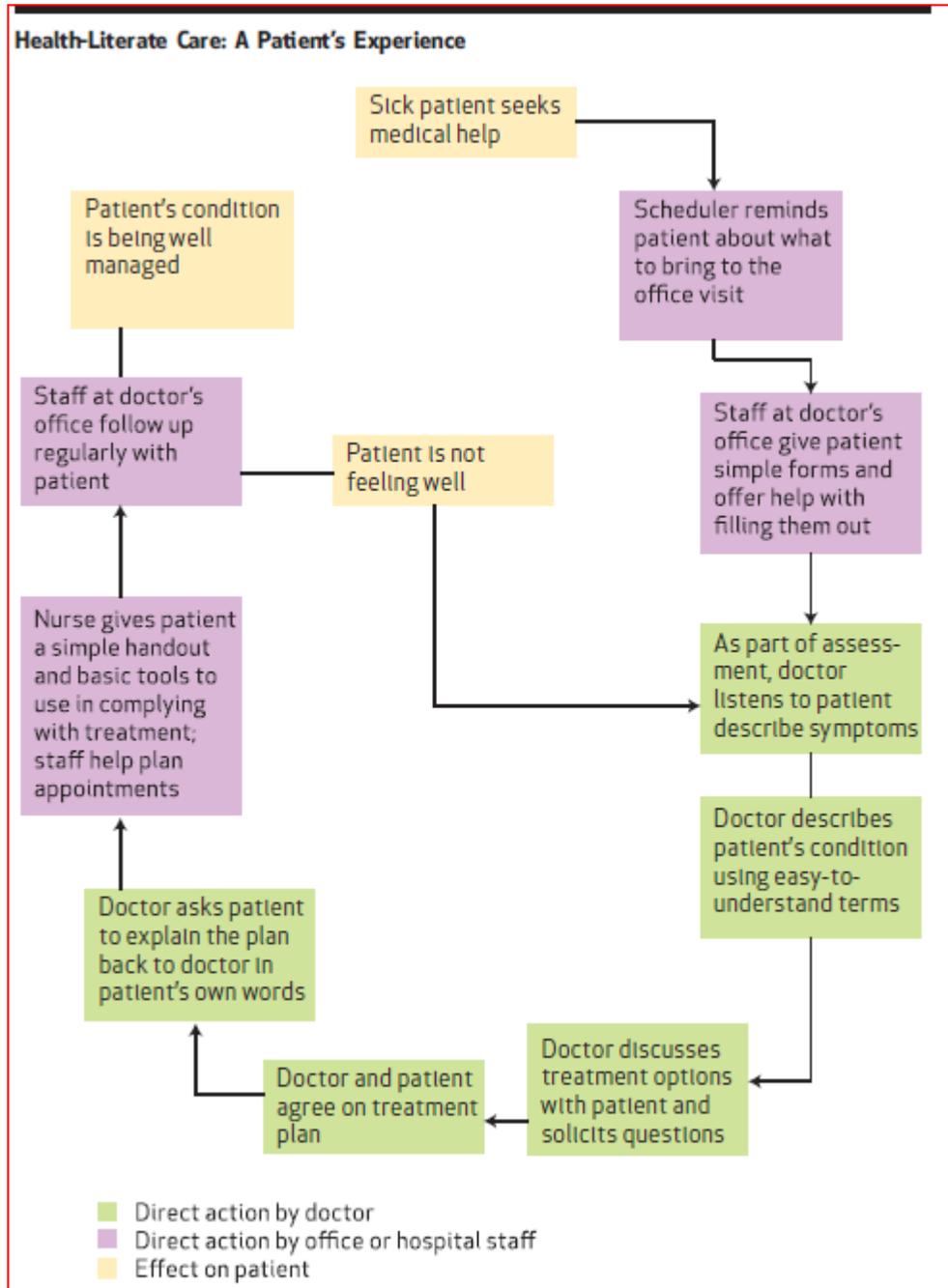
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APPENDIX A

The Health Literate Care Model

(Koh et al., 2012)



**APPENDIX B****Individual Interview Guide****I'd like to talk to you about your work related to health literacy in your organization.**

1. Please tell me about your experience in trying to initiate health literacy changes in your organization.
  - Probe: What can you tell me about how an *awareness* of health literacy began in your organization?
  - Probe: How did the *decision* to begin addressing health literacy come about?
2. What has made it easier for you to move the health literacy initiative forward?
3. What have been the barriers to moving the health literacy initiative forward?
4. What strategies did you use to build support for health literacy as it was getting started and as it spread?
  - Probe: How did you communicate about health literacy to others in the organization?
  - Probe: What communication channels were used, e.g., personal discussions with leaders, presentations to managers, internal newsletters?
6. Are you aware of any official models or frameworks for making change in your organization?
  - Probe: [If they were not aware of a formal model] How are organization-wide changes made in your organization?  
OR Is there a specific process for making change?
7. Is there anything else you'd like to share with me that we didn't talk about?

**The following questions were asked if there was time and it seemed appropriate in the context of the interview.**

8. How would you describe your experience of being responsible for the health literacy initiative in your organization?
9. What advice would you have for others starting HL initiatives?
10. One last question in closing, how would you describe your vision of what you'd like to see happen next in your organization related to health literacy?

(Follow-up probe and verification questions were asked as necessary.)

**APPENDIX C**

**Level One Nodes and Their Related Research Questions**

I repeat the research questions here for the reader’s convenience.

**RQ1:** How do participants describe the facilitators to adoption and implementation of health literacy initiatives in their organizations?

**RQ2:** How do participants describe the barriers to adoption and implementation of health literacy initiatives in their organizations?

**RQ3:** How do participants communicate with administrative leaders and healthcare providers at all levels to build support for health literacy activities?

**RQ4:** What models and methods for making organizational change are evident in participants’ reports of efforts to implement health literacy activities?

<b>RQ1: Facilitators</b>	<b>RQ2: Barriers</b>	<b>RQ3: Comm for Support</b>	<b>RQ4: Organi- zational Model</b>	<b>Other</b>
ACCESSUP; AWAREBEG; CHAMPS; CONSPERSP,INPUT; DEVELHL; EMBED_SUSTAINA BILITY; EVIDPROG;HISTOR Y; HLCLCHAR; HLCLEXP; HLCLHIRING; LDRSUPP; LOCHLPGM; ORG_CULT, HIERARCHY; ORG_ASSESS; ORG_FACILIT; PRVPERSP; STRUHL	ACCESSUP, HLCLEXP; LDRBARRS; LOCHLPGM; ORG_CULT, HIERARCHY; ORG_BARRS; PHYSICIANS MISC; PRVPERSP; RESIST;	BLDSUPP; EVIDPROG; EXPLAIN_ HL	ORGMODEL_ CHANGE STRATS; ORG_SYSTEM DESCRIP	ADVICE,QUAL; CULTCOMP,D&I; EXTOUTREACH; GREATQUOTES; HLACTVTS; LANGACCESS; METAPHOR; ORG_SYSTEM DESCRIP from DEMO; PTEDUC_HOs,DSC HINSTRUC; VISION

### NVivo Nodes, Child Nodes, and Detailed Descriptions

Name	Description (Key: P = Participant, HL= Health Literacy, HLCL = Health Literacy Change Leaders)	# of Sources Containing Theme
ACCESSUP	Access to people in positions above one's level, other than one's supervisor	10
ADVICE,QUAL	Participants' advice for others leading a HL initiative; needed qualifications	5
AWAREBEG	Influences in the early beginning of awareness of HL.	11
BLDSUPP	Strategies and/or content in communicating to senior leaders, clinicians, directors, etc. to build their support of HL (AKA "selling the case").	9
COST,ROI	Cost and/or ROI-related info used to build support for HL	8
DEMAND_SVCS	Showing demand for HL services, e.g., a 1,000% increase in requests for help	1
GENHLSTATS	Using HL stats for general national or international populations	7
HELPFUL VS BURDEN	Illustrating how HL can be helpful rather than just <i>another</i> thing to do.	3
IMPCAPHS & SAT SCORES	Potential for improving HCAHPS scores &/or other patient satisfaction scores	2
IMPCOMM	The benefits of HL activities improving communication with patients, family	4
INF IN ORG PUBS	Putting information about HL in organizational employee communications	2

Name	Description (Key: P = Participant, HL= Health Literacy, HLCL = Health Literacy Change Leaders)	# of Sources Containing Theme
KEEPTLKG ABOUT HL	Bringing up the issue repeatedly with leadership and others	4
LEGAL, RISK AVOID	Benefits of avoiding legal problems like lowering risks of lawsuits	1
LINK2INIT&STRATGOALS	Linking HL to other initiatives already underway, e.g., reducing readmissions	10
MEET REGS_STNDS	Meeting regulatory requirements and accreditation standards	1
PTSTATS_LOCAL	Using statistics about local patient populations, e.g., education levels	1
RSRCH_INTRNL	Using results of internal research and observations	2
SHOWPRGRSS	Showing progress of internal successes to build more support, engagement	6
SHOWPROB_OFFER PLAN	Giving an overview of the problem, then present strategic plan	2
STORIES_PT EXPRS	Telling stories and experiences of patients and families	6
ACTUAL STORIES	True stories from within (or outside) the organization	2
OBTAINING	How patient stories were obtained	1
CHAMPS	References to champions, their roles, recruitment, willingness, activities, etc.	8
CONSPERSP, INPUT	Consumer perspective, input on what they want/need/expect from org	8

Name	Description (Key: P = Participant, HL= Health Literacy, HLCL = Health Literacy Change Leaders)	# of Sources Containing Theme
CULTCOMP, D&I	Cultural competence; Diversity and Inclusion	5
DEVELHL	How HL initiative was developed, e.g., activities mandated or not	16
ROLLOUTS	“Rollouts” of new activities or initiatives, i.e., how did they make it happen	1
EMBED_SUSTAINABILITY	Evidence of HL being embedded or “hard-wired” for sustainability.	7
EVIDPROG	Evidence of progress in moving HL forward; evidence of the impact of HL	5
EXPLAIN_HL	The ways HL is explained or defined to people who are not familiar with it	1
BUSY PPL	Explaining HL as an issue of being busy people who don’t want to take time to read a lot of info, regardless of literacy skills. <b>Not</b> focusing on low literacy	1
COGNITIVE LOAD	How HL is an issue of the cognitive load it puts on a person	1
LACK KNOWLEDGE	How HL is caused by a lack of background knowledge about medical terms and info irrespective of a person's literacy or educational level.	0
LITERACY ISSUE	How HL is related to low or limited functional literacy.	1
SITUATION_STRESS	How HL is related to situational stresses people have in a health care setting	1

Name	Description (Key: P = Participant, HL= Health Literacy, HLCL = Health Literacy Change Leaders)	# of Sources Containing Theme
EXTOUTREACH	Outreach and partnerships with organizations outside the P's own org	4
GREATQUOTES	Quotes I may want to use in dissertation	10
HISTORY	What was going on in the organization that predated HL, set the stage	14
HLACTVTS	All activities intended to improve the HL of patients, families, and the org	11
HLTRNG	Training of employees--from top leadership to Medical Assistants--about HL.	15
MATS&VIDEO	Activities related to text- or video-based patient education, communication.	15
STANDARDIZATION	Issues around patient materials being standardized	8
SIGNAGE	Signs in the organization	5
TCHBK_VERBCOMM	Activities related to verbal communication such as teach back	12
HLCLCHAR	The HLCL's background, experience, history in org, personality, reputation	12
AUTH_RESPONSIBIL	The HLCL's role with regard to authority and responsibility	2
PASSION,PURPOSE, DRIVE	What keeps HLCLs going in HL work: passion, purpose, experiences as patient	2
PERCEP,KNOW,BLFS ON HL	The HLCL'S perceptions of, knowledge and beliefs about HL	2

Name	Description (Key: P = Participant, HL= Health Literacy, HLCL = Health Literacy Change Leaders)	# of Sources Containing Theme
PhD,NO CLINBKGRD	Impact of whether the HLCL has a PhD and/or clinical background	3
SELF DESCRBD SKILLS	HLCL’s description of their skill and knowledge level in HL	13
HLCLEXP	HLCL’s descriptions of how the experience their learning and their work	12
HLCLHIRING	What led to hiring a HL person or assigning HL duties to someone	11
1ST MOS, TASKS, ROLE	Descriptions of on-boarding process, early activities assigned or allowed, how bosses guided new HLCL, the way the role evolved or was defined	3
DESIRED TRNG, PREP	What training, prep for the job HLCLs <i>wish</i> they had before hired and now	12
HL TRNG bef HIRING	What training, prep for the job <i>did</i> HLCLs have before being hired	15
JOBDSCRP_TITLE	HLCL's job, position, responsibilities, structure, % of time to spend on HL (was coded both from interviews and demographic forms)	26
WORKLOAD	How HLCLs describe their workload	3
LANG ACCESS	Issues around patients who don’t speak English accessing services	2
LDRBARRS	Leadership barriers to HL, e.g., leaders’ views (“It’s a fluff topic”)	5
COMP_PRIORITIES	Leadership seeing HL in relation to	1

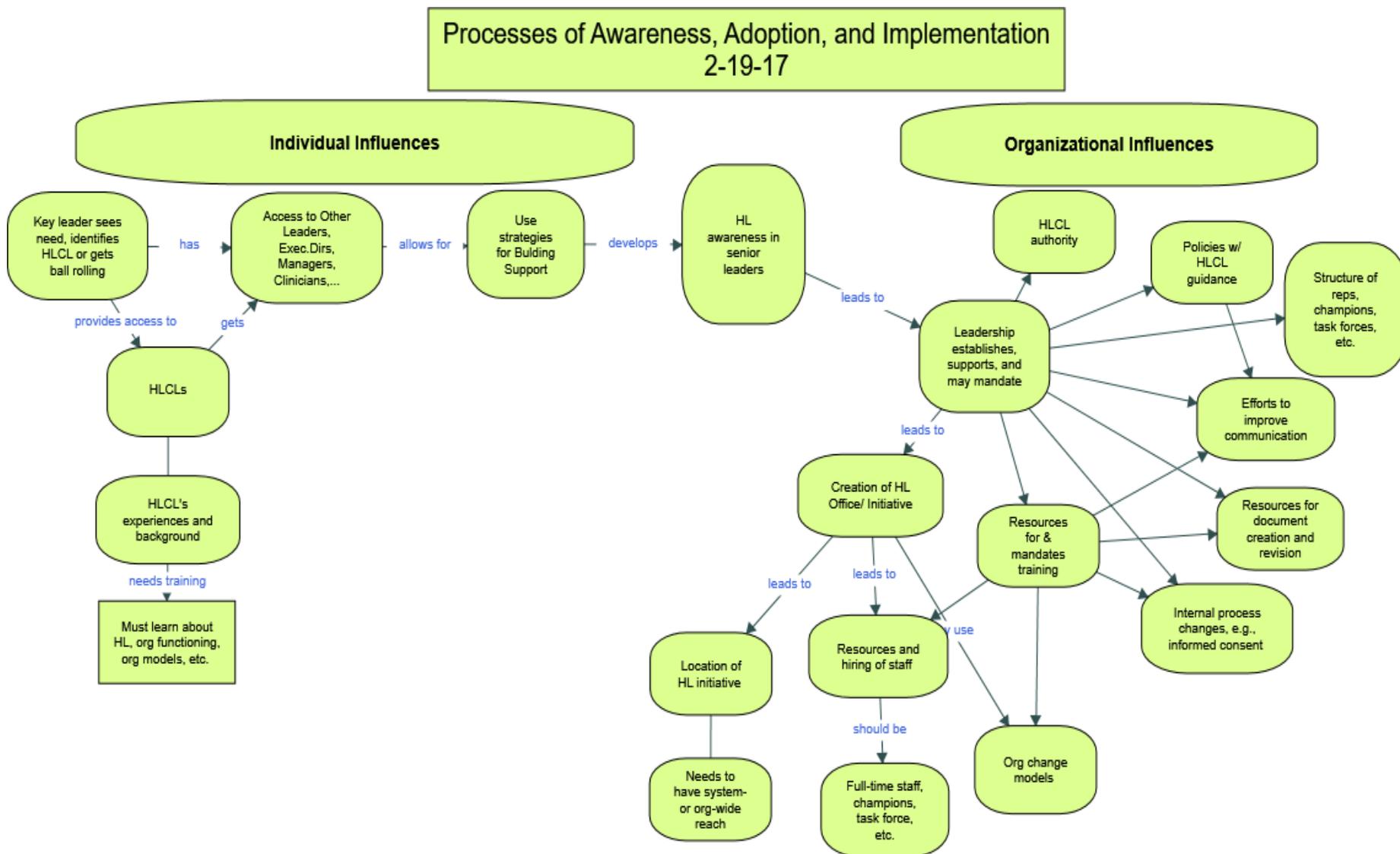
Name	Description (Key: P = Participant, HL= Health Literacy, HLCL = Health Literacy Change Leaders)	# of Sources Containing Theme
	competing priorities and agendas	
FUNDING CUTS	Leadership cutting funds for HL	1
LDRSUPP	Leadership support for HL, e.g., putting HL in strategic plans, telling others	16
FUNDING	Providing funding for various HL activities	4
MANDTRNG	Mandating training for various groups	6
POLICSUPP	Supporting development of, and adherence to, HL-related policies	7
LOCHLPGM	Location of the HL program in org chart; HLCL's views on where it should be (was coded both from interviews and demographic forms)	29
METAPHOR	Metaphors for HL work	2
ORG_CULTR,HIERARCHY	Organizational culture (expected behaviour, dress); hierarchical or not	6
ORG_ASSESS	Org assessments, e.g., assess the issues which could be addressed by HL	10
ORG_BARRS	Organizational barriers to implementation of HL activities	15
LACK COMM CHANNELS	Lack of communication channels to get the word out into the organization	1
LACK OF METRICS	Lack of ways to measure HL impact	1
LACKACCOUNTABILITY	Employees are <i>not</i> held accountable for doing HL activities, no penalty	1

Name	Description (Key: P = Participant, HL= Health Literacy, HLCL = Health Literacy Change Leaders)	# of Sources Containing Theme
NO FILE MNGMT SYS	Lack of a system to manage all the different versions of revised documents	1
POLTCS,WHO OWNS HL	The politics of who “owns” HL, e.g., who is responsible? Who must comply?	1
TALENT TO DO WORK	People with training and skills in HL available to do HL work	1
ORG_FACILIT	Org-level, or system-level, elements that make an org more health literate	12
ACCOUNTABILITY	Employees <i>are</i> held accountable for doing HL activities; incentives, penalties	1
CHOICE_FLEXIBILITY	Choice, flexibility in how HL activities are implemented	4
FUNDING, RESOURCES	Funding and resources for HL are provided	3
PARTNERS	Partnerships that facilitate HL growth in the organization	6
REP,RECOG	Reputation, recognition of HL program/leaders at local, state, or nat'l level	4
RLTNSHIPS	Existing, historical relationships or newly-developed around HL	9
ORG_SYSTEM DESCRIP from DEMO	Descriptive info on the org or system from the demographic form	6
ORGMODEL_CHANGE STRATS	Models, approaches for organizational change used in their org, HL program	16
LRNG COLLABS	Structure, use, examples of learning	1

Name	Description (Key: P = Participant, HL= Health Literacy, HLCL = Health Literacy Change Leaders)	# of Sources Containing Theme
	collaboratives	
PDSA EXAMPLES	Examples of ways the Plan-Do-Study-Act Cycle is used	3
PHYSICIANS MISC	Miscellaneous references to physicians	6
PRVPERSP	Providers’ perspectives and experiences working in healthcare, e.g., rewards	7
PTEDUC,HOs,DSCHINSTRUC	Patient education, handouts, discharge instructions, other print materials	2
EHR-IMPL, ISSUES	Electronic Health Record implementation and use, esp. in relation to HL	7
FIELDTESTING	Field testing (AKA user testing) of patient-facing information	1
RESIST	Resistance to HL as a concept, or HL activities	11
STRUCHL	Characteristics of the structure(s) that support HL in the org at any stage of development, e.g., Task Force, Steering Committee, FTE or part-time staff (was coded both from interviews and demographic forms)	27
INTERDISCIP	Interdisciplinary groups or workers from across the system	8
WHO RESP TO LEAD HL	Who is responsible for leading HL efforts	14
VISION	What HLCLs’ visions are for HL change and growth in their organization	10

APPENDIX D

Sample Version of Concept Map for Awareness, Adoption, and Implementation



APPENDIX E

Mind Map of Knowledge/Skills Needed by Health Literacy Change Leaders

