

Assessing Health Literacy in Diverse Primary Care Settings

by

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Dedication

This dissertation is dedicated to the inspirational women in my life representing three diverse generational viewpoints reflecting women's thought and action. Each woman provided unconditional love throughout my life and believed I could do more. To each one, I complete this dissertation in your honor.

Gloria Seppala Long (Mother)

Irena Haskin Long & Helmi Tikkanen Seppala (Grandmothers)

Evelyn Long Stalker (Aunt)

Meghan Yvonne McCune (Daughter)

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TABLE OF CONTENTS

Dedication	ii
Acknowledgements	iii
List of Figures	ix
List of Tables	x
List of Appendices	xi
Abstract	xii
CHAPTER I	
Introduction	1
Specific Aims	2
Significance	3
CHAPTER II	
Review of the Literature	7
Literacy	7
Historical Review of Literacy	9
Literacy Reporting	10
Socio-historical Role of Literacy	12
Literacy Education	15
Theories of Literacy	19
Linguistics	19

Psycholinguistic Theory	20
Cognitive Psychology	21
Sociolinguistic Theory	22
Meta-Cognitive Theory	24
Transactional Theory	25
Critical Theory	25
Literacy and Measurement	28
Literacy and Public Policy	33
Health Literacy	37
Historical Review of Health Literacy	38
Health Literacy Assessments	42
Health Literacy and Public Policy	47
Provider Awareness and Primary Care	50
Summary	61
CHAPTER III	
Conceptual Model	63
Culture and Society	64
Health System	66
Education System	68
Summary	74
CHAPTER IV	
Methods	76
Settings	78

Sample	80
Providers/Staff	80
Patients	82
Interventions	
Providers/staff	84
<i>Health Literacy in Primary Care</i> Intervention	85
Instruments	
Quantitative Data	88
Provider/Staff Instruments	
Demographic Survey	89
Provider/Staff Pre/Post Surveys	89
Patient Instruments	
Demographic Survey	90
Health Literacy Assessment Tool	90
NVS Perception Questions	93
Quantitative Analysis	93
Qualitative Data	
Provider/Staff Instruments - Focus Groups	94
Patient Instruments – NVS Perception Questions	96
Qualitative Analysis	96
Procedure	97

CHAPTER V

Results	99
Quantitative Data	99
Provider/Staff Findings	99
Research Aim 1	99
Post Survey	101
Research Aim 2	101
Patient Findings	102
Research Aim 3a	102
Research Aim 3b	104
Research Aim 3c	104
Center HL Levels and Patient Demographics	105
NVS Perceptions Questions	106
Demographic Associations to Low HL scores	107
Qualitative Data	109
Provider/Staff Focus Groups	109
Research Aim 1	109
Theme 1: Use of HL Assessment Tool	110
Theme 2: Value of HL Screening	111
Theme 3: Health System	113
Theme 4: Study Impact on Providers/Staff/Patient Interactions	114
Patient Findings	116
Research Aim 3d	116

NVS Perception Questions	116
Results Conclusion	117
CHAPTER VI	
Discussion	119
Limitations	126
Conclusion	129
Implications for Future Research	130
Tables	133
Appendices	147
References	159

LIST OF FIGURES

Figure		
2.1	Institute of Medicine (IOM) Health Literacy Framework	38
3.1	Institute of Medicine Health Literacy Intervention Points	64
4.1	IOM Health Intervention Points with Study Components	77
5.1	Pt. Perceived Level of Difficulty to Answer NVS Questions	107

LIST OF TABLES

Table

1.	Characteristics of Participating Primary Care Settings	133
2.	Providers-Staff Demographics: Frequencies	135
3.	Patient Demographics: Frequencies	137
4.	Assessed Pt. HL by site and Provider/Staff estimates	139
5.	Mean/Standard Deviation of HL KAB Scores among Providers/Staff	140
6.	Patients' Newest Vital Sign (NVS) Results	141
7.	Mean Differences of Pt. NVS Score by Demographic Variables	143
8.	Summary of Multiple Regression to explain the Pt. NVS Score	145

LIST OF APPENDICES

Appendix

A.	Pt. Consent and Pt .Experience with NVS Questions	147
B.	<i>Health Literacy in Primary Care</i> (screen shots)	149
C.	Provider-Staff Pre and Post KAB Survey	150
D.	Provider-Staff Demographic Survey	153
E.	Newest Vital Sign Tool & Score Sheet	154
F.	Patient Demographic Survey	155
G.	Provider-Staff Focus Group Script	156

Abstract

Assessing Health Literacy in Diverse Primary Care Settings

By

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Patient health literacy skills are critical to effective healthcare communication and safe care delivery in primary care settings. Methods and strategies to identify patient health literacy (HL) capabilities and provider/staff knowledge, attitudes and beliefs (KAB) regarding HL must be known before addressing provider/staff communication skills. This study employed a mixed methods design to examine provider-staff awareness of patient HL status, measure provider-staff KAB HL change after implementing a web-based educational intervention, and test feasibility of implementing a standardized HL measure (the *Newest Vital Sign* or NVS). Patient HL sampling per clinic measured clinic workflow time impact, identified demographic associations to low patient HL, and documented patient perspective of the NVS.

Using the Institute of Medicine's Health Literacy Intervention Points model, providers/staff (N=47) in seven primary care centers (five nurse managed and two physician-led) all serving diverse populations in five Michigan cities were enrolled in the study. Providers/staff completed a socio-demographic survey, pre/post-survey (HL/ KAB questions) and estimated the percentage of limited

literacy patients in their practice. Focus groups with providers/staff followed within 3-6 months after initial data collection. A convenience sample of patients (N=282) was recruited during visit intake or in the clinic waiting room. Patients verbally consented and completed a socio-demographic survey, NVS, and three NVS perception questions.

Quantitative data were analyzed using descriptive, correlational, and paired t-test methods. Multiple regression analysis was used to identify socio-demographic associations to low health literacy. Qualitative data were analyzed using grounded theory and comparative analysis identifying thematic responses.

The NVS proved to be time efficient and integrated well into clinic routine. The strongest associations to low NVS score were primary language, race/ethnicity, education level and health insurance status. Provider/staff data analysis regarding health literacy KAB revealed no significant change overall pre/post- survey. Focus group responses demonstrated four themes: Use of HL Assessment Tool, Value of HL Screening, Health System, and Study Impact on Provider/Staff/Patient Interactions.

The study demonstrated the NVS was easy to administer and well received by patients. Consistent with the literature, provider/staff awareness of health literacy was mixed and challenges in addressing health literacy in busy primary care practices were identified.

CHAPTER I

Introduction

In the past 30 years, health literacy has steadily garnered attention and recognition from the healthcare community as an essential skill required for optimum personal health. Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 1999). Health literacy skills are critical to *reducing errors* through improving the communication between provider and patient, understanding test results, following verbal and printed material directions, caring for oneself and family, and making decisions regarding care (Nielson-Bohlman, Panzer, & Kindig, 2004). Many patients will not reveal their literacy concerns with a health professional due to embarrassment, thus compounding the problem of effective delivery of health information (Parikh, Parker, Nurss, Baker, & Williams, 1996). Unknown literacy capabilities become especially problematic as most providers overestimate the health literacy level of their patients (i.e., Bass, Wilson, Griffith, & Barnett, 2002; Glanville, 2000; Lindau, Tomori, Lyons, Langseth, Bennett, & Garcia, 2002).

The following exploratory study was undertaken with two purposes: First, to test the feasibility, and efficacy, of a web-based intervention – *Health Literacy in Primary Care* (McCune, Springfield, & Pohl, 2006) – designed to raise providers/staff awareness and knowledge of patient health literacy. Second, to test the feasibility of using a patient health literacy assessment tool, the Newest Vital Sign (Weiss, Mays, Martz, Merriam-Castro, DeWalt, Pignone, et al., 2005), in primary care settings.

The *long term research goal* is to enhance safety in primary care by incorporating health literacy practices into the care delivery methods used by primary care providers, and staff, ultimately enhancing patient-provider communication.

Specific Aims

1) Examine provider-staff awareness of patient health literacy status within the primary care setting.

H1. After completing the module intervention, providers/staffs' prediction accuracy regarding the percentage of low health literate among clinic patients will improve between pre and post survey.

2) Measure change in provider-staff knowledge, attitudes, and beliefs related to health literacy after implementing a web based educational intervention, *Health Literacy in Primary Care* (McCune, Springfield, & Pohl, 2006).

H1. After completing the module intervention, providers/staffs' attitudes, awareness and knowledge (including definition, measurements, and need for

accommodations) related to patients' HL levels in primary care will increase from pre to post-survey.

- 3) Test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health literacy in primary care centers to:
 - a. obtain sample percentage of patient health literacy levels in each clinic
 - b. examine the impact on workflow in a primary care setting through measuring the time it takes to administer NVS: timed data
 - c. analyze the socio-demographic associations to low health literacy levels in a diverse primary care population
 - d. examine patient perceptions related to use of NVS

Significance

The health care community, which includes primary care, operates under the assumption that provider/patient communication and collaboration produce the best patient health outcomes. For this to happen, adequate health literacy is viewed as a key factor in managing personal health (Schloman, 2004).

Numerous studies have demonstrated a relationship between low health literacy and poor health outcomes (Gordon, Hampson, Capell, & Madhok, 2002; Kirsch, Jungeblut, Jenkins, & Kolstad, 1993; Schillinger et al., 2002; and Williams et al., 1995). Within healthcare, health literacy has been referred to as a “silent crisis” (Kelly, 2003) in a field that depends on provider to patient communication for successful health outcomes. Yet the health care community has been slow to recognize the “crisis” and become part of the solution. Communication and information are the currency (Vastag, 2004) utilized within the health care

community, and providers should be encouraged to manage this currency in a fashion that builds dividends for patients in terms of better health outcomes.

Optimal health literacy supports action and decision-making by consumers. Providers are challenged to share and impart their health literacy knowledge through establishing a collaborative health promoting relationship. How providers share this information is often communicated in ways that are contextually different from the way their patients learn best. Provider assumptions of patient health literacy, and lack of cultural sensitivity, often add to existing barriers to care (Glanville, 2000).

Culture provides context to health literacy and shapes language while influencing social relations, norms, and beliefs (Freebody & Freiberg, 1997). Even within a like-culture, norms may not be in agreement. Conflicting norms may lead to failure-to-communicate and missed health promotion opportunities, impacting the provider/patient relationship. Greenburg (2001) and the Institute of Medicine (IOM) report *Health Literacy: A Prescription to End Confusion* (Nielson-Bohlman, Panzar, & Kindig, 2004) both agree that cultural belief systems are a missing element within the definition of health literacy.

What better place to begin, than examining primary care which is the entry point into the broader health care system.

The challenges that continue to face the health care community revolve around building a culturally diverse health care system; a system capable of clearly communicating with the consumer population, varieties of health promoting information through a broad, cost effective, and comprehensible

model. A health care model should resonate within the context of individuals' lived experiences.

Before changes in care delivery and communication can occur, gaining a clear picture of patient skills has been complicated by the fact that health literacy assessment tools have not been tested in the primary care settings. Previous tools were too long, or time consuming, to be administered in a practical manner within busy clinical settings. A potential tool was developed for this purpose--the *Newest Vital Sign* (NVS) (Weiss et al, 2005), which is simple, short, non-threatening and has been shown to be a reliable and valid tool to accurately assess basic health literacy skills.

As background for this study, an examination of health literacy through the educational and theoretical lens of literacy and adult education will be presented. Historical background will be provided by exploring the changing root definitions of literacy, noting the expansion of required skills beyond the ability to read and write, and the challenges presented in moving into the educational realm addressing adult learning styles. The adult learner of health information will be discussed in regards to personal and societal expectations surrounding literacy.

Health literacy does not exist within a vacuum in the health community. Elements of general literacy are embedded in this new literacy category and health literacy depends upon the fundamental supportive base of basic personal literacy skills. The evolution of basic literacy has been reported and debated extensively within disciplines regarding what fosters best practices of teaching/learning in individual skill development; so too will health literacy evolve

as the health and educational communities begin to work collaboratively.
Discussion surrounding the concept of health literacy would not be complete
without examining literacy's historic progression.

CHAPTER II

Review of the Literature

Literacy

Literacy's conceptual evolution can be interpreted through specific cultural contexts, depending on the discipline. Instead of reflecting on the singular skills of individual abilities to "read" and "write", literacy is an all encompassing term describing skills necessary to perform tasks of daily living, the workplace, technological interactions, and management of personal health while navigating the health system. Not only are literacy definitions diverse, but the required individual competency skills of the literate have proven to be difficult to quantify through current assessment methods.

A multitude of definitions exist that seek to explain literacy. Literacy, in some circles, has been defined as "the ability to decode and comprehend written language at a rudimentary level – or the ability to say written words corresponding to ordinary oral discourse and to understand them" (Kaestle, Damon-Moore, Stedman, Tinsley, & Trollinger, 1991, p. 3). An expanded definition by Hull (1993) uses the term "literacies," which are "socially constructed and embedded practices based upon cultural symbol systems and organized around beliefs about how reading and writing might, or should, be used to serve particular social and personal purposes and ends." Hull's definition gives

credence not only to personal reading and writing abilities but also to the environment in which the individual chooses to use the skills. For most adults, the ability to demonstrate skill proficiency is not enough; there must also be practical applicability to possessing skills, which then drives the desire to attain mastery. What appears to be missing in the multitude of definitions, are the alternate ways in which literacy is used to communicate and accomplish tasks of daily living.

Today, adequate literacy is generally considered to be demonstrated by the possession of the reading and writing skills needed to accomplish tasks of daily living. Graff (1987, p. 374) states, "The literate and the illiterate tend to be diametrically and dichotomously opposed; with respect not only to reading and writing, but also to a range of personal, cultural, and communicative characteristics". The illiterate or low literate, individual experiences continuous challenges in accomplishing day-to-day tasks having never mastered basic literacy skills.

Considering all the multiple definitions and the defining communities of thought using the term "literacy", health care would do well to partner with the major stakeholders to learn more about the broader implications of fostering literacy in health. As individual healthcare responsibility increases, so too do the skills needed to support sound decisions based upon a well developed literacy foundation.

Historical Review of Literacy

A historical overview of literacy can be traced through the centuries, beginning with the invention of a form of writing in 3100 BC. The development of the alphabet by the Greeks occurred in 650-550 BC, followed by the first school developments in 500-400 BC which included the beginning of a tradition of literacy for civic purposes. From 800-900 AD the Carolingian language, writing, and bureaucratic developments emerged. (Graff, 1987).

Moving forward from the year 1200, Graff (1987) describes how society experienced commercial/urban “revolutions”, literacy use expansion in administration, lay-educational development, and the rise of vernacular. In the 1300s, the classical legacies were rediscovered, and by 1450 Christian humanism and the advent of printing occurred. By 1500, mass literacy was promoted in radical Protestant areas and the spread of printing led to a growth of vernacular literatures. During the 1600s, the Swedes began a national literacy campaign. The 1700s brought the Enlightenment with its consolidation of traditions. Moving closer to contemporary literacy, the 1800s ushered in mass literacy efforts through development of schools and public/compulsory education aiming at increasing social and economic development. The 1900s progressed with mass literacy efforts in public education from primary to secondary levels and increased college opportunities. These literacy patterns are a variation on a theme and repeated throughout history. Changing literacy skill accomplishments evolved from personal mastery, leading into mass education, and then increasing involvement in the social/political arena.

The twentieth century experienced literacy growth in non-print media and technology development, setting the stage for a literacy crisis (Graff, 1987). The continued crisis is evident in the expansion of literacy definitions encompassing health, computers, world culture, and the realization that as a skill, literacy is forever evolving and impacts daily living on multiple levels. As a result, the bar has been raised in relation to personal competency and the measurement of required literacy skills. Literacy, as a concept, may be a skill that continues to evolve related to the contextual nature of society and may prove elusive to entirely quantify.

Health Systems are new members in the literacy world and are challenged to add to not only a wide body of knowledge, but also to develop best practice models that will inform providers and staff. In the meantime, health care providers should consider forging a collaborative practice and learning from the literacy community; while providing care, support, and protecting patients and their personal decision-making. Developing a relationship with the education community, especially adult education, as a referral source could strengthen patient skills and enhance decision-making.

Literacy Reporting

Historically, quantifying the number of literate individuals within a given population has proven difficult. As Western Europe expanded mass literacy education from 1600 – 1900, there are few hard data available regarding the actual numbers of literate individuals (Kaestle et al., 1991). Beginning literacy measurements relied on a personal ability to sign legal documents. With a

document signature, the basic assumption was writing and reading abilities went hand-in-hand. There has been considerable discussion around this assumption, at the same time noting literacy rate reporting was biased in favor of the upper socio-economic class and urban males. Early reporting ignored women and the lower socio-economic class, both of whom may have possessed reading but not writing skills and rarely, if ever, signed documents (Kaestle et al., 1991).

During the same time period in the United States, literacy rates were noted to be higher than Western Europe's, based on signature evidence on wills, deeds, and marriage certificates (Graff, 1987; Kaestle et al., 1991). Moving from a signature base, the 1840 U.S. Census Bureau survey measured literacy based upon self-report obtained from the head of the household regarding the number of individuals within the family(over age 20) with the ability to read and write. Muddying the report were the individuals who reported themselves as illiterate in writing but not reading (believing one skill better than the other). By 1870, in an attempt to clear up the inconsistencies in reporting, the survey queried the household regarding the native language reading and writing abilities of all family members over the age of 10. Reported literacy levels for 1870 were lower than those of 1860, translating into number of illiterate individuals reported as 8.3% in 1860 and 20% in 1870 (Gordon & Gordon, 2003). Self report provided a look at the general literacy level of the population but not individual capabilities.

As history so aptly demonstrates, measuring and reporting literacy is difficult .It is no wonder healthcare struggles to explore the impact of health

literacy as a measurable skill, mediator, and/or moderator influencing provider and patient decisions and care.

Socio-Historical Role of Literacy

Described previously, the process of literacy has evolved from spoken word to written symbolism/script, to print, and is currently evolving in a rapidly expanding technological arena (i.e. electronic medical records, text messaging, online education, etc.). How this has been reflected in U.S. society can be examined through a historical review of the efforts to provide literacy education.

Kaestle et al. (1991) writes regarding the family home, whose role for centuries has been influenced by the Protestant church and given the responsibility to initiate, and support, children's education. Parents' verbal interactions with the child soon led to teaching the rudimentary skills of reading and writing. In turn, the child mirrored the parents' literacy level and aspects of the home community culture.

One of the most successful Protestant literacy education models was implemented in Sweden in the 1600s. Through a home and church model, with the church primary within the system, the country launched a successful reading initiative. The parish clergy would visit each home, assess the ability of the family members to read the catechism, and record the results in detailed written records. The educational objective was to have a pious, civil, orderly, and militarily prepared population. The effort produced a large number of literate individuals and was considered an overall success. (Graff, 1987).

The Puritans brought to the United States a strong literacy heritage fashioned by European events. They were dedicated to maintaining literacy through the linkage to their religious roots, as many of the men were university educated and held leadership positions within the church. The church assumed the lead in providing organized education to the new citizens as they faced the difficulties of settlement. Based upon the tenants of the church, the responsibility of education fell to the family, primarily the father assisted by the mother. The father's commitment, as head of household, was further reinforced and validated by Massachusetts law in 1642 (Gordon & Gordon, 2003). Guided by textbooks from England such as *A Godly Form of Household Government* (Cleaver, 1568), most households assumed the responsibility of educating their children. Support and follow-up by clergy were lacking in this model, leaving the head of house alone to ascertain literacy skill accomplishments of the family.

When families failed to fulfill their obligation to educate their children, the General Court of Massachusetts in 1647 enacted the "Old Deluder of Satan Act" (Orlich, 1979), which required communities of one hundred or more households to establish a grammar school. The Act held to the belief Satan worked through the lack of literacy, preventing the protection knowledge of scriptures provided; those able to read the scriptures could repel Satan (Gordon & Gordon, 2003). Though not all communities complied, it was the beginning of mandatory school provision. In the meantime, most children continued to be taught in the home by family or, if wealthy enough, by tutors.

Alternate means of education continued to evolve in the 1600-1700s in the forms of “Dame” schools run by literate, but untutored housewives in their homes. In contrast, some children attended grammar schools which were taught by cultured university graduates seeking sites on which to set up a makeshift classroom(i.e., stores, barns, churches) (Gordon & Gordon, 2003). When dedicated school buildings did exist, they were under the jurisdiction of the local government; but often parochial in nature, supported by the church, and requiring tuition. Another barrier to widespread school development was the largely scattered nature of the population, prohibiting the ability to centralize a place of education. The only exceptions were the establishment of centers of higher education for clergy and professional schools (e.g., Harvard in 1636 and Yale in 1701) (Gordon & Gordon, 2003).

In 1866, the Massachusetts courts defined “public” schools as institutions; school requirements were: “supported by general taxation, open to all free of expense, and under the immediate control and superintendence of agents appointed by the voters of each town and city” (Gordon & Gordon, 2003, p.263). Compulsory school attendance laws were developed by each state between 1852 –1918 but did little to provide equitable education to all U.S. citizens. School access was difficult for many children and preventing their attendance were geographical barriers, socioeconomic inequities, race, and gender.

During the 1900s the role of U.S. literacy education was considered an opportunity to liberate the citizens, through social justice and economic productivity (Graff, 1987). As was promoted many years previously in France, a

literate society would produce citizens with a common core of morality, patriotism, and knowledge. Unfortunately, the disenfranchised poor, ethnic minorities, immigrants, and women were often not able to fully realize the opportunities of a full education. Even when educated, these groups did not reap the economic benefits promised. Attaining literacy did not translate directly into observable social or economic mobility.

The history of education systems indicates health care must be cautious with health literacy and the expectations placed on skill set. As has been seen in the education domain, literacy is not the panacea for solving all of society's ills and is but a piece of the puzzle. Health literacy too is a puzzle piece to a much larger picture of a healthy nation.

Literacy Education

As schools began to educate larger portions of the population the classic methods utilized mirrored those of Europe. Children began with the pronunciation of alphabet letters and moved on to syllables; correct pronunciation was the goal, not comprehension (Graff, 1987; Resnick & Resnick, 1977). The next development was the method of whole word recognition which was promoted as an alternate way to learn the alphabet and spelling. Unfortunately, while oral reading fluency increased, comprehension did not.

According to Resnick and Resnick (1977) a call came in 1836 for teachers to use a curriculum involving the reader in learning the meaning of words to increase comprehension. While this call raised awareness, little change occurred until fifty years later when the sentence method of reading was promoted, again

intending to increase comprehension. Mastery of reading was considered comparable to oral language, the only difference was that comprehension was gained through text vs. speech; yet the methods taught to gain reading skills did not confer comprehension ability to all (Pearson & Stephens, 1994). As attention to refining reading skills continued, it was noted in the 1890s that “school reading” was also a way to promote the homogenization of speech and the elimination of the heterogeneity of class and superficial cultural distinctions (Graff, 1987).

Not until the twentieth century did a child-centered pedagogy of education evolve. In standardized testing of Army recruits in 1918, thirty percent were found to be unable to take even the test designated for the non-literate (Resnick & Resnick, 1977) though all had received reading education. The time was ripe to develop a new educational philosophy and Dewey and Dewey (1915) were ready to respond to the challenge. John Dewey drew his educational philosophy from the disciplines of experimental science, child psychology, evolutionary theory and American pragmatic moral theory. As a member of the Progressive movement, Dewey viewed American education as an opportunity for social evolution (de Castell & Luke, 1983/1994). Teachers were trained to consider their classrooms as learning environments and to eliminate the rote lessons of the past.

Again using a population that was easy to test, a significant number of military enlistees during WWII demonstrated a lack of reading ability to understand instructions, even at a “functional” literacy level of fourth to fifth grade

(Kaestle et al., 1991). Even with changes in educational delivery, improvement was slow to occur. With the advent of the Atomic Age, the U.S. government felt that it was unacceptable to have a population unable to keep pace with the advances of science. The educational system was challenged to address the continuing literacy deficit.

De Castell and Luke (1983/1994) cite how progressive, “child-centered” curriculums were replaced by a “technocratic” model based upon scientific principles. Kuhn (1962) wrote that this was science in the best textbook tradition. The goal was to instruct in a manner that was testable using the stimulus/response model of behavioral psychology. Curricula were packaged into standardized systems of instruction with behavioral objectives. The acquisition of basic reading skills was seen as an end point, only later to be supplemented with writing skills at secondary levels of education. If there is to be a pre-paradigm period, as espoused by Kuhn (1962), it would begin during the twentieth century and be led predominantly by the behavioral psychologists.

During the 1950’s Rudolf Flesch challenged the educational establishment to return to the basics of phonics to teach reading. His book, *Why Johnny Can’t Read* (1955), advocated phonics (sounding out words) with the abandonment of the “look/say” (memorization) method of reading. Flesch was a proponent of *Plain Language* (Flesch, 1972) and during his lifetime published numerous articles and books supporting a clearer form of communication in all walks of life. Today we use the Flesch-Kincaid Readability Test (included in computer

software) to assess for appropriate reading level of educational information (Kincaid, Kincaid, Thomas, Lang, & Kniffen, 1990).

The 1960s saw a return to the consideration of progressivism in the schools (de Castell & Luke, 1983/1994) in addition to looking at culture. Since then, a blending of approaches has occurred influenced by multiple domains: psychology, linguistics, sociology, anthropology, and education. What does this mean to literacy instruction? Quickly translated, it means that the theoretical underpinnings of literacy instruction have the advantage of multiple views. The downside is that this approach can lead to conflict in what constitutes best practice.

Pearson and Stephens (1994) wrap up the 1960s and continue onward, writing that reading education began a time of paradigm development guided by multiple theoretical models. Prior to the 1960's, reading was considered perceptual, requiring the brain to process text as a language and translate. An educator need only the teach skills necessary to decode the written word into oral sounds, as evidenced through phonics and whole word instruction. Easy as that was to understand, reading and comprehension are much more complex. Various disciplines have devoted many research hours to addressing the complexities of literacy. It is no wonder that with the advent of new literacy foci, such as health, the need for research continues. Following is an overview of the various theoretical bases and models of literacy.

Theories of Literacy

A historical overview detailing how the reading process caught the attention of scholars from a variety of fields is provided by Pearson and Stephens (1994). A successful individual was felt to be a literate individual.

Linguistics

Linguistics entered the literacy arena early, with beginning reading programs emphasizing word recognition over comprehension. Research interest was based on how language is formed and distributed through phonemes (minimal sound units of speech affecting word meaning) and morphemes (meaningful linguistic units that cannot be divided into smaller meaningful elements) (Smith, 2002). The transformational-generative grammar theory placed linguist, Noam Chomsky (1957, 1965), in the forefront of this field. His theory provided four main insights into how humans learn to read. First, all literate peoples have a form of written representation for their oral language. Second, written language does not have to contain things we normally infer through normal speech or writing; our experience in speaking provides us with a natural pronunciation of sounds (i.e., “ed” vs. “d”). Third, comprehension of language is more than the ability to string together words. And lastly, humans are born with an innate ability to understand and speak proficiently the language of their native culture (Pearson & Stephens, 1994). The linguists challenged the behaviorist method of education and questioned the teaching methods currently in use, encouraging teachers to consider the cultural context of language.

Psycholinguistic Theory

The psycholinguists, using the work of the linguists, explored the issue of whether linguistic findings regarding language comprehension and acquisition could be used in psychological models. The comprehension group developed a derivational theory of complexity, which even though later abandoned, continues to involve psychologists in the study of literacy through the use of complex theoretical tools. Psycholinguistic theory stated that comprehension involves a number of grammatical transformations involving a structural change within the sentence (passive to active voice or switching clauses to move to a complex sentence). The transformations are needed to move from the surface structure (speech or writing appearance), to the deep structure (hypothesized sentence form encoded in memory), and finally, to become an index of the language user's difficulty in their understanding of the sentence. Lasting a decade, this theory was followed by more complex theories and research and in turn replaced the simple elegance of the derivational model (Pearson & Stephens, 1994).

The psycholinguistic language acquisition group discovered that children were not innate learners but instead were able to create rules for language through active learning. This concept leads to questions around the structure of instructional change needed to foster this type of learning, where reading would mirror language acquisition. Rising to the challenge, Goodman and Smith (1971) found that children work at making sense of words when reading and do better when the words are presented in context. Researchers equated missed words with missed cues, rather than a mistake, and when cues are heeded they help

the reader to predict what will occur. Additionally, Pearson and Stephens (1994, p.28) reports "...reading was not something one was taught, but rather was something one *learned* to do". As a result, teachers were assigned the role of assisting in the learning process versus teaching.

There were four main points regarding reading, that evolved from the psycholinguists group. First, literacy experiences which focus on making meaning should be valued. Second, the value of texts should be promoted with emerging readers that placed value on natural language patterns, supporting existing knowledge of language to predict words and their meaning. Third, psycholinguists provided support to understanding children's efforts to read and the process required. Lastly, an understanding of how children use missed cues as part of a constructive process of reading, provided clear links between oral and written language acquisition (Pearson & Stephens, 1994). Teaching and learning were seen as different entities within the classroom; especially, related to teaching and learning interactions producing successful reading outcomes for students.

Cognitive Psychology

Within the field of psychology, multiple paradigms arose. While linguists and psycholinguists provided an antagonistic dialectic to behaviorism, following closely behind were the cognitive psychologists. This group began to examine psychological phenomena in terms of human perception, comprehension, memory, and executive control of cognitive processes (Pearson & Stephens, 1994). The preceding years of behavioral-focused research gave way to the

cognitive psychologists who centered on reading as a basic process. Schema theory (structured knowledge represented by memory) was generated by the cognitive psychologists. The theory is useful in describing reading comprehension by using schemata (the experiences of an individual) which are stored in areas of memory for later retrieval (Pearson & Stephens, 1994). These memory areas have relational value and schemata are identified as a type of experience accumulation. When the reader encounters an anomaly while reading, that experience results in progression to another level. At times, a whole new discovery may occur requiring a reorganization of the schema. Kuhn (1962) might view this process as the creation of a personal paradigm: pre- paradigm knowledge represented by a schema, appearance of an anomaly, restructuring of the original schema (revolution) to produce a new schemata (paradigm). The development of schema theory is important when considering the existing knowledge and cultural backgrounds of students and in relation to evaluating the connections they made between text ideas and personal representational thought. Enhanced comprehension leads to thoughtful and insightful students.

Sociolinguistic Theory

Sociolinguists and psycholinguistics were hard at work, at the same time, from a slightly different perspective (Pearson & Stephens, 1994). The sociolinguists were concerned with the issues of literacy within the realms of dialect and reading. In addition, they noted that each dialect contained a well-established unique linguistic system complete with rules and paths for learning. They felt that teaching reading should not be done to eradicate the dialect of the

students but to recognize it as a difference versus a deficit; a far cry from the cultural valuation of classroom homogenization. During the 1960s, texts were written in different dialect and reading was postponed until oral language was standardized. As the child acquired standard language skills, reading in dialect was instituted and the act of translation was recognized, with credit given to the child with a different dialect. Dialectical reading instruction has had a lasting impact, but not always broad support.

The interpretation of textual context was an area of interest to sociolinguists. The meaning of print on a page has the ability to evolve and expand in definition influencing instructional, non-instructional, home, and community contexts of literacy. Sociolinguists support the idea that reading is always accomplished within a context, shaping both the literacy event and the broader social event. Language assists with learning what to know, and being changed by the knowing.

During the sociolinguistic time, reading began to be viewed as a social process with associated behaviors that are learned, requiring interpretation within the context of the situation (Pearson & Stephens, 1994). Language and knowledge are viewed as a constructive process by sociolinguists, cognitive psychologists and psycholinguists. Similar views lead to a shared set of standards for curriculum but debate continues regarding the way to structure the curriculum experiences. Each discipline has a stake in dictating the delivery of their theoretical model, causing ongoing friction but also, an opportunity for cooperative programming.

Meta-cognitive Theory

Meta-cognitive theory takes cognitive theory to a different level and involves additional dimensions. The reader must have knowledge, or awareness, of their own cognitive process or ability to comprehend. The reader must understand the reasons for reading, the scope of the task, possess awareness of reading strategies, believe they are useful, and know how to use them to attain their goal. Lastly, an awareness of personal comprehension is needed to be able to generate plans to increase this skill (Swafford, 2002). Expert readers are thought to be able to tap into the meta-cognitive dimensions of literacy. In the 1980s, educational instruction turned to programs aimed at teaching these strategies (predicting, generating a question, summarizing, and clarifying difficult parts of a text) used by expert readers. One successful program was called Reciprocal Teaching (Palincsar & Brown, 1984) and used the technique of scaffolding. With scaffolding, each skill is strategically taught beginning with teacher instruction and progressing to the point of relinquishing control to the student as they master the strategies. The scaffolding technique is time consuming, needs reinforcement, and requires changes in text and task throughout the school years. Today, this model is found in the “Success for All” (Success for All Foundation, 1987) curriculum used in many schools. The amount of time and effort required are felt to be justified by the reported high literacy levels of the students.

Transactional Theory

More recently a philosophical influence has been introduced into the already multidisciplinary paradigmatic mix. Rosenblatt (1994) promoted a “transactional” theory of reading and writing based upon her expertise in English and comparative literature. Calling her theory explicitly “a new paradigm”, in the spirit of Kuhn (1962), it required a decidedly different approach to understanding reading. Drawing on the epistemology of John Dewey, Rosenblatt chose to use the term “transactional” to her view bringing the knower, the knowing and the known all into one process. Human beings and their environment are continuously in transaction with the fusion of culture and natural elements. Within the literacy realm, the transaction is between the reading act (an event) and the text (seen as a particular pattern of signs), occurring at a certain time, within a particular context, and creating a dynamic situation – comprehension. The meaning of the transaction is thought to be above the reader-text plane, neither objective nor subjective (Pearson & Stephens, 1994). While having the advantage of including culture, this theory is more philosophical and less applicable than others.

Critical Theory

Critical theorists round out the philosophical realm and propose to raise the consciousness of the literacy community by presenting insight into how past political decisions influenced the creation of the “present.” Examples include: 1) the encouragement of women, based upon temperament, to teach; only later to be requested to abandon that temperament and concentrate on pure knowledge

transmission, and 2) using literacy to promote moralism and nationalism many times over the centuries. (Pearson & Stephens, 1994)

According to Kuhn (1962), each successive paradigm developed is usually preceded by a revolution, leading to a shift. What happened, and continues to happen, within the literacy arena is the development of multiple paradigms by different, yet similar, disciplines. Whereas the psychologists have dominated the field, they have not emerged as the only science in education. They are joined by the health sciences adding yet another dimension.

Considering the possibility of applying the previous theories to health literacy, it is interesting to note that while the focus has been on education, and there is credence given to the contextual nature of literacy, personal health (mental or physical) has not been explored. This gap is especially evident when considering the multiple instances of health education infused into activities of daily living: health care visits, hospitalizations, public health messages, self-care classes, and prevention of disease, to name a few.

In summarizing the previous scholarly works, it serves well to consider each domain not only from a pure literacy education perspective but also from the broader view of the contextual pieces of adult life, including personal health. Linguists focused on language acquisition and use. Much debate in health care focuses on communication skills and the decoding of health information. What constitutes meaningful conversation is situated within individually learned skills and experiences, which may differ markedly from the health care provider. The psycholinguist would impart that health is a complex concept and for those with

low literacy skills this will prove to be a challenge. An individual may lose the essence of a health concept, if the material is presented, or written, in a word familiar approach eliminating the complex grammar needed to fully cover the topic; this is an issue discussed by Baker (2006) in *The Meaning and the Measure of Health Literacy*. Yet if collaborative partnerships between education and health care existed, the individual would have the literacy skills necessary to incorporate health information into their life.

The cognitive psychology domain and use of schemas have value in the field of health education. If the health information triggers a memory within the individual, and has cultural significance, the targeted health behavior has a much better chance of integration into an individual health plan. Research would be needed to validate if this process is best with written text or if verbal instruction would also work with schemas.

While of value in the educational community, the areas of meta-cognition, transactional, and critical theory are difficult to apply to the health literacy arena. All three impact a higher level of functioning and skill than is possible with a significant number of those seeking health care.

Theories of literacy have primarily focused on teaching reading skills and what skills the reader brought to the process or could learn. In conclusion, Pearson and Stephens (1994, p. 39) state, "...we wonder if, in the process of developing a 'science' of education and educational research, we have contrived a way of 'doing school' that bears little resemblance to the real learning and teaching that motivated human societies to create schools in the first place".

Literacy education has demonstrated it does not fit into a neat singular paradigm. Perhaps human nature provides us with a continuing ultimate puzzle (Kuhn, 1962).

Literacy and Measurement

Historically, adult literacy has received national attention only when a crisis presents (i.e. Army recruits who could not read basic instructions in 1918 and 1945) (Graff, 1987), National Adult Literacy Survey (National Center for Education Statistics, 1992), and the Workforce Investment Act (1998). Each time, a means to measure literacy was required and the outcomes encouraged action from the educational community to remedy. Finding the best literacy measurement, and how best to address the findings, has proven challenging.

In 1992, the National Adult Literacy Survey (NALS) adopted the following definition of literacy, “Using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” (National Center for Education Statistics, 1992). Fullness to the concept of literacy is absent in the NALS definition. Literacy transcends the written word and is embedded in the culture of the individual. Literacy’s definition can be further expanded through the use of speech, thought, world perceptions, community, and group interaction. All sectors involve changes in individual communication patterns and perceptions, and a variety of personal interactions (Akinnsaso, 1991, Brandt, 2001, & Heath, 1983).

The NALS was considered a landmark study and estimated that approximately 21-23 percent of the adult population, more than 40 million

Americans over the age of 16, had only rudimentary reading and writing skills, categorized as “level one”, with a subgroup (4 percent or 8 million people) unable to perform even the simplest literacy tasks (Kirsch et al., 1993). Fifty million more people (25-28 percent) scored in the second lowest level. The resulting total of 90 million individuals scoring below the minimum standard of Level III was alarming to educators and politicians alike.

The NALS was an attempt to obtain a detailed quantitative snapshot of the literacy skills of the population at large. The 1992 NALS measured literacy proficiency in three basic areas: prose, document, and quantitative (PDQ). The NALS assessed everyday literacy encounters i.e., newspaper articles, maps, personal information forms, and graphic/mathematical interpretation, which are reflective of adults’ knowledge and skills in activities of daily living (Smith & Reder, 1998). Literacy proficiency was reflected in scores ranging from Level I (lowest) to Level 5 (highest). Of interest in the final data, there was self report of adequate literacy skills, versus deficits, by individuals in the two lowest scoring levels.

Although the development of the NALS included survey opportunities to demonstrate the use of literacy in materials encountered through activities of daily living, it is administered with the assumption that these are contextually based uses of literacy occurring in the general population. “General literacy” as a hierarchal factor is a term presented by Smith and Reder (1998) when discussing the discriminant validity of the NALS. While the NALS was developed to represent a measure of general literacy in the three categories of prose,

document, and quantitative (PDQ), there is no individual specificity to the tool, and reports are generated in the aggregate. When the general literacy factor is emphasized by category, many of the questions are observed to contain skills present in one or both of the other two categories. For example, one must read the question (prose) related to calculating a checking account balance (quantitative) and interpret documents (check and ledger) (Smith & Reder, 1998). In ninety minutes of time, the ability to truly capture individual literacy nuances and capabilities is impossible. Upon a review of the literature, the researcher was unable to find a literacy assessment (general or health-based) that captures the full contextual aspects of an individual's abilities.

Concerns arose regarding the scoring and meaning of the five levels of NALS. Some critics have complained that Levels I and II have a disproportionate number of individuals, and the defining characteristics do not take in to consideration the context of material used (checkbook samples if you have never had a checking account) or the ability of individuals to be able to meet a portion, but not all, of the criteria in the next level (Comings, Reder, & Sum, 2001). If the NALS cannot separate out the category requirements of competency clearly, how reliable are the data in the final report?

Changes to the NALS, now entitled National Assessment of Adult Literacy (NAAL), for 2003 are significant (National Center for Education Statistics, 2006). Context specific questions were added regarding health literacy, as well as adding two new components related to basic reading processes. The Fluency Addition to NAAL (FAN) assesses adult ability to decode and recognize words,

and read fluently, utilizing speech recognition software. The Adult Literacy Supplemental Assessment (ALSA) will be utilized with the least literate, to assess reading and comprehension of simple prose. If an individual scores above the ALSA cutoff point, they will continue on to the main NALS. It is anticipated that this new process will help to distinguish the number of individuals in Level I who are low literate and minimally literate/illiterate. Again though, individual perceptions of literacy may be disparate to reported results if individuals function well within the contexts of their literacy skills. Concern has been voiced as to when to offer remediation, or augmentation, to those with low literacy skills. Additionally, there is question to the measure of adequate literacy skills when skills for accomplishing personal and occupational endeavors are unknown (Kirsch et al, 1993).

Unfortunately, results from the 2003 NAAL reported nearly flat scores after a decade of work. Receiving the reported minimal change in results, the educational community has commented that there is continued opportunity for interdisciplinary efforts to combat low literacy (Kirsch et al, 1993).

The Basic English Skills Test (BEST) (Center for Applied Linguistics, 2004) is utilized in English as Second Language (ESL) populations. Using real life examples, the assessment measures 1) oral listening comprehension, pronunciation, fluency, and speaking skills, 2) reading skills, and 3) writing skills. BEST is an accepted tool used by educators for placement in programs and by workplaces as a pre-employment screening assessment of language and reading.

skills. BEST measurements capture the English proficiency of literacy skills, but do not quantify the skills individuals possess in their native language. A highly educated professional with limited English skills could very well score low on this test, which in no way demonstrates their full capability and ignores socio-cultural background. Literacy may also be measured by other assessments such as the Wide Range Achievement Test (WRAT) which asks an individual to read from a 100 word list. After three missed words, an estimated literacy level can be calculated (Quirk, 2000).

While most assessments validate literacy level corresponding to a grade level, or acknowledge minimal accomplishment, they do not provide a view of the multiple personal literacies and contextual uses occurring daily. Literacy competency has been assumed with the attainment of a high school or college diploma (Graff, 1987), but as assessments have shown (Kirsch et al., 1993), this is not always true. Measuring the accomplishments and skills of a small business owner who cannot read, or write, but has built a successful business is not possible. Additionally, the single mother who reads at grade 4 level, worked to support her family, and raised three children who obtained college degrees is hard to classify through the general measurements currently available.

Reports on literacy capability and attainment continue to illustrate the ongoing reliance on measuring reading ability primarily, and writing, comprehension, numeracy, and listening tangentially. Individual adult learners are increasingly required to enhance their personal literacy skills, educators and evaluators are challenged to develop educational methods and assessment tools

that address the myriad skills noted in the multiple definitions of literacy and acknowledge the contextual and cultural knowledge adult learners possess.

Literacy, as a concept, has become more expansive and includes more than just reading and writing skills. The question arises as to whether to measure literacy as a basic skill, or as a culturally based means of communication.

Ferdman (1991) believes, “individuals’ experience and exhibit culture through behaviors, values, beliefs, and norms corresponding to their culture and with ethnic group identification.

Literacy and Public Policy

Public policy has historically driven literacy agendas. Earlier in U.S. history, legal acts and laws were passed requiring literacy education of children by parents, grammar school establishment in towns with over 100 in population to support the reading of scripture in response to the “Old Deluder of Satan Act” (Records of the Governor and Company of the Massachusetts Bay in New England, 1853) and compulsory school attendance (Kaestle et al., 1991). More recently, the National Literacy Act of 1991 (National Institute for Literacy, 2008) and the No Child Left Behind Act of 2001 (U.S. Department of Education, 2008) are impacting literacy through new calls for accountability and research-based initiatives.

The National Literacy Act of 1991 (National Institute for Literacy, 2008) was enacted, “To enhance the literacy and basic skills of adults, to ensure that all adults in the United States acquire the basic skills necessary to function effectively and achieve the greatest possible opportunity in their work and in their

lives, and to strengthen and coordinate adult literacy programs”. Evolving from this act was the National Institute for Literacy (NIFL) which is administered by the Secretaries of Education, Labor, Health, and Human Services to improve the quality of literacy programs nationwide through the development and support of literacy programs and services (National Institute for Literacy, 2008). The NIFL is one example of a recent collaborative to address literacy from multiple fronts.

One initiative supported by the National Institute for Literacy is the “Equipped for the Future” (EFF). (Equipped for the Future Assessment Consortium, 2005), targeting the elimination of adult illiteracy by year 2000. While not reaching the year 2000 goal, EFF has persevered and developed 16 standards for adult education divided into four categories: communication skills, decision-making skills, interpersonal skills, and lifelong skills. An added connection coordinates the EFF standards (Equipped for the Future Consortium) with five of the standards that are central to Title II of the Workforce Investment Act (1998). The connection between these two programs is a positive step towards building stronger initiatives focused on outcomes.

The Adult Education and Family Literacy Act (Workforce Investment Act, 1998) defines literacy as “an individual’s ability to read, write, and speak in English, compute, and solve problems at levels of proficiency necessary to function on the job, in the family of the individual, and in society”. This definition cites the importance of basic reading and writing skills, with the addition of English and math proficiency requirements. At an immediate disadvantage with this definition are immigrants enrolled in English as a Second Language

program. It has been noted that this group scored disproportionately low on the NALS due to a lack of English fluency or was considered illiterate.

Adult education accountability measurement standards became a part of Federal welfare reform initiatives through the Workforce Investment Act (1998). Within the initiative are requirements to streamline the process of workforce placement and link workforce and adult basic education. “One Stop Shopping” is the mantra used to promote opportunities for individuals to gain skills, support, and work placement all in one location. The most contentious part of this bill was the placement of adult literacy education funding under the umbrella of workforce development while eliminating the targeted funding it had previously enjoyed. The concern voiced was that education funding is more vulnerable than funding which targets job placement.

The basic education skills needed for employment now face increasing accountability as they relate to adult basic education and outcome measures. As a result, there are efforts to standardize adult education programs and report literacy outcomes. The ultimate goal of the Workforce Investment Act (1998) is to have fewer welfare recipients, higher numbers of employed adults, and an educated workforce capable of competing in a global market. Positive outcome measurements are based upon educational attainment (diploma/Graduate Education Degree -GED), employment, and personal empowerment to pursue employment or education (National Institute for Literacy, 2008). Again, the concern arises that a high school diploma is regarded as equivalent to basic literacy; they are two different measurements.

Through the EFF initiative there has been a methodical, interdisciplinary, research-based effort to develop adult education and literacy-based standards, develop educational and prototype assessment tools (“Read with Understanding”), and guidance to policymakers and practitioners surrounding the use of standards and assessments (Equipped For the Future Assessment Consortium, 2005). Even with the emphasis on workforce readiness, acknowledging the development of skills relevant to life experiences is a positive step and should not be lost on policymakers and program funders supporting adult learners.

Adult literacy education and adult basic education (ABE) are terms that are often used interchangeably (Belzer & St. Clair, 2003). While educators toil to define concepts, structure educational programs to promote the attainment of competency, and measure outcomes, the adult student remains mired, with little voice, in an evolving system of education. With distinct needs and learning styles, the adult student is often short-changed in the rush to provide “basic skills”. The educational system is struggling to find an approach that builds upon existing personal foundational life skills, which as mirrored within the Health System.

The previous overview illustrates the complexity of literacy. As a nation, we are struggling to develop a citizenry with a broad skill set for a rapidly changing world landscape. To compound the issue, the health care system is changing in many ways that adds to the individual’s burden by requiring increased self care dependent on a new set of literacy skills – health literacy.

Health Literacy

Health literacy is a relative newcomer to the literacy arena and was first reported in 1974 by Simonds, who discussed the broad impact of health education on multiple systems (health, education, and communication) by using the term “health literacy”. Since that time, health literacy has been recognized as a significant factor influencing health and the research base has continued to expand. Over the past ten years there has been an increased interest fueled by research initiatives and funding.

Data from the IOM health literacy report (Nielsen-Bohlman et al., 2004) revealed that 90 million Americans experience problems processing health information and those with low literacy skills experience higher rates of hospitalizations (Baker, Parker, & Clark, 1998), greater utilization of emergency services, poorer health, lower health status (Weiss, Hart, McGee, & D’Estelle, 1991), and barriers to seeking prevention services (Bennett et al., 1998). Almost half of the individuals in the U.S. are represented by the two lowest literacy categories.

Health literacy is a unique style of literacy practiced by health professionals and consumers of healthcare. The impact of health literacy is experienced not only in personal health issues but in the way the health information and care is delivered. Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health & Human Services, 2000). At this point, it

becomes clearer that health literacy includes multiple individual skills, impacting personal health in a variety of ways, throughout various points of life. Adult literacy expands holistically as a concept when defined through the health literacy lens. Using the Institute of Medicine's *Health Literacy Framework* (Figure 1), the following review will highlight different health contexts within health literacy.

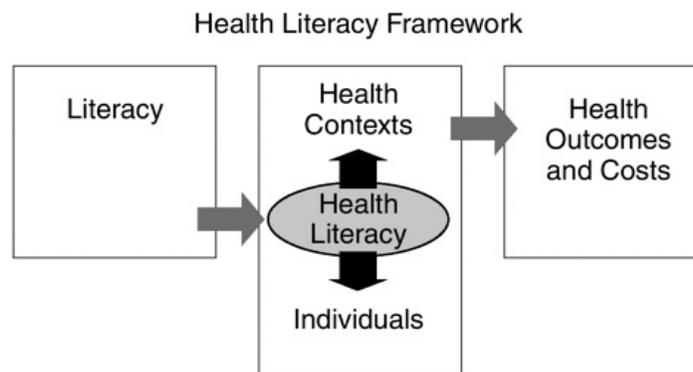


Figure 2.1

Health Literacy: A Prescription to End Confusion (2004). Health literacy potential interventions points, page 33

As previously discussed, basic literacy is composed of many individual and societal contextual pieces which influence the attainment of a personal skill set. As literacy moves into the health literacy framework, it is transformed by a new set of contexts (health) and the individual with an acquired skill set of skills to form a new type of literacy – health literacy. A brief overview is provided on this new field of health literacy in the following sections.

Historical Review of Health Literacy

While the field of health literacy is thought to have begun in 1974 (Simonds), it actually may have existed much earlier. Looking back in history, a multifaceted picture of marketing and educational efforts aimed at the general

public began around the time of patent medicine sales. The traveling medicine show and the oral sales pitch was replaced by print advertising with the advent of the printing press in the mid 17th century. During the 19th century, many individuals sought relief for a variety of health complaints from bottled medications that promised miracle curative powers. Most of these products were marketed via fancy bottling and catchy phrases. A certain amount of personal literacy was assumed, in order to sell the goods of the day and play on public interest regarding personal health care and thus, avoidance of unreliable medical care (Zarcadoolas, Pleasant, & Greer, 2006).

In the early 20th century mass public health campaigns were waged to combat tuberculosis and polio, through education regarding personal hygiene and activities to halt the spread of disease. Evolving during this period was the National Lung Association and the March of Dimes whose efforts contributed to the control of TB and polio (Zarcadoolas et al., 2006). These two organizations, and the public health service, employed a variety of marketing methods targeting the public and professional communities, and providing health promotion/disease prevention education through posters, brochures, presentations, and programs. The educational efforts proved to be reliable and effective, but still left opportunity for expansion and refinement.

In the 1950s, about the same time Flesch published *Why Johnny Can't Read*, the health community became aware that persons with low education skills and those from other cultural groups, or countries, had different needs not addressed by the current health care processes (Shohet, 2004). While literacy

was not targeted specifically, it was observed that there were populations requiring a different approach to care. As healthcare evolved, so too did the complexity of care and the means to effectively communicate health information in a standardized fashion.

In the 1970s, the health community was not yet aware of the observation that “plain language” (Flesch, 1972) was the best approach to sharing health information with the public at large. An early article explored consumer understanding of dietary information and found that “American consumers are not equipped by prior training to effectively interpret and use nutrition information” (Jacoby, Chestnut, & Silberman, 1977). Though the term health literacy was never used, this study highlighted the fact that even if the consumer could read, there was a lack of ability to understand and use the information for personal benefit. The authors called upon the educational system to improve and better prepare consumers. The health establishment was not held accountable to do more than alert educators of a problem, with the hope the deficit would be addressed by the educational community. No recommendation was made that clearer communication on the part of the health care community would be beneficial.

Rudd, Moeykens, and Colton (1999) reviewed the literature for articles targeted at health literacy from 1970 – 1999. Published literature illustrated a growing interest in this new field with eleven articles in the 1970s, thirty-seven in the 1980s, and more than two-hundred in the 1990s (Shohet, 2004). The majority of the articles were focused on reading ability, and comprehension, in

regard to adherence/compliance to medically prescribed care and encounters. In later articles, a movement had begun toward studying literacy skills and health outcomes.

Since the 1990s, health literacy research has predominately focused on measuring reading skills and correlating results to disease management (Baker et al., 2002; Bennett et al., 1998; Fortenberry et al., 2001; Kalichman, Ramachandran, & Catz, 1999; Schillinger et al., 2002; Shea et al., 2003; and Williams et al., 1998). Few studies have focused on examining health literacy from a health promotion, or disease prevention, perspective (Arnold et al., 2001; Brez & Taylor, 1997; Kaufman, Skipper, Small, & McGrew, 2001; and Lindau et al., 2002).

Health literacy is imbedded in activities of daily living: knowledge acquisition, communication, and power leverage. Certain groups such as the elderly, those with less schooling, and individuals of certain racial or ethnic groups exhibit lower overall literacy skills: (Kirsch et al., 1993). Other factors shown to be associated with low literacy include: living in the South or Northeast, being female, having an income status of poor or near poor, and a personal history of incarceration (Weiss & Palmer, 2004). The aforementioned are just a snapshot of the diverse groups of individuals accessing healthcare services at different points within the system. As the health system raises expectations of increased personal patient involvement in care, so too should providers increase their awareness of the individual skills, culture, and life experiences influencing health literacy and communicate accordingly.

Health Literacy Assessments

Education level has not proven to be a reliable indicator of reading ability but does influence health outcomes in relation to social deprivation (Foltz & Sullivan, 1996). The level of education attained does not reflect realistic reading skill capabilities, which are often three to five years lower than last grade completed (Doak, Doak, & Root, 1996). Schwartzberg, VanGeest, and Wang (2005) point out that reliance on reported education level results in overestimating individual skill level. Yet, educational level is often used to qualify personal ability to understand and act on health information and is often collected as a part of the health history.

Based upon the IOM report (Nielsen-Bohlman et al., 2004) which stated functional literacy is more than reading ability and it becomes imperative to patient safety that healthcare providers direct their attention to the assessment of individual health literacy capacities and how best to communicate within a common language. Providers are reluctant to screen their patients for a variety of reasons: exacerbating feelings of shame, under-estimation/denial of a health literacy problem within the practice, time constraints, or lack of training regarding what to do with the knowledge (Bass, Wilson, Griffith, & Barnett, 2002; Marcus, 2006; and VanGeest & Cummins, 2003).

While health systems and providers have received mandates to provide linguistically and culturally sensitive health information, the tools to meet the mandates have not been forthcoming from any level of healthcare empowered with quality oversight (Calderon & Beltran, 2004). Until recently, tools used to

measure health literacy had drawbacks for adaptation in the clinical setting. They were often lengthy (Test of Functional Health Literacy in Adults, or TOFHLA) and/or they measured literacy in a limited way, primarily evaluating reading ability only (Rapid Estimate of Adult Literacy in Medicine, or REALM). In the ambulatory care setting, a tool must be time efficient, easy to administer, and address the broader areas of health literacy such as reading ability, numeracy skills, and problem solving.

The knowledge provided by numerous studies, has led to an increase in health provider awareness and education. The American Medical Association has promoted an informational program and kit to practitioners emphasizing assessment of health literacy and the use of “living room” language in communicating to patients (American Medical Association Foundation, 2003). In the past few years, the Michigan State Medical Society facilitated the dissemination of the AMA kit through presentations at hospital medical grand rounds. While the educational effort has raised awareness, no data exists related to changes in medical practice.

Finding 2-4 in the IOM report on health literacy (Nielson-Bohlman et al., 2004, p.6) states, “While health literacy measures in current use have spurred research initiatives and yield valuable insights, they are indicators of reading skills, rather than measures of the full range of skills needed for health literacy (cultural and conceptual knowledge, listening, speaking, numeracy, writing, and reading)”. Moving health care providers’ awareness beyond the focus on patient reading ability, and acknowledging that there are numerous life skills that

contribute to health, would move research and care techniques in a positive direction.

Personal health literacy level has been most commonly assessed using the REALM (Rapid Estimate of Adult Literacy in Medicine) (Davis et al., 1991) or the TOFHLA (Test of Functional Health Literacy in Adults) (Nurss, Parker, & Baker, 1995) instruments. The REALM is easy to use and takes only 3-5 minutes to administer. REALM provides a snapshot of health literacy through an individual orally reading 66 medical terms, which increase in complexity over three columns (Davis et al., 1991). The score is calculated based upon the number of words correctly read and pronounced; word comprehension is not assessed. Scores are reflected in relation to grade level: 0 -18 < = 3rd grade, 19-44 = 4th- 6th grade, 45 – 60 = 8th grade and 61 - 66 = 9th or higher.

The TOFHLA assessment (Nurss et al., 1995) requires more time than the REALM, but has the advantage of providing information regarding comprehension of reading and numeracy. The TOFHLA utilizes examples of common medical instructions from clinical test procedures, or medication use, through a multiple choice, fill in the blank approach (Cloze procedure). Both instruments have been extensively used and have been proven to be reliable and valid, even the shortened versions.

It is not enough to be able to read medical words, as with the REALM (Nurss et al. 1995), but one must also comprehend the information to participate in the health decision process; it is felt the TOFHLA (Gordon et al., 2002) better meets these requirements. Additionally, TOFHLA evaluates comprehension of

numeracy, which is an integral component in medication usage, scheduling of appointments, and understanding health risks. Actual TOFHLA administration time is estimated to be 10 – 20 minutes.

Through the use of a modified Cloze procedure (fill in the blank by choosing a multiple choice answer), the reading comprehension section of the TOFHLA is administered through a 50 question pencil and paper test; testing is timed at 12 minutes. After 12 minutes the individual is thanked for responding and told, “That should give us what we are looking for. Thank you for your cooperation”. The test is removed and the answers are scored as correct (1) or incorrect (0). A total score is tallied into a raw score to be added to the numeracy score for the total TOFHLA score (Nurss et al., 1995).

The numeracy section of TOFHLA is administered verbally using a series of prompts mirroring real life situations (i.e., prescription bottle, appointment card, financial aid form, etc). It, too, is a timed test at 10 minutes. There are special directions for uniform administration and instances where responses are coded with exception. Responses are scored as correct (1) or incorrect (0). Responses are tallied for a Raw score (0 -17) and using an attached table, a weighted score is calculated. (Nurss et al., 1995)

The Total TOFHLA score is obtained by adding the weighted numeracy score with the Raw reading comprehension score. Using the table provided, the Total score is translated into one of three Functional Health Literacy levels: Inadequate (0-59), Marginal (60-74), or Adequate (75-100). Individuals with Adequate Functional Health Literacy should have the ability, using common

health texts, to read, understand and interpret those texts. Individuals in the other two categories will need the healthcare environment to modify methods of communication (i.e. verbal instructions, handouts, videos, etc.). (Gordon et al., 2002)

Self assessment of literacy skills has been studied by Williams et al. (1995), Chew, Bradley, and Boyko (2004) and Wallace et al. (2006). All three studies reported finding certain questions that appear to accurately predict patients with inadequate literacy. Williams et al. found that self reported questions related to reading the newspaper and health care materials, along with the use of a “reader” were validated against the TOFHLA. Chew and colleagues, also validating with the TOFHLA, asked patients 16 questions using Likert type responses and found three questions were sensitive to predicting low literacy. The questions addressed needing assistance with reading hospital materials, confidence in filling out medical forms, and difficulty understanding, or reading, medical information. Wallace and his team, tested Chew’s questions with 305 primary care patients and found that the question regarding confidence with filling out medical forms had the highest predictive value. As a broad estimate of patient skills, these questions are felt to provide enough of an assessment to raise provider awareness and allow opportunity for targeted communication.

A newcomer to the assessment scene is the Newest Vital Sign (NVS) (Weiss et al., 2005), which uses a nutrition label to capture reading and numeracy abilities when the patient answers six questions related to information on the label. Score translation based upon number of correct answers is:

0 -1 = limited literacy is highly likely, 2 – 3 = limited literacy is possible, and 4 – 6 = usually represents adequate literacy skills. NVS is easy to use, taking three minutes of time to complete, and correlates well with the TOFHLA and REALM demonstrating the ability to detect low literacy with a high degree of sensitivity (Osborn et al, 2007). Developed for use within the primary care setting, the NVS is felt to be “intuitively appealing” as nutrition is a common topic discussed in health management and related to health promotion and chronic disease care. (Weiss et al., 2005)

Current health literacy challenges could be presented through the following questions: does the healthcare community “test” all consumers, is the testing valid across all healthcare experiences, and what do the results mean within the provider/patient relationship? These are the types of questions being asked nationally and spurring research initiatives. With increased awareness of health literacy and the impact on health in regards to access, care, and outcomes, the previous questions are prime topics for healthcare policy makers, healthcare institutions, providers, and consumers.

Health Literacy and Public Policy

In 1977 President Nixon decreed that the *Federal Register* be written in “layman’s” terms, followed by President Carter’s Executive Order for federal regulations written to be “cost-effective and easy-to-understand by those who were required to comply with them” (Locke, 2004). Some agencies complied, but in the 1980’s President Reagan rescinded the Carter mandate, and no further progress was made until 1998 when “plain language” was advocated by

President Clinton and deemed a civil right by Vice President Gore (Locke). The Department of Health & Human Service, Food & Drug Administration, and the National Institutes of Health have all responded to the Plain Language movement and have worked to address public communication in an understandable manner.

Slowly, public interest in health literacy has begun to surface in public policy dialog and healthcare oversight. The Institute of Medicine published a report entitled, *Health Literacy: A Prescription to End Confusion* (Nielsen-Bohlman et al.,2004), which called upon the healthcare community to examine how they respond to the complex demands now placed upon the health consumer. The committee responsible for the report was asked to address four areas: define health literacy, identify obstacles to creating a health-literate public, assess approaches used in the U.S. and abroad, which attempt to increase health literacy, and identify goals and approaches to overcome health literacy barriers to reach the goals. The report responded to all four areas with a succinct and insightful approach that answered the questions, but also posed new questions to stimulate thought and future research into the area of health literacy. Of particular note to this paper is Finding 2-4 which states that “No current measures of health literacy include oral communication skills or writing skill and none measure the health literacy demands on individuals with different health contexts” (Nielsen-Bohlman, Panzer, & Kindig, p. 5, 2004), this point is particularly important when discussing provider/patient communication.

The Joint Commission (2007) developed health literacy based standards on patient communication, requiring that information be understandable to the patient through assessed needs, readiness and capabilities across the continuum of care. In ambulatory care requirements are stated that information must be timely and fall within four identified tactical areas (entry, healthcare encounter, transition and health management) which respond to patient communication needs across the continuum. Assigned areas of accountability encompass interdisciplinary care teams (providers, payer, social services, professional schools, administrators, patient educators, clinical staff, researchers, and patient safety experts). Tactics are suggested and assigned to team members to aid in supporting patient communication needs and improving patient safety (Joint Commission, 2007).

Healthy People 2010 Goal 11, Objective 11.2 addresses health literacy. In the objective it aims to “Improve the health literacy of persons with inadequate or marginal literacy skills” (U.S. Government, Office of Disease Prevention and Health Promotion, p. 15, 2005). Addressing health literacy through the communication goal is seen as a developmental step that encourages the use and dissemination of existing tools to train organizations and providers to work together on improving health literacy (Department of Health and Human Services, 2008). It is anticipated that improving health literacy will close the gap in existing health disparities.

Policy briefs are appearing to address health literacy from a variety of organizations and disciplines. Vernon, Trujillo, Rosenbaum, and DeBuono have

written *Low Health Literacy: Implications for National Health Policy* (2007) and point to the economic implications of low health literacy. It is estimated that improving health literacy could net a national savings of \$106 – 238 billion and that it is worth the social investment to include health literacy in healthcare reform efforts. The American Association of Retired Persons (AARP, 2004), advocates increasing policymakers' awareness of health literacy as a means to delivering cost effective programming with positive health outcomes.

Through the actions of policymakers, credentialing organizations, public health departments, and consumer action groups, the health literacy movement has gained momentum and spurred research. Health literacy is now viewed as an essential tool to improve personal health, combat disparities, improve communication and safety, and hold down healthcare costs.

Provider Awareness and Primary Care

The literature is replete with examples of poor patient outcomes linked to low patient health literacy. For example, often older patients are overwhelmed by diagnoses, complex treatments, and general self care issues (Wolf, Gazmararian, & Baker, 2005). Medication errors, inappropriate use of medication, evidence of poor adherence to health regimes, and the inability to fully utilize preventive services are common occurrences noted in the elderly (Zagaria, 2006).

Healthcare professionals often wrongly assume patients understand the importance of taking medications as prescribed. For example, an AIDS patient told an interviewer that on a bad day he takes all three medication doses by 3pm

versus a good day when doses are spaced throughout the day. This reporting illustrates how this individual lacked understanding of how his medication works (Health and Wellness Resource Center, 2004). In both cases, the patient felt he was following orders and managed to take all three doses versus missing a dose.

Additionally, providers are challenged by the health system, and their patients, to establish a patient-centered, collaborative health promoting relationship that prepares individuals to make informed decisions within a safe environment of care. Meeting this challenge may be possible if providers can demonstrate that they possess the communication capacities for productive and well-comprehended interactions with their patients and they must work within a Health System that supports their efforts through standardized practices (Paasche-Orlow, Schillinger, Greene, & Wagner, 2006).

Many individuals will not reveal their literacy concerns to a health professional, compounding the problem of effective delivery of health information. One inner city study reported 67% of respondents had inadequate reading skills, with 40% of the same individuals admitting shame regarding their literacy level (Parikh, Parker, Nurss, Baker, & Williams, 1996). The study sample included 202 patients, primarily African American, who sought services in an emergency room in Atlanta, GA. Each consenting patient was asked to complete the TOFHLA, a demographic survey, and answer questions (both personal and general) related to reading and shame. Interestingly, when both the low literate and adequate literacy patients were queried regarding low literacy and shame, approximately 50% of both groups said they would be ashamed of possessing

low literacy skills and would not tell anyone, and 60% felt others would feel the same. Both groups (80%-94%) felt the low literate would “hide” their lack of reading skills. In the group of patients in the lowest literacy group, 62.7% had never informed their spouses. This study has been oft cited when discussions regarding assessment are raised and used as an example of why screening should not be done. The researcher questions whether it is counter-intuitive to “ask” about literacy versus using a non-threatening tool to gain a sense of skills.

Marcus (2006) in a perspective paper written for the *New England Journal of Medicine*, entitled *The Silent Epidemic – The Health Effects of Illiteracy*, reported on a series of interviews with prominent names in health literacy research: Joanne Schwartzberg, Barry Weiss, Ruth Parker, and Dean Schillinger. Key points include: Schwartzberg - paperwork intimidates many patients going to an outpatient setting and leads to the use of emergency department services where questions are asked and forms are completed for the individual; Weiss - “I think most doctors are blind to the problem (health literacy) and it’s hard for them to believe”; Parker – was told by a psychologist that “the shame experienced by people with literacy problems is comparable to the shame experienced by incest victims”; and Schillinger – feels that the system of health care does not provide assistance to providers treating the low literate, nor are they prepared to respond to this dilemma.

With awareness of patient reluctance to inform providers of personal literacy skills, three studies (Bass et al., 2002; Lindau et al., 2002; & Rogers, Wallace, & Weiss, 2006) evaluated the ability of experienced medical

practitioners and residents to gauge patient literacy, or ability, to understand medical information. In all of the studies, the practitioners overestimated patient ability when compared to performed literacy assessments.

In the first study (Bass et al, 2002), forty-five resident physicians were asked to estimate the literacy levels of patients they interacted with in a general internal medicine clinic. One hundred eighty-two, mostly Caucasian, patients age 18-93 years, over an eight week period were given the REALM-R assessment and a patient satisfaction survey. The resident physicians estimated that 90% of the patients had no literacy problems. Patients were assessed after placement in the exam room, and assessment of patient literacy demonstrated 36% scored at or below the level of sixth grade. It is unclear in the study when the residents were asked about individual patient literacy, as the study also collected their satisfaction with the clinic experience in general. Additionally, patient satisfaction was not found to correlate to health literacy.

A study conducted in a women's health clinic reported that 32 resident physicians were able to only identify 20% of patients with low literacy; although 40% were found to be low literate (Lindau et al., 2002). Over one calendar year, female patients (n=529) age 18 and older were asked to participate in a 10 minute interview on patient understanding of communication regarding Pap tests. All patients were English speaking and more than half of the participants were African American (58%), with the remainder Hispanic (14%) or Caucasian (12%). Patient demographics and health history were collected, and assessment was performed using the REALM tool. Each woman was asked open-ended

questions related to cervical cancer knowledge, screening, and perception of physician interaction related to cervical cancer screening. The physicians were questioned after the patient visit regarding an estimate of patient literacy. As a caveat regarding the estimates of patient literacy, in the discussion the authors postulated that “experienced” physicians may possess better intuition when estimating, yet no such study was proposed.

A third study confirmed that provider perceptions and actual assessments are discordant, when resident physicians only identified 47% of the lowest literacy patients (Rogers, Wallace, and Weiss, 2006). Eighteen family medicine residents were asked to estimate the literacy skills of 140 English speaking patients (18 years and older) at a family medicine clinic. Patient demographics were collected, and each patient was assessed using the TOFHLA-S. Providers were asked after seeing the patient to provide their perception of patient understanding of medical information using a 5 point Likert scale. The term “medical understanding” was used to avoid sensitizing the provider to probe regarding literacy skills. This study was felt to extend the Bass et al. (2002) study, provide stronger evidence through a broader measure of literacy, and to draw attention to family medicine’s lack of ability to identify low literate patients in light of extensive training in patient communication skills.

A more recent study involving primary care practicing physicians found similar results in regards to erroneous estimation of patient literacy skills, as to those demonstrated by resident physicians. Kelly and Haidet (2007) examined a Veterans Affairs Medical Center clinic population of patients (n=100) and non-

academic physicians (n=12). The patients were asked after the physician visit to complete the REALM tool and a short demographic survey. The physicians were also asked after the patient visit to view a table with a REALM equivalent grid and estimate the patient's literacy level. Physicians also completed a demographic survey similar to the patients'. Results of the study showed that physicians overestimated patient literacy levels in 40% of the patients, as was found by Bass et al (2002) and Lindau et al (2002). An additional finding was that racial/ethnic patient skills were more often overestimated, especially in African-American patients.

These aforementioned studies illustrate the tendency of practitioners to overestimate literacy skills, which has the potential to result in inadequately addressing learning needs and comprehension. As some of these practitioners were primary care providers, this is especially troublesome as they are often the mainstay of personal healthcare. No studies of nurse practitioners were found in the literature. None of the studies mentioned if additional time was needed to perform the assessment, if assessments would be considered as a routine part of the initial office visit, or how assessment information would be used to communicate with the patient, or within the clinical setting with other staff members.

Health education and systems redesign have been targeted by researchers (Hironaka & Paasche-Orlow, 2007) looking at families and health literacy in a pediatric primary care setting as a means to improve communication. Limited individual health literacy was felt to be influenced by multiple factors that

may prevent engagement in healthcare activities. Some of these factors are the ever increasing literacy-based demands of the Health System and the complexity of healthcare. By using communication tools such as “Ask Me 3” (Partnership for Clear Health Communication, 2007), using living-room language, and confirming learning by asking for repetition, increased communication between provider and parent was supported. No mention was made regarding how these practices would be implemented, standardized, or evaluated based on patient outcomes. The continued recommendations for using these approaches appear in many of the studies reviewed, yet data are unavailable regarding if practitioners actually incorporated these tools into their practices.

Two family practice sites conducted a study (Kemp, Floyd, McCord-Duncan, & Lang, 2008) assessing patient preference for confirmation of understanding regarding communicated medical information. A convenience sample of 100 patients was recruited from practice site waiting rooms. The majority of the patients were Caucasian (94%), age 18 and older, and two thirds were women. In a private room, each patient was asked to view an instructional video followed by three different physician inquiry approaches ascertaining understanding. The patients were asked to rate the inquiry method, and the perceived efficacy, using a visual analog scale. The preferred learning method, identified by the patients, was to have the physician/provider ask for a demonstration of understanding through a collaborative teach-back experience. The alternate choices of understanding confirmation included: a physician explanation only, a physician question regarding understanding requiring yes/no

answer, or a tell-back directive. The collaborative method encouraged a dialogue that promoted understanding and increased communication consistent with the patient centered model of care.

Schillinger et al. (2003) demonstrated the efficacy of the “teach-back” technique with a group of primary care physicians working in a public hospital. During an observation of the provider/patient interaction, an assessment was made as to whether there was recall and comprehension of new information by the patient. Both Kemp and colleagues (2008) and Schillinger and colleagues (2003) reported patients were comfortable with the teach-back method, and the time taken to use this method did not adversely impact the work flow of patient care. A follow-up with the sites to assess continued use of this technique and long term outcomes would be interesting. No mention was made in either article (Kemp et al, 2008; Schillinger et al., 2003) if the patients felt there was improved patient/provider communication in other areas of their care.

In 2005, the Association of Clinicians for the Underserved (ACU) conducted an online survey of primary care centers regarding the effects of health literacy practices (Barrett & Puryear, 2006). As a result of the survey, further study of five selected primary care centers was carried out to identify specific health literacy communication practices utilized by these safety net providers (Barrett, Puryear, & Westpheling, 2008). The five practices noted by clinic staff to have a positive impact on communication were: a team effort in the clinic, from front desk to discharge; utilization of standardized communication tools; using Plain Language/pictures/educational materials in face to face

interactions; practitioners and patients partnering in setting goals; and the organization committed to the creation of an environment where literacy was not an assumption. Recommendations to replicate these practices include: clinician training on health literacy, quality care improvement initiatives, and advancing a research agenda to evaluate practices.

Barrett and colleagues' (2008) multi-site study provided information on best practices but did not provide much information regarding the responses of individual groups. While the mix of providers was 32% physicians, 25% nurses/advanced practice nurses, and 16% administrators, it was unclear if there were significant differences in how each group responded. Also, no information was provided as to the responses of ancillary personnel other than in the aggregate reporting. Assessing health literacy ranked high by practitioners (unclear if physician or nurse), yet little formal assessment was performed due to overall lack of knowledge and reliance on informal assessments such as soliciting questions. As indicated in other studies, the informal method often overestimates patient skills. Training of personnel at all sites was evident and practitioner comments were positive regarding involvement in learning about health literacy at the practice site.

Lastly, evaluation of patient literacy is a contentious topic within the healthcare community. With the array of assessment tools available, the ability to ascertain an estimated level of personal health literacy is possible but probably not performed. One study examining the net effect of literacy screening failed to show the beneficence to patients (Seligman et al., 2005). During an eight month

study at a public, academic, urban hospital, an experimental design study was performed with random assignment of physicians (n=63) and patients (n=118) to intervention (patient literacy knowledge) and control groups (unknown patient literacy). The study was part of a larger project examining physician communication with known diabetic patients. The physicians were aware of the two studies but not the eligibility criteria requiring patients to possess limited health literacy. Both physicians and patients completed study questionnaires. Intervention group physicians were asked to estimate patient literacy prior to notification that the patient had been found to have “inadequate/marginal functional health literacy and may have trouble understanding health information/materials”. In addition, the physician was asked to provide information as to management strategies used and a visit –specific satisfaction survey. Intervention physicians were more likely to use management strategies i.e., teach back or referral and to involve family members, but were less satisfied with visit outcomes. They also overestimated patient health literacy by 62%. Patients completed the TOFHLA-S, were measured for self-efficacy and asked about the usefulness of measuring understanding. Study outcomes demonstrated few differences between intervention and control groups, but a positive patient response to patient literacy measurement. Final discussion questioned if physician dissatisfaction could be attributed to lack of educational preparation and system supports to address patient literacy deficits. Both are valid points and suggest future research possibilities. Again, no mention was made regarding assessment time, if assessments would be routine in the future,

and if so, how that information would be communicated among staff. It is interesting to note that the previous postulation (Lindau et al., 2002) regarding “experienced” versus resident physicians having more refined “intuition” was not validated by this study.

With the intention of using health literacy assessments to tailor provider communication, Ryan et al. (2007), approached 289 patients in both private and public sites, to take part in a study using the Newest Vital Sign (NVS) and their satisfaction with the process. Of the 289 patients approached to participate, 98.3% agreed to undergo the assessment using the NVS and 46.7% of those assessed scored low, or possibly low, on literacy skills. Personnel administering the assessment included physicians, nurse practitioners, nurses, and physician assistants. No data were available as to whether the provider administering the assessment made a difference or if any changes in communication patterns occurred as a result of the assessment. Additionally, patient satisfaction was measured at both practice settings (study and control) with no significant differences found. This is an important study that disputes the claim that patients would be unwilling to undergo assessment or that doing so would negatively impact their visit. Further study is needed to examine how this information will be used in practice and the impact on patient outcomes and communication. An additional health literacy research void exists in regards to patient perceptions of health literacy, assessments, and supports/barriers.

Awareness of health literacy is increasing in the healthcare community. The challenge is to translate that awareness into practice that benefits both the

provider and consumer. Primary care is an excellent location to not only begin with individuals as they enter the healthcare system but to lead the way in developing system practices that support that individual through the healthcare maze.

Summary

Much has happened in the last century to literacy education and the required literacy skills needed for daily living. As healthcare increases in complexity, so too do the interactions within a global society. While the literature on health literacy continues to grow, there appears to be a lack of information available related to nurse practitioners, or nursing practice, and primary care. As a central access point for patients entering the healthcare system, opportunities exist to refine health literacy assessment measures, develop communication skills (between the patient and interdisciplinary team members), enhance healthcare records, train practitioners (in all disciplines), and empower patients.

Research has shown that the low literate experience more hospitalizations and utilize more emergency services (Baker et al., 2002). If individual literacy skills are identified, built upon, and strengthened, this will translate into better communication with healthcare providers, healthier patients, and ultimately, less costly health care. Nurse practitioners in the primary care setting have the capability to contribute much to the health literacy domain. The proposed study will address knowledge, attitudes, beliefs (KAB), and understanding of health literacy by providers/staff in primary care settings, especially nurse practitioners. Additionally, it will provide an opportunity to examine the use of the *Newest Vital*

Sign (NVS) to assess health literacy in primary care and address patient perceptions of health literacy assessment in the clinical setting.

CHAPTER III

Conceptual Model

The conceptual model for this study drew upon the writings of adult educators and used the Institute of Medicine's model for health literacy *Potential Intervention Points* (Nielson-Bohlman, Panzer, & Kindig, 2004, pg. 34). This study focuses on one intervention point, the Health System (see Figure 3.1) or more precisely, providers and staff in primary care health settings. The following discussion will highlight the influence of adult literacy theories as related to the potential invention points in this model. Tangentially, Culture and Society (see Figure 3.1) and the Education System (see Figure 3.1) provide context to the study through the data gathered from the demographic profiles of providers, staff, and patients.

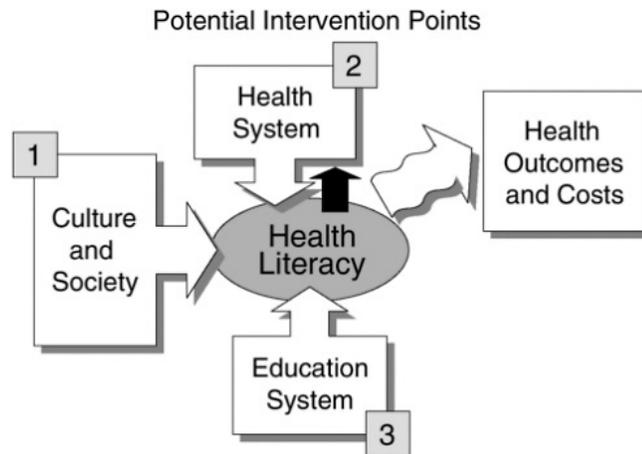


Figure 3.1

Health Literacy: A Prescription to End Confusion (2004). Health literacy potential interventions points, page 34

Cultural and Society (see Figure3.1)

The cultural and societal contributions to health literacy considered for this study include: 1) demographic surveys collected from providers/, staff, and patients and 2) pre and post-surveys completed by providers and staff measuring health literacy attitudes and beliefs following the educational intervention.

Using a “teacher as guide” philosophy, Freire (1999) decried the teaching of “monolithic skills”, which he felt were heavily curriculum driven educational programs aimed at correcting deficits and disregarded teaching life-skills. Contrary to the belief that learners were empty vessels waiting to be filled, Freire developed an approach he entitled “education for transformation.” This method of instruction was participatory in nature and empowered the learner. The Freirean literacy model is based on the belief education should lead to social action, aligning the basic contextual needs of the individual and community. This model of education supports the development of individual critical thinking skills through the use of problem solving techniques. Use of the Freirean process leads to root

cause discovery of cultural, political, and socioeconomic conditions impacting the individual while providing opportunities for action.

Supporting Freire's belief in the educational value of empowerment for social change, the use of authentic materials to tap into the interests of adult students has proven to be a successful approach in the Literacy Practices of Adult Learners Study (LPALS) (Jacobson, Degener, & Purcell-Gates, 2003). This study was based upon the premise that student success should be measured by individual use of literacy outside of the classroom versus standardized testing. Classes were built around the use authentic materials (voter's registration forms, recipes, notes from child's school, etc) and collaborative planning between adult students and educators. Positive results included increases in reading and writing "activities" outside of the classroom – these are everyday life-skills that students were previously unable to accomplish (Jacobson et al., 2003).

Culture and Society, looking out from the healthcare world, encompasses places people live (i.e., rural versus urban, apartment versus house versus shelter), services available, access points into care (i.e. clinic, private provider, or emergency room), personal culture of origin's concept of health and care providers, race/ethnicity, occupation, age, language(s) spoken, and other venues of social interaction; all these areas of personal contact influence individual health. Often the only glimpse provided of these points to the healthcare provider are the blanks completed on a health form. Weaving these major elements of personal life into a care regime through a filter of health literacy, adds a new challenge to assuring positive health outcomes.

Health System (see Figure 3.1)

The Health System was the focus of the study. The Health System is more than health care delivery sites and includes: patients and families, providers, and staff, government and regulating agencies, supportive disciplines and services, professional associations, funding sources, and the broader community. All of these components are active simultaneously and play a role in health outcomes. An integral piece of health literacy is health education, not only for the patient but for the educators and providers in health care. Within the health system, health education for providers/staff is addressed through continuing education, as it influences the continuum of care. In this study, continuing education was the module, *Health Literacy in Primary Care* (McCune, Springfield, & Pohl, 2006) delivered to the providers and staff at the health centers. Data collected included: providers and staff pre/post surveys of health literacy KAB following an educational intervention; and patient health literacy assessment.

In the field of health education, three distinct levels of health literacy have been proposed by Nutbeam (1999): functional, interactive, and critical health literacy. At the functional health literacy level an individual will possess basic reading and writing skills needed to understand health information communication. Interactive health literacy would be demonstrated by more advanced cognitive, literacy, and interpersonal skills leading to health management in partnership with professionals. Attaining a critical health literacy level would allow the individual to analyze information critically, possess increased health awareness, and actively participate in action to address

barriers. The World Health Organization, building upon Nutbeam's work, offered the following definition "literacy will be defined 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" (Nutbeam, 1998).

What can health educators take from the principles of these proponents of participatory action education regarding teaching adults? Adult learning benefits from educators as guides. Providing information is not as effective as assisting an individual in discovering the uses for the information. Individual learning occurs in relation to a relevancy, or need, within the immediate lived experience – which makes health promotion activities a challenge unless the information can be shown to be applicable to the individual. There is a process of discovery to learning that is self driven and directed. Listening to individual reasons for attending a presentation or visiting a healthcare provider, may assist the educator in identifying ways to support individual goal attainment. This process is supported by life experiences, social networks, and prior education. Effective learning is empowering and benefits not only the individual but their social network.

Knowledge regarding health literacy, the impact on patient care, and the role of the system to support the patient and the providers, are necessary components for a healthy society. The multiple levels of health literacy add an additional burden to the system, as there is no "one size fits all" approach and

challenges arise as to how to accomplish more, with less, in tough economic times.

Education System (Adult Learners and Adult Education) (see Figure 3.1)

As an intervention point for health literacy, the overall education system was not explored by this study. Data related to educational level of providers, staff, and patients were collected. It should be noted, the education system provides reading, writing, numeracy, problem solving, and myriad other skills used by individuals when making health decisions.

The education system has explored literacy, as was presented earlier. Much of literacy research has focused on the acquisition of skills by children, or school-aged population (under age 18). Health literacy encompasses a larger portion of the population; for this study it includes anyone age 18 or older. Studies of adult education participants again represent a subset of the general population but it is felt the research is applicable to the broader health-seeking population.

Who are adult learners? Traditionally, adult learners are known to be equally distributed between women and men, under age forty, who have a high school education, and are pursuing educational programs related to work or for personal enrichment. Sub-populations of adult learners are adults with low literacy, older adults, and immigrants in English as a Second Language (ESL) programs. Another sub-population, within the context of this study, is those who receive healthcare and are asked to participate in the health care decision process.

Research has shown that adults continue to experience developmental milestones and challenges. Life changes are often the trigger that motivates adults to enter into a learning atmosphere and thus accompany a significant life transition (Aslanian & Brickwell, 1980). For the individual entering into a basic adult education program, it may mean the completion of a GED to qualify for a higher employment opportunity. Or within the health arena, a diagnosis could be the life change trigger leading to learning new self health management skills. Whatever the case, many developmental models are available to study adults and education.

Adult developmental theories provide a holistic framework in which to understand the adult learner. Knowledge of developmental influences allows the educator to envision how individual life experiences impact learning positively and/or negatively. Armed with this understanding, the educator can tailor programs and provide opportunities for the adult to meet personal educational goals. By focusing on personal goal development, the transition from literacy of reading/writing to one of knowledge acquisition will occur.

Most adult developmental theories fall into one of three categories (Merriam & Brockett, 1997): sequential patterns of change, life events, and transitions. Sequential patterns of change involve stages or phases that the individual passes throughout life, growing from the experience. Life events are reflective of the personal and cultural experiences within a lifetime. Transitions are the events (i.e., college student to first job, single to married, childless to

parent, or healthy to chronic illness) that trigger changes in orientation, necessitating change and personal growth turning points.

Adult education comes in many forms, from basic education to workplace instruction to personal enrichment and most recently, health. As the understanding of the adult learner has expanded there has been a movement to go beyond the traditional teacher-driven classroom to a classroom cognizant of the needs of the adult learner; this is where attention to health literacy should begin. Following is an overview of a few of the adult education/literacy notables: Knowles (1970), Friere (1999), Jacobson, Degener, and Purcell-Gates (2000) and Nutbeam (1999).

In the 1970s, Knowles (1970) adapted the European phrase “andragogy” , meaning the “study of adult learning”, in direct opposition to a pedagogy, which he felt should be reserved for the study of childhood learning. Pedagogy’s long history dates back to times when monasteries were responsible for much of the education in Europe. These institutions based their theories of education upon what they observed teaching children through didactic methods. It was after World War II when a theoretical change began to occur (Knowles, 1970). The results of adult literacy levels of enlisted personnel was a sobering wake up call to educators, and the effort to remedy the situation called for new approaches to adult education.

Between 1929 and 1948, articles began to appear addressing how adult educators were altering their pedagogical approach to teaching, without a theoretical basis, but as an intuitive response to student needs. By the 1950’s,

authors began to publish books listing the principals of adult education. Knowles (1970) details how his work was built upon Houle's (1964) foundational research base on adult education; finding that there were three types of adult learners: goal oriented, activity oriented, and learning oriented. The direction of adult education began to change.

Knowles (1989) continued his work on adult learning and developed the following principles of adult learning: they move from dependent learning to more self-directed, accumulating life experiences provide resources for learning, the development of social roles drives a readiness to learn attitude, learning becomes more life-centered vs. subject-centered, and they are interested in learning only what they "need to know" vs. "learning for the sake of learning" (Knowles, pp. 83-84). Adult educators do well to keep these characteristics in mind as they develop instructional programming, building on existing adult assets and motivations. Instructors become more of a "guide" in a personal developmental process utilizing education on an individual level. The diversity of learning abilities and motivators exhibited by adult learners calls for attention from an educational community traditionally trained in K-12 methodology, and theory, to encompass the health community. True dialogue and co-learning between educators and adult students may provide the means to address diversity issues (Jacobson, Degener, & Purcell-Gates, 2003). Eliminating teacher driven models of education, which includes how we educate individuals regarding health, utilizing relevant contextual educational materials, and involving adult learners in the construction and delivery of adult educational programming are

key components identified as having the potential to positively impact adult learning. Practitioners must develop the ability to document outcomes in order to define what constitutes “best practice” in the field of adult health education.

Other factors influencing adult education include the learner’s personal history of educational successes/failures, location of the delivery of the educational information, the availability of multicultural educators and materials, and history of trauma (educationally and personally) (Purcell-Gates & Jacobson, 1998). And lastly, supporting adults in the attainment of literacy skills is dependent on how individual literacy is defined, measured, and used within individual lives; these points continue to challenge all who are adult educators.

The aforementioned models (Knowles, 1970; Freire, 1999; and Nutbeam, 1999) all illustrate the values the adult learner attaches to possessing skills to address personal needs, goals, experience, and abilities to function in society. The approaches and methods support empowerment of the learner to take the provided education and materials, and move beyond the teachings/classroom with new skills for enhancing their personal life and community. Unfortunately, these approaches are not globally embraced by all adult educators (including health educators and providers). In many instances the day-to-day educational interactions continue to resemble those of childhood - didactic delivery of information with expected compliance outcomes. Non-traditional teaching methods require development of tools to measure personal quality life enhancements brought about by the participatory models.

Freire's (1999) success with increasing literacy within impoverished adults in Brazil ultimately was viewed as a threat by the country's government. The role of "non-compliance" may be more a literacy deficit regarding health understanding. This may be coupled with a feeling of powerlessness by the individual regarding health management and decision-making. When patient participation is demonstrated in health care decisions, it may be viewed as a threat by the health community, as the responsibility for learning becomes the individual's and the provider is the participant. The prescriptive nature of health care currently leaves little opportunity for participatory action.

Adult literacy and education have experienced an ongoing defining process. From the humble beginnings of demonstrating the ability to sign one's name, to multiple markers of ability to live and function in a rapidly changing society. It has been posited that literacy testing would be unnecessary if everyone received education in a way that respected individual life experiences through an approach that was linguistically appropriate. In the desire to improve individuals' health, development of healthcare workers must focus on the acquisition of skills to "teach" to the relevancy of individual needs and expectations.

Adult literacy impacts society on many levels, individually, within families, in communities, and nationally through individual contributions and ability to compete in a global society. When the "costs" of illiteracy, or low literacy, are reported, they are consistently based on the economic costs to society quantified by the number of 'low' or 'no' wage earners requiring supportive assistance in the

form of welfare (housing and food) or health insurance and inability to contribute to the tax base. Little attention is given to the personal attributes that are critical for proficient health literacy - the costs to procure an intermediate or proficient level, the development of communication skills, and the calculated savings in health care dollars.

Summary

The *Health Literacy Potential Intervention Points model* (see Figure 3.1) attempts to describe the interrelationship of several large variables and the end point being a state of improved Health Outcomes. The ultimate measure of success is when a level of health literacy is possessed by the individual that is adequate to support informed personal health decisions. Figure 4.1 illustrates the IOM Health Literacy Intervention Points with study components included in the conceptual model highlighting the main study areas.

This study focused on the Health System component of the health literacy *Potential Intervention Points model* (see Figure 4.1)) and reflects the seven primary care centers, as well as payor mix, providers/staff (N=47), primary care center's university health system affiliation, and the continuing education conditions of the health system. Measurement of the educational intervention module was performed through the use of pre and post-education surveys. A post study focus group was held with providers and staff to gather thoughts on health literacy.

Culture and Society were explored through the collection of demographic variables to describe the patient participants in the study and included in models

examining health literacy in the study population. Additionally, the context of the communities in which the clinics are located was taken into consideration in the limited exploration of Culture and Society. The Education System was not examined in this study but the level of education of each participant was collected in the demographic survey. Health Outcomes and Cost were not examined at this time.

Patient health literacy, at the center of the model, was measured by the Newest Vital Sign (Weiss et al., 2005)), and is described in the following chapter. Patient perceptions of using the NVS were elicited following completion of the assessment.

Chapter IV

Methods

This exploratory study was undertaken with two purposes: First, to test the feasibility of a web-based educational intervention – *Health Literacy in Primary Care* (McCune, Springfield, and Pohl, 2006) – designed to raise providers/staff awareness and knowledge of patient health literacy. Second, to test the feasibility of using a patient health literacy assessment tool, the Newest Vital Sign (Weiss et al., 2005), in nurse managed health centers. Using the Institute of Medicine’s conceptual model for health literacy *Potential Intervention Points* (Nielson-Bohlman, Panzer, & Kindig, 2004, pg. 34) study variables within the Health System component and Health Literacy component were the main data collection points (see Figure 4.1). Explanations regarding the components are found in Chapter III.

2

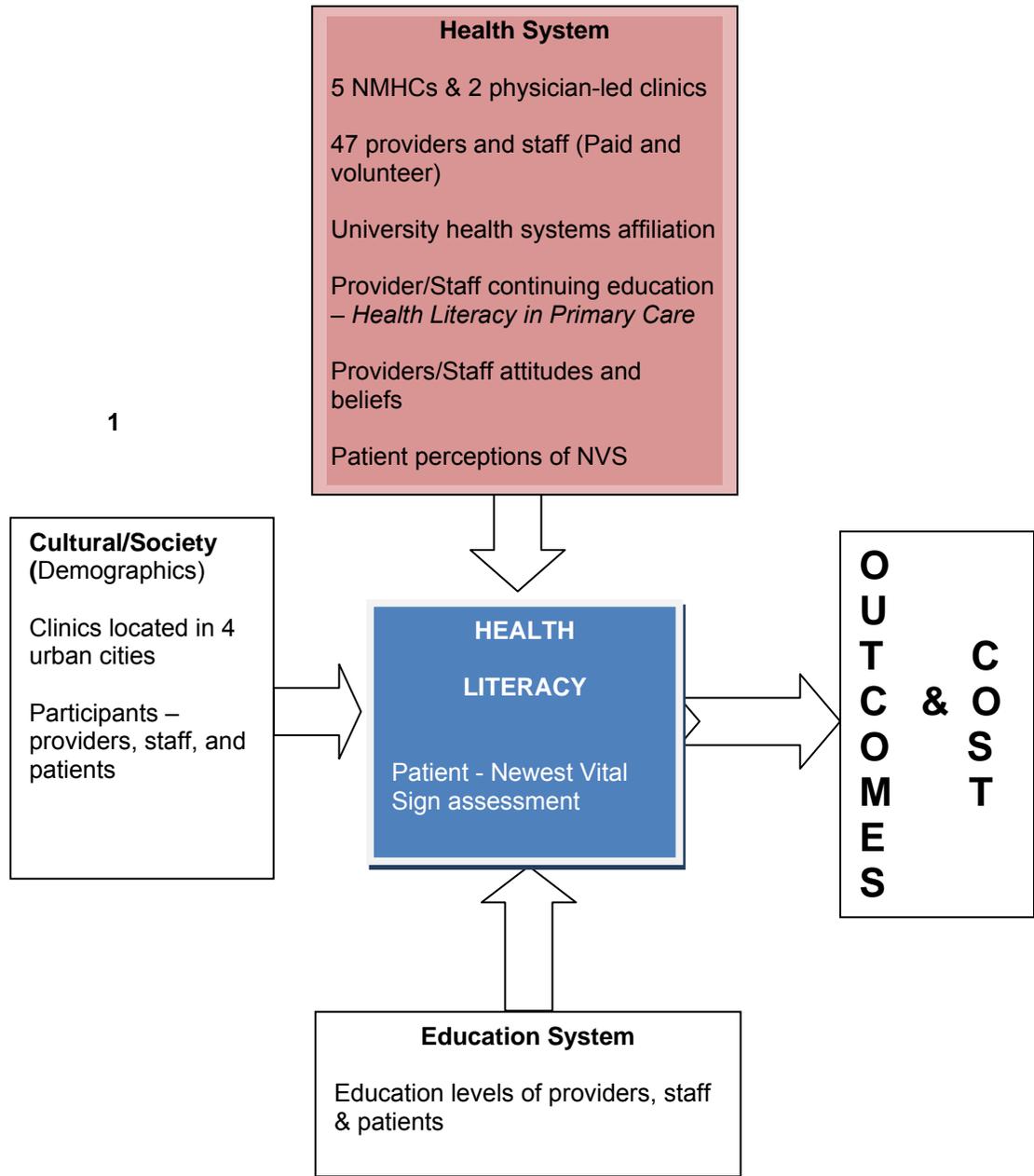


Figure 4.1
IOM Health Literacy Intervention Points with study components

A mixed-methods approach was used to examine the Health System component (see Figure 4.1), as the patient health literacy intervention point. The Health System characteristics that were examined and measured included the unique characteristics of each site: site location, the diverse socio-demographic make-up of the patients and providers/staff, the clinic's affiliation with the broader university health system, introduction of a provider/staff continuing education intervention, *Health Literacy in Primary Care* (McCune, Pohl, & Springfield, 2006), and the patients' perception of health literacy assessment (Newest Vital Sign). Further, the demographic surveys included items assessing the Cultural/Social component (see Figure 4.1) contextual background of providers, staff, and patients by profiling the multiple factors which influence health literacy, i.e. race, ethnicity, primary language, education level, gender, and age. The larger Educational System component (see Figure 4.1) was not examined in this study other than a description of the communities and populations served in the various clinics and the educational levels of the participants.

Settings

Identification of the nurse managed health centers to participate in the study was done prior to the submission of the study grant proposal to Blue Cross Blue Shield of Michigan by the co-investigators (Pohl and McCune), through membership in the Nurse Managed Health Centers consortium. Criteria for participation included center being a nurse managed health center, agreement to include support staff in the study, willing to complete the interventional education module, and access to patient population administer a health literacy assessment to a sample of center patients. After phone/email conversations, a copy of the

grant abstract and the specific aims of the study were provided to each site for participation consideration. In turn, each interested site sent a letter of support back to the research team to include in the grant application.

The final primary care practice settings chosen included five nurse-managed health centers (NMHC) and two physician-led multidisciplinary practices, all serve very diverse and high need populations in four major cities in a Midwestern state (see Table 1). Each clinic was uniquely situated in the community and easily accessible to the patient population. The location of each clinic added a certain individuality to the personality of the physical surroundings: 1) one was in the center of the city in a converted building housing low income and a special needs population, 2) one was in a converted apartment in a complex on a university campus, 3) one was in a small office building located on a busy corner intersection, 4) one was in a converted hospital emergency room with the remainder of the building serving as a large multi-service community center 5) another was in a large multi-specialty clinic building located on a larger medical center campus, 6) one was in an older bi-level office building on a stretch of road leading out of town with mixed use buildings, and 7) the last, was a stand-alone facility in a small rural suburb.

Our initial model was to study only NMHCs with the high patient satisfaction with care provided by this model (Benkert, Barkauskas, Pohl, Tanner, & Nagelkerk, 2002; Pohl, Barkauskas, Benkert, Breer, & Bostrom, 2007) and a feeling they would be a good fit with examining health literacy. When one NMHC was unable to participate, two multidisciplinary care centers agreed to join the

study. All of the five NMHCs were affiliated with colleges/schools of nursing. Two were located in (or near) the inner city of the state's largest city; one was located in the second largest city in the state, and two more were located in a university town. All of the NMHCs were serving very diverse populations. The two non-NMHCs were physician-led free clinics and provided care to rural and urban needy populations, and maintained a loose affiliation with the local university.

Aggregate data from the seven primary care centers revealed: total number of patient visits/year ranged from 1740 to 8776 and the payor mix was represented heavily by uninsured, county health plans, Medicaid, and Medicare. As each clinic was uniquely situated within a diverse city to service vulnerable populations, the collection site was coded on all demographic surveys for later analysis.

Sample (Demographic Surveys)

Two populations of interest were studied: clinic providers/staff and the patients receiving services at the practices. All participants were 18 years of age or older and able to consent to participation in the study. All participants completed an anonymous demographic survey providing basic descriptive personal information.

Providers/Staff (see Appendix D)

For the grant application supporting the study, each site provided an overview number of providers/staff working at the center and the job classifications. Prior to implementing site data collection, the researcher met with

center management to review the objectives of the study and the responsibilities of the clinic and the research staff. An introductory provider/staff meeting was then arranged, in conjunction with a routinely scheduled staff meeting, to explain the study to all providers and staff providing care at the site and to solicit their participation.

At each primary care center provider/staff meeting the researcher and a research assistant introduced an overview of the study and objectives, the project timeline, an explanation of provider/staff involvement and the researchers' expected interaction with the patients. Questions and concerns were addressed and providers/staff were then recruited to participate in the study. Providers and staff were assured that if they did not choose to participate, it would in no way affect their clinic role or employment and all information obtained would be anonymous and confidential. Participation was ascertained beginning with completion, or not, of a written consent. Following consent, each participant completed a demographic survey (see Appendix F) and pre-survey of health literacy knowledge, attitudes, and beliefs (KAB) (see Appendix C). The internet link to the educational module was provided to all provider/staff participants and clinic management.

From the seven clinics, a total of eleven providers and thirty-six staff members participated in the study (see Table 2). Of the 47 provider/staff participants, 42 (89.4%) were females and 31 (66%) were Caucasians. Age of the sample was evenly distributed at approximately 20% for each decade (22 to 30, 31 to 40, 41 to 50 and 51 to 60 years old). More than 40% (n = 20) reported

to have 17 years or more education. Out of the total number of providers/staff, approximately 30% were considered in the Provider Category (Nurse Practitioners, Physician Assistants, Physicians, or Clinical Nurse Specialists). Nurse Practitioners represented 19.1%, or approximately one fifth (n=9) of providers, and the two Physicians 4.3%. Of the total center staff, 21.3% were registered nurses, social workers, or dieticians (Provider Category II); and another 44.7% were support staff (Category III) such as medical assistants, clerks, billers, or licensed practical nurses. Almost half of the sample (n = 21 or 44.7%) reported to have worked 10 or more years in their position. Categorizing clinic personnel was done to examine the sub-group data based upon patient care responsibilities.

Patients (see Appendix F)

Research Aim 3 c: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health literacy in primary care centers to analyze the socio-demographic associations and low health literacy levels in a diverse primary care population (see Tables 7 & 8)

At each clinic, a convenience sample of approximately forty patient participants was recruited (see inclusion criteria in Procedure) and each patient completed all study components (N = 282) (see Table 3). Patient recruitment was tailored to the clinic environment and was undertaken in one of three scenarios by the researcher or research assistant (one of which was bilingual), and based on clinic management preference: 1) immediately following the

routine intake assessment (vital signs) performed by the research staff in the exam room, 2) after center staff completed the intake assessment and before the provider entered the exam room, or 3) in the patient waiting area.

As a concession for the study of health literacy, the requirement for a written consent was waived by the IRB and a verbal consent was obtained from each participant (see Procedure section at end of chapter). Using an IRB approved script (Appendix A); the researchers approached patients with a personal introduction and explanation: “I am currently conducting research under the supervision of Dr. Joanne Pohl/Renee McCune on patients’ understanding of written health information by using a food label.” Individuals were asked if they could provide ten minutes of time to answer questions about the food label and provide feedback. They were assured that their participation was voluntary and if they chose not to participate, it would not influence their care at the clinic. Patients were also informed that a \$15 gift card would be provided after the interview as a “thank you”. A total of two hundred eighty-five patients were asked to participate and all but three agreed; of those three two were finished with their visits and lacked time and one had a child with her and felt there would be distractions. The study used a short interview method with: consents, NVS assessments, three NVS perception questions, and demographic information; all of which was collected verbally in English, or Spanish, depending on the patient’s spoken language.

A majority (62%) of the sample was female ($n = 175$) and 72% were younger than 51 years old ($n = 203$). Almost a half (47%) of the sample was

Caucasian (n = 133) and approximately one third (32%) was African American (n = 90). English was the primary language of 83% of the patients (n = 234). Over one third (34.4%) reported to have 13 to 16 years of education (n = 97). Almost one third (30.5%) of the patients were insured through Medicaid (n = 86), slightly over one fourth (27%) were insured commercially (n = 76), another fifth (22%) were insured with a limited local County Health Plan option (n = 62), only five percent were insured through Medicare (n = 14) and fifteen percent were uninsured (n = 42). It is important to note that those insured by the County Health Plan would have been uninsured without this limited, and somewhat restricted, insurance plan.

Intervention (see Appendix B)

Providers/Staff

Research Aim 1: Examine provider-staff awareness of patient health literacy status within the primary care setting.

H1. After completing the module intervention, providers/staffs' prediction accuracy regarding the percentage of low health literate among clinic patients will improve between pre and post-survey.

Research aim 2: Measure change in provider-staff knowledge, attitudes, and beliefs related to health literacy after implementing a web based educational intervention, *Health Literacy in Primary Care* (McCune et al., 2006).

Research has shown that online continuing education is a convenient format to update a diverse range of healthcare professional's knowledge and disseminate best practice models (Pullen, 2006). A grant from Blue Cross Blue

Shield of Michigan supported the design of the intervention model, which was designed primarily by the researcher (study co-Investigator) as a health literacy education tool for primary care providers and staff. The module is evidence-based and unique, in that it has broad contextual content with built in reinforcements in the form of roll over pop-ups, videos of patients discussing their health literacy (AMA, 2004), and review questions at various points throughout the module – all of which engage the user. The module has been used in educational venues, especially with nursing students across the country and is available on www.nursingcenters.org/. Health literacy content experts reviewed the intervention module prior to implementation but reliability testing had not been performed. The module has been used by the researcher, and other research team members, with student nurses but no research link to change in behavior has been documented.

Health Literacy in Primary Care (McCune et al., 2006) (see Appendix B)

An online computer-based intervention was conducted to facilitate the education of busy providers and staff. Although the intent was to show the module at each primary care center study introductory meeting, the length of the intervention module exceeded the time allotted. The researcher was assured the participants would complete the module independently, prior to the post-survey and focus group meeting. Each site decided how and when the module would be completed by participants (either on center time and computers or on employee personal time).

During the introductory meeting, providers/staff were given an overview of the educational module, length of time needed to complete the module, and points were highlighted to entice participation. The overview of the module included a brief review of the content sections, examples of the patient vignettes, and description of the interactive knowledge quizzes as a way to peak curiosity and participation.

Providers/staff members were informed an online educational module included in the research study and they each were to complete the educational module within one month following the initial staff meeting. The internet link was provided to all the clinic managers to disseminate to providers/staff: (<http://www.nursing.umich.edu/ocp/modules/healthLit/healthLit.html>). Additionally, follow-up phone calls were made to the centers to track progress related to module completion and the internet address was re-supplied via email.

The module contains five sections:

1) Introduction - learning objectives

- a. Describe current U.S. literacy rates
- b. Define health literacy
- c. Explain the risks associated with low health literacy
- d. Identify risk factors and warning signs of low health literacy
- e. State examples of clear communication techniques

2) Literacy

- a. Definition of basic literacy
- b. Historical timeline of literacy and changing definitions(including statistics)
- c. 2006 U.S. literacy rates
- d. Overview of the National Assessment of Adult Literacy (NAAL)
- e. Comparison statistics from NAAL 1992 and 2003
- f. General literacy skill level examples
- g. Quiz

3) Health Literacy

- a. Illustration with roll over text: cake (basic literacy) and icing (health literacy)
- b. Inclusion in Healthy People 2010
- c. Measurement tools
- d. Health Activities Literacy Scale (HALS) (Rudd, Kirsch, & Yamamoto, 2004)
- e. Quiz

4) Why Worry

- a. Two vignettes (AMA, 2004) with added text regarding the impact of health literacy on the individual, the system, and health care providers
- b. Quizzes

5) How to Help

- a. Recognizing the signs of low literacy
- b. Document preparation
- c. Communication aids (provider and patient)
- d. "Teach back" technique (Schillinger et al., 2003)

A mechanism to verify individual completion via the module website was not available, nor did clinic management provide a process to track completion of the educational activity. As a result, completion of the educational module was on the "honor" system. The researcher emphasized that the module was to be completed by each provider and staff member before a scheduled post-survey visit. Self-report of module completion during the focus group interview was the only verification collected and, at best, was insufficient to capture actual numbers.

Quantitative Data

Providers and Staff Instruments

Demographic Survey. (see Appendix D)

During the introductory meeting, a limited profile of the clinic providers and staff was obtained by the researcher, and research assistant, through the use of a one page demographic survey. Basic demographics were collected: age, gender, race/ethnicity, education level, primary language, position at the clinic, length of time employed at the primary care center, and length of time working in professional role. Each provider/staff was asked to provide a unique identifier, of their choosing, to be used on all forms for anonymous tracking purposes during the study.

Pre/Post-Survey. (see Appendix C)

Research Aim 1: Examine provider-staff awareness of patient health literacy status within the primary care setting.

H1. After completing the module intervention, providers/staffs' prediction accuracy regarding the percentage of low health literate among clinic patients will improve between pre and post survey.

Research Aim 2: Measure change in provider-staff knowledge, attitudes, and beliefs related to health literacy after implementing a web based educational intervention, *Health Literacy in Primary Care* (McCune et al., 2006).

The last item completed at the introductory meeting was a pre-intervention health literacy KAB survey. The survey used multiple choice questions, Likert

style ratings, and fill-in-the blank statements, measuring providers/staff (N = 47) knowledge, attitudes, and beliefs (KAB) surrounding health literacy. The pre/post survey was administered before the health literacy education module intervention and contained 17-questions based upon a similar tool by Jette et al. (2003) - 6 knowledge and 11 attitude and beliefs questions. Questions were modified to capture health literacy KAB vs. attitudes, use, and benefits of evidenced based practice examined by Jette et al., (2003) In their study, instrument reporting by Jette et al., revealed intraclass, correlational coefficients (ICC) ranged from .37 to .90 with 50% of the items demonstrating ICCs of >70%.

A unique identifier was chosen by each participant on the surveys to protect privacy and included the ID of the clinic as well. The post-survey was completed after providers/staff completed the educational module and the patient health literacy assessments were finished. The final meeting was a wrap-up staff meeting, prior to the focus group. The wrap-up meeting was scheduled at the convenience of the health centers and occurred anywhere from three to six months after the initial meeting, although the original intent was to meet one month after finalizing data collection and staff completion of the module.

Reliability of the pre and post surveys was evaluated using Cronbach alpha (pre=.673 and post=.646). Test/retest results by virtue of non-equivalent design cannot be guaranteed for internal validity nor can post-test differences be quantified solidly, as pre-existing differences between groups is unknown. Additionally, not every provider-staff completed both surveys, or answered every question. Analysis was completed with the paired pre/post surveys from each site

and existing single (without a paired match) pre or post surveys were eliminated from data analysis. Missing data were few and did not significantly affect analysis (n = 2)

Patient Instruments

The researcher, and two research assistants, depending on time commitments performed patient data collection individually at the clinical sites over the course of two to three visits. The number of days and amount of time needed to reach the desired study sample (N=40 per site) was dependent on the center schedule and patient attendance on the available day.

Demographic Survey. (see Appendix F)

The researchers verbally administered a short demographic survey after completing administration of the health literacy assessment tool (NVS) either during the intake process or in the exam room/waiting room before or after the health visit. Patient profile data gathered included: age, gender, race/ethnicity, education level, primary language, and insurance. Each form was coded with the clinic ID and a patient number from 1-40 per site.

Health Literacy Assessment Tool. (see Appendix E)

Research aim 3a: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to obtain sample percentage of health literacy in each clinic.

The Newest Vital Sign (NVS) (Weiss et al., 2005) was used to measure patients' health literacy skills in this study. Through the use of a nutrition label (see Appendix E); the NVS captures reading, problem solving, and numeracy

abilities when the patient answers six questions (Figure 2). In the initial study by Weiss et al. (2005), they measured the NVS against the TOFHLA (Nurss et al., 1995) and found internal consistency using Cronbach alpha (0.76) and correlations of criterion validity ($r = 0.59, p < .001$).

In another study examining health literacy assessments, the NVS was validated against the TOFHLA (Nurss et al., 1995) and the REALM (Davis et al., 1991), both widely used assessments at two primary care clinics (Osborn et al., 2007). At the first clinic, 129 patients participated in a comparison of the NVS with the REALM and S-TOFHLA (Short Test of Functional Health Literacy). The reported results revealed when NVS score was 0 to 1 (limited literacy likely) the sensitivity/specificity to predict low literacy in relation to the REALM (limited literacy <45) was 100% for sensitivity and 6% for specificity. Concurrently, the NVS to S-TOFHLA (inadequate literacy) was 95% for sensitivity and 63% for specificity. When examining the sensitivity/specificity of NVS scores 2-3 (limited literacy possible) both values drop when compared to the REALM (low literacy). Findings revealed: NVS to REALM was 84% for sensitivity and 22% for specificity and the NVS to S-TOFHLA was 69% for sensitivity and 31% for specificity. The authors considered the reliability of the NVS “reasonable” with similar functionality in a variety of patient venues.

The NVS is based on the use of a familiar, short, and quick printed food label, which in the busy atmosphere of a primary care practice is imperative to patient flow. Each researcher used a laminated color copy of the Newest Vital Sign (NVS) (Weiss et al., 2005), which was handed to the patient after verbal consent

to participate. The patient was asked to review the food label, which was identified as “ice cream”. After reviewing the label, each participant was asked six questions pertaining to the label, which the researcher recorded on the score sheet. The researchers possessed a clip board with the questions and score sheet attached and the items were not viewable by the participants. Each question was read aloud by the researcher, and repeated if needed, and a check marked on the sheet to denote if the answer was correct, or incorrect. If the patient struggled with the question or stated, “I don’t know”, the researcher moved on to the next question. No confirmation of correct, or incorrect, responses was provided. After collecting the label, the activity proceeded to completing the demographics and patient perception questions.

Research aim 3b: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health literacy in primary care centers and to examine the impact on workflow in a primary care setting through measuring the time it takes to administer NVS.

For study patients, the NVS was completed at the scheduled health visit (in English or Spanish), before they were seen by their provider. As presented previously, the study was introduced and verbal consent obtained. A few clinics allowed the researchers to complete routine patient intakes and incorporate the health literacy assessment. This process allowed the researcher to introduce the tool with the proper name, the “Newest Vital Sign” (Weiss et al., 2005), and to integrate the questions into the clinic routine. The normal patient flow was

maintained during data collection process with total time taken to perform the consent, demographics, NVS assessment, and 3 perception questions in the 3-5 minute range. When the data collection was separated from the researcher assisted patient intakes the collection method of study items, whether in the exam room or waiting area, was maintained and clinic flow was uninterrupted.

NVS Perception Questions. (see Appendix F)

Research Question 3 d: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health literacy in primary care centers to examine patient perceptions related to use of the NVS.

Following the completion of the NVS and demographic data collection each patient was asked three perception questions, the first question used a Likert scale measuring difficulty of the NVS:

- 1) “On a scale of 1-10 (with 1 being “extremely easy” and 10 being “extremely difficult”, how would you rate answering questions about the ice cream label? “

Quantitative Analysis

For both provider/staff and patient data, analyses related to the research aims were completed using the Statistical Package for the Social Science (SPSS), Window version 18.0 (SPSS, Chicago). After data cleaning, preliminary analyses of both providers-staff and patient data were completed using frequencies, descriptive statistics, independent sample t-test, paired t-test, one-way ANOVA, correlation, and Chi-square methods according to each question.

In addition, demographic information from providers, staff, and patients was analyzed to provide a clear picture of the composition of each group for examination of association to study data. Multiple regression analysis was employed to determine the associations of important demographic variables (age, gender, race/ethnicity, insurance, primary language, and education level) to the levels of Newest Vital Sign (NVS) score of patients.

Qualitative Data

Provider/Staff Instruments

Focus Groups. (see Appendix G)

Research Aim 1: Examine provider-staff awareness of patient health literacy status within the primary care setting.

Focus groups with providers/staff were held after completion of the educational module and patient data collection at five sites- two sites had affiliated clinics that shared staff between sites. The focus groups were conducted during a scheduled staff meeting time and included all providers/staff that had completed the pre-survey. The researcher and a research assistant conducted the focus groups. Staff was informed the focus group would last 30-45 minutes and would be audio taped for later reference for confirmation of discussion topics by the researchers. Breakfast or lunch was provided to the group as a wrap-up thank you.

Prior to beginning the focus group, the provider/staff post-survey (see Appendix C) was completed. A signed consent was obtained from all participants to participate in the focus group process, as the original consent did not cover

focus group participation. All providers/staff were provided a copy of the NVS patient assessment results, pre-survey provider/staff estimated mean of patient population health literacy, and a copy of the NVS for discussion. Time was given for participants to review the documents before the discussion.

The purpose of the focus group was to collect data related to: 1) provider/staff reaction to the estimates of patient low literacy, 2) provider staff feedback on the impact at the clinic by this study (time flow, patient comments, and personal awareness of health literacy), 3) the introduction of health literacy screening in primary care clinics, and 4) the value of the health literacy module for raising personal awareness of health literacy.

As recommended by Cote-Asenault and Morrison-Beedy (1999) the focus group was led by an experienced leader (the researcher), audio taped, and a scribe (research assistant) was in attendance. While optimum focus group size is 6-10, our groups were occasionally slightly larger as all providers and staff working that day attended. After an introduction, the focus group began (Appendix G) with a review of the data from the clinic, a report of the time the NVS required, and the method of administration (i.e., with the vital signs or separate). The group was then queried on their thoughts regarding participation in the study, if their personal communication style changed as a result of the study or educational module, what did they think about the educational module, and the pros/cons of assessing patients for health literacy skills. Ample time was allowed for group discussion and verbal prompts were used as necessary to guide the discussion. As the focus group was conducted during an actual work

day, the comings and goings of staff to address clinic concerns was an added distracter.

Patient Instruments

NVS Perception Questions. (see Appendix F)

Research Question 3 d: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health literacy in primary care centers to examine patient perceptions related to use of the NVS.

Based upon previous research related to patient feelings (i.e. shame) regarding personal literacy skills, the researchers were interested in knowing what patients thought about using the NVS and answering the questions about the food label. With that in mind, upon completion of the NVS assessment and demographic questionnaire, patients were asked three questions, two of which were open-ended, related to their perceptions of the NVS. (see Appendix A). The two open-ended questions encouraged the patient to explain how the tool could be used in a health visit, and judge if friends and family would be willing to use the tool at a health visit. Patient responses were added to the bottom of the demographic data sheet by the researcher as free text. Answers were typically short, candid, and readily provided by the participants.

Qualitative Analysis

Analysis of the provider/staff focus group discussions and patient responses to the open ended questions (questions 2 & 3, Appendix F) regarding the NVS were analyzed using grounded theory methods with comparative

analysis. Each focus group session was transcribed verbatim from an audio tape recording. The researcher and transcriptionist reviewed and discussed “hard to hear” sections. After several listening attempts of the recordings final results were either reaching a consensus regarding the missing dialogue or accepting that the word was unintelligible. In a process similar to a study by Valerio et al. (2006), each focus group was coded line by line by the researcher (focus group leader) looking for themes related to health literacy that were then categorized (Patton,1990). Then a second rater analyzed each transcript independently: a nurse practitioner, non- participant in the focus group data collection. Several readings of the transcripts were performed by each rater and interpretive notes were taken. The notes were then assigned to thematic categories by each rater. The second rater and the researcher reviewed the themes and discussed coding differences and areas of disagreement. A joint review of the transcripts was done to resolve areas in conflict and after final discussion; agreement was reached on the thematic categories.

Patient responses to the open ended questions were analyzed by the research team (PI, co-PI, and project manager) and sorted by thematic response. Perceptions were noted as positive or negative. Individual comment data was entered into a spread sheet for later in-depth analysis beyond general themes. .

Procedure

All participants in the study were required to be adults, age 18 or older, and able to consent to the study either through written consent (providers/staff) or verbal consent (patients). Inclusion criteria for providers/staff consisted of the ability to read and speak English and employed/volunteering at the participating

primary care centers. One time observers and students were excluded. Inclusion criteria for patients consisted of an ability to speak English or Spanish, being 18 years of age or older, able to view the written NVS assessment tool, and not experiencing a significant disability that would interfere with their participation.

The study was approved by the University of Michigan Institutional Review Board (IRBMED), and the institutional review boards of four other participating institutions. For all samples, providers-staff and patient, data collection were completed over a nine month period, from November, 2008 to July, 2009. The co-investigator and two research assistants collected data at each of the seven ambulatory care settings.

Patient verbal versus written consent was approved by the IRB for two reasons: 1) the study was examining health literacy and the possibility that some participants would be low literate and intimidated by a written consent was foreseeable and 2) if the assessment were to occur in conjunction with normal clinic routine, obtaining written consent would be out of character and would interfere with the timing of patient flow.

Breakfast or lunch was provided to each site during the focus group. Each site received an honorarium of \$1000 after completion of the study. Patient participants received a \$15 gift card to compensate them for their time and input on this project.

Chapter V

Results

A mixed-methods analysis was used to address the three specific aims, associated research questions, and hypotheses of this exploratory health literacy study. Focusing on the Health System component of the conceptual model (see Figure 4.1), data were collected from providers, staff, and patients at seven primary care centers in four diverse Midwestern cities. Data are reported by research aim; quantitative data are reported first followed by qualitative data.

Quantitative Data

Provider/Staff Findings

Research Aim 1: Examine provider-staff awareness of patient health literacy status within the primary care setting.

H1. After completing the module intervention, providers/staffs' prediction accuracy regarding the percentage of low health literate among clinic patients will improve between pre and post-survey.

Researchers administered the KAB pre-survey to providers/staff during the staff informational meeting at each primary care center. The post-survey was administered at the end of study focus group. Pre/post surveys also

contained one question asking providers/staff to estimate the percentage of patients at their site they believed were low health literate. Completed surveys were reviewed by the project manager within two days of collection and data were entered into Statistical Package for the Social Science (SPSS), Window version 18.0 (SPSS, Chicago. No missing data was present for this variable.

Health literacy estimation data from the seven primary care center providers/staff (N=47) revealed no significant change between the pre and post module survey (see Table 4). More than half of the providers/staff estimated their patient population possessed low health literacy skills pre-survey (50.2%) and post-survey estimations remained high (47.5%). There were exceptions at three of the seven clinics: the GR providers estimated low health literacy in the 60% range and the AA1/AA2 (shared staff between the centers) estimated low health literacy in the 36% range during the pre-survey. In the post-survey period the estimates reversed at the AA1/AA2 sites with aggregate estimation of 49.9%. The assessment of health literacy at the GR center was not collected post survey due to an error in administration of the survey. The involvement of research staff at each site and the resultant influence on staff predictions was not examined.

The provider/staff estimations of patient health literacy skills at the two largest city clinics between pre and post survey remained relatively unchanged and measurement of statistical significance was not performed: D1 pre-survey 45% to post-survey 41% and D2 pre-survey 45% to post-survey 45.89%. However, the actual percentage of clinic patients at sites D1 and D2 scoring in the lowest Newest Vital Sign (NVS) category “High likelihood of limited literacy”

was 30% (D1) and D2 34.1%. What differed at these two sites from the other five primary care centers was the high number of patients who demonstrated “Possibility of low health literacy”, D1 at 47.5% and D2 at 51.2%; at the other sites patients in this category ranged from 10% (MC) to 27.5% (LC).

Post Survey

Research Aim 2: Measure change in provider-staff knowledge, attitudes, and beliefs related to health literacy after implementing a web based educational intervention, *Health Literacy in Primary Care* (McCune et al., 2006).

H1. After completing the module intervention, providers/staffs’ attitudes, awareness and knowledge (including definition, measurements, and need for accommodations) related to patients’ HL levels will increase from pre to post-survey.

Post-survey data were collected immediately following the focus group discussion. Provider/staff participants were reminded to use the unique identifier they chose during the pre-survey. Forms were collected and reviewed back at the research office by the project manager within two days of data collection and entered into SPSS. Missing data were noted; minimal data were missing (N=2 survey items). As the surveys bore unique identifiers, the ability to retrospectively gather data anonymously post-survey completion was not possible and data remained missing. Review and discussion of the data collected and entered were performed by the project team at regular meetings. Any discrepancies were identified and hand checked against the forms at each meeting.

Analysis of the data revealed no overall significant changes in the health literacy KAB scores of providers and staff post implementation of the *Health Literacy in Primary Care* module (see Table 5). As presented previously (see Chapter IV), providers and staff were divided into three groupings dependent on care giving role in the primary care center. In the Provider Group 1 a sub-grouping of the nurse practitioners ($n = 9$), revealed the number of correct knowledge-based answers ($n=5$) was 55.6% at pre-survey and 51.2% at post-survey. When examining the full Provider Group 1's (Physicians, Nurse Practitioners, Physician Assistants, and Clinical Nurse Specialists) attitudes and beliefs ($n=11$), measured using a Likert scale (4=strongly agree to 1=strongly disagree), no significant change was found from pre-survey (3.92) to post-survey(3.94). In examining the Provider Group 2 and Support Staff groups combined ($n = 22$), neither health literacy knowledge (pre-survey 45% and post-survey 40%), nor attitudes-beliefs (pre-survey 3.86 and post-survey 4.0) scores changed significantly.

On closer examination, Provider 1 and Support Staff groups demonstrated no statistical differences in health literacy KAB scores between pre and post-tests. In regards to attitude-beliefs scoring, Provider Group 2 revealed no statistically significant differences pre to post-survey, but they did demonstrate an unexpected significant decline in health literacy knowledge after implementing the *Health Literacy in Primary Care* module ($p < .05$) (pre-test mean = 3.14, *S.D.* = .69; post-test mean = 2.00, *S.D.* = 1.16; correct answer scores were pre-test 62.8% and post-test 40%).

Patient Findings

Research Aim3 a: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health literacy within primary care centers to obtain sample percentage of health literacy levels at each clinic.

Individual patient health literacy was assessed using the NVS in approximately forty patients per primary care center (N = 282) by the researcher and research assistants. As reported in Chapter IV, patients were recruited after being informed of the project and purpose. After time to review the NVS tool each patient answered the six verbal questions related to the food label (NVS). Hesitation or statements of “I don’t know” were counted as incorrect responses and the researcher continued to the next question. Answer sheets were marked with a check mark as correct/incorrect and totaled at the end for correct score. Score sheets were returned to the research office and entered into the SPSS data base by the project manager within a week of the assessment. All data were reviewed on a regular basis at project team meetings at which time discussion of findings in relation to the study aims were examined.

The NVS assessments were analyzed using descriptive statistical analysis and revealed overall, 21% (n = 60) of the patient population had scores indicating a high likelihood of limited literacy, 27% (n = 75) had the possibility of limited literacy, and 52% (n = 147) had adequate literacy. Study findings are consistent with national literacy statistics (NCES, 2006). The NVS mean score(s) at each clinic and the aggregate of all clinics are shown in Table 6. The mean NVS score

was 3.49, however, ranges were broad (2.10-4.52). The two primary care centers in the largest urban city scored lowest and only 22.5% and 14.6% of their patients demonstrated adequate health literacy skills.

Research Aim3 b: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health literacy within primary care centers to examine the impact on workflow in a primary care setting through measuring the time it takes to administer NVS: timed data.

Beginning with an introduction and after obtaining patient verbal consent, the researchers administered the NVS to individual patients at each site. Study findings indicate that the introduction of the NVS assessment at the health centers in combination with routine collection of vital signs did not disrupt the patient flow and accounted for an added 3-5 minutes of time (as timed by the researchers) after consent and before collection of the demographic data. At sites where the assessments were performed separate from the normal routine, clinic flow was maintained even though the assessment was outside of the normal pattern of a patient visit. Providers in post-study discussion reported not being unduly detained from patient visits and patients voiced positive interest in the added interaction. Additional findings regarding the perceptions of impact on work flow are presented in the focus group qualitative data. .

Research Aim3 c: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health

literacy in primary care centers to analyze the patient socio-demographic associations health literacy in a diverse primary care population (Tables 7 & 8)

Literacy levels in each clinic and by patient demographics.

As shown in Table 7, some significant differences by demographic variables in the NVS score were found. Although there was no significant difference in the overall NVS score by gender, when testing the difference for each NVS item individually, male patients had significantly more correct answers to the Item 4 (see Appendix D) which involves calculation of daily percentage of calories than did females and female patients were more likely to correctly answer Item 5 identifying food ingredients than males (both $p < .05$).

By age category younger patients (age 18-40 years) did better, especially with the complex item (NVS Item 3, see Appendix E) involving calculating the amount for one serving (45% answered correctly versus 30% of those older than 40 years). In relation to the food ingredients items: Item 5 - 85% of 18-50 years answered correctly versus 70% older than 50 and on Item 6-75% of those 18-40, 68% 41-50, & 55% 51 and older answered correctly (all $p < .05$). Education level demonstrated a strong positive correlation with NVS score ($r = .442, p < .01$).

Ethnic differences were also found (Table 7). When examining differences in each NVS score level, Caucasians ($n = 133$) overall did better with most of the NVS items: Asians did well with calculating the amount of nutrition for one serving of the ice cream (Item 2 - 84%) and calculating daily percentage calories

(Item 4 - 88%), whereas African Americans overall had a lower number of correct answers to all questions (12% - 55%) (all $p < .05$). Variations based on payor mix were noted as well: commercially insured patients (n=76) demonstrated significantly higher NVS scores (4.53 out of 6) overall, followed by uninsured (n=42 scoring 3.62), County Health Plans (n=62 scoring 3.44), Medicare (n=14 scoring 2.50), and Medicaid (n=86 scoring 2.72), (all $p < .05$).

NVS Perception Questions. (see Appendix F)

Patients were asked three perception questions; the first question used a Likert scale measuring difficulty of the NVS:

“On a scale of 1-10 (with 1 being “extremely easy” and 10 being “extremely difficult”, how would you rate answering questions about the ice cream label?”

Patients did not hesitate to rate the use of the NVS and the majority (78.9%) of patients rated the ease of use with the NVS as no harder than 5 on a scale of 1 to 10, with the scale anchors of 1 being “extremely easy” and 10 being “extremely difficult”. In fact, 47.9% rated the ease at a 3 or below on the scale. (see Figure 5.1) Additional comments often related the ease of the tool with the familiarity of using food labels in their diet.

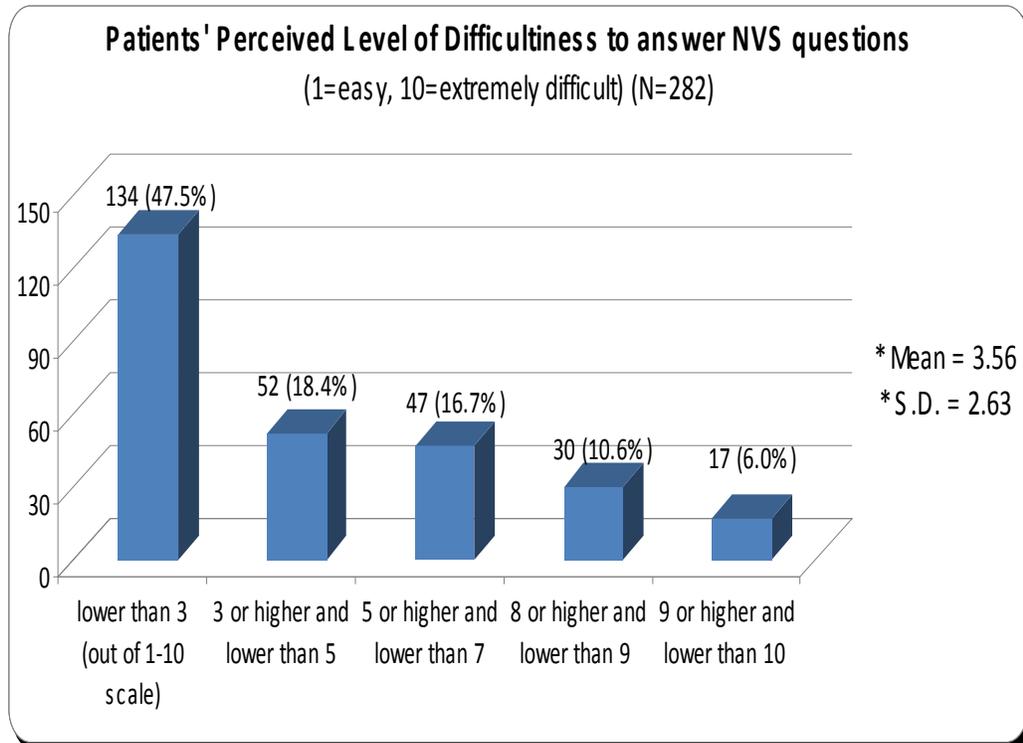


Figure 5.1

The perceived difficulty level showed significant, medium-level correlation with NVS score ($r = -.359, p < .001$).

Demographic Characteristics Associated to Low Patient Health

Literacy (NVS) Scores. (see Table 8)

The demographic characteristics of insurance and education have previously been shown to be strongly associated with low health literacy in a study by Schillinger et al., (2002). After the researchers adjusted for confounders, results demonstrated only insurance was independently associated with patient health literacy, as measured by the s-TOFHLA, and high HbA_{1C} : Medicare ($\beta = -0.90, p=.02$) and Uninsured ($\beta = -0.87, p=.03$).

For this study, multiple regression analyses were used to examine the associations between patient NVS scores and demographic characteristics. Ten of eighteen variables were significantly associated with levels of health literacy ($R^2 = .45$, $F(18,261) = 11.81$, $p < .001$) (see Table 8). Speaking a language other than English or Spanish had the strongest association to low health literacy ($\beta = -.37$), followed by Ethnicity/Race ($\beta = -0.28$), Years of education ($\beta = 0.25$) and having a Commercial insurance vs. Medicaid ($\beta = 0.20$). Forty-five percent (45%) of the variance in health literacy was explained with the multiple regression model. Standardized regression coefficients and t-tests (see Table 7) indicated demographic characteristics accounted for health literacy score, in order of significance, through education, race/ethnicity, insurance, and primary language. Multiple regression analysis indicated that the demographic characteristic strengths shifted with primary language having the strongest association with health literacy score

When examining the differences by primary care setting, the patients in center D2 located in a large urban area (predominantly African American and reporting less years of education) had significantly lower NVS scores (mean score 2.10) than those in centers AA-1 (mean score 3.55 and $\beta = 0.21$), AA-2 (clinic comprised of more international graduate students and their families) (mean score 4.52 and $\beta = 0.27$), LC (mean score 3.90) and MC (mean score 4.10 and combined with LC, $\beta = 0.21$). There was a stronger association between being a patient at these sites and scores on the NVS. These associations call for further study to ascertain meaning.

Qualitative Data

Provider/Staff Focus Groups (see Appendix G)

Research Aim 1: Examine provider-staff awareness of patient health literacy status within the primary care setting.

Five focus groups were conducted between December 2008 and June 2009 (N=47 participants); two of the sites had “sister” clinics with providers/staff in attendance at one focus group. The purpose of the focus group was previously described in Chapter IV. In response to the broad purpose of Research Aim 1, the focus groups provided valuable feedback and insight into the study influence on providers, staff and primary care center. Over a 30-40 minute breakfast or lunch, providers and staff reviewed patient health literacy assessment outcomes and discussed the meaning of the data, health literacy assessments and the health literacy educational module.

Audio-taped recordings were transcribed within 2-4 months following the focus groups. The transcriptionist and researcher reviewed the transcripts while listening to the recordings to confirm conversation and resolve “hard-to-understand” sections of the tape recordings. Coding of the transcripts was completed 2 months later by the researcher and a second reader. Analysis of the focus groups revealed four distinct themes based upon the focus group guided discussion: 1) the Use of a Health Literacy Assessment Tool; 2) the Value of Health Literacy Screening; 3) Health System; and 4) Study Impact on Providers/Staff/Patient Interactions.

Theme1: Use of a Health Literacy Assessment Tool (NVS)

Once providers/staff had completed the post-survey and received their site NVS results, they were informed of the patients' attitudes and acceptance of the implementation of the NVS. There was expressed "surprise" that patients with low health literacy often considered the tool "easy" to use and their perception that most people they know would "be OK" with implementation of the NVS. At one primary care center a short discussion ensued pertaining to the perceptions of low health literacy and differences between providers/staff expectations and patients' functional patterns. Providers/staff were then provided the following information and questions:

"In administering the NVS, we found it took _____ minutes.

- How do you see using such an assessment in your clinic?
- What is an acceptable amount of time for such an assessment?
- How would you see it impacting patient care?
- What are the pros/cons to using NVS? "

First, all participants across the clinical sites were intrigued by the successful implementation, acceptance of the NVS tool by patients and the almost non-existent refusal rate (N=3). Providers/Staff felt the NVS could be used at their site but there appeared to be a level of reluctance at two of the clinic sites to a "blanket implementation" of the NVS with existing versus new patients, with one staff member stating, "I would have a hard time having a patient I know well, answer questions to check their literacy." When it was explained that the researchers presented the tool as a way to verify understanding, the staff

member thought “maybe” she could phrase it in that way. The staff member’s discomfort with verifying literacy skills in long established patients was a scenario not considered by the researchers in anticipating barriers to implementation. Staff overall verbalizes the value of using a food label in a health setting to focus nutrition teaching. This same point was emphasized by the patient population.

Pros to NVS Use	Cons to NVS Use
“It is quick”	“It would take training to control facial expressions with wrong answers”
“Seems very non-threatening”	“It would not be a timely tool, as I could not leave the patient with known wrong answers I didn’t correct”

Although the providers perceived “cons” to the use and implementation of the NVS, the staff would consider the use of the tool with “new” patients, specifically those they had not met and did not “know”. Providers vocalized concern that the assessment would entail more one on one time in an already busy environment.

Theme 2: Value of Health Literacy Screening

Regardless of the acknowledgement that the NVS could be implemented and useful, comments both positive and negative pointed to the value of using a health literacy assessment. “Screening may clear up misperceptions of ‘non-compliance’ by revealing low health literacy” was a comment voiced by a NP in one of the lowest scoring clinics and was echoed by her colleagues. Discussion regarding “non-compliance” as a low health literacy indicator was examined in the group.

A medical provider at another site stated,

“I felt when I went through this and answered this questionnaire we do not do a very good job, at least I’m speaking for myself maybe of um being sensitive to the potential for our patients not to be able to read and assessing would be a way to address that concern”

However, the physician’s office nurse did not agree and stated,

“I think that for the most part we all know the patient population that we deal with there’s a high rate of essentially not understanding orally so you have to break it down to a level uh so it’s on an individual basis if I have somebody who just doesn’t get it I don’t have a problem breaking it down so they can understand it you know and I think that because we all are very aware of that for the most part that that’s what happened because quite frankly you can tell if a patient understands your directions or not – it doesn’t take a health literacy assessment.”

Screening results, as previously mentioned, were “surprising” to the clinics in relation to their estimates. Providers and staff alike felt they had a good idea of patient health literacy skills and accommodated based upon assessed need. Even when the estimated health literacy of the patient population closely reflected the patient scores, the number of patients with low health literacy was of concern. Comments reflecting the disbelief regarding the estimated number of patients with low health literacy included this comment at a site that had previously hosted a health literacy study, “I don’t know how the numbers could be so high, as the last time a study was done here we only had 45% and now you say there are 85%”.

Disbelief and skepticism regarding the estimated health literacy of the patient population appeared to be common denominators expressed by some of the clinical providers/staff. Many of the expressed concerns of the provider population centered around the impact on clinical workflow (discussed below

under theme of Hospital System) and the associated personal health consequences of low health literacy skills in the clinic patient population.

Theme 3: Health System

For purposes of this study, the Health System refers to the physical space, culture of the providers/staff, patient culture, language spoken (providers and patients) and the culture of documentation, economics and support. All of these elements come together to influence the clinical environment therefore the culture of provision and coordination of care. The over-riding barrier voiced by management and providers/staff was the potential impact of the NVS assessment on time, and/or thru- put, necessitating a change in the clinic routine to accommodate health literacy screening. The presentation of data showing that the time for administration of the NVS was a total investment of 3-5 minutes of patient time, at one point in time for each patient, did little to the eliminate the perception that assessing for patient health literacy using the NVS would not result in what clinic personnel perceived as a looming clinic “slow down”. The primary comment related to barriers in implementation of the NVS assessment was: “We are already overburdened with paperwork and handouts, how are we to do this?”

In identifying potential strategies for implementation of the NVS in primary care settings, site nursing staff provided suggestions, such as management could delegate the administration of the NVS assessment as an appropriate role for nursing students rotating through the site, as a way to “introduce them to patient care”. Centers observing the inclusion of the NVS with

the intake process (n=2) felt it would be an easy transition into adding this “newest” vital sign into the patient intake process.

The topic of staff communication patterns and work flow from one clinic member to another was discussed. The “need for a ‘system’ of assessment” of patient health literacy was discussed and seen as potentially including the report of patient health literacy level in the medical record system and/or computer. Another clinic member noted, “The problem list could contain the patient health literacy assessment”, only to be countered by a peer, “I can never find the problem list.” furthering the discussion surrounding “broken” communication. It was generally agreed by all providers that the current system of communication regarding patient health literacy skills was “hit or miss” and at best, informal verbal communication between clinical staff members was the norm. Another impediment to communication between center providers/staff related to patient health literacy skills in the clinical setting was the discussed potential impact of patient understanding of “foreign born” medical staff for whom English is a second language. This was reflected by clinical staff comments such as, “Making it hard for the patients to understand what is prescribed, leaving me to explain” (stated by a front desk clerk).

Theme 4: Study Impact on Providers/Staff/Patient Interactions

In interacting with each focus group, the researchers stated,

“While participating in this study:

- you have taken the pre/post health literacy surveys
- completed an educational module
- possibly observed us as we assessed your patients”

“In what ways has any of this changed your personal communication style?”

The primary care center focus groups were asked if the health literacy educational module was discussed at their clinic. At each site, many focus group members were quiet when the topic of the module was presented and a few at each site admitted they “Did it yesterday because you were coming”. At one site the staff reported, “It wasn’t very helpful, because the work computers don’t have speakers and we couldn’t hear what the people were saying”. At no time during the focus group discussion, at any site, did providers/staff reference if management had “required” completion of the module. Many of the providers and staff could not recall the health literacy tools presented in the module (i.e. teach back, *Ask Me 3*, etc.).

For those who did view the module, they felt it was “Very good” and “Surprised me that literacy was more than ‘if I can read’”. The most poignant points mentioned after viewing the module were related to the AMA video clips (2003), which confirmed the textual content of the module. Statements confirming staff viewed the module indicate adoption of changes in clinical practice and interaction with patients, “I now watch body language more” and “I make sure I provide information in two forms now [verbal and written]”

Not only did these comments demonstrate viewing of the module but also point to an increased awareness of patient health literacy for those who completed the module. The most vocal supporters of the module were the front desk staff from two clinics, who also chose to complete the NVS themselves to

“understand more from the patients’ point of view.” They willingly shared their experience with provider/staff members and encouraged each to consider completion of NVS assessment themselves.

Patient Findings

NVS Perception Questions.

Research Aim3 d: To test the feasibility of implementing a standardized tool (The Newest Vital Sign/NVS) to measure health literacy in primary care centers to examine patient perceptions related to use of the NVS.

When each patient had completed answering the NVS and demographic questions, researchers asked three additional questions regarding the use of the food label, two questions were open-ended :

- 1) “How do you think the ice cream label could be useful to your personal health when used at health visit?”

Patients overwhelmingly (90%) felt that this would be a positive addition to a health visit because, “It brings attention to labels and what you’re eating” and “It is an actual example to use with diet instructions”. Most of the patient comments related to nutrition and understanding of diet, much like the comments made by providers/staff. The patient perception that by way of “understanding written health information”, they were demonstrating reading, numeracy, and reasoning skills was not evident.

- 2) “What would people you know think about answering questions about the ice cream label at a health visit?”

More than half (60%) answered that friends and family would be willing to answer questions about an ice cream label stating, “They would like it” and “It would be helpful for them”. Of the 40% who answered that friends and family “would not be willing” to answer questions about a food label at a health visit, some offered alternate responses such as, “They would find it odd and wonder why” or “Depends on where they are in their life and their health”.

Overwhelmingly, patients were comfortable with the NVS assessment and participated in the assessment. Researchers did not observe evidence of “shame” in patients completing the NVS, even when the individual was unable to answer any of the six questions. Most often comments on the calculation question (NVS Item 3, see Appendix E) revolved around a fear of “story problems” and how those were always “hard” in math class. There was a level of comfort observed with the use of the food label, especially when they were informed it was “ice cream” which seemed to be a favorite treat for many and therefore perhaps non-threatening.

Results Conclusion

In summary, providers/staff estimation of patient health literacy skills was not always accurate and sources of influence were not examined in this study. Primary care centers stated that the implementation of a patient health literacy assessment within the clinical setting was possible, and may even have value, but numerous barriers to use and implementation were presented. The most prominent barrier stated across all sites was the time and manpower needed to administer the assessment.

Strong socio-demographic associations to health literacy assessment scores were found in the patient variables of primary language, race/ethnicity, education, and insurance. All of these variables point to the other two health literacy intervention points of the IOM model: Cultural/Society and the Education System. The significance of the interplay of all three systems on Health Literacy should be examined.

Patients received the NVS assessment well and thought it would be a good addition to their health visit, especially when discussing nutrition, and would recommend it to friends and family. Patient perception based upon the introduction of “understanding how patients understand written health information” was in favor of assisting primary care personnel in demonstrating this understanding through the use of the NVS. Researchers did not observe or note verbalized instances of humiliation, or shame, in patient use of the NVS. There was a verbalized concern by Support Staff that administration of the assessment to patients they knew well would cause them (the staff) embarrassment, which calls for further study to understand this phenomenon.

Chapter VI

Discussion

Understanding health literacy and its measurement in high need primary care settings was examined in this study, which is especially important to those sites serving as a safety net to vulnerable patients. To date, there are only a few studies in the literature on assessing the use of the NVS as a tool in primary care settings; the original study by Weiss et al. (2005), a follow-up by Osborn et al., (2007) and a new one by Shah et al. (2010). The current study was useful in addressing the gap but was met with several challenges in doing so.

While all of the health care centers agreed to fully participate in this study, actual implementation was controlled within acceptable time limits set by each site, not the researchers. We found staff, for the most part, accommodating within the confines of what they understood to be their level of personal involvement and with a focus on maintaining normal routine. For some, that meant allowing the researchers to interview patients in the waiting room, completing the pre/post surveys on their own time, and viewing the video only on work time, when not busy resulting in a threat to the fidelity of the study. Though all the primary care centers received an honorarium for participating in the study, the time commitment allotted to the study varied by site.

Aggregate staff estimates of patient literacy levels remained relatively unchanged pre/post survey. Only two of the seven centers demonstrated realistic estimations correlating to the actual assessed skills of patients with low health literacy. During post study meetings, clinic personnel were interested in the results of the NVS at their site, often times to validate their assumptions of patient health literacy skills. Three sites assumed the majority of patients had a health literacy deficit and two out of three felt they already adjusted accordingly when delivering care. Interestingly, these were the sites that estimated low literacy in the 60% range and patient results demonstrated the percentage of patients with low health literacy skills ranged between 27% - 40%. All three sites voiced concerns the assessments did not capture the “true” patient population and were convinced the study numbers were influenced by the temporary influx of “non-typical” patients. One of the three centers planned to continue assessing patients using the NVS and may have valid argument regarding “non-typical” patients, given that a number of the individuals assessed were university faculty receiving annual flu shots. Only two clinics underestimated as in the studies previously presented. The bottom line is there is difficulty estimating low patient health literacy when estimations are based on patient self-report, mannerisms, and educational history

Pre/post surveys of provider/staff KAB did not confirm significant changes overall, but in discussions with providers/staff they expressed positive/negative comments regarding the value of health literacy education and NVS assessments. The poor testing outcomes on the knowledge portion of the survey

point to the fact that few providers or staff viewed the module, as the answers were contained within the module and should have been reflected in the post-survey. The relatively unchanged attitudes and behaviors may reflect an inadequate amount of follow-up time to allow change to occur. Another possibility regarding changes in KAB is that the measurement tool failed to capture the outcomes related to health literacy the researchers sought.

The full impact of the educational module was difficult to ascertain as staff completion was validated through provider/staff self report. During post survey discussion, one site reported completion of the module but there had been a lack of sound on the center computers; consequently the impact of the vignettes was lost. A number of the sites completed the module just before the post-survey meeting, leaving inadequate time to process the information or use the tools provided in the module. Most likely, the lack of impact reflects the non-completion of the educational module and calls for further testing. Module completion required committed clinic management and involvement in encouraging staff to view the module in a timely fashion, which did not occur; nor was a tracking mechanism instituted by the centers to verify individual module completion.

The difficulty scheduling the post survey meeting and focus group, at all of the sites, was an additional impediment to data collection. The original purpose was to conduct a focus group one month following completion of the post-survey, patient data collection, and the health literacy module. In retrospect, it was an ambitious plan dependent on clinic cooperation and adequate patient visit numbers. Scheduling of the focus groups proved to be difficult around busy clinic

schedules. The majority (80%) of the focus groups occurred six months after the pre-survey; only one was earlier, three months following the pre-survey.

Differences in patient skills were found to be consistent with current reported assessments of residents in the cities where the centers were located. In the urban city where two of the NMHCs were located the high school graduation rate is extremely low, with an average of 25% of students finishing all twelve years of schooling (National Center for Educational Statistics, 2007). The two primary care centers also demonstrated the lowest patient NVS health literacy scores. Possessing less than adequate skills in both basic literacy and health literacy, patients served by the two primary care centers will be challenged to successfully manage their everyday living and health needs.

Current economic woes were evident in the results of the payor mix. With unemployment at a 13% high (U.S. Department of Labor Statistics, 2010) in Michigan, many former workers find themselves unemployed or employed part time and struggling to pay health care costs. In the sample for this study, the uninsured patients' NVS scores were actually more similar to those who were commercially insured and were higher than the Medicaid/Medicare groups. The uninsured are often times the recently laid off and/or newly part-time workers. The uninsured often reported during informal discussion, to be former auto workers, engineers, secretaries, administrators, and skilled trade workers.

The most significant demographic variables associated to health literacy scores in this sample included primary language (other than English); race (African Americans), years of education, and insurance type (Medicaid). The

recent study by Shah et al. (2010) confirms the study findings related to years of education and race. The association results were not surprising in order of predictability of health literacy assessment scoring. However, the investigator cautions assumptions based on the language and race findings. In our sample, a large portion of patients speaking languages other than English were ESL (English as a Second Language) Mexican immigrants and international college students. Race findings illustrate a majority percentage of African American participants from an urban area with extremely low levels of educational attainment, highlighting the likelihood that factors pertaining to the Education System are at work here. The relevance of Medicaid patients having lower literacy than any other group, including the uninsured, and that this is a statistically significant predictor of health literacy needs to be taken seriously by providers and primary care practices. All of these sites cared for a substantial number of Medicaid patients and addressing health literacy needs in these practices is critical.

The use of the NVS to assess patient health literacy was found to be a well accepted and efficient tool to identify patients with health literacy challenges. When used during the process of patient intake, it added no more than 5 minutes to the vital sign process. The patients' perception overall was that it was easy to use and their friends and family would also be likely to agree to answer questions about a food label (especially ice cream). Even when patients missed every question on the NVS, they stated the use of the tool was "easy", which confirms individuals do not perceive personal literacy deficits when other skills are

functional (Bass et al., 2002). The investigators also observed that patients enjoyed learning how to read a food label and often asked questions in relation to their specific health concern and nutrition – this was particularly true with diabetic patients. Two, of the seven, clinics have plans to incorporate the NVS into the patient care routine.

Provider questions regarding actions to be taken to address health literacy assessment outcomes was a common concern voiced in relation to health literacy screening. Baker (2006) questions the value of screening if it does nothing to improve communication, or correctly identify patient capabilities; instead he opts for “universal precautions” of “plain” language. This statement reinforces the need for further education of providers and staff related to communication and patient skill sets.

As was noted in the focus group discussions, the methods of communication (verbal and written) between staff members at each clinical site lacked a standardized process. Observations or conversations raising questions related to patient health literacy skills were not documented within the patient chart nor did staff members consistently pass the information to providers. This is especially troublesome as the patient with low literacy is often mislabeled as “non-compliant”; when instead there exists an inability to follow directions or understand health teaching due to low health literacy skills. In truth, patients may have every intention of following the care prescribed but lack the skill set to succeed.

Additionally, the assessment data raises anxiety in providers and staff in relation to their accountability in addressing the patient deficit as cited by one provider “I couldn’t just end the assessment without addressing what the patient had answered wrong and teaching them”. Coupled with the comments by staff related to assessing those they “knew well” as a point of personal discomfort, further study is needed to explore provider/staff personal health literacy and comfort with the concept and their own personal skills set.

Of note were the comments the researchers received during focus groups, stating, “The success of the NVS assessments was directly related to the communication skills of the researchers and their ability to make the patients feel comfortable”. The investigator questions if each center considers that their staff provides “caring, clear communication” routinely with patient care? If so, then why is it problematic assessing health literacy and/or communicating in a “plain” fashion? The topic of “clear” communication is supported by the efforts of the Partnership for Clear Health Communication (2007) in emphasizing the *Ask Me 3* campaign. This technique was presented in the module and encourages providers to encourage participation by patients to ask questions regarding their care through three questions. Maybe what has been lost on the provider/staff side of the equation is the fact providers/staff should be equally participating through appearing “open”, communicating clearly, and encouraging patient questions and dialogue.

The variations in literacy scores across practice sites were an interesting aspect of this study. The cities in which the primary care centers practiced were

varied and reflected in the patient populations they served. The affiliation of the NMHCs with university settings was particularly evident in the high NVS scores at one health center catering to graduate students. The health centers in the largest urban city, reflected the overall literacy capabilities of a large number of the county residents (National Center for Educational Statistics, 2003) At another center the uninsured were often the newly unemployed, whose literacy skills reflected more education and training when compared to the Medicaid population. In a state that is struggling to meet the general educational expectations of the citizenry, this study shines the light on a tangential concern that impacts communities – health and the associated literacy.

As an preliminary study, more work is needed to confirm the outcome data related to: indicators of patient health literacy, raise concerns related to the “new” face of the uninsured, disprove patients will refuse to participate in assessment of skills, and raise questions regarding the best method to educate and support providers and staff in busy primary care practices. Perhaps including the staff in the design of the intervention and taking a more participatory action approach would prove to lend weight and credence to the intervention and increase participation. Often times health educators tend to forget that the “community” is also those who may be professional colleagues and staff. .

Limitations

The small size of the provider-staff sample prevented meeting the requirements for a power analysis and was unavoidable based upon access to qualified NMHCs, normal staffing patterns, size, budget and clientele served.

The majority of the centers are subsidized to some extent by grants and university budgets while serving a clientele that is severely underserved. The small provider/staff sample size of this study prevents the ability to generalize results to a larger population and calls for a larger, national study of NMHCs after more preliminary work.

The patient sample contained significant power in aggregate reporting but was not sufficient to conclusively provide a reliable profile mean for individual clinics regarding patient literacy skills. This was an area of discussion during focus groups, when staff felt the data collection was performed at a time which did not include “typical” patients i.e. flu immunization clinics or sufficient numbers versus yearly total of patients.

The lack of control over the process of interacting with providers and staff to administer pre/post surveys and assure the educational module was completed was not only a handicap for data collection, but may have adversely affected outcomes related to all three domains (KAB). These small primary care practices are extremely busy with minimal staffing, leaving little time for staff development at scheduled clinic meetings. Unfortunately, the researchers agreed to center requests to use the “honor” system in terms of the literacy module and it was clear that not all staff took this seriously; which was an impediment to the overall study and ability to ascertain completion of the educational task. During focus group discussion, and informal conversations with providers/staff, the research concluded many believed they understood health literacy and knew implicitly when a patient had health literacy challenges. Providers/staff beliefs

reinforced the notion that the educational module would not provide new knowledge – this belief was not measured on the survey and warrants further examination in future studies.

There exists a lack of studies examining the role of continuing education in ambulatory clinical settings. Unanswered are questions related to the impact of the role of staff development and education at the primary point of access for patient health promotion and prevention education and care. Providers, physicians and nurse practitioners, through virtue of licensing must demonstrate continuing education but it is dependent on personal responsibility to enroll in a program of choice and may, or may not, be financed by the clinic. Clinic staffs receive education based upon the need of the clinic/ certifying agencies and outside attendance at workshops becomes the responsibility of the individual financially and educationally. In contrast, within the broader health system (i.e. hospitals), large amounts of money are spent supporting staff education, many times mandated but not always. In short, the focus of educating staff is built into the hospital environment but not so the clinic environment. This educational intervention was not considered a “necessity” for clinic function or certification, both of which would have guaranteed participation. Further research is needed to demonstrate how the role of continuing education influences provider and staff care practices in relation to patient health literacy.

Lastly, integrating the NVS into the health centers normal routine was integral to cultivating the acceptance of assessment. When prevented from demonstrating the ease of NVS assessments integration and use, skepticism

regarding impediment of work flow persisted and the perception of extended patient visit time. The two primary care centers who allowed the researchers to complete the patient intake routine with the NVS added, decided to implement the use of the NVS in their practice to routinely screen their patients for health literacy.

Conclusion

For the clinic providers and staff completing the module, statements of educational value and acknowledgement of learning “more” about health literacy were forthcoming. The use of an “honor” system agreement, when implementing an educational program was found to be inadequate for the means of educating staff and reaching a common understanding of patient health literacy. When left to employee choice vs. center requirement, the feasibility of implementing a web-based educational program was not supported by this study. Health literacy knowledge, attitudes and beliefs of providers and staff did not change significantly based upon a number of extraneous factors.

This study demonstrated the use of the NVS in a primary care setting is feasible within the constraints of time and patient flow. Contrary to an often referenced study (Parikh et al., 1996) patients did not exhibit shame, or embarrassment, when using the NVS and often enjoyed the interaction related to discussing nutrition. This study’s NVS assessment of patients (N=282) and three perception questions demonstrated similar results to a study (N=179) reported by VanGeest et al. (2010) using the NVS and eliciting reactions to the screening with post assessment questioning: comfort with the assessment,

recommendations to implementing the use of the NVS, and perception friends and family would agree to using the NVS.

Overall, providers and staff felt the addition of the NVS assessment at the primary care center would be beneficial in regards to identifying low health literate patients and in standardizing communication. Low health literacy in these primary care practices was considerable and demographic association were identified that will be beneficial to primary care providers/staff. Next steps should include the provision of interventions for both staff and patients, in terms of the safest and best outcomes for all.

Implications for Future Research

As previously stated, the *long term research goal* is to enhance safety in primary care by incorporating health literacy practices into the care delivery methods used by providers/staff, ultimately enhancing patient-provider communication. This study has significance related to health literacy and nurse practitioners, as nurse managed health centers have been shown to provide unique care in communities encouraging open communication and patient participation in self care. A study observing the communication skills practiced by NMHC's providers/staff, strengthened by the addition of the health literacy educational intervention would provide a platform to develop safety systems within the practice aimed at the health literacy skills of the patient population.

The clinical sites involved in this study overwhelmingly voiced interest in standardizing communication processes. As the participating Nurse Managed Health Centers have been introduced to the concept of health literacy and the

impact on patients and care, the next step would be to examine communication patterns within these clinics. Additionally, expanding the network to NMHCs nationally would provide the numbers to ascertain the statistical significance of health literacy education and communication practices. Targeting a specific diagnostic code (i.e. hypertension) would allow the researcher to observe communication patterns of providers and staff, tailor health messages to an appropriate health literacy understanding level, and measure outcomes.

Another intriguing area of study is family literacy, particularly in conjunction with health literacy. Using the health literacy intervention point model (Figure 2) interventions could be explored in a trans-disciplinary model approach. Focusing on the health literacy intervention point of the Education System: basic components of the federal program of Even Start address the following:” early childhood education, adult literacy, (adult basic and secondary-level education and /or instruction for English language learners), parenting education, and interactive literacy activities between parents and their children” (U.S. Department of Education, 2003). Opportunities to integrate health education supporting health literacy development exist within Even Start as the model promotes family literacy and is based upon 5 “R”s – recruitment (reassurance regarding the nature of the learning environment), retention (built around client needs/input), respect (staff modeling and positive reinforcement), responsibility (personal responsibility), and resourcefulness (creative teaching and attention to learning styles) (Tardewather, 1996). The 5 “R”s would be an excellent model for the health system to adopt. Beginning health literacy skill development with

families would pay off in large dividends to the health system, through educational programs aimed at health promotion, risk reduction, and health communication.

The possibilities are endless to exploring health literacy. If consideration is given to only to understanding patient skills and the broader health system; we as health care providers miss the opportunity to truly understand our patients at a deeper level and work in partnership for better health. By considering the three health literacy intervention points (see Figure 2) as the larger picture of patient health, we can truly make a difference in increasing the health literacy skills of individuals through collaborative trans-disciplinary endeavors.

Table 1

Characteristics of the Participating Primary Care Settings: Participant Centers (n=7)

Clinic	D1	D2	GR	AA 1	AA 2	LC	MC
Number of Pt. visits 2008 (Unduplicated)	1740 682	2594	3231 1118	620	636	8776 2205	3181 1024
Age Range (%)							
Infant-9	3	0	2	16	25	4	5
10-19	6	5	4	11	12	5	7
20-39	16	39	55	35	39	39	40
40-54	44	37	22	23	16	32	32
55 and above	31	19	15	15	7	19	15
Pt. Gender (%)							
Female	15	42	45	66	64	66	63
Male	85	58	55	34	36	28	40

Table 1 cont.

Characteristics of the Participating Primary Care Settings: Participant Centers (n=7)

Race/ Ethnic (%)						(missing)	(missing)
African American	95	83	9	20	20		
Asian	2	0	3	25	25		
Caucasian	0	7	78	45	45		
American Indian/Native Alaskan	0	0	1	1	1		
Hawaiian/Pacific Islander	0	0	1	0	0		
Two or More Races	3	0	1	9	9		
Other Race		8	2	0	0		
Unknown Race		18	3	0	0		
Hispanic	1	2	3	30	30		
Non-Hispanic		96	94	63	63		
Unknown Ethnicity		2	3	7	7		
Payor Mix (%)							
Private (third party)	2	26	17	31	61	11	1
Medicaid	8	19	10	29	12	23	20
Medicare	10	12	40	6	2	9	3
Other Government (County Health Plans)	80	1	0	23	15	52	67
Sliding scale/self pay	0	41	31	11	11	5	9

Table 2

Providers-Staff Demographics: Frequencies (%) (N = 47)

note. * () indicates valid %

		D1 (n=6)	D2 (n=9)	GR (n=8)	AA (n=14)	LC/MC (n=10)	Total (n=47)
Gender	Female	5 (83.3)	8 (88.9)*	7 (87.5)	14 (100.0)	8 (80.0)	42 (91.3)
	Male	1 (16.7)	1 (11.1)	1 (12.5)	-	2 (20.0)	4 (8.5)
Age	22-30 yrs	2 (40.0)	1 (12.5)	2 (25.0)	1 (9.1)	3 (30.0)	9 (21.4)
	31-40 yrs	2 (40.0)	2 (25.0)	-	3 (27.3)	1 (10.0)	8 (19.0)
	41-50 yrs	-	3 (37.5)	2 (25.0)	3 (27.3)	1 (10.0)	9 (21.4)
	51-60 yrs	1 (20.0)	1 (12.5)	3 (37.5)	3 (27.3)	2 (20.0)	10 (23.8)
	61-74 yrs	-	1 (12.5)	1 (12.5)	1 (9.1)	3 (30.0)	6 (14.3)
Ethnicity	Caucasian	1 (20.0)	3 (33.3)	7 (87.5)	12 (85.7)	8 (80.0)	31 (66.0)
	African American	4 (80.0)	6 (66.7)	-	-	-	10 (21.7)
	Hispanic/Latino	-	-	-	1 (7.1)	1 (10.0)	2 (4.3)
	Asian	-	-	-	1 (7.1)	-	1 (2.2)
	Other	-	-	1 (12.5)	-	-	2 (4.3)

Table 2 cont.

Providers-Staff Demographics: Frequencies (%) (N = 47)

note. * () indicates valid %

Highest Education	Lower than High school	1 (20.0)	-	-	-	-	1 (2.3)
	High school	1 (20.0)	-	-	1 (7.7)	1 (11.1)	3 (7.0)
	College or University	1 (20.0)	4 (50.0)	3 (37.5)	5 (38.5)	6 (66.7)	19 (44.2)
	Graduate school	2 (40.0)	4 (50.0)	5 (62.5)	7 (53.8)	2 (22.2)	20 (46.5)
Clinic Role	Biller	-	-	1 (12.5)	1 (7.7)	1 (10.0)	3 (6.7)
	Clerk/Office Asst.	1 (20.0)	1 (11.1)	1 (12.5)	1 (7.7)	3 (30.0)	7 (15.6)
	Educator	-	-	-	1 (7.7)	-	1 (2.2)
	Medical Asst.	2 (40.0)	3 (33.3)	-	3 (23.1)	2 (20.0)	10 (22.2)
	Nurse Practitioner	2 (40.0)	3 (33.3)	2 (25.0)	2 (15.4)	-	9 (20.0)
	Physician	-	-	-	-	2 (20.0)	2 (4.4)
	Registered Nurse	-	1 (11.1)	1 (12.5)	1 (7.7)	-	3 (6.7)
	Social Worker	-	-	-	2 (15.4)	-	2 (4.4)
	Other	-	1 (11.1)	3 (37.5)	2 (15.4)	2 (20.0)	8 (17.8)
Length in Position	Less than 10 years	5 (83.3)	4 (50.0)	3 (37.5)	3 (27.3)	5 (55.6)	20 (48.8)
	10 years or more	1 (16.7)	4 (50.0)	5 (62.5)	8 (72.7)	4 (44.4)	21 (51.2)

Table 3

Patient Demographics: Frequencies (%) (N = 282)

		D1 (n=40)	D2 (n=41)	GR (n=41)	AA 1 (n=40)	AA 2 (n=40)	LC (n=40)	MC (n=40)	Total (n=282)
Gender	Female	31 (77.5)	19 (46.3)*	25 (61.0)	30 (75.0)	23 (57.5)	20 (50.0)	27 (67.5)	175 (62.1)
	Male	9 (22.5)	22 (53.7)	15 (36.6)	10 (25.0)	17 (42.5)	20 (50.0)	13 (32.5)	106 (37.6)
Age	<30 yrs	5 (12.5)	2 (4.9)	10 (24.4)	16 (40.0)	14 (35.0)	12 (30.0)	10 (25.0)	69 (24.5)
	31-40 yrs	6 (15.0)	6 (14.6)	12 (29.3)	9 (22.5)	18 (45.0)	8 (20.0)	8 (20.0)	67 (23.8)
	41-50 yrs	7 (17.5)	18 (43.9)	9 (22.0)	7 (17.5)	5 (12.5)	11 (27.5)	10 (25.0)	67 (23.8)
	51-60 yrs	13 (32.5)	13 (31.7)	8 (19.5)	5 (12.5)	2 (5.0)	7 (17.5)	9 (22.5)	57 (20.2)
	61+ yrs	9 (22.5)	2 (4.9)	2 (4.9)	3 (7.5)	1 (2.5)	2 (5.0)	3 (7.5)	22 (7.8)
Ethnicity	Caucasian	3 (7.5)	7 (17.1)	27 (65.9)	17 (42.5)	15 (37.5)	28 (70.0)	36 (90.0)	133 (47.2)
	African American	37 (92.5)	31 (75.6)	7 (17.1)	3 (7.5)	3 (7.5)	8 (20.0)	1 (2.5)	90 (31.9)
	Hispanic/Latino	0 (0.0)	0 (0.0)	4 (9.8)	16 (40.0)	3 (7.5)	1 (2.5)	1 (2.5)	25 (8.9)
	Asian	0 (0.0)	1 (2.4)	0 (0.0)	0 (0.0)	16 (40.0)	0 (0.0)	1 (2.5)	18 (6.4)
	Other	0 (0.0)	2 (4.8)	2 (4.9)	4 (10.0)	3 (7.5)	3 (7.5)	1 (2.5)	15 (5.3)

Table 3 cont.

Patient Demographics: Frequencies (%) (N = 282)

Primary Language	English	39 (97.5)	40 (97.6)	40 (97.6)	25 (62.5)	15 (37.5)	37 (92.5)	38 (95.0)	234 (83.0)
	Spanish	0 (0.0)	0 (0.0)	0 (0.0)	13 (32.5)	3 (7.5)	1 (2.5)	1 (2.5)	18 (6.4)
	Other	1 (2.5)	1 (2.4)	1 (2.4)	2 (5.0)	22 (55.0)	2 (5.0)	1 (2.5)	30 (10.6)
Highest Education	Lower than High school	13 (32.5)	9 (22.0)	7 (17.5)	8 (20.0)	1 (2.5)	7 (17.5)	6 (15.0)	51 (18.1)
	High school	14 (35.0)	22 (53.7)	11 (27.5)	9 (22.5)	2 (5.0)	10 (25.0)	17 (42.5)	85 (30.2)
	College or University	12 (30.0)	9 (22.0)	15 (37.5)	16 (40.0)	10 (25.0)	19 (47.5)	16 (40.0)	97 (34.5)
	Graduate school	1 (2.5)	1 (2.4)	7 (17.5)	7 (17.5)	27 (67.5)	4 (10.0)	1 (2.5)	48 (17.1)
Insurance	Medicare	4 (10.0)	2 (4.9)	2 (4.9)	4 (10.0)	1 (2.5)	1 (2.5)	0 (0.0)	14 (5.0)
	Medicaid	26 (65.0)	17 (41.5)	9 (22.0)	8 (20.0)	2 (5.0)	14 (35.0)	10 (25.0)	86 (30.5)
	Commercial	2 (5.0)	4 (9.8)	18 (43.9)	15 (37.5)	30 (75.0)	4 (10.0)	3 (7.5)	76 (27.0)
	County Health Plan	0 (0.0)	8 (19.5)	0 (0.0)	10 (25.0)	3 (7.5)	17 (42.5)	24 (60.0)	62 (22.0)
	Uninsured	6 (15.0)	10 (24.4)	12 (29.3)	3 (7.5)	4 (10.0)	4 (10.0)	3 (7.5)	42 (14.9)
	Other	2 (5.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.7)

Note. * () indicates valid %.

Table 4

Assessed Pt. HL by site and Provider/Staff estimations of pt. low health literacy pre and post HL module

		Actual percentage of patients with:			Staff's mean estimation of patients with low literacy	
		High likelihood of limited literacy	Possibility of limited literacy	Adequate literacy	at pre-test	at post-test
D2		34.1%	51.2%	14.6%	45.0%	48.9%
D1		30.0%	47.5%	22.5%	45.8%	41.2%
GR		17.1%	19.5%	63.4%	62.5%	N/A
AA	AA1	32.5%	15.0%	52.5%	36.7%	49.9%
	AA2	5.0%	15.0%	80.0%		
C	LC	12.5%	27.5%	60.0%	64.9%	48.4%
	MC	17.5%	10.0%	72.5%		

Table 5

Mean and Standard Deviation of HL KAB Scores among Providers/Staff at Pre and Post Surveys

Providers/Staff group*	Health Literacy Knowledge					Attitude & Belief				
	n	pre Mean±SD	post Mean±SD	t(df)	p	n	pre Mean±SD	post Mean±SD	t(df)	p
Provider 1	11	2.64±0.92	2.55±1.04	0.36 (10)	0.72	10	3.94±0.26	3.95±0.27	0.22 (9)	0.83
Provider 2	7	3.14±0.69	2.00±1.16	3.36 (6)	0.02	7	3.96±0.35	4.12±0.44	2.20 (6)	0.07
Support staff	13	1.85±0.90	1.92±0.64	0.43 (12)	0.67	16	3.81±0.32	3.94±0.31	1.37 (15)	0.19

Note. *Provider 1 group includes NP, physician, PA, and CNS; Provider 2 group includes RN, social worker, educator, dietician, and student nurse; and Support staff group includes biller, clerk, MA, and LPN.

Table 6

Patients' Newest Vital Sign (NVS) Result (*N* = 282)

	D1 (n=40)	D2 (n=41)	GR (n=41)	AA1 (n=40)	AA2 (n=40)	LC (n=40)	MC (n=40)	Total (n=282)
1) Patient with Correct Answers to NVS questions								
NVS#1. Calculating calories of the entire container	15 (27.5)	10 (24.4)*	28 (68.3)	23 (57.5)	28 (70.0)	29 (72.5)	31 (77.5)	164 (58.2)
NVS#2. Calculating the amount for an intake of 60 grams of carbohydrates	15 (37.5)	17 (41.5)	23 (56.1)	25 (62.5)	34 (85.0)	23 (57.5)	28 (70.0)	165 (58.5)
NVS#3. Calculating grams of saturated fat when subtracting one serving from 42 grams of saturated fat	10 (25.0)	4 (9.8)	19 (46.3)	20 (50.0)	24 (60.0)	14 (35.0)	18 (45.0)	109 (38.7)
NVS#4. Calculating a percentage for one serving calories out of the total daily intake calories	3 (7.5)	7 (17.1)	23 (56.1)	18 (45.0)	29 (72.5)	23 (57.5)	25 (62.5)	128 (45.4)
NVS#5. Detecting allergenic food ingredients-1	30 (75.0)	29 (70.7)	35 (85.4)	33 (82.5)	36 (90.0)	35 (87.5)	32 (80.0)	230 (81.6)
NVS#6. Detecting allergenic food ingredients-2	21 (52.5)	19 (46.3)	32 (78.0)	23 (57.5)	31 (77.5)	32 (80.0)	30 (80.0)	188 (66.7)

Table 6 cont.

Patients' Newest Vital Sign (NVS) Result (*N* = 282)

2) NVS total score: Mean±	2.35±	2.10±	3.90±	3.55±	4.52±	3.90±	4.10±	3.49±
S.D.	1.66	1.34	1.96	2.32	1.52	1.91	1.85	1.99
3) Patients' Health Literacy Level								
High likelihood (50% or more) of limited literacy	12 (30.0)	14 (34.1)	7 (17.1)	13 (32.5)	2 (5.0)	5 (12.5)	7 (17.5)	60 (21.3)
Possibility of limited literacy	19 (47.5)	21 (51.2)	8 (19.5)	6 (15.0)	6 (15.0)	11 (27.5)	4 (10.0)	75 (26.6)
Adequate literacy	9 (22.5)	6 (14.6)	26 (63.4)	21 (52.5)	32 (80.0)	24 (60.0)	29 (72.5)	147 (52.1)

Note. * () indicates valid %.

Table 7

Mean Differences of Patients' Newest Vital Sign (NVS) Score by Demographic Variables ($N = 282$)

Variable	Category	n	Mean±S.D.	t or F	p
Gender	Female	175	3.57±1.95	0.83	0.406
	Male	106	3.37±2.05		
Age	-30 yrs	69	3.81±1.89	2.50	0.043
	31-40 yrs	67	3.82±1.98		
	41-50 yrs	67	3.46±1.93		
	51-60 yrs	57	2.93±2.11		
	61+ yrs	22	2.95±1.89		
Ethnicity	Caucasian ^{abc}	133	4.49±1.69	26.22	0.000
	African American ^{ad}	90	2.34±1.58		
	Hispanic/Latino ^{be}	25	2.40±2.16		
	Asian ^{de}	18	4.06±1.86		
	Other ^c	15	2.40±1.50		

Table 7 cont.

Mean Differences of Patients' Newest Vital Sign (NVS) Score by Demographic Variables (*N* = 282)

Primary Language	English ^a	234	3.61±1.96	7.44	0.001
	Spanish ^{ab}	18	1.78±1.80		
	Other ^b	30	3.53±1.91		
Highest Education	Lower than High school ^{ab}	51	2.14±1.71	26.51	0.000
	High school ^{cd}	85	2.91±1.86		
	College or University ^{ace}	97	4.05±1.77		
	Graduate school ^{bde}	48	4.88±1.57		
Insurance	Medicare ^a	14	2.50±2.18	8.56	0.000
	Medicaid ^b	86	2.72±1.88		
	Commercial ^{abc}	76	4.53±1.82		
	County Health Plan ^c	62	3.44±1.94		
	Uninsured	42	3.62±1.72		
	Other	2	2.50±0.71		

Note. ^{a-e} Groups with same letter are significantly different according to Bonferroni post hoc test.

Table 8

Summary of Multiple Regression to explain the Patients' Newest Vital Sign (NVS) Score ($N = 282$)

Variables	<i>B</i>	β	<i>t</i>
Age	-0.01	-0.05	-0.96
Years of Education	0.15	0.25	3.84***
Primary Care Setting			
GR vs. D2	0.62	0.11	1.53
D1 vs. D2	0.69	0.12	1.95
AA1 vs. D2	1.18	0.21	2.65**
AA2 vs. D2	1.54	0.27	3.15**
LC vs. D2	1.12	0.20	2.71**
MC vs. D2	1.21	0.21	2.72**

Table 8 cont.

Summary of Multiple Regression to explain the Patients' Newest Vital Sign (NVS) Score ($N = 282$)

Variables	<i>B</i>	β	<i>t</i>
Insurance			
Medicare vs. Medicaid	-0.08	-0.01	-0.18
Commercial vs. Medicaid	0.89	0.20	2.77**
CHP vs. Medicaid	0.05	0.01	0.15
Other vs. Medicaid	0.31	0.03	0.58
Uninsured vs. Medicaid	0.63	0.11	2.08*
Ethnicity			
Asian vs. Caucasian	0.27	0.03	0.49
African American vs. Caucasian	-1.21	-0.28	-4.06***
Other vs. Caucasian	-0.65	-0.09	-1.18
Primary Language			
Spanish vs. English	-1.79	-0.22	-2.79**
Other vs. English	-2.35	-0.37	-5.13***

Note. $R^2 = .45$, $F(18, 261) = 11.81$, $p < .001$

* $p < .05$, ** $p < .01$, *** $p < .001$

Appendix A
Patient Consent and
Patient Experience with NVS Questions

NVS Interview Script

P = Potential Participant

I = Interviewer

I: Hello, my name is _____ and I am a graduate student at the University of Michigan - School of Nursing. I am currently conducting research under the supervision of Dr. Joanne Pohl/Renee McCune on patients' understanding of written health information by using a food label.

Would you be willing to help us by taking about ten minutes to answer a few questions related to the food label, and give us some feedback on the use of this method of evaluating personal understanding of written information? If you do not wish to take part in this study, it will not change your care at this clinic. If you do choose to assist us, and provide your time, we would like to give you a gift card for \$15.

P: No, I am not interested (thank them for their time in considering)

OR

P: Yes.

I: The purpose of the study is to use a food label to see how people understand written health information. Care providers often use written handouts as a reminder of what is discussed at a visit and to provide health education.

- Involvement is voluntary and you may stop at any time and continue on with your clinic visit
- The time involved is 10-15 minutes. You will look at the food label and answer 6 questions about the information on the label. After that, you will be asked 3 questions about using the label.
- There are no known risks to taking part in this study.
- While you will not directly benefit from this study, by taking part you will help us understand how to better communicate with individuals to improve understanding of health information.
- All information collected is private and you will not be identified in any reporting

- All information will be kept in a secure location
- If you have any questions you may contact the following individuals:
 - Joanne Pohl, PhD, RN
 - Renee McCune, MEd, RN
 - UM Institutional Review Board.

I: By looking at the food label and answering the questions, you are agreeing to participate in this pilot project. Do you have any questions?

(Provide copy of contact list with study name and time to read the document. Answer any questions that the participant may have.)

I: I would now like to have you look at the Newest Vital Sign, which is the food label I mentioned. Take a minute to look over the label and then I will ask you six questions about the information on the label. Give me what you feel is the best answer to the question. I will be marking a record sheet as you answer.
(Ask six questions on score sheet related to the NVS)

I: I am now going to ask you three questions about using the NVS. Feel free to give me your honest feelings. I will be writing your comments down to add to a list of comments made by others using the NVS. (Ask three standard open ended questions)

1) On a scale of 1-10 (with 1 being “extremely easy” and 10 being “extremely difficult”,

How would you rate answering questions about the ice cream label?

2) How do you think the ice cream label could be useful to your personal health when

used at health visit?

3) What would people you know think about answering questions about the ice cream

label at a health visit?

I: We are now finished. Do you have any questions?
Thank you for taking the time to participate in our study. As a token of our appreciation for taking time out of your day, we would like you to have this \$15 gift card.

APPENDIX B

Health Literacy in Primary Care (screen shots)

(McCune et al, 2006)

This screenshot shows a presentation slide with a navigation bar at the top containing 'Intro', 'Literacy', 'Health Literacy', 'Why Worry?', and 'How to Help'. The main title is '2006 US Literacy Rates'. On the left, there is a photograph of an elderly woman with glasses looking at a pill bottle, with the text 'Health Literacy: Not Just Reading' overlaid. The central text states: 'Approximately 21-23% percent of the adult population have only rudimentary reading and writing skills.' To the right is a map of Michigan with a star and an information icon. Below the text are icons for a stack of books, a medical form, and hospital beds. At the bottom right are navigation icons for 'Prev.', 'Home', and 'Next'.

This screenshot shows a presentation slide with a navigation bar at the top containing 'Intro', 'Literacy', 'Health Literacy', 'Why Worry?', and 'How to Help'. The main title is '2006 US Literacy Rates'. On the left, there is a photograph of an elderly woman with glasses looking at a pill bottle, with the text 'Health Literacy: Not Just Reading' overlaid. The central text states: '50% of all patients that enter the hospital have literacy challenges. Even those with average to high literacy skills experience challenges due to impaired cognition influenced by stress and pain.' To the right is a map of Michigan with a star and an information icon. Below the text are icons for a stack of books, a medical form, and hospital beds. At the bottom right are navigation icons for 'Prev.', 'Home', and 'Next'.

APPENDIX C
Provider-Staff Pre and Post Knowledge, Attitudes and Beliefs Survey

Health Literacy Survey

Please answer each question by circling an answer - there may be more than one answer to some questions.

- 1) Health literacy is:**
 - a. the ability to read health information and follow written instructions
 - b. the ability to find information regarding health and staying healthy
 - c. the ability to obtain, process, and understand basic health information and make appropriate decisions
 - d. none of above

- 2) In the U.S., _____ of the population is low literate** (includes those that are illiterate and marginally literate).
 - a. 16%
 - b. 21%
 - c. 39%
 - d. 48%

- 3) What percentage of individuals applying for Medicaid, can understand the rights and responsibilities section of the application?**
 - a. 10%
 - b. 14%
 - c. 24%
 - d. 50%

- 4) An individual at our clinic with low health literacy may** (circle all that apply):
 - a. act hostile
 - b. express dissatisfaction with care
 - c. experience more hospitalizations
 - d. say they forgot their glasses at home when asked to review forms

- 5) Tasks requiring health literacy skills include** (circle all that apply):
 - a) planning and shopping for family meals
 - b) locating a provider's office, or lab, for tests
 - c) balancing a checkbook
 - d) voting on healthcare or environmental issues
 - e) understanding the risk of a procedure or disease

Write in your estimate.

- 6) I believe _____% of our clinic population has limited health literacy.**

APPENDIX C (cont.)

ID: Site _____

Health Literacy practices include:

- Use of forms and handouts written at a low reading level (4th – 5th grade),
- Observing for signs of low literacy – incomplete forms, forgotten reading glasses, anger
- Performing a health literacy assessment
- Assessing for comprehension at the visit conclusion or after teaching

151

For each question, check the box in the column to the right that best indicates your response.	Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
7) When communicating with patients, I use different techniques to assure understanding					
8) All of our clinic patient forms and patient education materials are written at a grade level to allow patients to:					
8a. Understand					
8b. Provide, or use, health information					
8c. Make health care decisions					
9) If I notice that an individual has difficulty with the paperwork, or directions given, I share this information with other staff members through:					
9a. Verbal communication					
9b. Chart documentation					
10) I am aware of different ways to assess health literacy in a clinic setting.					
11) Use of health literacy practices improve the quality of patient care.					

APPENDIX C (cont.)

12) Use of health literacy practices are encouraged in our clinic setting.					
13) I need to increase the use of health literacy practices in my daily patient care.					
14) I am interested in learning, or improving, the skills necessary to include health literacy in my daily patient care.					
15) Knowledge of health literacy helps me make decisions about patient care.					
16) Awareness of patient health literacy is necessary in the primary care setting.					
17) Use of health literacy practices will increase visit times.					

APPENDIX D
Provider-Staff Demographic Survey

Date: _____

Subject Code: *clinic code and unique ID* _____

Female: _____ **Male:** _____ **Age:** _____

Ethnic/Racial Identity:

Asian	_____
Caucasian	_____
African-American	_____
American Indian/Native Alaskan	_____
Hispanic/Latino	_____
Middle Eastern	_____
Two or more groups	_____
Other	_____
Unknown	_____

Primary language: _____ **Other languages spoken:**

Highest level of education:

Grade: _____ **Years of College:** _____

Clinic Role:

Biller	_____	Physician	_____
Clerk/Office Asst.	_____	Registered Nurse	_____
Dietician	_____	Resident	_____
Educator	_____	Student Nurse	_____
Medical Assistant	_____	Social Worker	_____
Nurse Practitioner	_____	Other	_____

Length of time in your profession: _____

Length of time at this clinic: _____

APPENDIX E

Newest Vital Sign Tool & Score Sheet

(Weiss et al., 2005)

Nutrition Facts			
Serving Size		½ cup	
Servings per container		4	
<hr/>			
Amount per serving			
Calories	250	Fat Cal	120
<hr/>			
			%DV
Total Fat	13g		20%
Sat Fat	9g		40%
Cholesterol	28mg		12%
Sodium	55mg		2%
Total Carbohydrate	30g		12%
Dietary Fiber	2g		
Sugars	23g		
Protein	4g		8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?

Answer: 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?

Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl."

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Answer: 33 is the only correct answer

4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Answer: 10% is the only correct answer

READ TO SUBJECT: Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?

Answer: No

6. (Ask only if the patient responds "no" to question 5): Why not?

Answer: Because it has peanut oil.

ANSWER CORRECT?

	yes	no
1.	<input type="checkbox"/>	<input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>
3.	<input type="checkbox"/>	<input type="checkbox"/>
4.	<input type="checkbox"/>	<input type="checkbox"/>
5.	<input type="checkbox"/>	<input type="checkbox"/>
6.	<input type="checkbox"/>	<input type="checkbox"/>
Interpretation		Number of correct answers:
Score of 0-1 suggests high likelihood (50% or more) of limited literacy		<input type="checkbox"/>
Score of 2-3 indicates the possibility of limited literacy.		<input type="checkbox"/>
Score of 4-6 almost always indicates adequate literacy.		<input type="checkbox"/>

APPENDIX F
Patient Demographic Survey

Date: _____

Data Collector Initials:

Subject Code: *clinic code and patient number*

Female: _____ **Male:**

Age: _____

Race:
Caucasian _____
African-American _____
American Indian/Native Alaskan _____
Two or more races _____
Other race _____
Unknown _____

Ethnic group:
Hispanic/Latino
Non-Hispanic
Unknown

Primary language _____

Highest level of education:

Grade: _____ Years of College: _____

Insurance:
Medicare _____
Medicaid _____
Commercial _____
Other _____
None _____

NVS Questions:

- 1)
- 2)
- 3)

APPENDIX G
Provider-Staff Focus Group Script

Clinic Focus Group Script

F = Facilitator

RA = Research Assistant

Welcome to our focus group and thank you for coming. I am _____ (facilitator) and with me is _____ (research assistant). We are here today to discuss the health literacy study you and your clinic have participated in this year.

I (F) will be leading the discussion today assisted by _____ (RA) who will be recording your responses on paper and on a tape recorder. It is important that we have a good record of what is said, in order to transcribe the sessions and compile results across the clinical sites – no identifiers will be included in the transcription. All tapes will be kept in a locked file cabinet and available only to the study team. Once the project is complete, all tape recordings will be destroyed.

Everything you say here today will be held confidentially and no names, or identifiers, will be used when we report the data collected. We want you to feel free to express your thoughts.

The plan for the next 60 – 90 minutes is:

- to present the results of the health literacy assessment done in your clinic on a sample of patients
- discuss the educational module everyone completed
- conclude with questions related personal communication

Everyone is encouraged to participate in the discussion. As there are multiple discussion points, it may be necessary to move on to the next point in an effort to cover everything we have scheduled.

We also ask that you be patient if the recorder asks to clarify a point in the discussion. Please talk one at a time.

Your participation in this focus group is important in gaining the views of care providers in relation to improving and working with patient health literacy.

We view your participation as a beginning point to improve communication between caregivers and patients and ultimately improving patient safety.

I would like to begin by sharing with you the health literacy assessment results from a sample of your patient population.

- We have provided each of you with a copy of the tool used, the Newest Vital Sign, which is a nutrition label.
- After your patients reviewed the label we asked them six questions related to information on the label.
- From the total of correct answers, an estimate of literacy skills was calculated.

In the initial survey you completed, you provided an estimate of the % of patients in your clinic population that may have limited health literacy.

- The average estimated was _____%

Using the Newest Vital Sign (NVS) we assessed a sample of patients (___#) and found that _____% had limited health literacy. This sample included: # Female/Male, between the ages of # & #, with an average educational level of _____ and with the primary language(s) of _____.

- What do these numbers mean to you?
- How could you see using this information in daily interactions with patients?

In administering the NVS, we found it took _____minutes.

- How do you see using such an assessment in your clinic?
- What is an acceptable amount of time for such an assessment?
- How would you see it impacting patient care?
- What are the pros/cons to using NVS?

While participating in this study:

- you have taken the pre/post health literacy surveys
- completed an educational module
- possibly observed us as we assessed your patients

In what ways has any of this changed your personal communication style?

- Prompters
 - o what have you observed regarding health literacy during this study in your patient interactions?
 - o what techniques have you tried in encounters with patients?

- describe any clinic routine changes
- discuss if the clinic has implemented changes to standard means of communication among staff regarding patient needs and concerns

We have reached the end of our time. Before we end, do you have any additional comments?

Thank you for participating in this focus group and contributing such insightful comments. We have refreshments available as a wrap up to all of your hard work.

Thank you again for being a participant in this study.

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