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Health Literacy Best Practices in Policy Development

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2018

Abstract

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MS, Southern New Hampshire University, 2008

BS, Plymouth State (College) University, 1983

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Policy and Administration

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Abstract

Low health literacy is a problem the U.S. faces and, like health care itself, is a complex issue stemming from patient demographics and the healthcare providers being very diverse. Tools have been developed to mitigate the risks of low health literacy, however, without formal policy. The purpose of this qualitative case study was to explore and compare commonalities in health literacy best practices of organizations that are recognized as leaders in health literacy and are addressing low health literacy in their communities. By comparing the organizations' abilities to implement standards of plain language and health literacy tools/guidelines, best practice and policy recommendations could be made to various organizations regardless of level (local, state, federal, or nonprofit). The theoretical framework was based on the Evans and Stoddart framework of determinants of health and the health behavioral theories. The conceptual framework was based on health literacy best practices and policy. The research questions focused on how organizations implement health literacy tools/guidelines, the impact of health literacy best practices on policy development and addressing health literacy through formal policy. The qualitative multiple case study used open-ended interview questions via telephone conferencing, with 13 participants from health literacy organizations. The analysis was done by coding and bracketing the responses manually and with NVivo software. Results indicate that health literacy policy development and involvement exists but it is not derived from the health literacy best practices. The implications for positive social change for this study impacts the patient (individual), community, organization, and society through best practices and recommendations for policy development.

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Dedication

This dissertation is dedicated to my sister, Lisa Jo (Trueheart) Moher, who passed away too young, too soon, too suddenly. If it were not for her, there are many things in my life I would not have taken that one more step…and she still inspires me. This dissertation is just the first step of a new journey.

I also dedicate this work to my mother, who has always shown me what unconditional love is. She never finished her degree, but this is her honorary degree.

To my father, United States Army Lieutenant Colonel William Trueheart (Retired), who directed me to finish my Bachelor's degree, go into the military as an officer, and told me if I wanted to teach to do it right and get my PhD…then asked why I was getting my PhD. I would not be where I am today if it was not for him.

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I would like to thank Dr. Joanne Kurt-Hilditch and Elyse Luke. Our Skype nights and “dissercations” kept me focused and accountable. Our little “HOB” is forever. Joanne, your friendship means so much to me.

I also want to thank all my brothers-in-law, nieces, and nephews who loved me through this. Family support is everything.

I would like to express my sincere gratitude to the Walden University faculty and staff who have guided me through this. I appreciate Dr. Mark Gordon who wisely counseled me and directed the initial topic. I sincerely thank Dr. Gregory Dixon and Dr. Lori Demeter for their painstaking reviews, patience, and direction in my dissertation journey.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Introduction

In the United States, patients are having problems understanding basic health information given to them and navigating the services they need to make appropriate decisions about their health. This is known as having low health literacy. Health literacy is defined by Ratazan, Parker, Seldon, and Zorn (2000), editors for the National Institute of Health, 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” (“Introduction”, p. vi).

The topic of health literacy has been on the forefront of health care for the past 10 years or more and has gone through numerous variations and changes, the definition itself, and the evolution and relationship between the concept and application (Kindig & McGinnis, 2007; Mackert, 2015; Rudd, 2010). Multiple studies have been conducted to analyze how to make hospitals and patients more health literate. Studies were conducted by individual researchers as well as commissioned by federal and nongovernment agencies:

- Literacy and Health Outcomes (Agency for Healthcare Research and Quality [AHRQ], 2004);
- Improving Health Literacy for Older Adults (Department of Health and Human Services, Centers for Disease Control and Prevention [CDC], 2009);
- FDA’s Strategic Plan for Risk Communication (Department of Health and Human Services, Food and Drug Administration [FDA], 2009);

- Proceedings of the Surgeon General’s Workshop on Improving Health Literacy (Department of Health and Human Services, Office of the Surgeon General (U.S.) [OSG], 2006);
- Clear Communication (Department of Health and Human Services, National Institutes of Health [NIH], n.d.);
- Health Literacy: A Tool Kit for Communicators (America’s Health Insurance Plans [AHIP], 2010);
- Health Literacy: Report of the Council on Scientific Affairs (American Medical Association, 1999);
- The Institute of Medicine: Health Literacy – A Prescription to End Confusion (Nielsen-Bohlman, Panzer, & Kindig, 2004); and
- Facts About Patient-Centered Communications (JCAHO, 2012).

Each study reached the consensus that there are variables that assess both the individual’s and the healthcare provider’s effectiveness of the patient’s health outcome. Most of the research showed two prominent findings that laid the basis of this study’s conceptual framework: (a) health is very complex, and (b) there is a correlation of low health literacy to healthcare costs, a patient’s health outcome, and a patient’s demographics (which includes socioeconomic status).

There have been multiple formal avenues to define, standardize, and legislate health literacy: two federal bills and the developing of performance measures or accreditation standards by the Joint Commission. While all were developed separately, it appears that work has ceased in both of the top-down endeavors at legislation (the two bills were not enacted and cleared from the books [Civic Impulse, 2018a, 2018b; see also Health Literacy Act of 2007]) and the setting of criteria to standards incomplete (C. Cordero, perosnal communication, March 25, 2014). Community-based efforts are now the central focus and the impetus to address health literacy, and patient education now rests at the grassroots level. In this study, I explored and compared commonalities in health literacy best practices of organizations that are recognized as leaders in health literacy by the Department of Health and Human Services' (DHHS), Centers for Disease Control and Prevention (CDC) and on the Health Literacy List Serve, and I examined the process of policy development at the health grassroots-level by interviewing members from 13 organizations.

These organizations' best practices are promoting tools that mitigate the risk of low health literacy. The health literacy community, in each of the states these organizations reside, reaches out to other organizations and communities to develop tools and to educate medical providers. In this study, I compared these organizations' health literacy best practices to examine the process for developing policy.

This chapter has 12 major sections: Background, Problem Statement, Purpose of the Study, Research Questions, Theoretical Framework, Conceptual Framework, Nature of the Study, Definitions, Assumptions, Scope and Delimitations, Limitations, and Significance.

Background

Health is a concern for everyone. Kimbrough (2007) found that health affects the quality of life and the ability of people to obtain their life's goals. It is the ability to take care of one’s self that will enhance quality of life, but can be impacted by race, socioeconomics, gender, and the environment (Kimbrough, 2007). Kimbrough also stated that society is morally responsible to ensure the health and well-being of each individual as well as for public health as a whole, rather than the onus being put soley on the individual.

Health literacy is an important factor in preventive medicine and is critical to transforming and maintaining public health care quality (Brach et al., 2012; Schnitzer, Rozenzweig, & Harris, 2011). Studies have shown that health literacy affects patients’ health outcomes (Berkman et al., 2011; Bodie & Dutta, 2008; Brach et al., 2012; North Carolina Institute of Medicine [NCIOM], 2007; Paasche-Orlow & Wolf, 2007, 2010; OSG, 2006) and is a leading contributor to rising health costs (Berkman et al., 2011; Glassman, 2012; Kimbrough, 2007; NCIOM, 2007; Peters, Hibbard, Slovic, & Dieckman, 2007; Schnitzer et al., 2011; Somers & Mahadevan, 2010). Public health, as defined by C.E.A. Winslow in 1920 (as cited by Evans, 2009, p. 35), is the “science and of preventing disease, prolonging life, and promoting health and efficiency through organized community efforts.” This is to be done by cleaning the environment, educating people in their personal health, organizating health services to diagnose early and prevent disease, and developing a societal mechanism to ensure to every individual a standard of living that will improve or maintain their health (Winslow, 1920, as referenced by Evans, 2009). Currently, according to the American Public Health Association, public health is the prevention of disease and promotion of good heatlh from small communities to entire countries (Evans, 2009).

Chatterjee (2003) pointed out that in the 1990s, the delivery of health care went through changes within organizations, developing and establishing new types of organizations and growing and integrating managed care. Along with these changes, the United States has had vast changes in demographics and new populations and communities are developed from immigrants dispersing throughout United States (Abu Dagga, 2009). Abu Dagga (2009) found that these demographic shifts affect health care in varying ways but mostly how the delivery is tailored due to the diverse cultures and languages. According to Chatterjee (2003), these changes and the healthcare market complexities make it hard to pinpoint the effects on patients. Abu Dagga, however, pointed out that the deviations in the use of health services is abetted by socioeconomic status, and that more needs to be understood about how it affects the patient outcomes. Andrulis and Brach (2007) supported this by stating that organizations are finding it difficult to address the breadth of literacy, cultural, and language issues. Health providers in the United States expect that patients can and will read, as well as act on, and adhere to healthcare literature and other types of communication no matter what level the literature originates from: federal, state, or local governments, private industry, or managed care organizations (Aruru, 2009).

With the above stated findings in literature and the shift/changes in demographics, the affect to health care and healthcare issues are becoming more complex in communities. In Valente’s (2005) view, the challenge is to be able to manage the complexities and problems that are common to the public’s health, within communities, regardless of size. Kimbrough (2007) equated community subgroups with a greater need for attention in managing public health. Both Demakakos, Nazroo, Breeze, and Marmot (2008) and Nobles, Weintraub, and Adler (2013) found that there is a direct association between the socioeconomic status components of income, education, and occupation and health status.

According to Benjamin (2010), in 2003, the health literacy skills of half the adults in the United States, were found to be poor or inadequate. There are no studies of late that state this has changed. Healthcare organizations and providers coordinate initiatives between them for communities to become health literate (Benjamin, 2010). Parker and Ratzan (2010) made four statements in their research that not only support the conceptual framework of this study but also summarize within literature health literacy, defined as the degree to which individuals can obtain, process, and understand health information and services to make decisions for their health:

- Health literacy has developed from an unknown to a recognized health policy issue;
- The focus has shifted from focusing on individual patient health literacy skills to include the health provider’s and health organization’s health literacy skills;
- Health care quality transformation in the 21st century to a patient-centered approach is a formidable task; and
- It took a surmountable amount of time to cataloug the problem, define and promote the issue of health literacy as fundamental to decreasing the costs, reducing inequalities, and improving quality of health care.

Low health literacy is considered a critical piece missing from health care quality (Brach et al., 2012) and is being attributed to culture and demographic variables such as age, race, and socioeconomic status. According to Vernon, Trujillo, Rosenbaum, and DeBuonod (2007), over 30 % of America's adult population – approximately 87 million – are functionally illiterate. Chao, Anderson, and Hernandez (2009) found that due to the difficulty in untangling the health literacy issues that contribute to health outcomes and disparities, low health literacy is practically an epidemic connections and commonalities were also found as both health literacy and disparities focus on communication. According to Black (2009), what is overlooked are the tools that health care providers can use to assess patients' needs quicker.

Health literacy's use as a tool is twofold. It is a tool to assist in helping patients make a more informed decision about their health care as well as a tool for advocacy of healthcare for the patients themselves and their communities. The patient must be involved and educated/informed in order to be his/her own health advocate. Though this is an issue that cannot be ignored when looking holistically at health literacy, it is not the focus of this study and is not addressed.

Low health literacy conditions have been studied and documented by several agencies, both federal and private (AHRQ, 2004; AHIP, 2010; AMA, 1999; CDC, 2009; FDA, 2009; JCAHO, 2012; Nielsen-Bohlman et al., 2004; NIH, n.d.; OSG, 2006). Though there is much previous research, and the awareness of the impact of low health literacy is growing, the ability to maintain that momentum is questionable due to the growth in patient population diversity. The engagement of health literacy within the communities, even from a policy perspective, will impact individuals more when it directly affects the patients themselves. Those with low health literacy due to low socioeconomics (Kimbrough, 2007) experience a greater impact.

It is organizations at the grassroots level that are now using and promoting the tools and guidelines to educate both citizens and the medical community. The main goals of these organizations could have implications beyond their local efforts. Keefe, Lane, and Swarts (2006) stated that the possibility could be viewed in two significant ways:

- Empower people living with health conditions to give them more control of their health and the decisions about them with the medical provider; and
- Provide services with alternative clinical solutions to care to better address individuals' needs than found in traditional health care facilities.

Though Whitman (2009) agreed, he asked three questions about an organization's abilities:

- Could an organization participate with this national advocacy without losing its ability to care for the ordinary people?
- Could an organization influence both local decision and integrate the state and federal policies and issues into their program?
- Could a nationwide organization influence the decisions that are not made locally but in another part of the United States?

The motivation of these organizations could determine how far reaching their effect is. However, it is questionable whether they can affect the standardization or legislation of health literacy. Keefe et al. (2006) stated that could possibly be done by rephrasing what is stated about health care and socioeconomics, reshaping research and the federal agendas, lobbying for the approval of pilot projects, and changing laws and/or how they are enforced by challenging the status quo through legal avenues.

Whether changing laws is possible is not the focus of the intent; rather people with the ability to impact through organizing and health-based social movements should not be ignored (Keefe Lane, & Swarts, 2006). However, even if these movements are successful, their advocacy to affect policy, funding, or health care issues may not be as effective (Keefe et al., 2006). In this study, I did not compare or focus on the organizations' policies, as the focus was on the best practices, the process of health literacy policy development, and the impact to patients' outcomes.

Problem Statement

Low health literacy is a problem the United States faces. Health literacy, like health care itself, is a complex issue. The complexity stems from patient demographics, the communities they live in, and medical and healthcare providers being very diverse. The medical community acknowledges low health literacy as a problem. Tools have been developed to assist providers in mitigating the risks of low health literacy. However, currently in the healthcare community, there is a lack of formal policy on health literacy. Most policy has focused on the delivery/providing of health care, but that threshold of what provision can do exclusive of improvements in literacy may have been reached. Though health literacy is not much use without healthcare provision, healthcare provision is of limited use without health literacy.

This problem impacts everyone, from the patient, to the doctors, to the community, and to society. The patient's health outcome is the most obvious as health literacy is necessary for a patient to have an active role in his or her own health care. Other impacts, such as the rising cost of health care, are not as readily noticeable but are quite significant. There are many possible factors contributing to this problem:

- The complexity of health care (to include medical language and insurance);
- The complexity of health literacy (which includes language and the variables of demographics); and
- That the construction of an individual's approach to care is based on health literacy.

Poor literacy leads to a construction that undermines effective service, and good literacy has the opposite effect. This study contributes to the body of knowledge needed to address this problem by comparing health literacy best practices and its effect on the process of policy development to address health literacy through formal policy.

Purpose of the Study

The purpose of this qualitative case study was to explore and compare commonalities in health literacy best practices of organizations that are recognized as leaders in health literacy by the CDC and are addressing low health literacy in their communities. By comparing the organizations' abilities to implement standards of plain language (regulated through accreditation) and other health literacy tools/guidelines (without regulation), best practice recommendations could be made to various organizations regardless of level (local, state, federal, or nonprofit). By also exploring these organizations, potential health literacy policy could be determined by examining what is currently being shaped, taught, and applied. Exploring commonalities of organizations that are addressing the complexity of health literacy within their communities would allow patients and healthcare providers to better address health concerns.

Research Questions

There were three research questions in this study. These questions were derived from the concept of healthcare complexity and that health literacy issues further complicate this.

Research Question (RQ)1: How are organizations implementing health literacy tools/guidelines without formal regulation?

RQ2: What impact does health literacy best practices have on the process of developing formal policy?

RQ3: How can health literacy be addressed through formal policy?

Theoretical Framework

The theoretical framework of this study was based on the Evans and Stoddart framework of determinants of health (also known as the model of health and well-being) and health behavioral theories. The following conceptual framework is based on health literacy best practices and policy, which are part of both theories.

The social determinants of health are the social, environmental, and economic conditions that influence and affect individuals’ health and influence the functioning and well-being of a community (CDC, 2009; Department of Health and Human Services, Office of Disease Prevention and Health Promotion [DPHP], 2016). These conditions are shaped by the socioeconomics, which are influenced by policy (CDC, 2009; Kindig & McGinnis, 2007).

The Evans and Stoddart field model of health and well-being is used to recognize the determinants of population health (Kindig & McGinnis, 2007). The World Health Organization (WHO) uses three main health behavioral theories in research: individual capacity (or intrapersonal), relationships (or interpersonal supports), and environmental contexts (or institutional factors, community factors, and public policy). The Office of Disease Prevention and Health Promotion (DPHP, 2010) stated that an individual's health is inseparable to a communities' health, which in turn establishes the health status of the nation.

The environmental context factor of the behavioral theories and the health and function and well-being components of the Evans and Stoddart model are the basis of this study's theoretical framework that ties into the conceptual framework. Both theories tie into the research questions, the Evans and Stoddart model through the third and fourth stages (additions of the health field and the focus on policy), and the behavioral through the environmental factor, which emphasizes on the policy aspect of health care.

Conceptual Framework

The construct of the conceptual framework was based on health literacy best practices and the process of policy development. The underlying concepts that surround the framework are as follows:

- Health care is complex;
- Low health literacy is a problem;

- Health literacy is a complex issue;
- There is a lack of policy direction at the federal level; and
- Organizations at the grassroots level are shaping their role in the local communities implementing health literacy without the foundation of policy or centralized coordination.

In this study, I investigated how organizations implement health literacy tools and guidelines and promote policies. This is done in an environment of complex related issues and interlinked with complex network effects and specific elements that are complex as well. I explored the best practices of the organizations that have adapted most effectively.

Nature of the Study

By exploring how the organizations are implementing tools and best practices, a comparison was made to find commonalities to assist other organizations as well as the development of health literacy policy. These organizations were in diverse communities, thereby mirroring the concept of complexity. I interviewed members within organizations that are considered by the CDC to be leaders in the health literacy community and other members from organizations found on the health literacy list serve.

These organizations were a mixture of local, state, academia, government, and non-profit. This allowed an in-depth look at how health literacy tools/guidelines are being implemented. Participants were asked open-ended questions allowing the capture of multiple perspectives for better validity of the complexity and phenomenon.

Key Concept and Phenomenon

The key concept of this study is health literacy. The vast amount of literature shows that public health and health care alone are complex issues. Though health literacy is only one issue within the health care arena, it is among the most complex with a large – perhaps the largest – number of variables. Figure 1 depicts the complexity of health literacy.

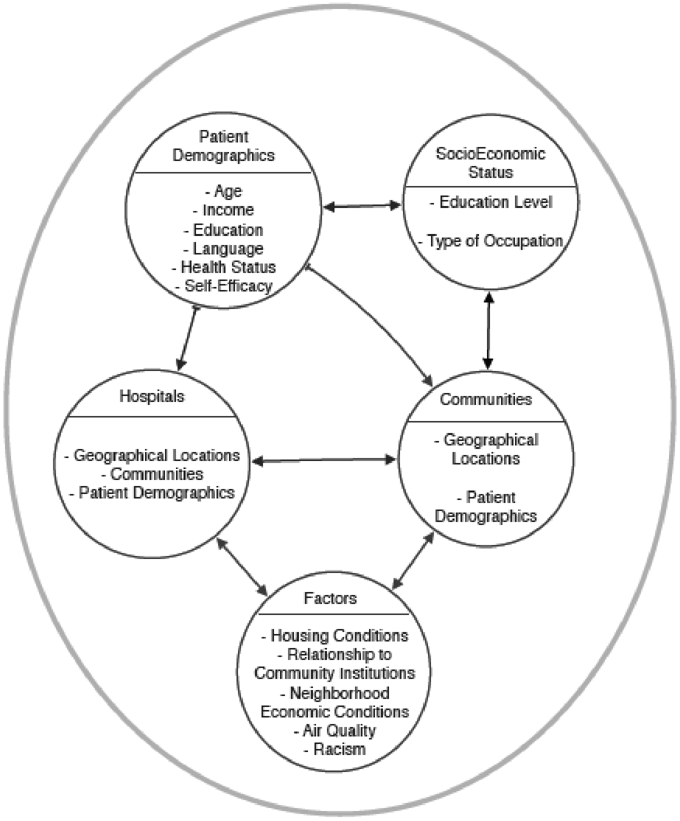


Figure 1. Variables that directly affect health literacy. Variables that directly affect health literacy are patient demographics, socioeconomic status, hospitals, communities, and other various factors. This is a concept that depicts how variables interact exclusively with other variables which all affect health literacy.

Health literacy is considered a major contributor to health care complexity. Studies have shown that low health literacy affects patients' health outcomes and contributes to increased health care costs. These concepts are discussed in more detail later Chapter 2.

The results of this study can impact hospitals, healthcare organizations, and other organizations that are currently shaping and implementing tools to lessen the effect of low health literacy. This study can further impact doctors, nurses, patients, and family members who are recipients of the applications of best practices and policies.

Summary of Methodology

The qualitative method for this study allowed for causal relationships but was constrained by the availability of data (see Esensoy & Carter, 2015). As this study was particularly based on the concept of health literacy complexity and without concrete policy research, capturing nonquantifiable information enhanced what was known – either by communities or organizations.

The multiple-case design was chosen to research health literacy best practices due to its descriptive nature and to give better validity to the findings. Through this design, I could view the construct of the managing behavior of the leading health literacy organizations. The multiple-case study design is also a leading method of examining policy and public administration. The multiple-case design replicated the holistic/single-unit of analysis with each case (organization's best practices) embedded in context (demographics). According to Yin (2012), using the case study as a research method usually shows that the researcher wants to get an up-close and in-depth understanding of a real-world phenomenon.

In this study, I used a phenomenological approach using conventional and summative content analysis. The phenomenological approach challenges these perceptions by marrying the objective and subjective thinking and approaching the social activity with altered knowledge (Bazzul, 2015). I explored the phenomenon and understanding of how the organizations accomplish health literacy best practices and how the organizations accomplish integrating them with the objective development of policy. The data analysis of this study was done using Moustakas's (1994) phenomenological reduction – bracketing, horizontalizing, and clustering.

The multiple-case study method of exploration was done through using a series of in-depth interview questions that specifically addressed health literacy best practices and policy. These interviews were conducted with participants of organizations that are noted to be leaders in health literacy by the CDC and organizations on the health literacy list serve. There are currently 22 organizations on the CDC website and more on the health literacy list serve that are coalitions or collaboratives that include but are not all inclusive of the following: doctors, researchers, academia and educational resource groups, health services departments, health associations, agencies, and medical societies.

Purposive and expert sampling techniques were used because the organizations/populations were known (see Latham, 2007; Teddlie & Yu, 2007). The purposive technique allows a community of health literacy experts to be interviewed with questions that supported the conceptual framework.

In this study, I used nonprobability, purposive sampling. This is because the population was known and was not random. The sampling was purposeful and predefined within these organizations. To further clarify, the sampling was expert sampling, as it involved the gathering of known organizations, known staff, and committee members within a panel of subject matter experts on health literacy (see Elliott, McCaffrey, Perlman, Marshall, & Hambarsoomians, 2009). The variations of each coalition/collaborative/ group ensured the participants were representative of the desired population of the organizations. As the interviews were conducted, the rule of saturation was not a factor in dictating the final number of participants. According to Nastasi (n.d.), the benefit to qualitative sampling is flexibility and the counter to that is the high degree of ambiguity. The focus is not what the member/participant represents outside of the organization, but rather his or her participation in the organization itself. The interviews were based on availability.

The interviews were conducted through the online video- and tele-conferencing software, AnyMeeting, due to the high cost of travelling and limited availability of funds. Though AnyMeeting allows a face-to-face interview in real time, only one participant had the availability to do so. The other participants used the teleconferencing ability I set up through AnyMeeting. The use of AnyMeeting allows the interview to be recorded externally to a handheld micro digital voice recorder that was plugged into a USB port on the computer and internally to the computer. However, the sound was not of quality to understand the responses properly. The online video- and tele-conferencing program, AnyMeeting, has the ability to record and download the recording to the computer being used. No data were recorded onto the cloud or to the database of AnyMeeting. The interviews were then transcribed with speech recognition software. These transcripts were imported into the analytical software, NVivo, for coding and data connection. The NVivo software allowed me to be more thorough, attentive, and methodical, as well as helped me to reshape and reorganize coding, interrogate the data, and have rigor in dealing with a large amount of data (see Hilal & Alabri, 2013; Welsh, 2002; Zamawe, 2015). The analytical software was used to code with bracketing, horizontalizing, and clustering. The bracketing allowed understanding while lessening preconceived experiences. The horizontalizing listed relevant significant statements to the topic and marked them with equal value. The clustering identified themes and removed overlapping and repetitiveness. The methodology is described in detail in Chapter 3.

Definitions of Terms

Accreditation: A recognition given to a school or health care institution by a professional association or non-governmental agency for meeting established criteria and standards (Mosby’s Medical Dictionary, 2009).

Adherence to health behavior: A sustained health behavior over a period of time that can determine the health outcome of an individual (Berkman et al., 2011).

Agency for Healthcare Research and Quality: Is a lead agency for the federal government with the responsibility to improve the quality, safety, efficiency, and effectiveness of health care (National Committee for Quality Assurance [NCQA], n.d.).

American Health Quality Association: A non-government agency that represents organizations and professionals working to improve health care quality in the United States (NCQA, n.d.).

American Hospital Association: A non-government national organization that represents hospitals, health care networks, communities, and patients (NCQA, n.d.).

American Medical Association: The largest physician group in the United States that advocates on issues of national health, patient safety, and health care quality (NCQA, n.d.).

Criterion/Criteria: A specific, measurable, predetermined rule or guideline on which an action or decision is based (Mosby's Medical Dictionary, 2009).

Department of Health and Human Services: A principal government agency for protecting the health of all Americans (DHHS, 2012).

Grassroots: A horizontal integrated organization that stems from the need for a larger coordinating capability (Couto, 1990).

Health benefit: In use with health literacy, implies that health literacy is a resource that can lead to personal health benefits, and higher levels of health literacy has social benefits within a larger population (Nutbeam, 2000).

Healthcare provider: An organization or individual that provides/gives health services or medical care to patients/health care consumers (American Heritage Medical Dictionary, 2007).

Health literacy: A patient's ability to find and understand basic health information, to navigate the process for health services, and make appropriate health decisions (Ratazan, Parker, Seldon, and Zorn, 2000; see also Berkman et al., 2011).

Hospital: An institution that provides medical, surgical, or psychiatric care and treatment for the sick or the injured (AHMD, 2007).

Hospital accreditation: A self-regulating process by an independent non-governmental agency that defines and monitors the quality of standards by which hospitals receive a symbol of quality (Heuer, 2002; NCQA, n.d.).

Health status: A health-related and quality-of-life standing related to either generic or condition-specific measures (Berkman et al., 2011).

Institute of Medicine (IOM): An independent, nonprofit, and nongovernment organization that provides an unbiased, evidence-based, and authoritative view, analysis, and independent guidance or advice on health and science policy to policy makers, professionals, decision makers and the public (Brach et al., 2012; NCQA, n.d.).

Joint Commission for Accreditation of Healthcare Organizations (JCAHO): An independent, nongovernment, nonprofit organization that accredits hospitals and other healthcare organizations and programs in the United States whose accreditation and certification is globally recognized (JCAHO, 2012; Heuer, 2002; NCQA, n.d.).

Managed care: A general term regarding the delivery and strategies for controlling costs to health care access by using primary care and prepayment options within a business framework (Simmons, 2004; Thomas, 2006).

National Association for Healthcare Quality: A non-government organization that promotes the improvement to the quality of health care through educational and developmental opportunities for professionals at all levels and health care settings (NCQA, n.d.).

National Committee for Quality Assurance: A foremost non-government organization for accreditation of health plans (NCQA, n.d.).

Patient-centered care: A concept that while ensuring different healthcare providers and care settings are coordinated, puts patients' cultural traditions, personal preferences and values, family situations, and lifestyles first (NCQA, n.d.).

Public health: The prevention of disease and promotion good heatlh within communities and nations by the use of health education, sanitation, and the control of communicable disease and environmental hazards (AHMD, 2007; Evans, 2009).

Quality health care: Is defined as giving the best (correct and timely) care (diagnosis and treatment) to an individual patient NCQA, n.d.).

Self-efficacy: In the context of health care, it refers to the confidence a patient has in his/her own ability to successfully managing his/her health care needs" (Seligman et al., 2007).

Socioeconomic status: Education, occupation type, and income, indicating material resources and perceived level of prestige (Black, 2009; Sentell, 2003).

Assumptions

There were five assumptions for this study. The first assumption was that hospitals and healthcare providers want to be patient-centered organizations, and they have identified potential gaps in providing health care to patients, other than demographics. The second assumption was that while some aspects that impact patient care cannot be easily changed (i.e., demographics), others (i.e., health literacy) can be changed with policy. Underlying this assumption is that while self-efficacy, numeracy, and education are basic variables that can be manipulated by the patient and can affect demographics (i.e., socioeconomics), demographics itself cannot be fully manipulated by the patient. Self-efficacy, numeracy, and education are identified in this study but not fully explored.

The third assumption was that the respondents were willing participants and would be honest in their answers to the interview questions in order to further the exploration of health literacy. It was my role as the researcher to assure them that this study has only positive implications. As there were a limited number of resources and there were a limited number of best practice organizations, the fourth assumption was that saturation was not expected with the sample number of participants. The organizations sampled were from 20 states, thereby having varying communities and demographics. The fifth assumption was that the responses would have recurring trigger phrases or words that would be used to code and match research questions.

Scope and Delimitations

Scope

The scope of this research was limited to organizations within the United States that have been identified by the CDC as promoting health literacy within the healthcare communities of their states. The leaders, or individuals who were selected to represent them, were interviewed. The postpositivist approach was used to measure the phenomena. This allowed the descriptive method paired with deductive reasoning and understanding. Both interpretive theory and appreciative inquiry were used. The interpretive theory enhanced the exploration into the intentions and constructs of developing the tools in promoting actions to mitigate the risks of low health literacy. The appreciative inquiry allowed support to the methodology in that the organizations responded to positive inquiries.

Delimitations

There were four delimitations that were significant to this study:

1. Interviews were the primary source of data collection, which provided depth of understanding at the expense of breadth.

2. In order to allow a more complete understanding of how health literacy was being explored and/or addressed by these organizations, open-ended questions were used during the interviews.

3. The sampling and sample size was affected by having a set number of organizations. However, there results allowed a varied look at the health literacy issue at the different organizations.

4. In order to assure manageability, this study only included the organizations included on the CDC website and on the health literacy list serve. Some of the participants were associated with healthcare providers and/or other healthcare associations or organizations. This allowed diversity in the responses.

Limitations

There were several limitations of this study. One limitation stated prior to conducting the research is that health literacy affects such a broad range of culture and diversity in patients, healthcare providers, and communities, and examining the specificity of any of these attributes was not possible within this study. This was furthered by a limitation that emerged on the definition of community. There were five definitions of community between the 13 participating organizations.

Another limitation stated prior to conducting the research was the limiting of organizations shown on the CDC website, as they were recognized as having involvement in health literacy and interacting at the state and regional levels. This population was widened to use organizations that were found on the health literacy list serve as stated as a back-up plan. This allowed the minimum sampling size ($N = 6$) to be met and exceeded ($N = 13$).

A third limitation stated prior to conducting the research was that I would use voluntary interviews of personnel at these organizations associated with health literacy. Accordingly, a limitation that arose was the differing job roles of the participants. This was due in part to the organizations' scopes of practice being divergent and therefore the understanding or ideas of health literacy best practices and policy development and/or involvement also differs.

Significance

The importance of health literacy to the patient is significant to their wellbeing. It impacts not only the patient but their families, their communities, the healthcare provider, and society as well. In this study, I explored how organizations are implementing best practices in health literacy. This exploration derived the organizations' process of developing policy.

Examining how organizations are implementing health literacy best practices could further the awareness and the necessity to further the process of developing health literacy policy. By comparing these organizations' ability to implement best practices, standards of plain language, and other health literacy tools/guidelines, recommendations can be made to various organizations regardless of level (local, state, or federal). By also exploring these organizations, extended measures and tools on health literacy and literacy in the education field might be developed by comparing what is currently being shaped, taught, and applied. Therefore, through this study, I can potentially impact other professional communities to take measures in reducing illiteracy, which will contribute in reducing the percentage of patients with low health literacy. The information found can also lend to further research.

Summary

For years, physicians held the power of knowledge, and patients were to listen and take their advice without questioning (Kimbrough, 2007). In time, patients have been given more control over their health issues. However, it has become increasingly clear that there is one main obstacle in doing so – the patient's health literacy level. Today, there is little doubt to the importance of health literacy in the healthcare community to include the provider and patient.

It is well documented that one of the biggest challenges in healthcare today is low health literacy. This phenomenon has been studied for over 30 years. The gap between just reading and the ability to read written health information has been growing (Stableford & Mettger, 2007). Researchers have indicated that the United States faces major issues of risk of threat to the health of the populace as well as the increase of fiscal spending due to chronic health conditions, leading to more frequent hospitalizations

(Kimbrough, 2007; Stableford & Mettger, 2007). Variables of issues (e.g., demographics, socioeconomic status, and the environment) impact health literacy. Addressing these issues is a step towards reducing health disparities in various healthcare environments (Koh et al., 2012). However, exploring and understanding the best level to address these issues will allow the policies at various levels to be written and potentially empower accreditation standard development to resume.

In order for a patient to properly process the information given to them by a physician or pharmacist, the patient must understand the circumstances of his or her health and health needs. For this, they must be health literate. However, the onus is not entirely on the patient. A health provider must understand the intricacies of helping that patient understand.

This phenomenon is affected by variables of demographics, socioeconomic status, community, education, and environment. The number of combinations of these variables is infinitesimal, and any combination affects the level of health literacy in patients and healthcare providers. This directly affects a patient’s health, a community’s well-being, and the cost of health care to the nation.

Policies that direct or ensure the patient’s safety are imperative, and accreditation ensures standards across the nation are met. However, policies and accreditations each must be able to define and specify criterion for either to succeed. If neither succeeds, low health literacy will continue to cultivate, and the cost of health care will continue to increase.

In Chapter 1, I set the framework and the purpose of this phenomenological study. In Chapter 2, I provide a literature review. I look more in-depth at the history of health literacy and policies and concepts from the literature such as the complexity of health care and related concepts of policies, accreditation, and governance. In Chapter 3, the methodology is discussed in detail as well as the design of the study, the qualitative analysis, and the procedures that were explored. In Chapter 4, I explain the how I conducted the research and discuss the results of the analysis. In Chapter 5, I present my findings of the results and discuss the future research and the implications for positive social change.

Chapter 2: Literature Review

Introduction

Low health literacy is a problem the United States faces. Health literacy, like health care itself, is a complex issue. The complexity stems from patient demographics, the communities they live in, and medical and healthcare providers being very diverse (see Figure 1). The medical community has also acknowledged low health literacy as a problem. Tools have been developed to assist providers in mitigating the risks of low health literacy. However, currently in the healthcare community, there is a lack of formal policy on health literacy. Most policy has focused on the provision, but the threshold of what provision can do exclusive of improvements in literacy may have been reached. Though health literacy is not much use without health care provisions, health care provisions are of limited use without health literacy, and policy is the foundation for literacy and health work (Shohet & Renaud, 2006). However, Evans and Stoddart (1990) found a growing gap between the determinants of health and health policy.

This problem impacts everyone – from the patient, to the doctors, to the community, and to society. The patient's health outcome is the most obvious as health literacy is necessary for a patient to have an active role in his or her own health care. Other impacts, such as the rising cost of health care, are not as readily noticeable; however, are quite significant. There are many possible factors contributing to this problem:

- The complexity of health care (to include medical language and insurance);

- The complexity of health literacy (which includes language and the variables of demographics); and
- That the construction of an individual’s approach to care is based on health literacy.

Whereas poor literacy leads to a construction that undermines effective service, and good literacy has the opposite effect. This study contributes to the body of knowledge needed to address this problem by exploring how health literacy can be addressed through formal policy.

The purpose of this case study was to explore and compare commonalities in health literacy best practices of organizations that are recognized as leaders in health literacy by the CDC and are addressing low health literacy in their communities. By comparing these organizations’ ability to implement standards of plain language (regulated through accreditation) and other health literacy tools/guidelines (without regulation), best practice recommendations could be made to various organizations regardless of level (local, state, or federal). By also exploring these organizations, potential health literacy policy might be determined by examining what is currently being shaped, taught, and applied. Exploring commonalities of organizations that are addressing the complexity of health literacy within their communities will allow patients and healthcare providers to better address health concerns.

Synopsis of Current Literature

Health literacy is defined as a patient’s ability to find and understand basic health information, to navigate the process for health services, and make appropriate health decisions (Ratazan et al., 2000; see also Berkman et al., 2011). It is considered a major contributor to health care complexity. Studies have shown that health literacy affects patients' health outcomes (Berkman et al., 2011; Bodie & Dutta, 2008; Brach et al., 2012; Chao, Anderson, & Hernandez, 2009; Kimbrough, 2007; Lurie & Parker, 2007; NCIOM, 2007; OSG, 2006; Peters et al., 2007; Somers & Mahadevan, 2010), and that low health literacy is a leading contributor to rising health care costs (Berkman et al., 2011; Glassman, 2012; Kimbrough, 2007; NCIOM, 2007; Peters et al., 2007; Schnitzer et al., 2011; Somers & Mahadevan, 2010). Health literacy not only affects patients but hospitals and healthcare providers as well. The complexity of health literacy is driven by multiple variances such as demographics and socioeconomic statuses. However, improving health literacy can reduce hospitalizations and use of emergency care, and potentially limit crisis care (Mitka, 2012).

Social determinants of health. A determinant can be defined as any factor (event, characteristic, etc.) that changes a condition or defined characteristic (Kindig & McGinnis, 2007). The social determinants of health are further defined as conditions that currently exist or changes to those conditions that affect the health and/or quality of life of people and the communities they live in (DPHP, 2016). These conditions or changes can be social, economic, and/or physical environments (to include schools, churches, workplaces, and communities/ neighborhoods) and can be influenced by money, power, and/or resources. Policy has a direct effect on these determinants. According to Kindig and McGinnis (2007), positive determinants, such as education and preventive medical care, will be effective in generations to come.

Public Health. In 1920, Winslow defined public health as the “science and of preventing disease, prolonging life, and promoting health and efficiency through organized community efforts” (Winslow, 1920, as cited in Evans, 2009, p. 35). The American Public Health Association defined it as preventing disease coupled with promoting the health of people and communities (American Public Health Association, n.d.). According to the National Center for Chronic Disease Prevention and Health Promotion, in 2005, the United States population had approximately 35 million adults who were at the age of 65 or older, and this number is predicted to double by the year 2030 (as cited in Valente, 2005). Whereas older adults use health care more often than other age groups and make up a large percentage of communities, the challenge then is to ensure that communities, regardless of size, are enabled to combat health problems and manage the complexities that are embedded in the concept of public health (Valente, 2005).

Complexity. Bureaucracies complicate health care and public health procedures and processes (Peters et al., 2007), making health literacy a complex concept (Brach et al., 2012; Schyve, 2007. However, not adding health literacy makes it harder to determine how changes made by bureaucracies will impact health care system and services (see Figure 2).

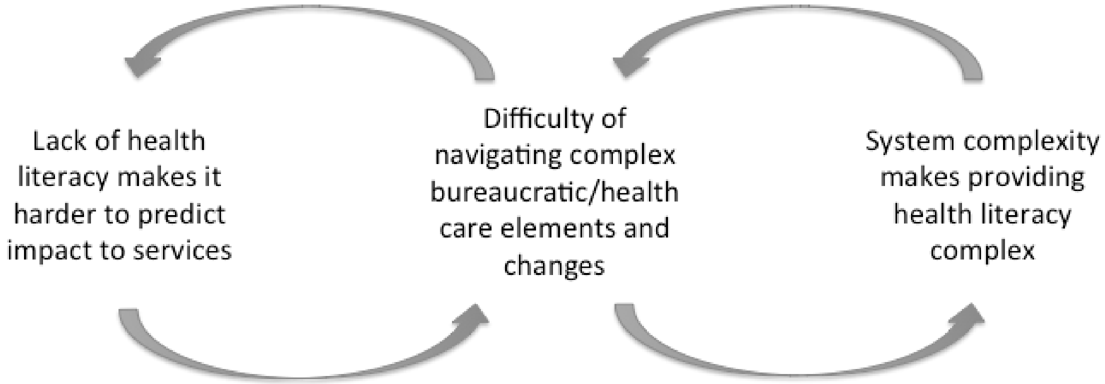


Figure 2. Cycle of complexity. The cycle of complexity shows that health literacy is the link to health care complexity.

This complexity is evolving and is putting health care further in crisis (Thomas, 2006) and, as Lackey (2009) stated, the advertising, employing, and insuring of health care and medical knowledge conflict with having the access, money, and education to health care. Between the differences in languages, for example, English and Spanish, cultures, and education levels, health literacy can put patients at a disadvantage in managing their health care. Low health literacy puts patients at an even greater disadvantage, which is a major challenge to lowering the costs yet providing good health care (Schnitzer et al., 2011; Stableford & Mettger, 2007). Any changes made are difficult to identify due to the complexity of health care markets.

The complexity is not just at the level of public health and health care. Much of the literature on health literacy proposed that there is a relationship between literacy and health that impacts health knowledge and status and the access to health services (Berkman et al., 2011; Chiarelli & Edwards, 2006; Glassman, 2012; Parker & Ratzan, 2010). The relationship is based, as most relationships are, on commonalities and expectations. What provides those commonalities and expectations are standards and policies. The complexities of these are driven by several factors: socioeconomic status, language (medical and that spoken by the patient), age, education, income, occupation, geographic area, numeracy, and self-efficacy to name a few (AbuDagga, 2009; Black, 2009; Chao et al., 2009; Kimbrough, 2007; Sentell, 2003).

Patient-centered care. The patient is at the center of attention in health care, whether it is in relation to insurance or just medical treatment, and is becoming increasingly so in regards to managing one's own health (NCIOM, 2007). Government agencies and administrators, health care management agencies, professionals, and producers (i.e., pharmaceuticals and purchasers) are pushing healthcare to the forefront of attention in all venues but safety and quality in particular (Noble, 2008). However, stakeholders trying to build better health care and using various sources for their basis can be inconsistent (Peters et al., 2007) and information further complicates this. To emphasize their analysis, Wiltshire, Roberts, Brown, and Sarto (2009) use the framework from Beisecker and Beisecker's 1990 study:

> Patient power in the doctor-patient communication is influenced by a complex interaction of patient and doctor sociodemographic characteristics (e.g., age, patient income, cultural background), attitudes (e.g., patient's information seeking and assertiveness, doctor receptiveness, patient trust in doctor, and patient-doctor role expectations), and situational factors (e.g., type of visit, type of illness, length of visit, presence of a companion, and physician's communicative style of behavior; pp. 316-317).

The quality of health care and patient-physician communication are directly affected by addressing health literacy. They are interrelated and interdependent (Black, 2009). Decision making, patient adherence, and treatment outcome goals should be centered on patient care and health literacy (Black, 2009; Chao et al., 2009).

Health Literacy Policy. There is little literature regarding how health organizations are addressing the problem of low health literacy (Gazmararian, Beditz, Pisano, & Carreon, 2010). Sentell (2003) supported this stating that national health surveys do not include literacy or health literacy. However, researchers have shown that there is a need for oversight in various aspects of health care. According to Koh (2011), accountability is needed from the government and organizations that are responsible for improving population health, and Epstein, Fiscella, Lesser, and Stange (2010) called for a national-level policy for patient-centered care. Kimbrough (2007) stated that to gain health literacy, we have to understand why there is low health literacy, then framework in the provisions to help people become health literate, thereby using health literacy as a tool for positive social change.

Intervening may take unconventional routes/ways to get the message forefront and possibly affect policy at local, state, and perhaps federal levels. Henry et al. (2011) stated that intervention is one thing and implementation is another. They found that one of the biggest barriers and challenges, is changing the mindset for professionals from being a coined phrase to an everyday practice (Henry et al., 2011).

Researchers have shown that one way to effect change in both the medical and political professions is to frame it with a bottom-up model. One limitation to that, however, can be the make-up of the community (Henry et al., 2011). Despite the limitation, grassroots efforts can fill the gap among health care activists and the population (Hoffman, 2003). Tharp and Hollar (2002) stated, change takes educating, thereby, calling on the grassroots organizations to have educational and informing activities about public policy issues. Other researchers have called for identifying gaps within current health policy and health literacy best practices to close these gaps and lead to actionable changes (Shone, 2012).

Researchers have not given a definitive model for capacity building for any one specific or all health issues. Specific issues often face very different needs and have potentially different policy gaps. There have been many health-based social movements organized by grassroots activists trying to impact health and social policy, but few studies have been done to show the effectiveness of their policy change efforts (Keefe et al., 2006).

Major Sections of Chapter 2

In this chapter, I briefly look at the strategy used in the literature search and discuss the accessed databases and search engines, search terms, and iterative search process. The following section address the conceptual framework expounding what was discussed in Chapter 1 through the literature, and how health literacy and policy has been applied in previous research. This leads into the main portion of the chapter, discussing the literature reviewed. This section is divided into three subsections: (a) health literacy; (b) policy and governance; and (c) health literate organizations. Finally, I conclude this chapter with a summary of the themes found in the literature and introduce Chapter 3.

Literature Search Strategy

Health literacy crosses various disciplines, such as health, education, and policy, and variables such as community, economic conditions/status, and demographics. To narrow a search down to a few databases would limit the understanding of the integral complex interactions of health literacy, health care provisions, and policy under just one of the mentioned disciplines and/or variables. Though the subject of complexity is discussed later in this chapter, it is because of the complexity of health literacy and the impact that culture, society, health systems, and education systems have on health outcomes (American Association of Family and Consumer Services, 2010) that multiple databases were searched, and the Walden Thoreau was used. The Google search engine was also used to find organizations promoting health literacy as well as the federal legislative bills.

The search terms used through the Walden Thoreau were *health*, *health care* (used both as a single word and separate words), *health literacy* (used both as a single word and separate words), *accreditation*, *policy and federal* (also used as a term and as two separate search variables), *hospital*, *health provider and health care provider*, *standards, criteria*, *education;* and *culture*. The search results were varied and therefore put into three main categories (described above): (a) health literacy; (b) policy and governance; and (c) health literate organizations.

The literature on health literacy was found to have a broad range of information and research on health literacy. However, the literature that was available specifically on policy or relative to policy was limited, and the literature reviewed was outside of the standard of 5 years or newer. The literature that is most current has not changed much from other years, though some researchers are looking forward to what can be done electronically with health literacy, which is a discussion for Chapter 5. That there are still questions on health literacy policy supports the rationale for this study.

Theoretical Framework

The theoretical framework of this study was based on the Evans and Stoddart framework of determinants of health (also known as the model of health and well-being) and health behavioral theories. The following conceptual framework is based on health literacy best practices and policy, which are part of both theories.

Determinants of Health

The social determinants of health are the social, environmental, and economic conditions that influence and affect individuals' health and influence the functioning and well-being of a community (CDC, 2009; DPHP, 2016). These conditions are shaped by the socioeconomics, which are influenced by policy (CDC, 2009; Kindig & McGinnis, 2007).

As the original model, the Evans and Stoddart Field Model of Health and Well-Being is often used to recognize the factors of population health (Kindig & McGinnis, 2007) and approach to achieving health and well-being (CDC, 2009). Health equity is defined as having no health disparities among social groups of all level of social hierarchy (CDC, 2007).

The purpose of the model was not to present a comprehensive view of the determinants of health – but to construct an analytical framework highlighting how the various factors and forces interact to the differing concepts of health (Evans & Stoddart, 1990). The framework was built by adding the complex components of health as well as the basis of health policy. The model was built in five stages (Evans & Stoddart, 1990):

1. The understanding of the interaction of disease and health care was conceived.
2. The cost and effectiveness of health care were integrated.
3. The factoring of the effects of the health field (lifestyle, environment, human biology, and health care organizations) was added.
4. The health and function, and disease are separated; well-being and a focus toward policy is added.
5. The understanding that prosperity is linked to health care was made.

Health Behavioral Theories

The World Health Organization (2012) uses three main health behavioral theories in research: (a) individual capacity (or intrapersonal); (b) relationships (or interpersonal supports); and (c) environmental contexts (or institutional factors, community factors, and public policy).

The individual or intrapersonal is defined as having six levels of capacity or having characteristics that influences behavior: (a) awareness and knowledge; (b) beliefs; (c) opinions and attitudes; (d) self-efficacy; intentions; and (e) skills and personal power (World Health Organization [WHO], 2012). In the literature reviewed, the majority of the research is based upon this theory and focused on the individual’s health literacy level and capability and is being recognized in works such as Wong (2012).

The relationship/interpersonal support is defined as having the processes and primary groups, to included family, friends, and peers, that gives the individual their social identity, support, and role definition (WHO, 2012). This is also known as social learning theory and based on the idea that people generate the environment that they live in, which impacts their health (WHO, 2012).

The environmental contexts theory is defined by three factors – institutional/ organizational, community, and public policy – that influence the social system function and change (WHO, 2012). The institutional factor is the rules, regulations, laws, and policies of how we are governed and the formal-type structure of the institutions we engage in (e.g., schools). These institutional factors may limit or encourage the individual's social identity and role in society (WHO, 2012). The community factor is the formal and informal norms and standards that are designed by social networks that occur within individuals, groups, and organizations (WHO, 2012). The public policy factor is the policies and laws (local, state, and federal) that legalize, standardize, or influence health actions and practices that affect disease prevention, control, and management (WHO, 2012).

Theoretical to Conceptual

The environmental context factor of the behavioral theories and the health & function and well-being components of the Evans and Stoddart model are the basis of this study's theoretical framework that ties into the conceptual framework. Much of health literacy research has focused on just the individuals and/or the individuals with specific conditions (Mackert, Champlin, Su, & Guadagno, 2015). A good portion of the research done has also focused on the interactions between the individual and those around them, such as a caregiver, family, etc., and/or the life stage of the individual (Mackert et al., 2015).

New research is now starting to look beyond the intra- and interpersonal to focusing on the environment of the healthcare provider and searching for the gaps between what has been researched and how it can be translated to support this new direction (Mackert, 2015; Mackert et al., 2015; Rudd, 2010; Weaver, Wray, Zellin, Guatam, & Jupka, 2012; Weiss, 2015; Wong, 2012). In this study, I tied together the fourth stage of the Evans and Stoddart model, the environmental context of the behavioral theories, and the following conceptual framework by exploring the utilization of health literacy best practices on the process of policy development.

Conceptual Framework

The construct of the conceptual framework was based on health literacy best practices and the process of policy development. The underlying concepts that surround the framework are:

- Health care is complex;
- Low health literacy is a problem;
- Health literacy is a complex issue;
- There is a lack of policy direction at the federal level; and
- Organizations at the grassroots level are shaping their role in the local communities implementing health literacy without the foundation of policy or centralized coordination.

In this study, I looked at how organizations implement health literacy tools and guidelines and promote policies in an environment of complex related issues and interlinked with complex network effects and specific elements that are complex as well. I also explored the best practices of the organizations that have adapted most effectively.

The multiple case design was chosen to research health literacy best practices due to its descriptive nature. It allows the construct to view the managing behavior of the leading health literacy organizations and is a leading method of examining policy and public administration. The purposive and expert sampling techniques are being used as the organizations/populations are known. The purposive allows a community of health literacy experts to be interviewed with questions that supported the conceptual framework.

Literature Review

Health Literacy

According the Ad Hoc Committee on Health Literacy in 1999, the term health literacy has been in use in literature for approximately 30 years (Nutbeam, 2000). It is noted that the term was first used in the paper *Health Education as Social Policy*, written by Simonds in 1974 that discussed health education as a policy issue that affected the health care and education systems as well as mass communication (Ratzan, 2001). However, according to the American Association of Family & Consumer Sciences (2010), the concept of health literacy is much more recent in the literacy community and there are no set definitions or conceptual frameworks for health literacy.

Schnitzer, Rosenzweig, and Harris (2011) stated that former definitions lend to merely having the ability to read and that the definition has evolved to having wider and understated factors. There are four basic definitions of health literacy that are in use today:

- World Health Organization (1998) – “represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use, the information in ways which promote and maintain good health” (p. 10);
- Ratazan et al. (2000) – “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”;
- National Health Education Standards (NHES) – “the capacity of an individual to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which are health-enhancing” (Marx, Hudson, Deal, Pateman, & Middleton, 2007, p. 158); and
- Schnitzer et al. (2011) – “these are the basic cognitive skills that all people need, for instance, to find their way to the right unit in a hospital or other health facility, to fill out medical and insurance forms accurately and completely, to understand specific medical instructions, and to communicate their history and health needs to health care providers” (p. 164).

There is considerable ambiguity in defining health literacy and what should be individual skill or community/global-level ability which affects the research being done to try to improve health literacy as well as measuring health literacy (Mackert, 2015; Mackert, Chaplin, Su, & Guadagno, 2015; Menzies, 2012; Rudd, 2010).

Although defining health literacy is important, understanding its impact on society is critical to minimalizing the effects of low health literacy. The AAFCS (2012) stated that health literacy is complex and is affected by societal culture, and the health and educational systems, which, in turn, affects health. The Office of Disease Prevention of Health Promotion (n.d.) delineates this further:

- Health literacy is affected by:
    - Communications skills – lay persons and professionals
    - Knowledge of health topics – lay persons and professionals
    - Culture
    - Demands of health care and public health systems
    - Demands of situation/context;
- Health literacy affects ability to:
    - Navigate health care system (filling out forms and locating providers and services)
    - Share personal information with providers (health history)
    - Perform self-care and chronic-disease management
    - Understand mathematical concepts (probability and/or risk).

Therefore, studies show that, by definition, health literacy is not just a patient's problem, that it is also the provider's and health care system's problem that affects the quality of medical care the patient receives (VanGeest, Welch, & Weiner, 2010; see also Nielsen-Bohlman et al., 2004; Parker, Ratzan, & Lurie, 2003; Wong, 2012). Health literacy, according to Ratzan (2001), is also not just health knowledge. Lackey (2009) describes the relationship with physicians as a difficult partnership which requires changing their disciplinary knowledge and ideologies. Kimbrough (2007) supports this but stated that race, ethnicity, and income disparity is a lot of the obstacles.

Prior research shows that there isn't one single factor, phenomenon, directive, policy, action, or even person that can be singularly pinpointed as the justification for low health literacy or health care problems within the industry. Research on health literacy has been primarily defining it and examining the effects low health literacy has or what conditions arise from it. Literature shows that there are appeals to move beyond the same type of research and written articles on health literacy (Mackert, 2015; Ross, Culbert, Gasper, & Kimmey, 2009; Rudd, 2010; Weaver et al., 2012). Research on the development and/or implementation of policy regarding health literacy is non-existent. Reasons for this could be that research has focused on the impact of health care provision (services) and policy has focused on provision. Research literature on provision absent of health literacy and its impact was not found. This study's scope of the phenomenon of health literacy policy has not previously been addressed and can potentially impact the approach of improvements in health literacy.

The complexity of the problems of low health literacy is only a portion of the full concept of complexity. There are three major concepts of health literacy found in the literature that were explored:

- The complexity of health care (Brach et al., 2012; Chao et al., 2009; Chatterjee, 2003; Schyve, 2007; Thomas, 2006; DHHS, 2003);
- The correlation of health literacy to health care costs and outcomes (Berkman et al., 2011; Glassman, 2012; Kimbrough, 2007; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Rudd, 2012; Schnitzer et al., 2011; Somers & Mahadevan, 2010; Williams & Marks, 2011; OSG, 2006); and
- The use of organizations to influence policy (Schauffler & Wilkerson, 1997; Kissam, 2011; Hoffman, 2003; Gordon, 2003; Keefe et al., 2006; Whitman, 2009; Couto, 1990).

Health literacy complexity. As discussed, the definition of health literacy through literature varies, as does the explanation of what contributes to these variables. Simply put, because of the complexity of the healthcare system, it is easy to comprehend that limited health literacy can be associated with poor health (DPHP, n.d.). Chao et al. (2009) stated that health care complexity and the patients themselves contribute to the difficulties of health literacy and addressing the disparities is daunting because health literacy is a combination of social and individual factors, and those are education, culture, and language.

The individual factors and the variables that are affected by health literacy are more than just education, culture, and language. There are five major variables that categorize this phenomenon: patient demographics, socioeconomic status, hospitals, communities, and various factors such as housing conditions, air quality, racism, the relationship to community institutions, and neighborhood economic conditions. Though socioeconomic status is often incorporated as part of demographics, for the purpose of this study, it is considered a separate variable that is discussed through literature. Patient demographics include age, language, health status, numeracy, and self-efficacy. Socioeconomic status includes, income, education level, and type of occupation. The hospital variable includes the hospital geographical location, the community it serves, and the patient demographics (which includes socioeconomic status). The community variable also includes the geographical location, the patient demographics, and socioeconomic status. Though all the factors (mentioned previously) are important to the communities and hospitals, in this study, I did not focus on the housing conditions, air quality, or the racism.

The complexity of health care is not anything new. It goes back as far as medicine and the treatment of illnesses. However, health care isn’t the only complexity. As stated by DHHS, the Office of the Surgeon General (OSG, 2006), limited health literacy problems are immeasurable and complex. The issue of health care being complex doesn’t stay at the health care organizations level; it goes down into the systems to a clinic or the clinician’s office (Schyve, 2007). This complexity impinges on the ability to clearly identify effects to changes and contributes to making health literacy more difficult to those that have low health literacy (Chao et al., 2009; Chatterjee, 2003). According to Glassman (2012), health complexity is related to health literacy in that patients face complex decisions about their treatments and therefore it impacts their health knowledge, their health status, and their access to health care.

The correlation of health literacy to health care concept states that 1) health literacy influences the cost of medicine; 2) health literacy affects the health outcome of the patient; and 3) health literacy is affected by five key variables that embodies a patient:

- Demographics (Kimbrough, 2007; Rudd, 2012; Somers & Mahadevan, 2010; OSG, 2006);
- Socioeconomic status (AbuDagga, 2009; Arcaya & Briggs, 2011; Black, 2009; Chao et al., 2009; NCIOM, 2007; Nutbeam, 2000; Sentell, 2003; OSG, 2006; Wood, 2006);
- Education (NCIOM, 2007; Nutbeam, 2000; Sentell, 2003; Stableford and Mettger, 2007);
- Self-efficacy (Black, 2009; Nutbeam, 2000; Seligman et al., 2007; Villaire & Mayer, 2009); and
- Numeracy (Peters et al., 2007).

There is debate among researchers regarding a direct correlation of the patients’ health literacy skill levels to the rise and fall of healthcare costs (Berkman et al., 2011; Glassman, 2012; Paasche-Orlow et al., 2005; Schnitzer et al., 2011; Somers & Mahadevan, 2010; Williams & Marks, 2011).

The National Assessment of Adult Literacy stated, 12 % of Americans are health literate (OSG, 2006). That leaves the majority of the country with poor health literacy skills and the difficulty with complex information that accompanies everyday tasks (Paasche-Orlow et al., 2005). This substantiated *Health People 2010* broadening the definition of health literacy to include the “by-product of system-level contributions” and not put the full burden on the individual (Somers & Mahadevan, 2010, p. 5).

However, the early definition of health literacy alludes to the complex nature that surrounds the individual patient. According to Bodie and Dutta (2008), the definitions of health literacy highlight four aspects of the construct:

1. People need the ability to gain appropriate health information must have the drive to do so.
2. Health literate people are able to understand the information that s/he has gathered.
3. Health literacy involves a confidence competency in using health information.
4. Health literacy definitions advocate that having the motivation and capability to gather, comprehend, and use health information in proper ways should impact health and well-being positively.

The key variables of patients will determine the level of health literacy and their ability to navigate through healthcare issues and complex healthcare systems. This is a broad perception as seen in the WHO’s definition of health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (Bodie & Dutta, 2008, p. 18).

Though the field and research of health literacy has advanced since acknowledging that health literacy has implications for health outcomes, it's still a significant problem in the United States. Ten years ago, approximately 80 million adults (36 %) had low health literacy (Berkman et al., 2011). Berkman et al.'s (2011) findings show that five studies showed lower health literacy may be potentially associated with increased hospitalization, a greater use of emergency care services in nine studies, a lower use of mammography in four studies, and four studies showed a lower receipt of influenza vaccine. One study suggested that health literacy could lower the effect of education, income, and the geographical community on health outcomes (Berkman et al., 2011). There is obviously a clear association of higher risk of mortality in seniors but high evidence stated that poor ability to take medications properly (five studies), poorer ability to interpret labels and health messages (three studies), and poor overall health status among seniors (five studies) is associated with lower health literacy (Berkman et al, 2011). Low, Low, Baumer, and Huynh (2005) stated that health is distributed unevenly due to socioeconomics. It is widely known and understood that the effects of social economics encompass both the individual and the community. Thereby, the health of the individual is affected by his or her own social economics and of those of the community (Lurie & Parker, 2007).

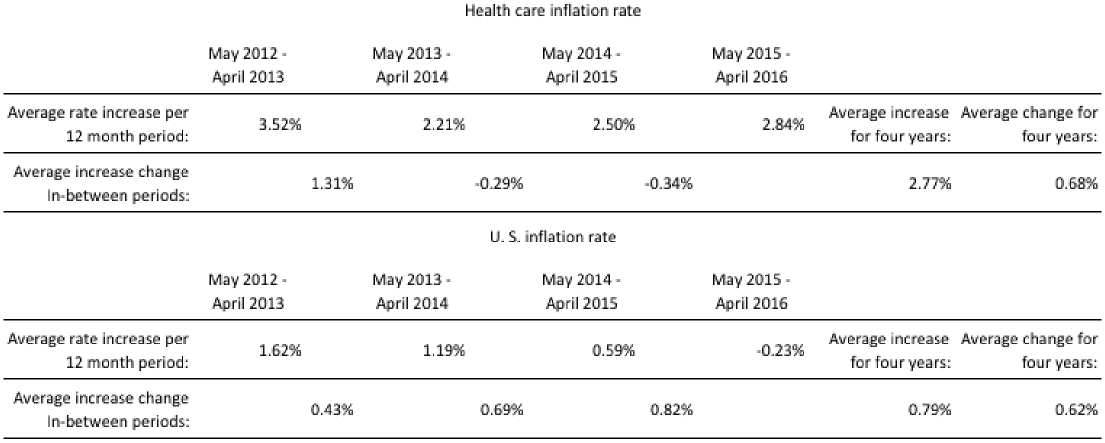
A lot of attention and research focuses on quality of care as a way to improve patient health outcomes thereby also reducing the cost of healthcare. However, the North

Carolina Institute of Medicine (NCIOM, 2007) stated these initiatives could fail if the healthcare system and community does not efficiently integrate more effective communication with those that have low health literacy skills. Williams and Marks (2011) agree and stated that opportunities need to be created for both individuals and communities to increase healthier choices and healthier living.

Within the last 5 to 10 years, the cost of healthcare has been the focus of the healthcare community. Some research shows that health literacy is driving the cost of healthcare and estimates that the cost to the US economy is an average of $168 billion per year (Schnitzer et al., 2011; Somers & Mahadevan, 2010) with an increase of no less than $30 billion in approximately a decade (Glassman, 2012; Paasche-Orlow et al., 2005). With the economy strapped, this becomes a concern, as the cost is not just to the patients themselves but also those who deliver their care and to the taxpayers as well. In the current decade, the government has had more focus on health literacy with the notion that it is linked to economic outcomes (Hunter & Franken, 2012). As publicized in OECD International Literacy Surveys between 1990 and 2000, this situation is not new (Hunter & Franken, 2012). The late 1990s found the nation looking at a financial crisis due to healthcare costs with the growth of the United States healthcare spending outpacing the growth of the Gross Domestic Product by more than 2% per year over the previous 30 years (Ginsburg as quoted by Black, 2009). According to YCharts.com, that trend has continued and shows that the health care inflation rate is far above the consumer price index. From May 2012 to April 2016, the health care inflation rate was 2.77% and the United States inflation rate was 0.79% shown in Table 1.

Table 1

Health Care and United States Inflation Rates



Health care inflation rate

	May 2012 - April 2013	May 2013 - April 2014	May 2014 - April 2015	May 2015 - April 2016	Average increase for four years:	Average change for four years:
Average rate increase per 12 month period:	3.52%	2.21%	2.50%	2.84%		
Average increase change In-between periods:	1.31%	-0.29%	-0.34%		2.77%	0.68%

U. S. inflation rate

	May 2012 - April 2013	May 2013 - April 2014	May 2014 - April 2015	May 2015 - April 2016	Average increase for four years:	Average change for four years:
Average rate increase per 12 month period:	1.62%	1.19%	0.59%	-0.23%		
Average increase change In-between periods:	0.43%	0.69%	0.82%		0.79%	0.62%

Note. Data was retrieved from public information distributed by YCharts.com, 2016.

The effects of inflating costs and other issues due to low health literacy can also be exacerbated by the effects of market factors and stakeholders working at times concurrently with each other while times consecutively (AbuDagga, 2009; Hassan, 2006). According to Seligman et al. (2007), stakeholders are the health care providers, as well as the patients, families, and the caregivers.

The blurred line between market factors and stakeholders is hinging on the socioeconomic and the demographic of the patient stakeholder (AbuDagga, 2009; Chiarelli & Edwards, 2006; Collins, 2008). In his research, AbuDagga (2009) substantiated this “hinging” in two of his ten hypotheses equating them to markets with higher per-capita incomes (hypothesis 9) and markets with lower percentage of minority population (hypothesis 10). Sentell (2003) stated that an autonomous relationship between literacy and health in any aspect is complex due to various factors associated with literacy and health.

Impact of health care and outcomes. Low health literacy is known to impact the patient's ability to self-care thereby increasing the visits to hospitals (DPHP, n.d.; Kennedy, 2005; Kimbrough, 2007; OSG, 2006; Rowlands, Berry, Protheroe, & Rudd, 2015; VanGeest et al., 2010). It is easy to understand that the more a patient uses health care, the more it will cost the patient. However, literature shows that patients with low health literacy will have poor health outcomes thereby using health care more and perhaps incorrectly (AAFCS, n.d.; Kimbrough, 2007; Chao et al., 2009). In 2007, a study was conducted that assessed the annual cost of low health literacy was approximately $106 billion to $238 billion (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). In 2003, Berkman et al. (2011) found that approximately 80 million adults in the United States (36 %) had limited health literacy.

Low health literacy isn't limited to patients with English as a second language. One of the largest groups is adults over 65 (DPHP, 2010; NCIOM, 2007). According to Thomas (2006), this number will increase going from 35 million to 70 million by 2030. The next largest group is the growing immigrant population (Chao et al., 2007). According to Sentell (2003), minorities are represented disproportionately and, though faulty, race is more commonly measured and compared than is socioeconomic status or even literacy. Sentell (2003) also points out that income and better health are associated – as income rises, the health of the individual rises as well. Kimbrough (2007) stated that this type of disparity demonstrates the inequities of health in society and the impact of social issues, such as health literacy, contributes to it and shouldn't be overlooked.

As stated previously, health literacy is affected by and affects various variables to include demographics, etc. However, there is also a correlation to basic functions of education (literacy and numeracy), education level itself, culture, and self-efficacy that affects and is affected by health literacy.

Literacy and education. Literature shows that there is a relationship and correlation of health literacy to literacy and education (DHHS, 2003; Nutbeam, 2000; Glassman, 2012; Chao et al., 2009). According to Ratzan (2001), health education can have a great impact if it provides information and knowledge that can be used beyond the school walls or a health facility. Sentell (2003) stated that education is the most obvious link to literacy itself but that literacy is independently associated with income and occupation that affects and is affected by health literacy. Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, and Rudd (2005) concur stating that education and income are the most common demographic features associated with health literacy and significant in regression analysis.

Because health literacy is dependent on fundamental literacy, those that do not have health education, will not have the skills to use health information and strategies to increase health literacy levels which are linked to increasing literacy (Nutbeam, 2000; NCIOM, 2007). Mogford, Gould, and DeVoght (2010) propose that education shouldn’t focus on to eliminate only individual inequities but rather individuals and communities. Lurie and Parker (2007) agree stating that an individual’s health is affected by their socioeconomic status and individuals that live in their communities and neighborhoods and view health literacy as a community issue. Perhaps encouraging schools to start educating early would be a long-term impact if not a step towards a healthier pathway even though it may be a policy battle in changing curriculum (Menzies, 2012).

Numeracy. Like literacy, numeracy has a strong relationship with health literacy. Numeracy is defined as being a part of literacy that facilitates basic math skills that allows probability and numerical notions that are needed to function in society every day (DPHP, 2010. These skills are necessary to be able to calculate cholesterol and blood sugar levels, measure medications, and understand nutrition labels, all of which require math skills (DPHP, n.d.). Numeracy is also necessary to understand health plans in which an individual must compare coverage percentages, calculate premiums, co pays, and deductibles (DPHP, n.d.).

Self-efficacy. According to Seligman et al. (2007), “self-efficacy in health care, is an individual’s confidence in being able to successfully organize and perform the activities essential to managing their own health and care. Bodie and Dutta (2008) found that in four studies, knowledge, self-efficacy, and stigma may mediate the fundamentals between health literacy and health outcomes which explains how low health literacy affects health outcomes. The Office of Disease Prevention and Health Promotion (n.d.) stated increasing self-efficacy, confidence in one’s ability, is key to increasing decision making.

Policy and Governance

Most policy in the past forty years has focused on provision. It should be questioned whether we have hit the limit of what provision can do without improvements in literacy. Kickbusch (2001) stated that health is an increasingly complex societal system and the connection between health literacy, socioeconomics, and health will increase. Williams and Marks (2011) found that opportunities need to be created for both individuals and communities to increase healthier choices and healthier living. This in turn will improve the nation's health as well as the economic benefits (Williams & Marks, 2011).

Health care changes mirror and are shaped by society that are driven by developments in science, medicine, and pharmacology as well as economics, government regulations, and patient demographics (Thomas, 2006). Thomas (2006) stated that health policy has evolved from individualism and entrepreneurism but is not organized in its methods thereby making public policy increasingly important to the future of health care. Kickbusch (2001) outlined three challenges to policy:

- Reliable measures of health literacy of societies and populations;
- Scientifically quantifying policy's impact on the quality of life and health outcomes; and
- Public health involvements that notably increase health literacy use.

Kickbusch (2001) also found that health literacy and societal wealth are both measurable determinants of health outcomes and that the conceptual model for health literacy's political goal should be capability not function and to develop the measures and indicators within a community.

Bryan's (2008) findings support this stating to engage the stakeholders on the status (demographics, socioeconomics, and literary data) for their communities, to petition state and national legislators with the initiatives and broad effects on their communities, and to outline a plan with health literacy approaches that can be used to communicate needs. Williams-Crowe and Aultman's (1994) research found that to participate in the policy process, the health agency must be organized, develop political relationships within the communities and with legislative representatives, combine exacting knowledge of public health with practical and realistic approaches, and early on, involve the community in the policy process. Ratzan (2001) mirrors this stating decision should be based on sound science and theory and involve a partnership between the legislators, public health officials, and society. Ratzan also stated policymakers that are familiar with health sector must be conscious of the determinants of health illiteracy.

So far, literature shows that policy shouldn't be formed in a vacuum. Health policies, according to Longest in 1998, are the primary avenues society uses to strive for health, with respect to the working definitions of health and the key factors that measure health (as cited by Wood, 2006). This must be managed formally to meet the clinical and social objectives within budgetary limits with many believing this should be the governments and the dominant authority of the national government can provide planning and distribution of health care resources and the institutions/organizations provide formal structure and can influence the society (Wood, 2006).

According to McDonald (2006), legislators who are not experts whom write public health policy, possibly do not comprehend medical terminology or related health issues and the end results potentially impact the population's health and well-being. Two other findings support this stating, that policy writers and public leaders need to recognize this, and that it is essential that policy makers correctly define the problem enabling solutions to ensure positive public health outcomes for everyone regardless of their socioeconomic status (Frist, 2005; Koh, 2009). The extent to which one can be informed with understanding of policy issues shaped by the larger social entity and addressed in the past is the level of health policy literacy (Wolbring, Leopatza, & Yumakulov, 2012). This includes:

- Understanding policy development and social embeddedness, history of arguments of a health policy discussion and the consequences; and
- How emerging social, scientific, and technological developments affect policy and formal discussions (Wolbring et al., 2012).

Arcaya and Briggs (2011) argue that the government needs to be innovative and have structured practices enabling them to focus on policy that addresses the social determinants of health. Koh's (2011) findings support this – there is a need for a broad social determinants approach, putting health in all policies, and having clear accountability from all key players involved in improving the population's health. In fact, the Institute of Medicine (IOM, 1988) recommends that every public health agency should serve their communities by leading in the developing of comprehensive health polices by using scientific knowledge in public health decision-making. IOM (1988) also stated that responsible leadership in health policy is approaching the process strategically and communicates with other related groups (i.e., state agencies and advocacy groups) to affect policies and policy development as well as serve the communities' needs.

There are challenges with formulating public health policy even without bringing health literacy to the table. Wood (2006) stated policy decisions are based on the availability of financial resources and on economic feasibilities. This not only affects people’s out-of-pocket expenses but produces an excess of health providers in underprivileged areas (Wood, 2006). This will affect also the health literacy level of the community and particularly those that are greatly affected by low health literacy – in essence, the minorities and socioeconomically disadvantaged (Schnitzer et al., 2011).

So far, literature has shown that policymaking should not be legislation without the representation of key players (i.e., politicians, health organizations and agencies are often the gatekeeper that intercede and implement policy and changes (Watt, Sword, & Krueger, 2005). Parker and Kindig (2006) found that health literacy improvement should be a shared responsibility with a significant share to be held by the health care system. However, it is in question whether policy will assist the health care system in any capacity to improve health literacy. Watt, Sword, and Krueger (2005) stated that though a health care system must have a provider’s commitment as the foundation to effective policy implementation, political objectives and policies by themselves, regardless of intention, won’t change a health care system’s practice. Though health literacy has begun to make headway into policy, it is largely ignored in the practice arena and is insufficient in meeting the needs of society and relatively useless to the healthcare community (Pleasant, Cabe, Patel, Cosenza, & Carmona, 2015).

Ratzan (2001) found that health literacy can link the concepts of knowledge and practice. Implementation of policy should include health literacy (Somers & Mahadevan, 2010); however, research linking or studying the relationship between health literacy and public policy is little perhaps due to barriers bridging research and policy (McDonald, 2006; Davis, Gross, & Clancy, 2012). Bell and Standish (2005) found that perhaps combining policy and community can bridge the gap. Arcaya and Briggs (2011) agree finding that community involvement and development while improving other means of intervening creating an impact on the population. According to Ross (2004), this should be done by organizations with consistent influence with both the communities and legislators.

Health Literate Organizations

Health literacy has been studied and research has been done on the impact of low health literacy and the understanding is evolving. Abrams, Kurtz-Rossi, Riffenburgh, and Savage (2014) published “Building Health Literate Organizations: A Guidebook to Achieving Organizational Change”. The authors capitalized on tools, guidelines, and resources that organizations need and use effectively and reliably; and thereby stated before making any of the tools policy on a grand scale, it should be tested and refined on a smaller scale first (Abrams, Kurtz-Rossi, Riffenburgh, & Savage, 2014).

Health literate organizations are focused on the communities as well as individual patients. The patient population is becoming more and more diverse and healthcare professionals and organizations seek ways to communicate to the various cultures, languages, and education (Wynia & Matiasek, 2006; Schnitzer et al., 2011; Schyve, 2007). Wynia and Matiasek (2006) found organizations within local communities raise the awareness of health care, services and are key for health education efforts. Lurie and Parker’s (2007) findings matched this stating that because health literacy is related to income and education, health literacy is a neighborhood and community issue.

Summary

The vast amount of literature shows us that public health and health care are complex with complex issues. Health literacy is only one issue but perhaps the most complex due to so many variables such as (but not all inclusive) education, age, health condition, language, and environment. In their study, Parker, Ratzan, and Lurie's (2003) called for the development of indicators and mechanisms that these variables can be held accountable, and Epstein et al. (2010) called for a directed and dedicated national policy for patient-centered care. However, there is not a one-size-fits-all solution (OSG, 2006).

Major health policy developments at the federal level brought health literacy to the "tipping point" moving health literacy from the margins to mainstream healthcare practice:

- The Patient Protection and Affordable Care Act (2010);
- The National Action Plan to Improve Health Literacy (2010); and
- The Plain Writing Act of 2010.

Likewise, major legislation, Health Literacy Act of 2007, was not signed and the development of standards for health literacy accreditation was limited to using plain language after 2 years. Therefore, policymakers need to focus on the policy intent or objective, the pros and cons of alternate methods, and the possible obstacles during the implementation of the policy (Watt et al., 2005).

Health literacy is considered to be the foundation of patient-centered care. However, as Schnitzer et al. (2011) pointed out, it is improbable that patients' health literacy skills will notably improve during a medical visit. It must be a comprehensive approach that includes assessment and policy development, identifying the contributing factors such as education, economics, physical environment, politics and government, communication, and accessibility to health services (Anderko, 2010). Any assessment on health can be used to fabricate new laws and develop programs within communities that impact public health (Williams & Mark, 2011). Health affects the quality of life and the ability of people to reach their goals (Kimbrough, 2007). This quality is impacted by our demographics, socioeconomic statuses, and environment. Kimbrough (2007) argues that society has a responsibility to ensure quality health and well-being that is diverse and will fit people as individuals as opposed to making a diverse society and environments fit one type of healthcare. The sense of community is rapidly disappearing; it is the organizations within the communities that are paying attention to the impact of public policy's impact on public health within communities where it may be a fair assumption that the populace is vastly unaware of health literacy (Couto, 1990; Pleasant et al., 2015).

Health literacy, as research to improve health care, as well as policy, has experienced growth but has focused on documenting relevance and now needs to focus on an approach to use this research within the communities (Pleasant et al., 2015). This has been argued for many years. The scope of health literacy research is too narrow – focused on reading levels, patient comprehension, utilization of services, and health outcomes – and best practices were focused on language and culture (Shohet & Renaud, 2006). Future research should include assessments with tools that meet that need and relevancy of a health literate organization (Weaver et al., 2012). Weiss (2015) questioned whether our tax money is being spent on the right things with the funds obligated for health literacy research.

Through this study, I advocated for the understanding of critical heath literacy in our society. My exploration on the extent of organizations' influence on health literacy policy not only contributes to the body of knowledge but by comparing these organizations' best practices with health literacy tools/guidelines (without regulation), best practice recommendations can be made to various organizations regardless of level (local, state, or federal). By also exploring these organizations, possible health literacy policy might be determined by comparing what is currently being shaped, taught, and applied. Exploring commonalities of organizations that are addressing the complexity of health literacy within their communities allows patients and healthcare providers to better address health concerns and potentially influence how health care providers improve patients' ability to maintain their own health and help them be their own advocate. The next chapter of this study, Chapter 3, discusses the methodology in more detail.

Chapter 3: Research Method

Purpose

The purpose of this qualitative case study was to explore and compare commonalities in health literacy best practices of organizations that are recognized as leaders in health literacy by the CDC and organizations found on the health literacy list serve. These organizations are addressing low health literacy in their communities. By comparing the organizations' abilities to implement standards of plain language (regulated through accreditation) and other health literacy tools/guidelines (without regulation), best practice recommendations can be made to various organizations regardless of level (local, state, federal, or nonprofit). By also exploring these organizations, potential health literacy policy might be determined by examining what is currently being shaped, taught, and applied. Exploring commonalities of organizations that are addressing the complexity of health literacy within their communities will allow patients and healthcare providers to better address health concerns.

Low health literacy is a problem the United States faces. Health literacy, like health care itself, is a complex issue. The complexity stems from patient demographics, the communities they live in, and medical and healthcare providers being very diverse (see Figure 1). The medical community acknowledges low health literacy as a problem. Tools have been developed to assist providers in mitigating the risks of low health literacy. However, currently in the health care community, there is a lack of formal policy on health literacy. Most policy has focused on the delivery/providing of health care, but that threshold may have been reached of what provision can do exclusive of improvements in literacy. Though health literacy is not much use without healthcare provision, healthcare provision is of limited use without health literacy.

This problem impacts everyone, from the patient, to the doctors, to the community, and to society. The patient's health outcome is the most obvious as health literacy is necessary for a patient to have an active role in his or her own health care. Other impacts, such as the rising cost of health care, are not as readily noticeable; however, they are quite significant. There are many possible factors contributing to this problem:

- The complexity of health care (to include medical language and insurance);
- The complexity of health literacy (which includes language and the variables of demographics); and
- That the construction of an individual's approach to care is based on health literacy.

Poor literacy leads to a construction that undermines effective service and good literacy has the opposite effect. This study contributes to the body of knowledge needed to address this problem by comparing health literacy best practices and its effect on the process of policy development to address health literacy through formal policy.

Major Sections of Chapter 3

Chapter 3 has four major sections that follow the chapter's introduction: Research Design and Rationale, Role of the Researcher, Methodology, and Issues of Trustworthiness. I concluded Chapter 3 with a summarization of the main points and an introduction to Chapter 4.

Research Design and Rationale

Research Questions

There were three research questions in this study. These questions were derived from the concept of healthcare complexity and that health literacy issues further complicate this.

RQ1: How are organizations implementing health literacy tools/guidelines without formal regulation?

RQ2: What impact does health literacy best practices have on the process of developing formal policy?

RQ3: How can health literacy be addressed through formal policy?

Concept of the Study

The key concept of this study was health literacy. The vast amount of literature has shown that public health and health care alone are complex issues. Though health literacy is only one issue within the health care arena, it is among the most complex with a large – perhaps the largest – number of variables. Health literacy is considered a major contributor to health care complexity. Studies have shown that low health literacy affects patients' health outcomes and contributes to increased health care costs.

This study impacts hospitals, healthcare organizations, and other organizations that are currently shaping and implementing tools to lessen the effect of low health literacy. This study can potentially also impact doctors, nurses, patients, and family members who will be recipients of the applications of best practices and policies.

Research Method

In this study, I examined the interaction (health literacy best practices) of organizations and the surrounding communities. What is seen as reality in regards to health literacy is part of the construction of information that the organization gathers and that was represented by the organization to this study. Both the reality of the communities or the interpretation of the organizations can exist separately due to the construct of this study, whose purpose and intent is to seek to understand, rely on the participant's expert knowledge, and use broad, general, and open-ended questions.

In this study, I used a qualitative method with a phenomenological approach using the multiple case study design. The data collection was from an expert purposive sampling of participants – from organizations identified by the CDC as being exemplars of strong health literacy policy and organizations from the health literacy list serve – sacrificing the detail from a focused sample, without moving away from the basic interview approach.

The qualitative method allows for causal relationships but is constrained by the availability of data (see Esensoy & Carter, 2015). As the perspective of this study was particularly based on the concept of health literacy complexity and without concrete policy research, capturing nonquantifiable information can enhance what is known – either by communities or organizations. Qualitative context analysis of verbal data collection is dynamic and permits summarization of the information drawn from the interviews (see Sandelowski, 2000). Consideration for using this methodology was that this study was self-funded and I had to generalize from the responses. The qualitative method for this study allowed generalization of the phenomenon versus the possibility of confusion if confronted by too much detail (see Sandelowski, 1993). The potential variables of this study were expected, and the qualitative setting incorporated them in the responses of the participants (see Krefting, 1991).

To be able to generate theories/hypothesis, using the case study design allowed me to become more experienced in the phenomenon of health literacy best practices. Though specifics of each organization were stated in the responses to the interview questions, in this study, I employed the generalities of health literacy best practices.

Bonoma (1985) defined a case study as using interviews, data, observation, and information to describe a situation of behavior in which all characteristics of cases are the same. The health literacy best practice processes and their potential interaction with the process of developing policy can be potentially applied to other/all organizations.

According to Yin (2012, 2014), using a case study as a research method usually shows that the researcher wants to get an up-close and in-depth understanding of a real-world phenomenon. Yin also stated that there are three situations relevant to the use of case studies to use research question(s) to address either what is happening or how it happened, emphasize a phenomenon with real-world context, and conduct evaluations. The third situation debunks the myth of using case studies as a method. According to Yin (2012), the case study is used for exploring and collecting data to determine if the topic is feasible or needs further exploring.

In this research, I used the multiple-case design, which will give better validity to the findings. The multiple-case design replicated the holistic/single-unit of analysis with each case (organization' best practices) embedded in context (demographics). Figure 3 depicts this holistic and multiple case designs.

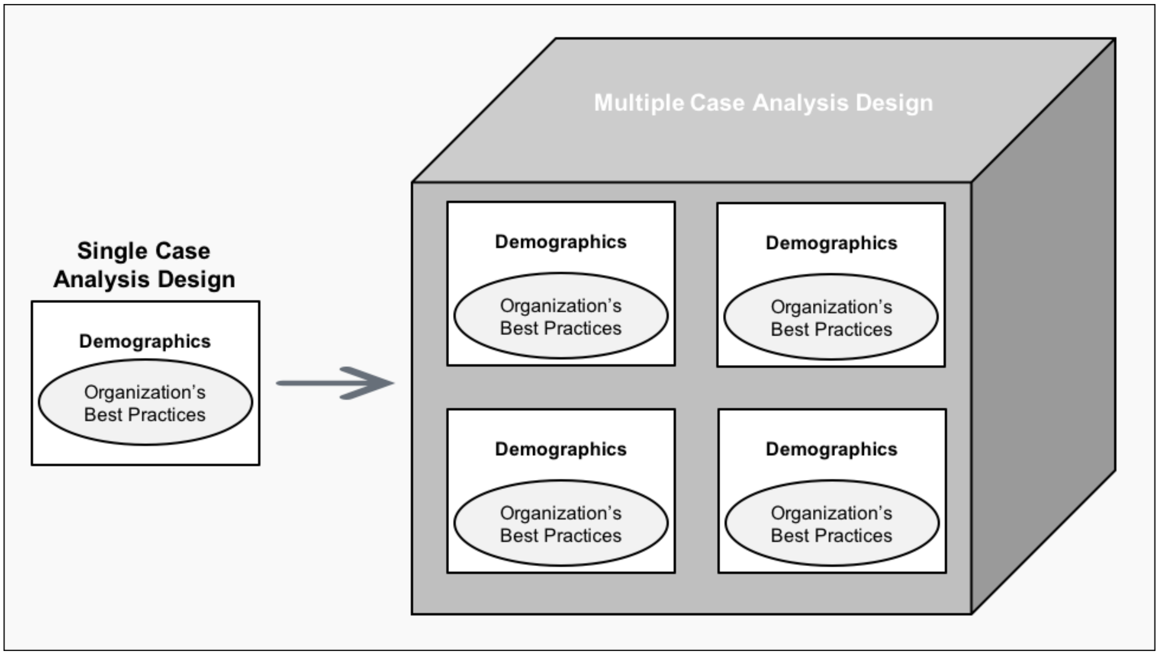


Figure 3. Single and multiple case designs. The multiple case analysis design is the single case analysis repeated multiple times to compare and find the relationship, similarities, and/or association.

Phenomenology itself looks at the everyday, normal perceptions of the world and tries to make sense of it by integrating science and education (Bazzul, 2015). The phenomenological approach challenges these perceptions by marrying the objective and subjective thinking and approaching of the social activity with altered knowledge (Bazzul, 2015). In this study, I explored the phenomenon and understanding how the organizations accomplish health literacy best practices and how the organizations accomplish integrating it with objective development of policy.

The data analysis of this study was done using Moustakas's (1994) phenomenological reduction – bracketing, horizontalizing, and clustering. Bracketing focuses the research and roots the process on the topic and question (Moustakas, 1994). Horizontaling statements initially gives them equal value where later those values that overlap or are repetitive are deleted, leaving the main textural meanings (or horizons) of the phenomenon (Moustakas, 1994). Clustering puts the horizons into themes and organizes them into a succinct description of the phenomenon (Moustakas, 1994).

Role of the Researcher

My primary role as the researcher in this phenomenological case study was that of an interviewer. That role was not one to only ask questions and take mark of the answers but also to conduct the interviews using open-ended questions.

Motivating the interviewees to want to participate in answering the questions honestly and openly was essential to gathering the data. It is hard to interview someone who is closed off. One way to accomplish this is to put the participant at ease if necessary, but most importantly to convey the importance of their participation. Every person has good and bad days. Therefore, it is critical to ensure that as the interviewer, all personal distractions were dealt with knowing what can be done prior and what must be done later.

While the optimal interview is done in person, this was not possible due to the expense of travel. Therefore, the interviews were done through the Internet using the online video and telephone conferencing program, AnyMeeting. A verbatim transcript is a must but does not convey intonation, body language, or gestures. That is one of the limitations of this study – the availability of the participant to be interviewed in person. However, this did not limit the ability to put the participant at ease.

Any confusion or concerns on the participants' part would have skewed their responses. As the interviewer, clarification was pertinent. To alleviate this, a script (Appendix A) was used to ensure that all participants followed the same pattern of questions. This also allowed for preparation for possible objections or questions, foreseeable or not.

I did not have any personal or professional relationships with anyone who worked for any of the organizations that are listed on the CDC website (http://www.cdc.gov/healthliteracy/statedata/index.html). However, any biases on my part were strictly from the anticipation of conducting this study. This study was born from the personal loss of my sister due inadequate doctor/patient communication (with possible low health literacy involved) and my desire to find answers. This study evolved to one that is rooted in the desire to participate in researching and developing policies to mitigate the effects of and/or low health literacy itself.

To eliminate any remaining biases, a script was used (see Appendix A). There were three parts to the script: (a) the introduction and explanation of the study, (b) the interview, and (c) the conclusion and acknowledging their participation. During the interview, each participant was asked all the same questions in the same order. This supported the validity of the study. One possible limitation of interviewing is the interviewer finishing the sentences of the participant. To mitigate this, the use of silent encouragement for the participant to continue or elaborate a train of thought as well as asking for clarification was used. However, clarification questions were possible and were unscripted.

Methodology

Participant Selection

The participants were members of organizations that are considered by the CDC to be leaders in health literacy best practices and from organizations found on the health literacy list serve. The target populations were subject matter experts (SME) on health literacy. In these types of organizations, the SMEs are usually a member of the steering committee, a board member, and/or a principal staff (dependent on their given title). Each organization is a coalition or collaborative that includes but is not all inclusive of doctors, researchers, academia and educational resource groups, health services departments and providers, health associations, agencies, and medical societies. The ethnicity, gender, or race were not a determination or bias in the selection of participants.

In this study, I used non-probability, purposive sampling. This is because the population was known and was not random. The sampling was purposeful and predefined within these organizations (Latham, 2007). To further clarify, the sampling was expert sampling, as it involved the gathering of known organizations, known staff, and committee members from within a panel of SMEs on health literacy. The sampling strategy also used the nonproportional quota sampling. With this strategy, if there were not participants from each of the organizations, it assured the representation of the varying organizations.

Five other sampling strategies (convenience, snowballing, simple, systematic, and stratified random) were considered but not used due to the demographics of the population. The participants are in organizations that are located in approximately 20 states. Therefore, the convenience sampling technique would not be suitable as the participants are not within a convenient proximity to the researcher (Latham, 2007; Teddlie & Yu, 2007). However, though the participants are not in a close proximity, they are accessible and so the snowballing is also not fitting sampling technique to use (Latham, 2007; Teddlie & Yu, 2007). The simple, systematic, and stratified random techniques were not applicable as these strategies target the population randomly and not specifically as is needed to address the specific topic of health literacy best practices (Latham, 2007; Teddlie & Yu, 2007).

The purposive sampling technique further describes the strategy, answers the theoretical and practical issues, and explains the participant criterion (Latham, 2007). The target list is known – the leaders are stated on the web sites of each of the organizations. The access was open to everyone and supported further studies. The sampling technique also allows the community of health literacy experts to be interviewed with questions that are supported by the theoretical framework of this study. The purposive sampling technique also eliminated sampling bias, as the units (organization's leadership) were characteristic of the population of experts and allowed the ability to gather from individuals with the health literacy knowledge base.

Galvin (2014) defines saturation as the point at which no new relevant information is forthcoming. In qualitative studies, if saturation is reached prior to assessing the *N* population, then fewer may be used (Nastasi, n.d.), and if performing in-depth interviews, that number can reach to 30 people (Nastasi, n.d.). Both of these were applied. However, as the interviews were conducted, the rule of saturation did not dictate the final number of participants. According to Nastasi (n.d.), the benefit to qualitative sampling is flexibility and the counter to that is the high degree of ambiguity.

Through this method, a base of 20 people was to be selected. This is the number of organizations listed on the CDC web site and predicates the determination of the base number. It was not expected that saturation would be reached because the organizations are from different states thereby having varying communities and demographics. However, if saturation was reached prior to interviewing the base number, then the interviews would have ceased and any interviews from the same state would have been noted to determine significance. However, the base number was not reached with 13 participants from 13 different organizations were interviewed.

According to Marshall, Cardon, Poddar, and Fontenot (2013), the sample size is directly related to the saturation and for case studies; the recommended number of interviews is six. In the review of literature, I had not found any prior research that was related to this particular study, and I expected the quality of this study to be high. Therefore, based on the Guest, Bunce, and Johnson (2006) scale of data saturation, I would not have reached saturation with one interview per organization but perhaps would have with two interviews per organization based on the number of studies directly related to mine (not found and assumed to be zero), the number of interviews per study (20), and the study quality (assumed to be high). Although there are approximately 20 organizations on the CDC website and more on the health literacy list serve, only 13 organizations participated.

Recruitment of participants for a researcher is akin to cold calls for a sales representative. It can be hard to plan in detail, since it is dependent on the participants' responses and therefore unpredictable, as well as emotionally draining trying to 'sell' their study to people they've never met (Kristensen & Ravn, 2015). Although it is not an integral part of the methodological narrative in qualitative studies and is a part of the technical background to a study, it is not considered to be of scientific interest and therefore is not an established method or process described in length in textbooks (Kristensen & Ravn, 2015).

The participants were initially contacted by email introducing the study and myself with a request for a response within 3 days. Some organizations were contacted by phone as their websites did not list email addresses. If I did not receive a response after the initial email, I followed-up with a phone call. If the contact was not available, a message was left. If the contact still did not respond within 3 days, it was assumed that s/he does not wish to participate. A follow-up phone call or email was also placed once the contact responded with an affirmative response to participate to schedule the interview.

Instrumentation

The data collection instruments used in this study were open-ended interview questions and responses that were captured on voice recorder, video, and written notes. The interview questions were devised through the research questions and the intent of this study. The interview questions can be found under the *Creditability and Validity* section of this chapter and in *Appendix B.*

The organizations that made up the sampling population were in different states. This study was not funded by any outside party that would have allowed me to travel with paid time-off. Therefore, face-to-face interviews were not a viable option whereas a virtual face-to-face interview could be done with less funds and better time-management. The interviews were conducted through the online video- and tele-conferencing software, AnyMeeting, due to the high cost of travelling and limited availability of funds. Though AnyMeeting allowed a face-to-face interview in real time, only one participant had the availability to do so. The other participants used the teleconferencing ability I set up through AnyMeeting. The use of AnyMeeting allowed the interview to be recorded externally to a handheld micro digital voice recorder that was plugged into a USB port on the computer and internally to the computer. However, the sound was not of quality to understand the responses. The online video- and tele-conferencing program, AnyMeeting, had the ability to record the interview and download the recording to the computer being used. No data was recorded on to the “cloud” or to the database of AnyMeeting.

Each participant was sent the interview questions at the time they are sent the consent and permission forms. The participant used the questions during the interview. The participants’ responses were analyzed using NVivo software, which allowed me to bracket and code the responses to identify the themes and concepts. This was done quickly after the interviews due to the proficiency of the software.

The interview script was the only instrument used to gather data. The survey was considered as a potential method of data collection. However, this would have limited the detail in the information given by the participant. The open-ended interviews allowed for a large amount of detailed answers that provided the depth of information important to this study’s data collection (Husain, Bais, Hussain, & Samad, 2012; Seidman, 2012). Open-ended questions provided information and allowed the participant to respond without presumption (Husain et al., 2012; Seidman, 2012).

Recruitment, Participation, and Data Collection

The data were collected directly from the participants being interviewed remotely via tele-conferencing and one via video-conferencing. Initially the participants were contacted directly by email. A few organizations had to initially be called to request email addresses. Any emails that were not responded to were followed by a phone call (if a phone number was available) requesting the interview. Through this method, 13 participants were interviewed; eight out of the 20 organizations (the number of organizations listed on the CDC web site which determined the original base number of 20); and five organizations from the health literacy list serve. The data collection tools used in this study were the interview script and researcher notes, the teleconferencing and videoconferencing recordings, the audio transcription software, and the data analysis software. The participants were interviewed through the means of online videoconferencing (e.g., AnyMeeting). Only one organization had the ability to do videoconferencing, the other participants a telephonic interview was conducted. By utilizing the online conferencing method, the interviews were captured by the online media and transmitted directly to and stored locally on the computer. A transcription software program was then used to transcribe the recordings. The voice was also recorded externally to a handheld micro digital voice recorder plugged into a USB port on the computer and internally to the computer. This method was not effective for quality of sound. As the majority of the interviews were not done by videoconferencing due to the participant's not having the ability to do so, the online conferencing software still allowed me to use this method to capture the interview without video. Both the videoconferencing software and transcription software are "off-the-shelf" and available to the public. The online videoconferencing program, AnyMeeting, has the ability to record and download the recording to the computer being used. No data was recorded on to the "cloud" or to the database of AnyMeeting.

I conducted all interviews. The frequency of the interviews depended upon the availability of each participant and his or her time zone. The goal, however, was to interview two to four participants per day thereby taking 5 to 10 days to complete the interviews. Each interview consisted of seven questions. The expected response to each question was 5 minutes in length, and the minimum length of the full interview to be approximately 45 minutes with an expectation to take up to 90 or more minutes. Each interview was therefore given the allotment of 120 minutes (2 hours) to allow the participants to not feel rushed thereby giving fuller responses adding to the data available for capturing the information needed to construct the bracketing and themes to understand the impact of the organizations. In reality, 11 interviews took between 30-45 minutes each with two interviews being 55 minutes in length.

The contingency plan used was that if fewer than 10 organizations from the original plan of the 20 organizations on the CDC website accepted the invitation to participate, the personnel actively communicating on the health literacy list-serve email (an email with a restricted distribution to an audience on a specific topic) would be requested to participate. The minimum number of respondents needed was the difference of how many organizations willing to participate from the minimum of the sampling number of ten. This plan was used as there were only eight from the CDC website that participated.

Data Analysis

Each interview question was correlated to one or more research questions. The responses of the participants were expected to have trigger words and/or specific phrasing that addresses the research question(s). The recurring trigger words and/or phrasing was used to code and match to the research questions. The recordings were transcribed using speech recognition software and manually. I and a disinterested party reviewed each transcription three times to ensure there were not be any misinterpretations by the software. Once done, the transcripts were emailed to the participant to review. This was to allow for any clarification by my request or by the participant. This contributed to the validity of the study.

These transcripts were imported into the analytical software, NVivo, for coding and data connection. The NVivo software allowed me to be more thorough, attentive, and methodical (Hilal & Alabri, 2013; Welsh, 2002; Zamawe, 2015). It also helped to reshape and reorganize coding, interrogate the data, and have rigor in dealing with a large amount of data (Hilal & Alabri, 2013; Welsh, 2002; Zamawe, 2015). The analytical software was used to code with bracketing, horizontalizing, and clustering. The bracketing allowed understanding while lessening preconceived experiences. The horizontalizing listed relevant significant statements to the topic and marked them with equal value. The clustering aided in identifying themes and removed overlapping and repetitiveness and the NVivo software also kept track of emerging themes (Odena, 2013).

The software Mindjet was also used for mapping the responses to the research questions. Mindjet allowed the ability to recognize overlapping themes and phrasing to more than one research question. If there was a question about or seeming ambiguity to the meaning of the response, it was initially addressed during the interview; however, any further need for clarification was be obtained at the point of coding and mapping.

Each interview question corresponded to one or more research questions. In some cases, the research question was used as an interview question (see Table 2). This ensured the validity of the research question as well as the sufficiency of the interview question. The interviews identified the themes and concepts embedded in the participant's responses.

Table 2

Research and Interview Question Alignments

	Research questions	Interview questions
1	How are organizations implementing health literacy tools/guidelines without regulation?	What is involved in addressing health literacy in the communities? To what extent would formal regulations impact the implementation of health literacy tools/guidelines?
2	What impact does health literacy best practices have on the process of developing formal policy?	What are your organization's top three health literacy best practices? How did your organization develop each of these best practices? How is your organization using health literacy best practices in developing policy? Not all experts agree. How does this organization build congruency on policy?
3	How can health literacy be addressed through formal policy?	How can health literacy be addressed through formal policy?

Issues of Trustworthiness

Credibility and Validity

Cope (2014) refers to research believability as credibility. Social qualitative research is meant to understand interaction and meanings and is not based on a measurement (Drost, 2011; Feldman, 2007; Galvin, 2014; Gershon, 2008). The term validity in qualitative research is based on the concept that the researcher provides and is a means of ensuring that there are indicators to tap into that concept (Drost, 2011). Validity is, however, a case of trustworthiness of the researcher in showing the accuracy of the findings and how they are conveyed (Marshall & Rossman, 2016; Power & Gendron, 2015). Gershon (2008) suggested using the intentionality of the study as opposed to a construct of measurement.

The use of triangulation validates this multiple case study with the use of several organizations as sources (see Yin, 2014). Using triangulation to check the interpretation of the participants’ responses was another form of trustworthiness (see Bell, 2013). It increased the validity and credibility of the study as well as strengthened the data analysis for clearer interpretation (see Koc & Boz, 2014). The triangulation was from the interviews, my notes, the transcripts, and the audit trails.

Dependability is defined as the ability to replicate a study with the same conditions and participants (Cope, 2014). The strategies to ensure dependability was having the participants check the transcripts for correctness and the audit trail of the process (see Marshall & Rossman, 2016) for those that did. For those that did not respond, the transcripts were reviewed by a disinterested third party. The dependability of the results of this study was reliable only upon the respondent’s ability to answer the question. It was also dependent on the respondent’s availability to be interviewed. However, the single strategy was to have the respondent verify that the transcript was a valid response.

Transferability is defined as to the degree the study findings meet the criteria for other studies (Cope, 2014). The strategies were continually checked on any biases that might have come up and a continuous audit trail on the conduct of this study. The results of this study have a high degree of transferability to any research on health literacy complexity, standardization and/or grassroots phenomena. The transferability contributes to the existing body of knowledge on health literacy by comparing common health literacy priorities and implementation of tools and guidelines without standardization or regulation.

The single strategy available to confirm or corroborate the results is to have a disinterested party review the audio and typed transcripts for mistakes. This eliminated any bias or distortion. This also supported the intercoder reliability in which the coding was crosschecked to ensure that the code definitions were the same in every use.

Ethical Procedures

The organizations and the participants remain confidential. They are referred to as “Participant 1”, “Participant 2”, etc. There were only one respondents from each of the 13 organizations. This study’s focus was to consider anyone, including the participants, that may be impacted by low health literacy and improve that awareness and understanding.

This study used one agreement forms in the data collection: Consent Form for Participation in a Research Study. This Agreement ensured the participants understood what this study was regarding. This Agreement became an informed consent upon the explanation of the study. The agreement to tape the interview was also be verbally captured on tape. The permission to use information obtained in the interview was also on the consent form. The organizations had the right to request me to sign an agreement prior to interviewing any persons but did not exercise it.

Though the Agreements collected have printed and signed names, none of the Agreements are published, thereby preserving the confidentiality of the participants. Names remained associated to the participants’ responses through the validity process. Once the respondents validated the transcriptions, the coding and bracketing process started. The names were disassociated from the responses at this time. Pseudonyms were used for control purposes. This also would have applied during the interview. If a participant was not willing to answer a particular question, s/he would not be coerced into doing so.

This study’s data will be kept for the recommended time period of 5 years. The relevancy will determine whether the data is to be used for comparison purposes on later research. The data may also be used to expand this study at a later time as well.

As this study cannot guarantee complete confidentiality or indirect identification, due to identifying the participants by narrowing down from the organization level, security measures are emplaced for the ethical protection of their identity. The following are included in the security protocols:

- Interviews - recorded by video, voice recordings, and hand-written notes;
- Transcripts – electrons within the software applications and hand written;
- Emails; and
- Signed consent forms – possibly mailed or scanned in and sent by email.

Any portion that is hand written or in paper-form was scanned to a pdf format. Upon ensuring that it has properly scanned, the paper format was shredded. All participant data has been securely deleted from the computer and voice recorder as it has successfully transferred to the external hard drive.

This study was conducted with high integrity. My intent in conducting this study was to aid in the understanding and lessening the impact of low health literacy. It would be a detriment to any health literacy research to suppress, falsify, or invent findings. It would also go against the integrity I hold. There is a great need to ensure that there is no omission of information, falsifying what was stated, or fabricating the findings. This serves as a checks-and-balance and will mitigate any ethical concerns and lend credibility, validity, and integrity to the study. This study was approved by the Walden University Institutional Review Board (06-02-17-0078136).

Summary

Health care is a complex issue. Health literacy is also a complex issue and possibly more so. Communities, health care providers and patients have commonalities but will never be the same as their neighboring community or the patients’ neighbors. Therefore, health care providers cannot treat everyone the same and the tools and guidelines used will differ as well.

This study impact hospitals, healthcare organizations, other organizations, doctors, nurses, patients, and health care administrators. In examining the health literacy best practices of organizations and the surrounding communities, this study explores how the organizations specifically addresses health literacy holistically as well as their perceptions at a broader level in respect to policy. This study interviewed participants from 13 organizations from different states. All of these organizations focus on health literacy within their communities. These organizations are at the state level and local levels.

This study used a qualitative method with a phenomenological approach using the multiple case study design and using expert purposive sampling to collect data. The multiple-case design gives better validity to the findings. A base of 13 people was selected, of which eight organizations are listed on the CDC web site and five were found from the health literacy list serve. Most of the participants were initially contacted by email introducing the study and myself with a request for a response. I followed-up with a phone call to affirm the response to participate and to be able to schedule the interview. Some organizations were initially contacted by phone requesting an email address for a potential participant. If the contact did not respond within 3 days, it was assumed that s/he does not wish to participate.

The instruments used in this study were the interview questions and responses. The interview questions were devised through the research questions and the intent of this study. The interviews were remotely conducted via teleconferencing or videoconferencing. If the organization did not have the ability to videoconference, then the interviews were done by phone. This was due to the limited availability of funds. I conducted all interviews and depending upon the availability of each participant, it was expected that there would be two to four interviews per day thereby taking 5 to 10 days total to complete the interviews. The interviews were usually one per day and the interviews were spread over a six-week period. Each interview consisted of seven questions with the length of the interview averaging 30 to 45 minutes.

This multiple case study used several organizations as sources, using triangulation to check the interpretation of the participants' response from the interviews, my notes, the transcripts, and the audit trails. This increased the validity and credibility of the study. The dependability strategies that were used had the respondent verify that the transcript was a valid response and a disinterested third party review the transcripts for correctness. The strategy of transferability of this study to any research on health literacy complexity, standardization and/or grassroots phenomena strategy was to continually check on any biases that may come up and conduct a continuous audit trail.

The organizations and the participants will remain confidential. They are referred to as "Participant 1", "Participant 2", etc. There was only one respondent from each of the 13 organizations. This study's focus is to consider anyone, including the participants, that may be impacted by low health literacy and improve that awareness and understanding. All uses of electronic data (video and voice recording, computer files, etc.) and paper data, interview notes, agreements, etc. are secured and treated with the utmost confidentiality. This study was conducted with high integrity.

Chapter 4 examines the results that are addressed by research question and the associated interview question, and presents the data supporting the findings. The next chapter also discusses in detail the demographics, data collection, and the data analysis of this study.

Chapter 4: Results

Introduction

In this qualitative case study, I explored and compared commonalities in health literacy best practices of organizations that are recognized as leaders in health literacy by the CDC and are addressing low health literacy in their communities. Exploring and comparing the organizations' best practices permitted recommendations made to various organizations regardless of level (local, state, federal, or nonprofit). The potential of a health literacy policy might also be determined as well as addressing the complexity of health literacy allowing patients and healthcare providers to better address health concerns.

Low health literacy is a problem the United States faces and, like health care itself, is a complex issue that stems from patient demographics, the communities they live in, and medical and healthcare providers being very diverse (see Figure 1). Tools have been developed to assist providers in mitigating the risks of low health literacy, but there is currently a lack of formal policy on health literacy. Most policy has focused on the delivery/providing of health care, but that threshold of what provision can do exclusive of improvements in literacy may have been reached. Though health literacy is not much use without healthcare provision, healthcare provision is of limited use without health literacy.

This problem impacts everyone – from the patient, to the doctors, to the community, and to society – to include the rising cost of health care. Low or poor literacy leads to a construction that undermines effective service and good literacy has the opposite effect. This study contributes to the body of knowledge needed to address this problem by comparing health literacy best practices and its effect on the process of policy development to address health literacy through formal policy.

Research Questions

There were three research questions in this study. These questions were derived from the concept of healthcare complexity and that health literacy issues further complicate this:

RQ1: How are organizations implementing health literacy tools/guidelines without formal regulation?

RQ2: What impact does health literacy best practices have on the process of developing formal policy?

RQ3: How can health literacy be addressed through formal policy?

Chapter Organization

Chapter 4 has six major sections that follow the chapter's introduction: Setting and Demographics, Data Collection, Data Analysis, Methodology, Evidence of Trustworthiness, and Results. Chapter 4 concludes with a summarization of the main points and an introduction to Chapter 5.

Setting and Demographics

For this study, 58 people or organizations were either emailed or contacted by phone. The intent was to request two participants per organization. Some organizations only listed a phone number or an email for the organization, while other websites listed the individuals’ contact information. Of these phone calls and emails, 33 declined to do an interview for various reasons, which included

- stating they were not the right person or organization to be interviewed – couldn’t speak to the organization’s health literacy best practices and/or policy development, teaching, and research, not policy and practices;
- the organization was still forming – could not meaningfully participate;
- competing demands on the team;
- not currently involved in the organization; and/or
- the individual felt one person should interview not two.

There were no responses from 12 people after the initial emails, which included a follow-up email or phone call/voicemail, leaving 13 interviews that were conducted. There were no known or stated special circumstances or conditions that influenced the participants or their knowledge of health literacy, the organization, or policy that would thereby influence the data and/or the interpretation of the study.

Of the 13 participants, eight were from organizations found on the CDC website, and five were from the health literacy list serve. The organizations included were three coalitions, five collaborative/partnerships, one consortium, two education/academic, and two that did not categorize themselves. The United States geographic attributes of the participants’ organizations included six from the East Coast, three from the North-Central region, three from the South-Central region, and one from the West Coast.

Data Collection

All data were collected through the online application, AnyMeeting. Though a video conference was requested, only one participant had the capability to conduct the interview as a video conference. The other 12 interviews were done through AnyMeeting as well but as a teleconference. Twelve interviews were recorded in the entirety, while one interview was only recorded at the end due technical difficulties. Once the recording was processed and saved to the hard drive of the computer, I ensured that the recording did not exist anywhere else (i.e., the cloud). Notes were also taken to ensure that I gained the main points of the conversation. The notes were then used during the transcription process as a guide to those main ideas and bullet points.

The recordings were run through a software application that transcribed them from the voice to written word. The software application did not work as well with some as with others due to either the recording quality or voice tone. The transcription was reviewed twice while listening to the recording allowing for corrective edits. These transcriptions were sent to the participants for review and validation to the interview data.

All interviews lasted between 25 to 60 minutes depending on the participant’s length of answers. The original presumption was that the interviews would be 45 to 90 minutes in length. In reality, most interviews were approximately 30 minutes in length. The longest interview was 55 minutes in length. All participants were at a location that was at their organization, in their home, or in their car. My location was at my home or in a conference room at my workplace. At all times, I was not in the presence of others during the interview.

The interviews were done over a 6-week period performing as few as one for the week to three interviews in 1 day. The scheduled date was a collaboration between my schedule and the participant's schedule and the time zone that they were in. All but one participant had a scheduled AnyMeeting conference reminder sent to them. That one participant requested to have the interview while on the spot due to the tight scheduling, and it was conducted and recorded through AnyMeeting.

The original plan and ideal was to conduct 20 to 40 interviews. However, 33 people or organizations declined, and 12 never responded to the requests. The minimum number of 10 interviews was surpassed by three for a total of 13 respondents.

Data Analysis

The early coding theory was taken from the main ideas of the questions with health literacy as the parent (Figure 4). The three main sibling nodes were policy, best

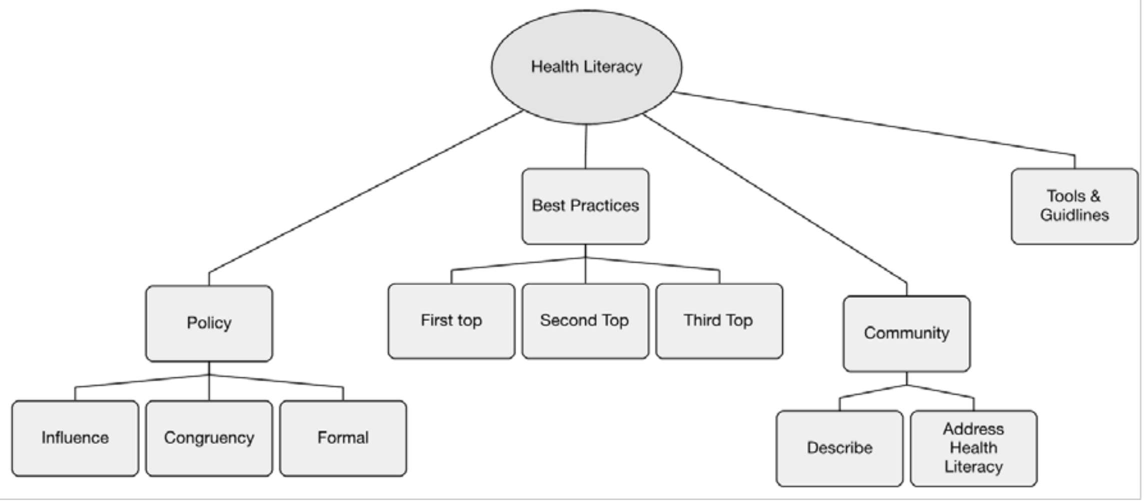


Figure 4. Early coding thoughts. This depicts the early coding thoughts on the expectations of results prior to the research being conducted.

practices, and community. The fourth sibling node was tools and guidelines as it was thought that it would possibly be an emerging theme. The child nodes under the policy node were the main ideas of the questions on policy. The “influence” node replaced the word “impact” in Question 2. The word “congruency” relates to Question 6 and “formal” relates to Questions 2 and 7. Under the “community” node, it was thought that the participants would describe what community they were working with in addressing health literacy in Question 1.

As the analysis was conducted, this coding depicted the emerging themes and patterns and the correlation to the Stoddard Evans framework to the determinants of health, and the original Mind Jet map (Figure 5) became evident. The correlations to these are discussed in detail in Chapter 5.

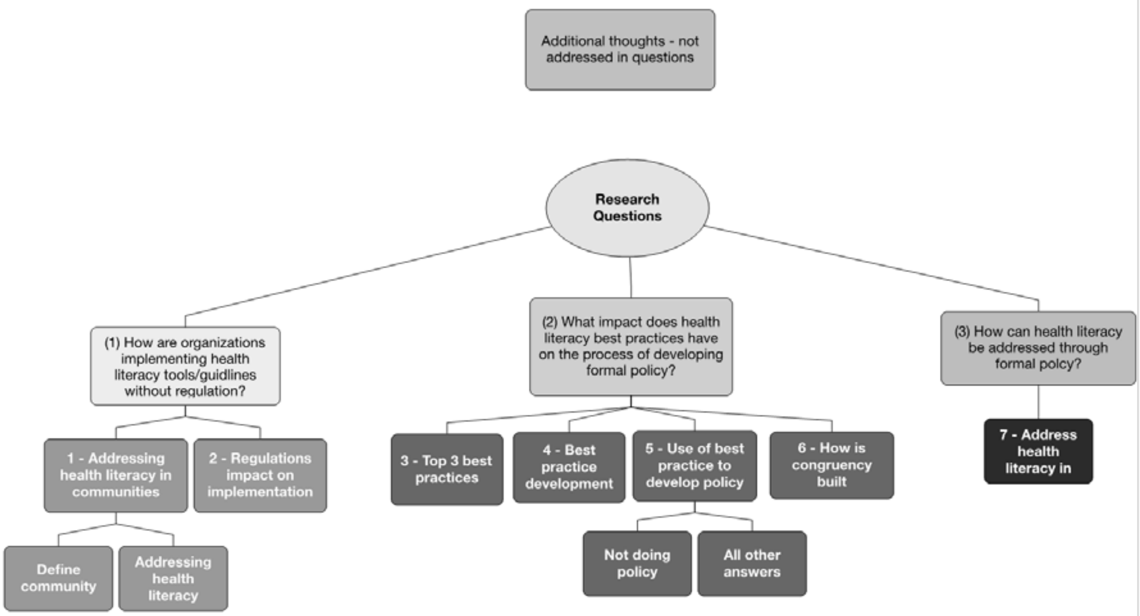


Figure 5. Actual coding from research. This illustrates the actual coding resulting from the research.

Using this coding structure allowed me to highlight the terms and phrases most often used. However, it did not allow for the themes and patterns for the questions and responses. For this, the research questions would need to be the main codes and the interview questions would become the child nodes with subsequent child nodes below them depicting emerging patterns. The coding and queries in NVivo substantiated the main themes that emerged throughout the interviews as the participants responded to the questions.

Evidence of Trustworthiness

Social qualitative research is meant to understand interaction and meanings and is not based on a measurement (Drost, 2011; Feldman, 2007; Galvin, 2014; Gershon, 2008). In establishing the trustworthiness of this study, processes were established and conducted from start through the finish of the data collection. Prior to submission to the IRB, the interview questions were reviewed by two disinterested parties for language content and comprehension.

Cope (2014) referred to research believability as credibility. The term validity in qualitative research is based on the concept that the researcher provides and is a means of ensuring that there are indicators to tap into that concept (Drost, 2011). Validity is, however, a case of trustworthiness of the researcher in showing the accuracy of the findings and how they are conveyed (Marshall & Rossman, 2016; Power & Gendron, 2015). The use of triangulation was used to validate this case study using 13 organizations as sources, and the audit trails – which include checking the interpretation of the participants’ responses by each of them reviewing (and editing if appropriate) their transcripts, and my notes – thereby increasing the validity and credibility as well as strengthening the data analysis (see Bell, 2013; Koc & Boz, 2014; Yin, 2014).

Dependability is defined as the ability to replicate a study with the same conditions and participants (Cope, 2014). The dependability of the results of this study relied upon the participant’s availability to be interviewed and ability to answer the question. However, the single strategy was to have the participant verify that the transcript was a valid response. Each of the participants was sent a copy of their transcript to review and edit to ensure that notes and interpretations of their responses to the questions were valid to ensure dependability (see Marshall & Rossman, 2016). Transferability is defined as to the degree the study findings meet the criteria for other studies (Cope, 2014). Credibility and transferability were also established by the description of the processes involved in the data collection, including identifying the potential participants. There was a continuous check on potential biases and a continuous audit trail on the conduct of this study. The results of this study will have a high degree of transferability to any research on health literacy complexity, standardization, grassroots phenomena, and/or the mandating/regulating of tools/guidelines.

To ensure confirmability, I set up a checklist that allowed me to check and recheck the processes and data throughout the study. To further the confirmability, the audio recordings and typed transcripts were reviewed twice for mistakes to eliminate any bias or distortion. This also supported the intercoder reliability in which the coding was crosschecked to ensure that the code definitions were the same in every use.

Galvin (2014) defined saturation as the point at which no new relevant information is forthcoming. In qualitative studies, if saturation is reached prior to assessing the *N* population, then fewer may be used (Nastasi, n.d.), and if performing in-depth interviews, that number can reach to 30 people (Nastasi, n.d.). As there was a limited number of resources and a limited number of best practice organizations, the base of 20 people was selected; the number of organizations was listed on the CDC website, and this determined the base number. According to Marshall et al. (2013), the sample size is directly related to the saturation and for case studies; the recommended number of interviews was six. According to Nastasi (n.d.), the benefit to qualitative sampling is flexibility, and the counter to that is the high degree of ambiguity.

The number of organizations from the CDC website that responded and agreed to be involved in the interview was less than initially expected. Therefore, organizations found on the health literacy list serve were contacted. The total number of participants, 13, was 65% of the total number, 20, that was initially thought would be participating, and 43% of the saturation number of 30. Therefore, saturation was not met.

Results

This study’s theoretical framework was based on the premiss that the social determinants of health are the social, environmental, and economic conditions that influence and affect individuals’ health and influence the functioning and well-being of a community (CDC, 2009; DPHP, 2016), and these conditions are shaped by the socioeconomics, which are influenced by policy (CDC, 2009; Kindig & McGinnis, 2007). The construct of the conceptual framework is based on health literacy best practices and the process of policy development. The underlying concepts that surround the framework are as follows:

- Health care is complex;
- Low health literacy is a problem;
- Health literacy is a complex issue;
- There is a lack of policy direction at the federal level; and
- Organizations at the grassroots level are shaping their role in the local communities implementing health literacy without the foundation of policy or centralized coordination.

The research questions were based on the understanding of the social determinants of health and the conceptual framework. The responses to the interview questions formed patterns within each question and therefore were structured by research question and the interview questions that were designed to examine each research question.

Research Question 1

There are two interview questions that were asked to participants in order to establish the basis of conditions that influence implementing tools/guidelines.

1. What is involved in addressing health literacy in the communities?
2. To what extent would formal regulations impact the implementation of health literacy tools/guidelines?

Interview question 1. The first question brought out the theme of defining what a community was to each of the participants and organizations. Each participant questioned what was meant by “community”. My response was to ask the participant to define community in their terms. There were five definitions of communities

- patients/consumers;
- providers/health professionals;
- healthcare systems;
- geographical communities – towns, cities, states, etc.;
- demographical communities/population-based – tribal, refugee, etc.

The diverse definitions widen, and perhaps, reconfigures the understanding of community that is depicted in Figure 1 as a narrowly defined variable.

Another theme that developed in question one but would continue through the seven questions, is education, training, and awareness. Though being aware or having awareness is not specific to being educated or trained, it does have an understanding that an individual being made aware has then been educated. It is also the same communities that are being educated that are being made aware or being made to “understand”.

Interview question 2. The responses to the second interview question had two separate lines of thinking – system and regulation and mandates and regulation. The first line of thinking, system, pointed to the bigger picture of system complexity and the use of a framework. The framework involves the individual or patient being at the center surrounded by the family, the neighborhood, the geographical community, the systems (schools, churches, support organizations, etc.), with the policy and law being the outside ring of these concentric circles. This framework of the policy to the patient shows that there are complex sets of variables in implementing regulations and mandates.

The second line of answers were put into two groups – mandates and regulations. The mandates were defined as pre- and in-service education/certification and plain language/clear communication. The discussion on these definitions were both positive and negative.

- If mandated, “it would ensure organizations take health literacy seriously.”
- These mandates are seen as busy work, a “check-the-box” action.
- They would have to be mandated by the government or the Joint Commission.

The discussion on regulations, the group questioned the aspects of the regulation

- narrow or broad;
- incentivized or punished;
- how they are developed; and
- if they are reviewed.

The discussion was also positive and negative.

- It will make people more aware.
- It will support alignment of the healthcare system to health literacy issues.
- It will minimize negative health outcomes.
- It could cause closures due to the impacts on various hospitals, etc., and the lack of resources.
- It will raise awareness.
- Not sure how it will help health literacy.
- It will need research to see the impact of regulations to determine what is and isn’t working.

- There will have to be training on regulations to change behaviors.

Using these results to answer the first research question shows that there were pros and cons to formal regulations and that addressing health literacy in all environments and communities is not impacted by the lack of formal regulations. Regulations would need to be further defined and structured to meet varying communities' needs.

Research Question 2

For this research question, interview questions three through six were asked to participants:

3. What are your organization's top three health literacy best practices?
4. How did your organization develop each of these best practices?
5. How is your organization using health literacy best practices in developing policy?
6. Not all experts agree. How does this organization build congruency on policy?

Interview question 3. The participants' responses to the third interview question were diverse with some overlapping components of best practices. Four best practices that emerged were training, team, plain language/clear communication, and research. Training firstly consisted of gaining or being awarded grants or funding to develop or implement the training. The training is for both patients and providers. However, not all organizations had both. The patients are trained on learning how to question what the doctor/nurse has stated/ instructed or being prepared to ask the doctor/provider and/or pharmacist the right questions. Patients and consumers are also trained on how to negotiate the system – both online and within the physical establishments. The importance of this training was stated that it was broader than literacy or conventional education because is about patients understanding what to do between doctor visits or hospital stays.

Training for the healthcare provider (includes, but not limited to, doctors, nurses, pharmacists, hospitals, and medical students) a more robust list.

- The use of workshops and conferences for networking, training, and exchanging of ideas such as the review of accreditation process and implementation practices – pre- and post-assessments.
- Understanding the patient’s emotional and mental component, cultural learning modalities, and being able to explain the why and how.
- Using tools such as
    - teach-back;
    - plain language/clear communications (also explained as “layman’s language” and “living room language”);
    - patient screening; and
    - universal precautions.

The “team” best practice is one that over laps with the provider education. The team approach to a best practice brings, as one respondent stated, “the right people to the table” which is defined as being those within the medical community (e.g., medical students and doctors/providers), medical professionals (e.g., medical librarians), health organizations and agencies, etc. The team idea also includes interacting with patients and consumers from various communities as focus groups (includes cap surveys and interviews) within a classroom setting for medical students and/or providers to ask questions of the patients, and to shadow and observe in specific environments (e.g., hospices). These direct interactions with patients outside of the hospital or clinical environments allow the medical team to learn and understand:

- the patients' mental and emotional component;
- how to explain the "how and the why;" and
- the cultural learning modalities.

The plain language or clear communication best practice is also a tool used in educating as well as in research and the development of tools and materials. As a best practice of training and developing materials for educating/training or informational purposes. This is illustrated by two participants – "good writing is clear writing and plain language is good writing" and "our first principle is plain language." As a tool, plain language is used in various multi-media:

- published written materials such as books, magazines, and informational pamphlets;
- signage in hospitals and clinics enabling patients to navigate easier;
- insurance coded on medical bills;
- consent forms;
- verbal or audio communications;
- websites; and
- videos.

Clear communication is considered synonymous with plain language. However clear communication is also utilizing the visual aspect – the design. Two participants stated the importance of design.

- “Most written information never looked at how well it was designed for struggling readers, which is, not an insignificant number.”
- “That means it is using a cognitive theory of multimedia where people can build connections to both, the video and the audio channels, and then it’s easier to understand, absorb, and remember the information and therefore develop a better attitude towards it.”

The fourth best practice that emerged was research. Each organization does research to some degree whether it’s for developing tools or policy, or to fully substantiate findings. Both approaches use evidence-based practices. Within a training environment research and evidence-based practices help support the credibility of that educational tool. This is supported by one participant that stated, “if people would be compelled to take health literacy research and findings, practices, and principles into consideration within the healthcare system, we could have so much better outcomes health-wise, and less wasted resources.” One organization uses research as the top best practice – “evidence for everything” – in their health literacy, training, outreach programs, and plain language services.

Interview question 4. The fourth interview question asked about developing the organizations’ best practices. Though there are variations, five patterns emerged.

- Grants or funding were received by four organizations to specifically develop tools or conduct research.
- Conferences and/or workshops were either conducted or attended by four organizations. In one instance a conference eventually became an interactive workshop.
- Three organizations developed tools and/or best practices through a former occupation as a film editor and interactive game designer and understood that information needs to be put together so to not lose people (i.e., an engaging narrative/story versus facts; a physician wanted to learn teach-back which developed into an 8-hour class; and a 20-year relationship with a utility company building the informational insert for the bill which was too complicated.
- Research, specifically by four organizations, concentrated on research to develop best practices and tools (e.g., literature reviews, expert consensus, and trial-and-error).
- Not all best practices could be readily categorized:
    - developed by people organically – bottom-up approach by people doing the work and knowing what needs to be done;
    - non-systematically looking for expertise and talents within organizational membership; and
    - using partners – input from consumer, working with clinicians, and field testing.

Interview question 5. The responses given to the fifth interview question – using health literacy best practices in developing policy – were multifarious. Though five organizations had stated they were not developing policy, three of them: a) were tracking policies to understand them; b) advocated for policies; and c) had started research in developing policy. Other organizations are new to developing policy as stated by one participant, "just found a resource for policy," or used already-developed policy as stated by another respondent, "we have the provision of education policy."

The responses were be itemized as the following approaches:

- top-down or trickle-down approach – need buy-in from leadership to drive policy decisions (e.g., organization conducted a crosswalk of accreditation systems with what was stated about health literacy to share with leadership);
- bottom-up approach – tie-in with state and federal governments for reimbursement (e.g., one organization partnered with their state's public health department to get in to the state level where policies are made);
- skills-building approach – one respondent summed this up as policy looks at skills-building because best practices used as policy help build policy (in example from one participant "[best] practices and skills building serve as examples that help policy makers understand exactly what we're talking about when we talk about health literacy");
- non-priority approach – in example from a respondent, "we do some work around policy but it is not a priority – we'd like to make it a priority;"

- influence approach – through lobbying, implementing, or intervening that uses the understanding that the attention goes to health literacy for effectiveness – examples from participants:
    - Policy at the state level was not health literacy and too confusing to try to influence policy to be health literate which is important because policymakers “are not medical professionals in large part;”
    - “We lobbied for insurance policies to be written at an eighth-grade level…so here and there we try to influence policy that’s not patient-friendly;” and
    - We developed a health literacy position statement – with one policy recommendation goals that “the state will possess the literacy skills needed to function in their community workplace and family,” and with health literacy efforts addressing children and adults.
- support approach – providing information for developing policy or through education (e.g., one respondent stated on local initiatives, “our role is the convener and disseminator of information amongst others and provide a forum for discussions – our biggest contribution into infusing health literacy into the healthcare system”).

The participants’ overall responses were esoteric to the question asked, this was a theme that is further addressed in Chapter 5. However, one participant’s statement was a good summation stating that being a part of a community that talks about health literacy and the more the issues are discussed, the field of health literacy is a commonality that brings together a wide variety of areas of practice that may not cross paths otherwise and thereby reach an audience that the health providers serve.

Interview question 6. The sixth interview question asked how the participant's organization builds congruency on policy. For the participants that stated that they either did not do policy or was not active in policy, I acknowledged that fact and reframed the question to ask, "How would you build congruency?" Every participant, regardless of how the question was worded, asked what was meant by "congruency". My response was to equate it to "consensus". The responses signified, however, that some participants also used an alternate understanding of the word defined as whether the message matched the action.

Prompting some of the participants to respond to the hypothetical (if you were doing policy), their responses paralleled to those who were effecting policy. Three main themes emerged – education, communication, and partnering or networking. Five of the 13 participants stated that their organization educated policymakers and legislators to influence or inform policy, six out of the 13 used communication, and three out of the 13 used both.

There were some overlapping ideas between educating and communication. For example, one participant's response was that "most of the work gets done in in the committees" and that they worked "hard on educating the committee members." The tie between educating and communicating is using one to engage with the other. In responses from other participants, it is not clear what format was being used to educate. For example, one participant stated that they educate elected officials and policymakers.

In one participant’s response, communication was paired with listening as an active role – “first, we listen, and then, we answer the question the community has.”

The last theme, partnering or networking, was used by four out of the 13 participants with two out of the four also using communication and education with it. One participant referenced partners as “champions” – “it’s a matter of finding a champion among their leadership.”

Research Question 3 and Interview Question 7

The third research question is also the seventh interview question. Similar to responses on the fifth interview question, the responses to this question are also multifarious. However, a few patterns did emerge. The patterns were the levels at which health literacy is being addressed through policy: organizational, health system, state, and undefined.

The type of organization or level was not clearly expressed in each response. One response does define the organization to be “like The Joint Commission” while others responses imply that the organization practices medical care. Addressing health literacy at this level, the response showed the following:

- mandate universal precautions;
- needs leadership engagement;
- health literacy needs to be a term written into policy and be a foundation for quality of care organizations and quality of care metrics;
- training and performance management expectations that tie to health literacy best practices; and

- set of health literacy standards.

Health systems is another level stated in responses. At this level, addressing health literacy in policy was stated succinctly.

- There is enough research to support setting policies in a health system to ensure health information for patients is easy to understand.
- There is potential and advantage to systemizing and building a system-wide approach.
- Using a patient-quality perspective and a liability perspective around the informed consent.

At the state level in addressing health literacy in policy, the responses were varied in perspective with some using an example to illustrate their point. For example, one participant discussed a policy shift that overall, may not be favorable, but a task-force was able to refocus efforts on bridging medical providers to the community resulting in a health literacy practice. Another participant was specific in addressing regulation verbiage stating that having a committee through which all health care legislation flowed, would “routinely insert some language or some clause that would say, ‘Implementation: This regulation will adhere to all best practices of plain language and health literacy’.”

Other participants looked at the overarching approach to state-level legislation.

- “It has to be hit head-on.” There has to be regulation around health literacy at the state levels and mandates on reading levels for different materials.

- "It's a multi-pronged approach because the agencies and state agencies have their own agendas…. They could have a state senator or representative help author a bill."
- "In terms of states and national policy, there's room for tying funding sources to a policy and incentivizing those who are drawing down on federal and state resources, such as Medicaid."

In the last pattern, undefined, the responses were not directly tied to a level. Levels could be considered implied. For example, one participant stated that health literacy needs to be made part of public and clinician education with policy on specialty training and certification/re-certification. Other responses were similar.

- "Establishing benchmarks around health literacy and establishing goals around reading levels."
- "Without pressure from the government, these best practices will never be adopted by other organizations or hospitals."

Follow-up Questions

After the last interview question, I asked if there were anything that they would like to say that wasn't asked in the questions regarding health literacy and policy. Nine out of the 13 participants responded. The responses were inclusive of policy, best practices, and summations of thoughts. There are not emerging themes but echo what the responses were to the seven interview questions.

I also asked if they had any questions for me. Many of them asked what I was going to do with the results, could they be giving a copy of the dissertation when done, about my background in health literacy, what I did for a living, and/or how these questions were generated. All my responses are able to be found in this study except that of what I did for a living. All the participants were given a curtesy copy of the dissertation upon publication. The participants were not only interested in the initiation and direction of the study, but in the origins as well.

Word Patterns

The analysis of the interview questions through NVivo substantiated the word patterns that were emerging through the participants' responses during the interview process. Some of the patterns were connected by grouping the words and others were stand-alone as shown by the following:

- education (or educate), training, raising awareness, and changing behavior;
- plain language and clear writing;
- evidence-based practices, research, and universal precautions;
- leadership; and
- complexity.

Education, training, awareness, and behavior. One emerging theme had three main ideas within that are somewhat synonymous to each other: educating/training; raising awareness; and changing the behavior of providers, patients, legislators, communities, etc. These words/phrases were used in the answers to each of the seven questions; however, not always by the same person. These phrases were referenced 149 times throughout the interview responses. The phrase, education (or educate), is referenced 73 times, almost half of all the phrases by 11 of the 13 participants. The phrase training, was referenced 29 times by 12 of the 13 participants where eight of the same participants used both. The phrase awareness, was referenced 42 times by 12 of the 13 participants. Seven of the same participants used all three phrases. The last phrase, changing the behavior, was referenced five times by four of the 13 participants. Three participants used all four phrases. See Table 3 and Figure 6.

Table 3

Phrases: Education, Training, Awareness, and Behavior

	Participants	References
Multiple words totals	13	149

	Participants	References		Participants	References		Participants	References		Participants	References
Education	Participant 01	7	Behavior	Participant 03	2	Train	Participant 01	5	Awareness	Participant 01	1
	Participant 02	14		Participant 05	1		Participant 02	6		Participant 02	5
	Participant 03	3		Participant 06	1		Participant 03	5		Participant 04	1
	Participant 04	9		Participant 11	1		Participant 04	1		Participant 05	1
	Participant 05	5	Total	4	5		Participant 05	4		Participant 07	6
	Participant 06	6					Participant 08	4		Participant 08	1
	Participant 07	2					Participant 09	1		Participant 10	13
	Participant 10	2					Participant 10	1		Participant 11	7
	Participant 11	5					Participant 11	1		Participant 12	6
	Participant 12	9					Participant 13	1		Participant 13	1
	Participant 13	11				Total	10	29	Total	10	42
Total	11	73									

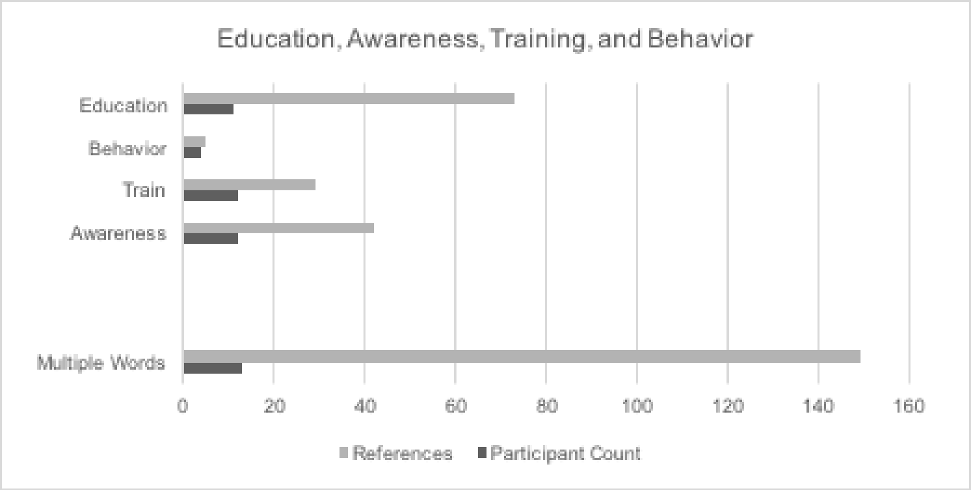


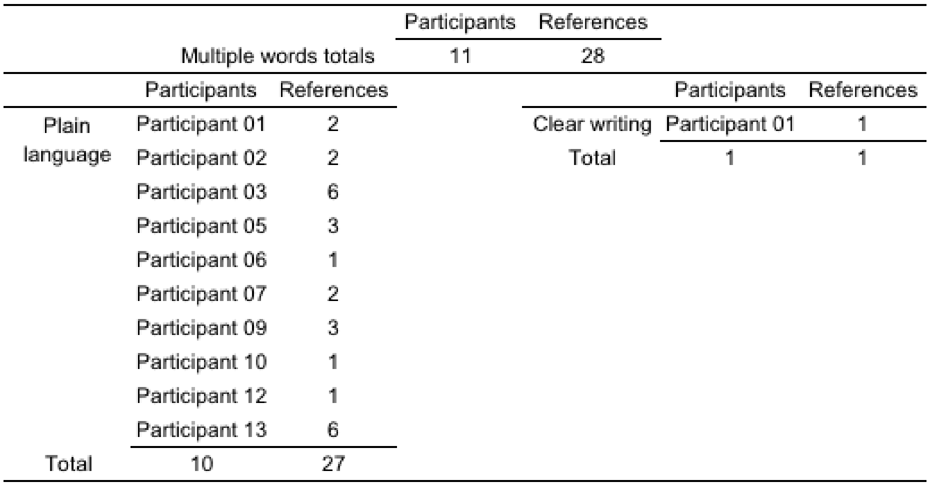
Figure 6. Graph of Table 3. This depicts Table 3 as bar graph showing the usage of the phrases.

The connection between these phrases is based on education. Awareness was mostly referenced in making someone educated to the issue. Changing the behavior was also used in the equivalent of educating. To illustrate these, in the second interview question regarding formal regulations impacting the implementation of health literacy, one participant stated that the organization was educating the state legislation to be aware of the issues and address health literacy. Also in the second interview question, another participant stated, “Policy and regulations are important to enforcing best practices that we know work but you have to have the training, outreach, and support to actually change the behaviors and make this happen.”

Plain language and clear writing. The second set of phrases that emerged as a pattern is plain language and clear writing. Both are best practices. I’ve included clear writing though it was only referenced once by a participant equating the two – “Good writing is clear writing and plain language writing is good writing.” Plain language was referenced 27 times by 10 participants. Table 4 and Figure 7 show this correlation.

Table 4

Phrases: Plain Language and Clear Writing



	Participants	References
Multiple words totals	11	28

		Participants	References		Participants	References
Plain language	Participant 01	2		Clear writing	Participant 01	1
	Participant 02	2		Total	1	1
	Participant 03	6				
	Participant 05	3				
	Participant 06	1				
	Participant 07	2				
	Participant 09	3				
	Participant 10	1				
	Participant 12	1				
	Participant 13	6				
Total	10	27				

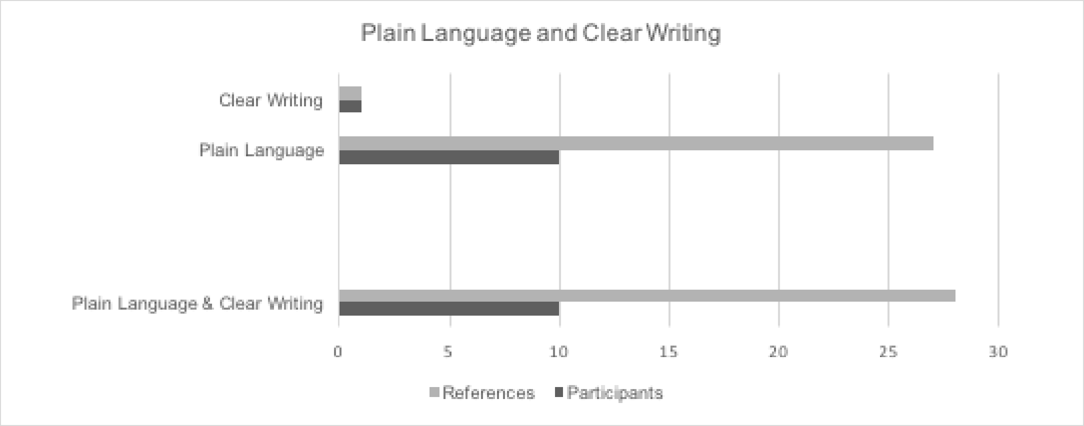
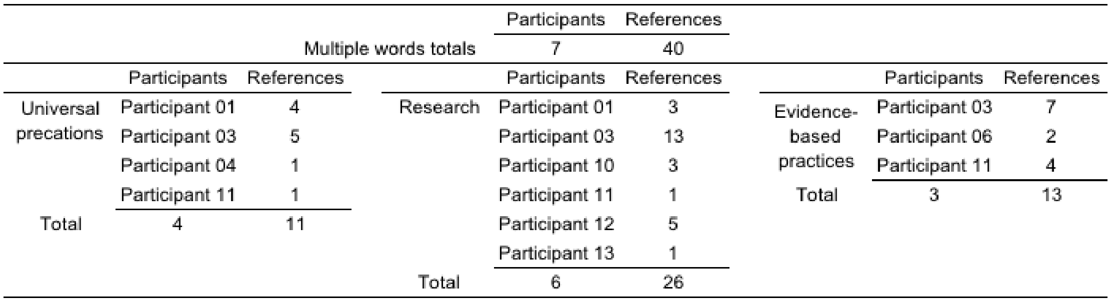


Figure 7. Graph of Table 4. This depicts Table 4 as bar graph showing the usage of the phrases.

Evidence-based practices, research, and universal precautions. The third set of phrases that emerged is evidence-based practices, research, and universal precautions. All three are best practices used by seven participant's organizations and referenced 40 times. The term research was referenced 26 times by six participants. Three participants referenced evidence-based practices 18 times and two of those three participants also referenced research. Universal precautions were referenced 11 times by four participants where three of those participants also mentioned research. The connection between these phrases is based on the direct connection between conducting research and the resulting evidence-based practices, as stated by on participant, “Our approach is called ‘evidence for everything’ because our organization is part of an academic medical institution and we do research. We focus on making sure that what we do, has some kind of evidence base.” The universal precautions approach is then connected and is based on health literacy research as a stated as a response to Question 3, “We are currently seeking evidence to determine if ‘universal precautions’ are enough for patients with known health literacy issues.” This correlation is depicted in Table 5 and Figure 8.

Table 5

Phrases: Evidence-Based Practices, Research, and Universal Precautions



	Participants	References
Multiple words totals	7	40

	Participants	References		Participants	References		Participants	References
Universal precations	Participant 01	4	Research	Participant 01	3	Evidence-based practices	Participant 03	7
	Participant 03	5		Participant 03	13		Participant 06	2
	Participant 04	1		Participant 10	3		Participant 11	4
	Participant 11	1		Participant 11	1	Total	3	13
Total	4	11		Participant 12	5			
				Participant 13	1			
			Total	6	26			

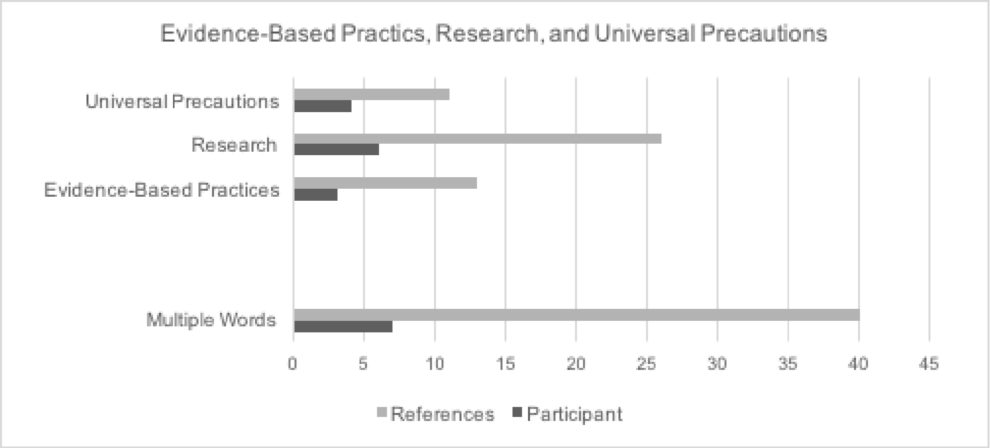


Figure 8. Graph of Table 5. This depicts Table 5 as bar graph showing the usage of the phrases.

Leadership and complexity. The last two phrases, leadership and complexity, are not related in usage. They are grouped for graphic convenience and discussed separately.

Leadership is referenced 16 times by seven participants. This term was used primarily in two ways. One way was to describe the leader (e.g., political leader). This reference was only used four out of the 16 references. The second way of usage was in regarding the leader influence. This was stated in various ways by multiple participants.

- “…it’s a matter of finding a champion among their leadership….”
- “If we’re going to influence policy, the leadership has to be on board because leadership drives policy decisions.”
- “We are always promoting the focus group and having community input – top-down engagement – senior leadership needs to be involved.”
- “It boils down to the senior leadership not making an emphasis.”

- “The idea came from that people want to implement health literacy best practices in organizations and the leadership understands it’s the right thing to do and that there will be good outcomes….”
- “You have to get leadership’s buy-in as to why that’s a good idea and what the trade-offs are.”

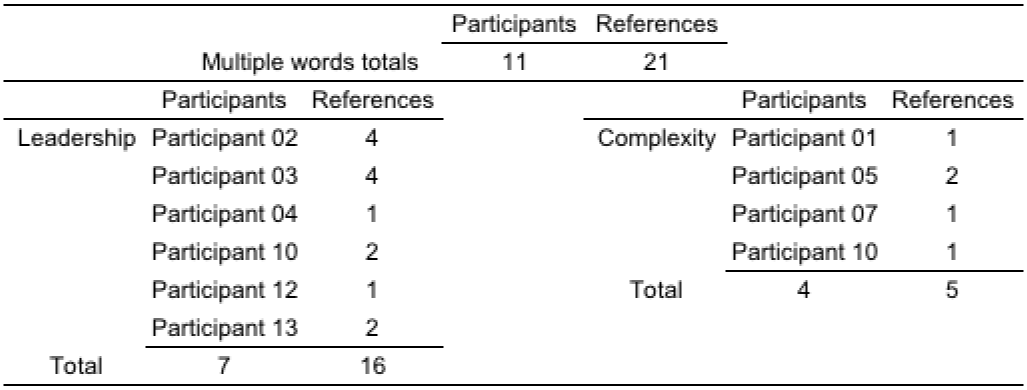
The last phrase, complexity or complex, was used five times by four participants. Two of the references are in regards to developing decision tools to aid in complex decisions that patients have to make. Both of these references are in response to Question 2 – What impact does health literacy have on the process of developing formal policy? Three of these references tie directly to understanding that the health system is complex.

- “The system should be made less complex/complicated.”
- “On the professional side, raising awareness on how complex the system is for the average consumer and help professionals understand the way they communicate.”
- “We understand that the healthcare system is a complex entity and being aware of and implementing health literacy into what we do in general is always a good thing.”

This correlation is depicted in Table 6 and Figure 9.

Table 6

Leadership and Complexity



	Participants	References
Multiple words totals	11	21

	Participants	References		Participants	References
Leadership	Participant 02	4	Complexity	Participant 01	1
	Participant 03	4		Participant 05	2
	Participant 04	1		Participant 07	1
	Participant 10	2		Participant 10	1
	Participant 12	1	Total	4	5
	Participant 13	2			
Total	7	16			

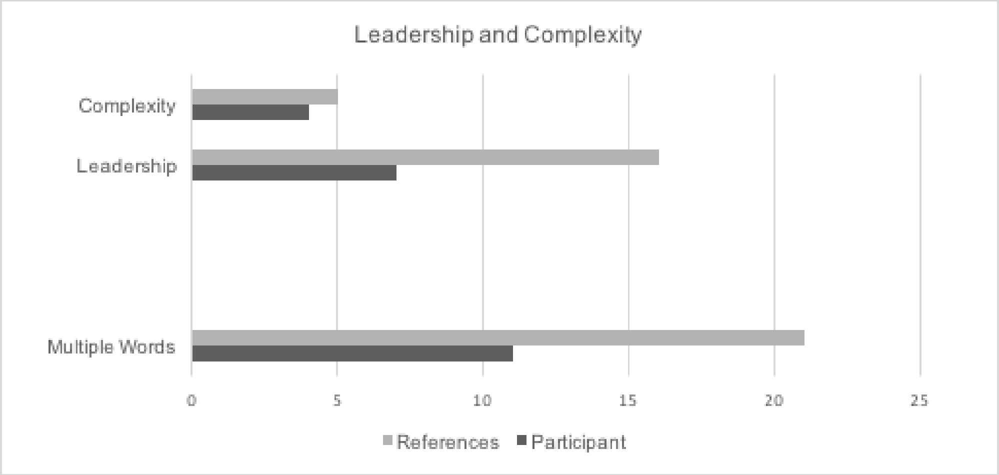


Figure 9. Graph of Table 6. This depicts Table 6 as bar graph showing the usage of the words “leadership” and “complexity”.

Unexpected Themes

Two themes that emerged that were not expected, were the definitions of community (as opposed to the description of the community/ies as expected) that the participants were working with and the word “congruency”. After the first question, “What is involved in addressing health literacy in the communities?”, was stated, each participant asked for the definition of the community I was inquiring about. Though some communities were similar, each community was unique in some aspect. The word “congruency”, from question six, “How does this organization build congruency on policy?”, was expected to have an understanding of “consensus” and the participants were given that meaning. However, the answers to question six from the participants, signified that some also used an alternate understanding of the word as whether the message matches the action.

A second unexpected theme that emerged was the participants’ conceptual answers to the questions. The concept of utilizing best practices to develop or even to impact or influence policy were not met with structured answers and for some, esoteric answers.

Summary

The research for this case study was accomplished by interviewing 13 participants of the 58 people and/or organizations contacted. The responses to the seven interview questions were as varied as the organizations and participants themselves. The coding for the interview transcripts was challenging due to the variation of the responses. The early coding was based on the main ideas of the questions which proved to be parallel with the emerging themes. The coding then became the structure of the research and interview questions.

The research used triangulation to validate the case using sources (13 organizations/participants) and audit trails. The dependability for the study was dependent on the availability of the participants for the interview and the ability of their knowledge to respond to the questions. Confirmability was ensured by utilizing a checklist that allowed me to check and recheck the processes and data during the research and data mining. This included reviewing the audio recordings and typed transcripts for mistakes to eliminate any bias or distortion and supported the intercoder reliability. This study met all the requirements that were proposed. The total number of participants, 13, was 65 % of the total number, 20, that was initially thought would be participating, and 43 % of the saturation number of 30. The number of organizations from the CDC website that responded and agreed to be involved in the interview was less than initially expected. Therefore, organizations found on the health literacy list serve were contacted.

The results of this study are outlined by research question and the interview questions that were designed to examine each. The first research question had two interview questions that established the basis of conditions that influence implanting tools and guidelines. The first interview question asked the participants to define and discuss the community in which they were involved. This drew a range of different communities but all interacting with the others. The second interview question asked how formal regulations impact the implementation of tools and guidelines. The responses pointed to the complexity of the health system and that regulations would need to be further defined and structured.

The second research question had four interview questions. The third interview question was asking the participant to list the top three health literacy best practices of the organization. The responses were diverse and yet had associated components with best practices. Four best practices that emerged were training, team, plain language/clear communication, and research. The fourth interview question asked about developing the best practices for their organization. Five patterns emerged: grants or funding was used, conferences and workshops were conducted or attended, tools and/or best practices were developed through a former occupational skill, research, and best practices that cannot be categorized. The fifth interview question asked about using the health literacy best practices in developing policy. The responses to this question were multifarious and esoteric and are discussed further in Chapter 5. The sixth interview question asked the respondents about their organization building congruency on policy. This drew the question to define “congruency”. There were three themes that emerged with some having overlapping ideas: education, communication, and partnering or networking.

The third research question is also the seventh interview question asking how could health literacy be addressed through formal policy. Four patterns regarding the level at which health literacy is addressed emerged through the responses: organizational, health system, state, and undefined.

A “follow-up” of two questions was asked to the participants – “Is there anything you would like to add or state that wasn’t asked through the questions? Do you have any questions of me?” Both drew varied responses. The responses to the first part of the questions were inclusive of policy, best practices, and summations of thoughts with no emerging themes but echoed each participants’ response to the interview questions. The questions for me asked about my background in work and in the health literacy field, how the questions were generated, if they could get a copy of the published dissertation, and how were the results going to be used.

The analysis of the interview questions through NVivo corroborated word patterns and definition themes that emerged through the participants' responses during the interview process. The word patterns are connected by grouping the words and others were stand-alone as shown by the following:

- education (or educate), training, raising awareness, and changing behavior;
- plain language and clear writing;
- evidence-based practices, research, and universal precautions;
- leadership; and
- complexity.

Two definition themes that emerged were not expected – the definitions of community (as opposed to the description of the community/ies as expected) that the participants were working with and the word "congruency". The last unexpected theme was the participants' conceptual unstructured responses to the questions regarding utilizing best practices to develop or even to impact or influence policy. These results are discussed in detail in Chapter 5 summarizing the key findings, and interpreting the findings, recommending future research, and discussing the potential impact for positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Purpose, Nature, and Key Findings of Study

The purpose of this qualitative case study was to explore and compare commonalities in health literacy best practices of organizations that are recognized as leaders in health literacy by the CDC and are addressing low health literacy in their communities. By comparing the organizations' abilities to implement standards of plain language (regulated through accreditation) and other health literacy tools/guidelines (without regulation), best practice recommendations can be made to various organizations regardless of level (local, state, federal, or nonprofit). By also exploring these organizations, potential health literacy policy might be determined by examining what is currently being shaped, taught, and applied. Exploring commonalities of organizations that are addressing the complexity of health literacy within their communities will allow patients and healthcare providers to better address health concerns.

By exploring how the organizations are implementing tools and best practices, a comparison can be made to find commonalities that will help other organizations as well as the development of health literacy policy. These organizations are in diverse communities, thereby mirroring the concept of complexity. I interviewed members within organizations that are considered by the CDC to be leaders in the health literacy community as well as organizations from the health literacy list serve. These organizations are a mixture of local, state, academia, government, and nonprofit. This allowed an in-depth look at how health literacy tools/guidelines are being implemented.

Participants were asked open-ended questions allowing the capture of multiple perspectives for better validity of the complexity and phenomenon.

The phrase community was not intuitive to any participant, and each participant asked for the phrase to be clarified. This is also a theme under Word Definitions in Chapter 4. The theme that emerged in Interview Question 1 for the phrase community is education, training, and awareness but is seen throughout the following interview questions.

The responses to Interview Question 2 were based on system (i.e., complexity and framework) and regulation (i.e., aspect and pros/cons) and mandates (i.e., plain language and education). The best practices discussed in Interview Question 3 are diverse with overlapping components of best practices. Four best practices that emerged are training, team, plain language, and research.

Five phrases that are also found in the responses to other interview questions but emerged as patterns in Interview Question 4 are (a) grants/funding received, (b) conferences/workshops, (c) development of tools/best practices, (d) research, and (e) noncategorical best practices. Participants’ responses to Interview Question 5 were multifarious. What was found was that most of the participants’ organizations that are not developing policy are tracking, advocating, and/or have started research activities towards developing policy. Other participants’ organizations involved in policy use one or more of six types of approaches: (a) top-down (trickle-down), (b) bottom-up, (c) skills-building, (d) nonpriority, (e) influence, and (f) support.

The common response to Interview Question 6 was asking what was meant by congruency. The intention was to reference consensus. Three themes emerged: (a) education, (b) communication, and (c) partnering (networking). This is also found in the Word Definitions in Chapter 4. Interview Question 7 and Research Question 3 are the same question. The participants' responses to this question are also multifarious. Four patterns to the levels at which health literacy is being addressed through policy emerged: (a) organizational, (b) health system, (c) state, and (d) undefined.

The follow-up question was responded to by nine of the 13 participants. The responses included policy, best practices, and summation of thoughts, and some asked about my intentions with the results of the study as well as about me. The participants were inquisitive as well as informative. There were five word patterns that emerged throughout the responses. Three patters connected by grouping words: (a) education, training, raising awareness, and changing behavior; b) plain language and clear language; and (c) evidence-based practices, research, and universal precautions. Two patterns that were not grouped are leadership and complexity. Two unexpected themes that are mentioned in Interview Questions 1 and 6 are the definitions of community and congruency. Each participant asked what was meant by both words when responding to their respective questions.

Interpretation of Findings

Comparison to Literature

In the literature review, it was found that understanding health literacy's impact on society is critical to minimalizing the effects on low health literacy and is more important than defining health literacy. Throughout the 13 interviews, the participants neither defined health literacy nor mentioned if there was any importance to doing so.

Winslow’s 1920 definition of public health was “the science and preventing of disease, prolonging life, and promoting health and efficiency through organized community efforts” (Winslow, 1920, as cited in Evans, 2009, p. 35). In his definition, Winslow did not define community. Evans (2009) came close but only stated that communities have differing social issues and cultural norms which may determine the populations’ health. Each of the organizations’ definitions to what the communities they were involved with were varied making it difficult to define. Researchers have stated that a community is an environmental factor in which formally and informally harbors the social networks, norms, and/or standards, within individuals, groups and organizations (WHO, 2012). The responses by the participants support this showing that the communities are social networks defined as geographical (towns, cities, states, etc.) and demographical (tribal, refugee, etc.). Both of these have norms and standards that exist formally and informally in individuals and groups. The groups and organizations are also defined by the participants as patients/consumers, health providers/professionals, and health systems. The participants’ definitions also support Winslow’s definition of public health by stating that the communities are organizing efforts.

Responses to the second interview question with the use of the terms system and framework aligns and continues the understanding of community. Both connect the community to the complexity of health literacy and health care. The framework involves the individual surrounded by each of the communities defined by the participants, ultimately surrounded by policy or law. These are complex sets of variables.

The AAFCS (2012) stated that the complexity of health literacy is impacted by culture, society, and health and education systems, and all of these affect health outcomes. Bureaucracies complicate health care and public health procedures and processes (Peters et al., 2007).

Though only five of the 13 participants referenced complexity, three responses tied directly into the concept of the complexity of health care. However, the other two references are regarding developing tools to help patients with complex decisions. This aligns with literature that has shown health complexity is related to health literacy because patients often face decisions about complex treatments (Glassman, 2012).

Though health literacy is affected by and affects various variables (i.e., demographics), there is also a relationship and correlation to basic functions of education and culture (Chao et al., 2009; DHHS, 2003; Glassman, 2012; Nutbeam, 2000). Sentell (2003) stated that education is the most obvious link to health literacy and affects and is affected by health literacy. Paasche-Orlow et al. (2005) also stated that education is one demographic feature associated with health literacy. The responses show that education, training, and awareness is imperative to mitigating low health literacy. This was a theme found throughout the responses to each question by the participants. Education, training, awareness, and changing behavior were the most used (149 times) terms throughout the interviews. The first references were in response to the first question regarding communities. This supports Mogford et al.'s (2010) proposal that education should focus on eliminating inequities in both individuals and communities.

As noted in Chapter 2, the literature that was available specifically on policy or related to policy was limited, and the literature reviewed was outside the standard of 5 years or newer. The responses to the questions focusing on policy show that marrying policy with health literacy is quintessential to what was found in the literature. As the participants were asked how their organizations use best practices to develop policies and build congruency on policy, the answers were multifarious and overall esoteric.

Responses to addressing health literacy through formal policy were also multifarious. However, the answers tie to many of the themes found and were stated in the results section of Chapter 4 as well as in the literature. For example, one participant stated that there is enough research to support setting policies in a health system to ensure health information for patients is easy to understand. This supports Williams and Marks' (2011) findings that opportunities need to be created for both individuals and communities to increase healthier choices and healthier living.

Another example is in regards to using metrics. One participant stated that health literacy needs to be a term written into policy and be a foundation for quality of care organizations and quality of care metrics. This is similar to Kickbusch's (2001) findings that health literacy and socioeconomic status are measurable elements of health outcomes.

Williams-Crowe and Aultman (1994), 23 years ago, found that to participate in the policy process, develop political relationships within the communities and with legislative representatives, and early on, involve the community in the policy process. Ratzan (2001) also stated that there should be a partnership between the policymakers that are not part of the health community. One participant’s response mirrored this stating that “they could have a state senator or representative help author a bill.”

Another area where the responses align with the literature is regarding leadership. Seven participants referenced leaders or leadership 16 times. In literature, Frist (2005) and Koh (2009) stated that public leaders need to acknowledge the challenges and correctly define the problem to ensure that everyone can access the health system regardless of socioeconomic status. IOM (1988) has also stated that responsible leadership in health policy is approaching the process strategically and communicates to affect policy development and serve communities’ needs. Participants’ responses include that the leadership has to be “on board,” involved, and be a “champion,” as leadership drives policy decisions.

Findings, Analysis, and Interpretation

The theoretical framework of this study was based on the Evans and Stoddart framework of determinants of health and health behavioral theories. The conceptual framework was based on health literacy best practices and policy, which are part of both theories.

The social determinants of health are the social, environmental, and economic conditions that influence and affect individual’s health and influence the functioning and well-being of a community (CDC, 2009; DPHP, 2016). The World Health Organization uses three health behavioral theories in research: individual capacity, relationships, and environmental contexts (institutional and community factors, and public policy).

The individual capacity is defined as having six levels of capacity or the characteristics that influences behavior: awareness and knowledge, beliefs, opinions and attitudes, self-efficacy, intentions, and skills and personal power (WHO, 2012). In the literature reviewed, the majority of the research is based upon this theory and is focused on the individual's health literacy level and capability.

The relationship theory is defined as having the processes and primary groups (family, friends, peers, etc.) giving the individual social identity, support, and role definition (WHO, 2012). This is also known as social learning theory based on the idea that people generate their environments, which impacts their health (WHO, 2012).

The environmental contexts theory is defined by the community, organization, and policy. All three influence the social system function and change (WHO, 2012). This factor, with the health and function and the well-being components of the Evans and Stoddart model were the basis of this study.

The responses to the second interview question best reflected the behavioral theory. One line of responses focused on a framework that involves the individual or patient being at the center of concentric circles. The circles envelope the individual and grow larger. They are the family, the neighborhood, the geographical community, and the systems, with law and policy as the outside ring. These rings are complex sets of variables that align with the Evans and Stoddart model and the variables depicted in Figure 1.

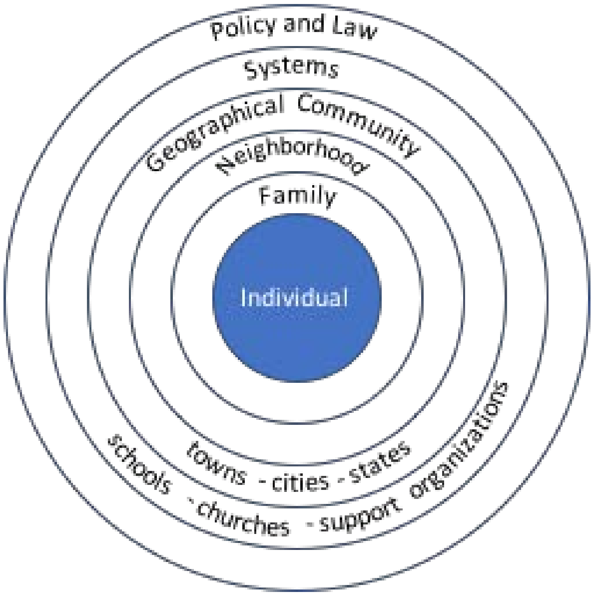


Figure 10. Concentric circles. These are depicted by the participants' responses as a framework that aligns with the Evans and Stoddart model.

The other line of responses to the second interview question have to do with mandates and regulations. The specific responses that aligned with the individual capacity behavioral theory stated that regulations will raise the awareness and will force training and education to change behaviors. Responses to this question also support the public policy factor of the environmental context theory stating that regulations will support the alignment of the healthcare system to health literacy issues.

Responses to Interview Question 3 paralleled the individual capacity behavioral theory. This theory's definition – the influencing characteristics – aligns with the best practices of training/educating patients to change how they interact with the physician as well as understand what they are being told. It also aligns with training/educating the physician/provider to understand the patient's emotional and mental components as well as the cultural learning modalities that speak to changing the interpersonal behaviors.

The interview responses align to the conceptual framework as a response to the framework's five concepts. This alignment is shown in Table 7.

Table 7

Conceptual Framework and Interview Responses Alignments

Conceptual framework	Participant's responses
Health care is complex	"The system should be made less complex/complicated" "…raising awareness on how complex the system is." "We understand that the healthcare system Is a complex entity…"
Low health literacy is a problem	"When we talk about health literacy, it's often in terms of 'it's them not us and we don't have that problem' – well, frankly, you do – you just don't know it yet." "Because health literacy is nobody's problem, it's everybody's problem."
Health literacy is a complex issue	"They're confused on what the problem is around health literacy, and that's health literacy as it's conceptualized. Being that health literacy is a system and a system that can meet the abilities of the consumers." [In response to Interview Question Two:] "It's a complex question."
Lack of policy direction at the federal level	"Not familiar with state or federal regulations that would impact work we're doing – except – workshops on plain language for prescriptions – the work is around communications and haven't bumped into any state or federal regulations that impact any of our work in the communities." "Without pressure from the government, these best practices will never be adopted by other organizations or hospitals."
Organizations at the grassroots level are shaping their role in the local communities implementing health literacy without the foundation of policy or centralized coordination	"Health literacy lives at the community base level where interventions and opportunities to help people understand lives. Sometimes it requires policy but a lot of times they don't but require a better guidance on how to do things so people understand them."

Overall, the participants' responses to the interview questions support the theoretical and conceptual frameworks. The Evans and Stoddart model, the health behavioral theories, and the five concepts depict the understanding that a patient's well-being is not on one factor alone. It is neither just the individual nor just the health care that the patient is receiving, nor is it just the environmental effects. The participants' responses in the interviews align with this.

- "We all make the system complicated and the onus is on all of us, not just the patients."
- "Addressing health literacy in the community of professionals, involves training, outreach, research, and policy. All of these things have to happen."
- "There is the social component not just the environment. People don't see or are not aware of others that have the same issue that they are coping with and this is a bigger issue within the community."

"Environmentally, there are within the communities that help to support good health and when we look at what is available environmentally, that translates into health literacy a lot of times because if people understand that this equates to better health, then, if it's available, we utilize it."

Limitations of Study

There were several limitations of this study. A limitation, stated earlier in Chapter 1, was that health literacy affects such a broad range of culture and diversity in patients, health care providers, and communities, examining the specificity of any of these attributes is not possible within this study. This was furthered by a limitation that emerged on the definition of community. There were five definitions of community between the 13 participating organizations.

Another limitation stated prior to conducting the research, was the limiting of organizations shown on the CDC website as they are recognized as having involvement in health literacy and interacting at the state and regional levels. This population was widened to use organizations that were found on the health literacy list serve as stated as a back-up plan. This allowed the minimum sampling size ($N = 6$) to be met and exceeded ($N = 13$).

A third limitation stated in Chapter 1 was the methodology used voluntary interviews of personnel at these organizations associated with health literacy. Accordingly, a limitation that arose was the differing job roles of the participants. This was due in part to the organizations' scopes of practice being divergent and therefore the understanding or ideas of health literacy best practices and policy development and/or involvement also differs.

Recommendations of Future Research

Based on the results of this study, there are several recommendations of future study/research. These recommendations highlight both, best practices and policy. The first recommendation is to define the community that the study will focus on. The research should be within one type of community or a multi-case comparison of communities. Defining the community will help to understand which best practices work with specific communities. It will also pinpoint to assist in developing policies directed at those specific communities.

The second recommendation is to limit the study to a specific health literacy best practice within a defined community or a group of non-defined communities. This will allow the understanding of how to develop policies by the utilization of a specific health literacy best practice. Another study recommendation is to compare the effects of best practices within a defined community. This can be expanded to the development of policy implementation for that health literacy best practice.

A third recommendation of study is why health literacy organizations are not involving themselves in policy development. This can extend to a comparison to those organizations that are developing or are involved in policy (i.e., influencing). An understanding of involvement in policy will show how to involve organizations in developing health literacy policy. A secondary effect of this will show more specifically engaging health literacy in policy and policy development.

The fourth recommendation for further research is a comparison of leadership involvement in health literacy policy in health literacy organizations. Comparing the top-down versus bottom-up approaches within organizations will identify an effective approach to the involvement in, or development of, health literacy policy.

The final recommendation for future study is the comparison of one or more health literacy best practices and/or policies of hospitals within a defined community. The expansion of this study to compare the utilization of health literacy best practices in the hospital or health care facilities would presumably be too expansive without defining the specifications and parameters (i.e., the community, the health literacy best practice, or the implementation of a specific policy).

These recommendations focus on mitigating low health literacy. This will subsequently move towards bettering the ability to ensure the well-being and healthy outcome of patients.

Implications

Positive Social Change

The implications for positive social change for this study impacts the patient (individual), community, organizational, and policy (societal) levels. There are two main categories that they fall under – policy implications and best practices implications. This study explored 13 organizations' health literacy best practices and how they used them in developing policy.

The policy implications can impact the determination of what resources (e.g., funding and manpower) are needed to develop policy as well as learning how other organizations use best practices in developing policy. Hospitals can determine from policy (organizational or legislative) an implementation plan and needed resources for future sustainment. Accordingly, this will impact patients' interactions with the healthcare facility for potentially more positive health outcomes, a higher health literacy, and lower health costs.

The best practices implications for positive social change can also impact society at all levels. The overall best practices found throughout the study as being the most effective is awareness, education/training, and changing behaviors. Awareness is the start of any impact to positive social change. The results found that making

- The legislators aware of the impact of low health literacy lead to a positive change in policy;
- The doctors/physicians awareness leads to education/training and better interaction with the patient;
- The patients’ awareness leads to their education and potentially bettering their ability to be more in control of their health thereby increasing their health literacy and lowering their health costs and hospital visits.

Positive social change can only happen with the awareness and education of the patients, physicians, and legislators. Otherwise, there is no positive social impact to them or to society.

Methodological/Theoretical/Empirical Implications

The methodological implications of this study can impact future research of health literacy. This study shows that there is need to the defining of what community is to be studied in order to understand what effect best practices and policies might potentially have on that specific community. This study also shows the complexity of pinpointing best practices within a community as well as the complexity of engaging in policy development.

This study’s theoretical implications lie within the ability to impact the awareness, education, and behaviors of patients, communities, healthcare providers, and policymakers. The Evans and Stoddart Model shows us that various factor and forces impact the health and well-being of an individual which triggers the complex component of health and health policy. Disease and health care interact bringing in the cost to potentially impact the effectiveness of the care. This is determined by the individual's lifestyle/environment and biological make-up influencing their health and function, well-being, and ultimately their long-term prosperity.

The political implications of this study are undetermined. The results show that the impact to this theory can either be positive or negative. The awareness and education within the political realm is clear on how it impacts policy and legislation development. If the legislator is aware/educated, the potential impact is positive whereas the reverse is also true.

The healthcare system and provider implications impacts policy within the health system and/or institution and the education/training of the providers. The patient implications impact the individual's self-awareness and behavior and education thereby impacting the foundation of their well-being. This also impacts the family, communities, and institutions (e.g., schools), and society (e.g., the workplace).

The empirical implications of this study are thematic in nature. Interview Question Five drew esoteric responses regarding using best practices to develop policy. This is more than simply having abstract answers on policy. The answers to the question were not congruent. This depicts how policy might be perceived and approached by organizations that are not developing policy.

Recommendations for Practice

This study examined the health literacy best practices of organizations. There are no recommendations on the application of these best practices. That is beyond the scope of this study. However, the recommendation for these organizations developing and utilizing their best practice is to encourage local government’s involvement in the implementation of health literacy best practices within the communities they serve, as appropriate.

This involvement aligns with the main theme derived from the responses that awareness, education, and changing behavior impacts for positive social change. Involving legislators will also provide credibility when developing policy utilizing health literacy best practices.

Another recommendation is the publishing of the health literacy best practices. It is impossible to communicate with every organization that also develops or uses health literacy best practices. This is a potential tool to communicate on a broad spectrum.

Conclusions

Health is the one topic that society is aware of every day. Health is an asset and good health is desirable. It is a patient’s health literacy that will help determine the efficacy and health outcome.

In this study, I explored the health literacy best practices of 13 organizations recognized as leaders in health literacy practices. I also examined the utilization of those best practices in developing health literacy policy. As stated in the literature review, research on health literacy has been focused on defining it and examining the effects of low health literacy. Likewise, research on policy has focused on provision with little information regarding how health literacy organizations are addressing low health literacy.

The results of this study show that there are organizations taking great strides to mitigate the effects of low health literacy. It also shows that communities are as different as the individuals within them and there are multiple approaches to best practices. Policy development and involvement exists but it is abstract when deriving it from best practices. There is no model for applying health literacy best practices to policy development. Though this study cannot recommend an application of health literacy best practices, organizations should endeavor to gain the local government's interest in supporting health literacy best practices within the communities they serve. Future research recommendations are to define the community that the study will focus on, limit the study to a specific health literacy best practice within a defined community or a group of non-defined communities, examine why health literacy organizations are not involving themselves in policy development, compare leadership involvement in health literacy policy in health literacy organizations, and compare one or more health literacy best practices and/or policies of hospitals within a defined community.

Implications for positive social change include learning how other organizations use overall health literacy best practices as being the most effective in potentially developing policy. The consistent theme resulting from this study is awareness, education, training, communication, and changing behavior. One participant concluded the interview stating, "There are a lot of ways to do health literacy – all different ways – there is no one way." The organizations are provisioning health literacy best practices for the communities they serve.

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Appendix A: Interview Script

1. Introductions

A. Myself

I am Stacie Lee Trueheart, a doctoral student at Walden University.

B. Research intent

This study will look at how organizations attempt to implement health literacy tools and guidelines and promote policies. This is done in an environment of complex related issues and interlinked with complex network effects and specific elements that are complex as well. This study will explore the best practices of the organizations who have adapted most effectively.

C. Explanation of the study

By exploring how the organizations are implementing tools and best practices, a comparison can be made to find commonalities that will help other organizations as well as the development of health literacy policy. These organizations are in diverse communities thereby mirroring the concept of complexity. This study will interview members within organizations that are considered, by the CDC, to be leaders in the health literacy community. These organizations are a mixture of local, state, academia, government, and non-profit. This will allow an in-depth look at how health literacy tools/guidelines are being implemented. Participants will be asked open-ended questions allowing the capture of multiple perspectives for better validity of the complexity and phenomenon.

D. Do you have any questions at this time?

2. Interview

   A. Question 1: What is involved in addressing health literacy in the communities?

   B. Question 2: To what extent would formal regulations impact the implementation of health literacy tools/guidelines?

   C. Question 3: What are your organization’s top three health literacy best practices?

   D. Question 4: How did your organization develop each of these best practices?

   E. Question 5: How is your organization using health literacy best practices in developing policy?

   F. Question 6: Not all experts agree. How does this organization build congruency on policy?

   G. Question 7: How can health literacy be addressed through formal policy?

3. Conclusion

   A. Is there anything you would like to add?

   B. Is there anything you would like to ask me?

   C. Acknowledge their participation.

Appendix B: Question Alignment Map

	Research Questions	Interview Questions
1	How are organizations implementing health literacy tools/guidelines without regulation?	What is involved in addressing health literacy in the communities? To what extent would formal regulations impact the implementation of health literacy tools/guidelines?
2	What impact does health literacy best practices have on the process of developing formal policy?	What are your organization's top three health literacy best practices? How did your organization develop each of these best practices? How is your organization using health literacy best practices in developing policy? Not all experts agree. How does this organization build congruency on policy?
3	How can health literacy be addressed through formal policy?	How can health literacy be addressed through formal policy?

Appendix C: Email Request for Participation in a Research Study

Subject: Research Study Participation Request

Dear Invitee,

My name is Stacie Lee Trueheart. I am a doctoral student at Walden University’s College of Social and Behavioral Sciences, School of Public Policy and Administration. I am kindly requesting your participation in a doctoral research study that I am conducting titled: The Utilization of Health Literacy Best Practices on the Process of Policy Development. The purpose is to explore and compare commonalities in health literacy best practices of organizations, such as yours, so that recommendations can be made to various organizations, and potential health literacy policy might be determined by examining what is currently being shaped, taught, and applied.

The study involves interviews answering seven open-ended questions regarding your organization’s health literacy best practices and policy development. This will take approximately 30-45 minutes, depending upon the length of the responses, and will be conducted via the online video & teleconferencing website, AnyMeeting.

Your participation in this research study is strictly voluntary. You may choose not to participate and you may withdraw your consent to participate at any time.

If you would like to participate, please reply to this email or call me at 301-467-4960 to schedule time. Prior to the interview I will send you an Informed Consent form and Permission to Use Personal Communication form.

Your participation in this research will be of great importance in exploring commonalities of organizations that are addressing the complexity of health literacy within their communities will allow patients and healthcare providers to better address health concerns.

Thank you in advance for your consideration and participation.

Sincerely,

Stacie Lee Trueheart, M.S., Doctoral Student, Walden University