Understanding Health Literacy Skills of Patients with Cardiovascular Disease and Diabetes:

The Health Literacy Instructional Model

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HEALTH LITERACY

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Chapter 1

Health literacy in patients with cardiovascular disease and diabetes

Health literacy is the ability of a person to understand and act on the information provided to them by healthcare professionals and health education resources to manage their health (Parker & Ratzan, 2012). In addition to understanding the terms and concepts, health literacy also includes the ability to manipulate numbers (numeracy), navigate the healthcare system, communicate with healthcare professionals and care givers, and make good, well informed decisions (Nielsen-Bohlman, Panzer, & Kinzig, 2004). Health literacy, therefore, involves building the knowledge and skills of the patient to meet the demands and complexity of the condition.

Cardiovascular disease and metabolic conditions, such as coronary artery disease, heart failure, high blood pressure, high cholesterol, and diabetes are complex, demanding conditions requiring knowledge and skill on the part of the patient (Artininan et al., 2010). In comparison to conditions that are simple to detect and treat, cardiovascular disease and diabetes require a high level of patient involvement (Smith et al., 2013). Patients must know what, when, and how to monitor key signs and symptoms, understand nutrition labels, and medication instructions, must effectively communicate this information to their healthcare team, and can make good, well informed decisions that pertain to their health.

Since the publication of *"Health Literacy: A prescription to end confusion"* by the Institute of Medicine, health literacy has been a public health priority (Nielsen-Bohlman et al., 2004). It is estimated that as many as 90 million Americans lack the health literacy skills necessary to manage their conditions, resulting in the need to make health literacy a public health priority (Kutner, Greengerg, Jin, & Paulsen, 2006). Health literacy is not just a public health issue in the United States. It is a global problem. The European Health Literacy Survey (HLS-EU) indicated that 47% of Europeans have insufficient or problematic health literacy skills (Sorenson et al., 2015). Health literacy is considered a public health priority in Europe with a broad and more inclusive definition of health literacy by the World Health Organization Regional Office for Europe (Kickbusch, Pelikan, Apfel, & Tsouros, 2013). The European definition of health literacy includes

knowledge, motivation, competencies to access and apply health information, and the ability to make judgments concerning their health.

While differences in methodologies and populations make it difficult to compare rates of low health literacy in the United States to other parts of the world, there is an increase in the number of peer reviewed publications and public health initiatives that address health literacy worldwide (Pleasant, 2011). Pleasant and Kurvuvilla (2008) found a difference in clinical and public health perspectives in China, Mexico, Ghana, and India, suggesting challenges in both assessing and developing health literacy. The European Health Literacy Survey was scientifically grounded, derived from the definition and concepts, and pre-tested and field tested with input from health literacy experts, and was carried out in cooperation with partners in the Netherlands, Greece, Ireland, Austria, Poland, Spain, Bulgaria, and Germany and in collaboration with over 20 academic institutions and public health agencies (Sorensen et al., 2015). Cathery-Goulart et al., (2009) administered a translated version of the Test of Functional Health Literacy in Adults (TOFHLA) to 312 healthy individuals in Brazil, finding that 32% had limited health literacy skills.

The purpose of this work is to go beyond the description of low health literacy groups and to find ways to accommodate those with low literacy skills, to a better understanding of how to build health literacy skills in patients with cardiovascular disease throughout the range of health literacy. While awareness of health literacy among healthcare professionals and health educators is higher than it was 10-15 years ago, more work needs to be done to build knowledge, health literacy, and self-management skills in all patients with cardiovascular disease and diabetes. Current strategies, including using plain language is a great start, but is not enough to result in behavior change leading to better health outcomes.

The U.S. Department of Health and Human Services, Office of Health Promotion and Disease Prevention (2010) published a national action plan calling for evidence based and innovative approaches to promote health literacy and create a vision for a more health literacy population. This national action plan had led to research focused on the prevalence and health impact of low health literacy, and a better understanding of the causal pathways linking low health literacy to poor health outcomes. Policies, strategies, and interventions are based on the use of plain language, and the elimination of jargon,

with clear and concise messaging (Koh et al., 2011). Figure 1 is an illustration of the different ways in which patients acquire health knowledge, which is the first step to developing health literacy skills.
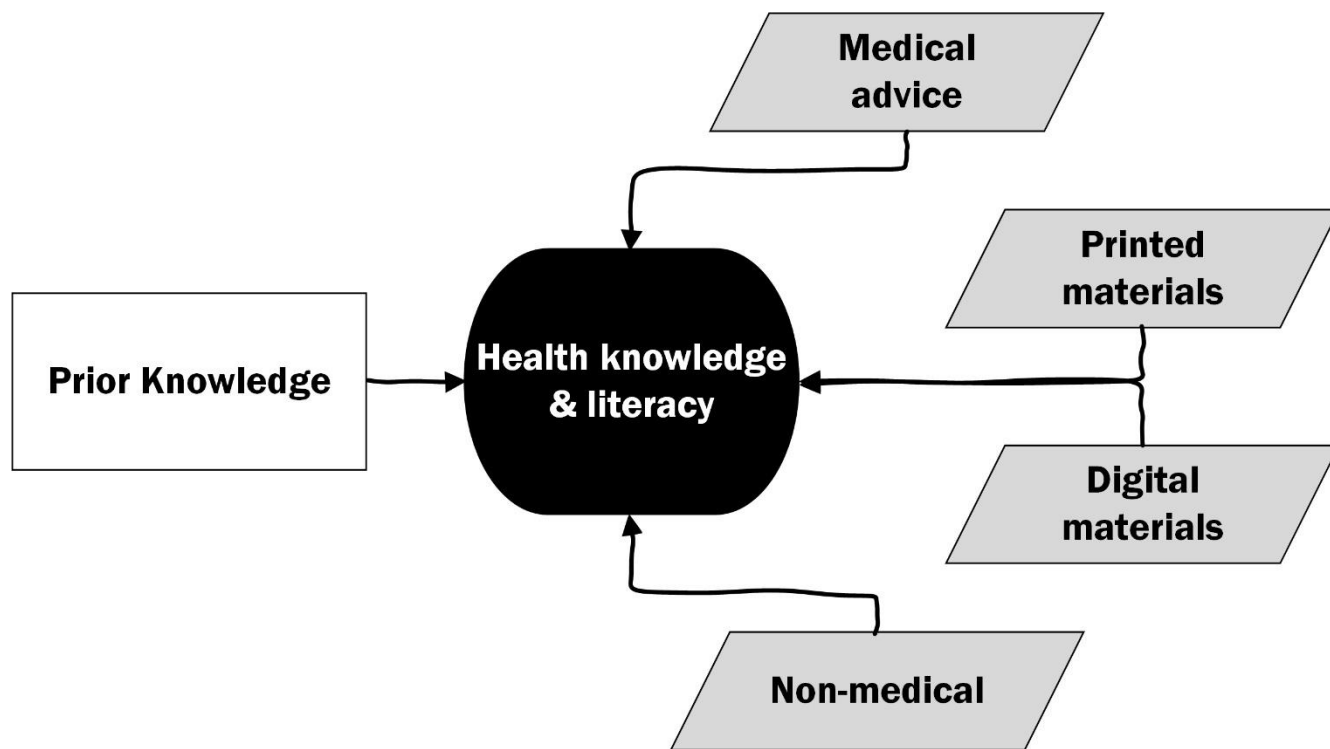

Figure 1. Common ways to gain health knowledge

Causal pathways

We care about health literacy because it is linked to poor health outcomes. Low health literacy mirrors social determinants of health and is linked to poor health outcomes. As with social determinants, cultural, demographic, and physical factors impact health literacy, and the relationship between low health literacy and health outcomes is mediated by access and utilization of healthcare services, patient/provider interaction, and self-care (Paasche-Orlow & Wolf, 2007). This relationship between social factors and health literacy is shown in Figure 2. Ironically, these factors closely resemble the components of functional and critical health literacy, navigation (access and utilization of health care services), communication (patient/provider interaction), and decision making (self-care). While these factors might "define" the baseline health literacy of the patients, the pathways, including access and utilization of healthcare, patient/provider interaction, and self-care and areas that can, in fact be modified. At least conceptually, therefore, as health literacy skills improve, the health outcomes should also improve.

For example, if the access and utilization of healthcare improves, the patient might be diagnosed with hypertension or diabetes prior to the onset of further complications. A patient with coronary artery disease might be placed on the correct treatment earlier, resulting in a prevented heart attack or stroke. Improved patient/provider interaction might allow for the patient to be more precise in their description of symptoms, allowing the physician to make a more accurate diagnosis. This interaction may also include the use of digital tools, allowing for two way sharing of information. Finally, improved self-care may result in behavior change, such as eating habits, physical activity, and smoking cessation, as well as better compliance with medications.
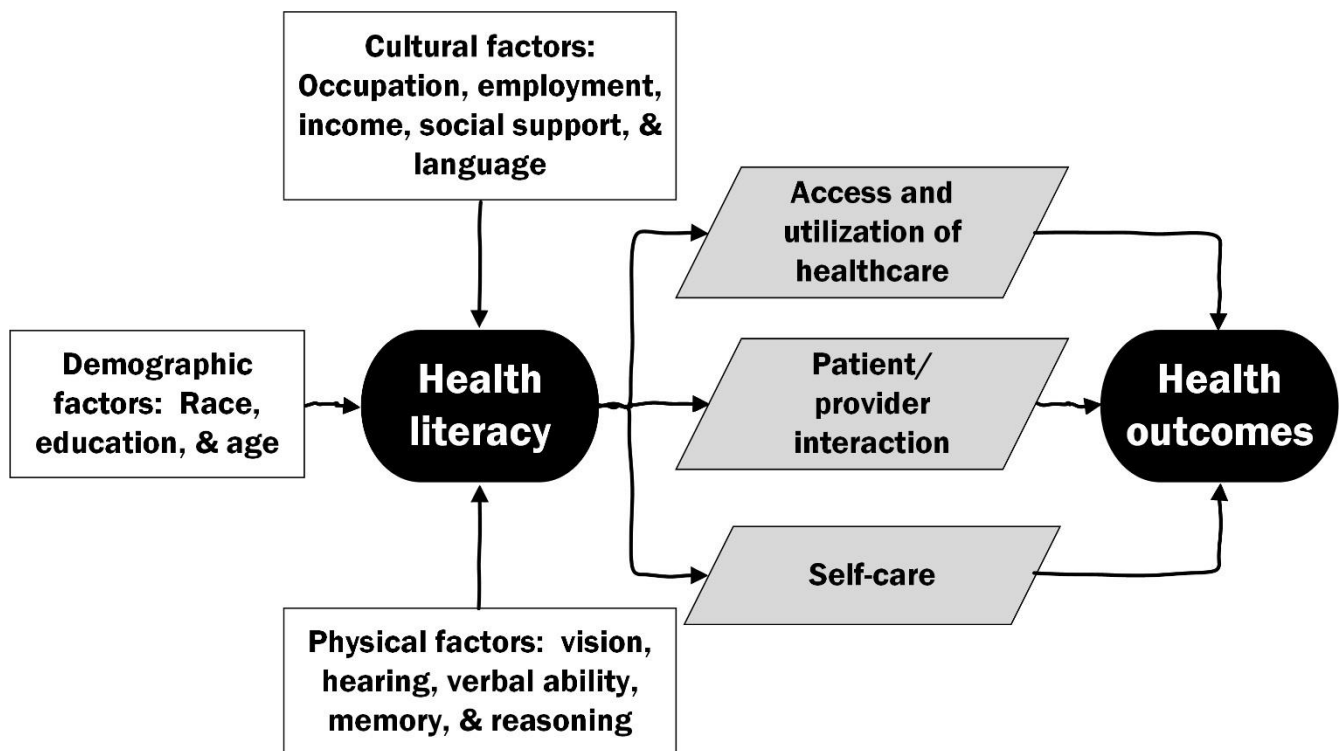
Figure 2. Health literacy and health outcomes pathway

This causal relationship between health literacy, specific health behaviors, and health outcomes was validated in a hypertensive population by Osborne, Paasche-Orlow, Cooper Bailey, & Wolf (2011). Low health literacy also has been shown to be related to poor health outcomes in heart failure, and diabetes populations, as well as health behaviors, such as medication adherence (Macabasco-O'Connell et al., 2011; Chen et al., 2014; and Gazmaranian et al., 2006).

To gain deeper insights into how patients with a new diagnosis of a cardiovascular disease or diabetes, Dunn, Margaritis, and Anderson (2017) conducted a qualitative study using grounded theory. The results of this study have become the foundation of the health literacy instructional model. Based on interviews with both patients and healthcare professionals, and using the grounded theory methodology, as defined by Corbin and Strauss (2015), the health literacy instructional model is a three-step process (Figure 3). It was apparent from both patients and healthcare professionals that the process of gaining knowledge and learning skills is compromised by the stress and anxiety associated with dealing with this new, life changing condition. It is critical, therefore, to address the emotional state of the patients prior to beginning an instructional intervention. This can range from formal methods, such as counseling and therapy, to informal methods, such as support groups, and if necessary may include medications.
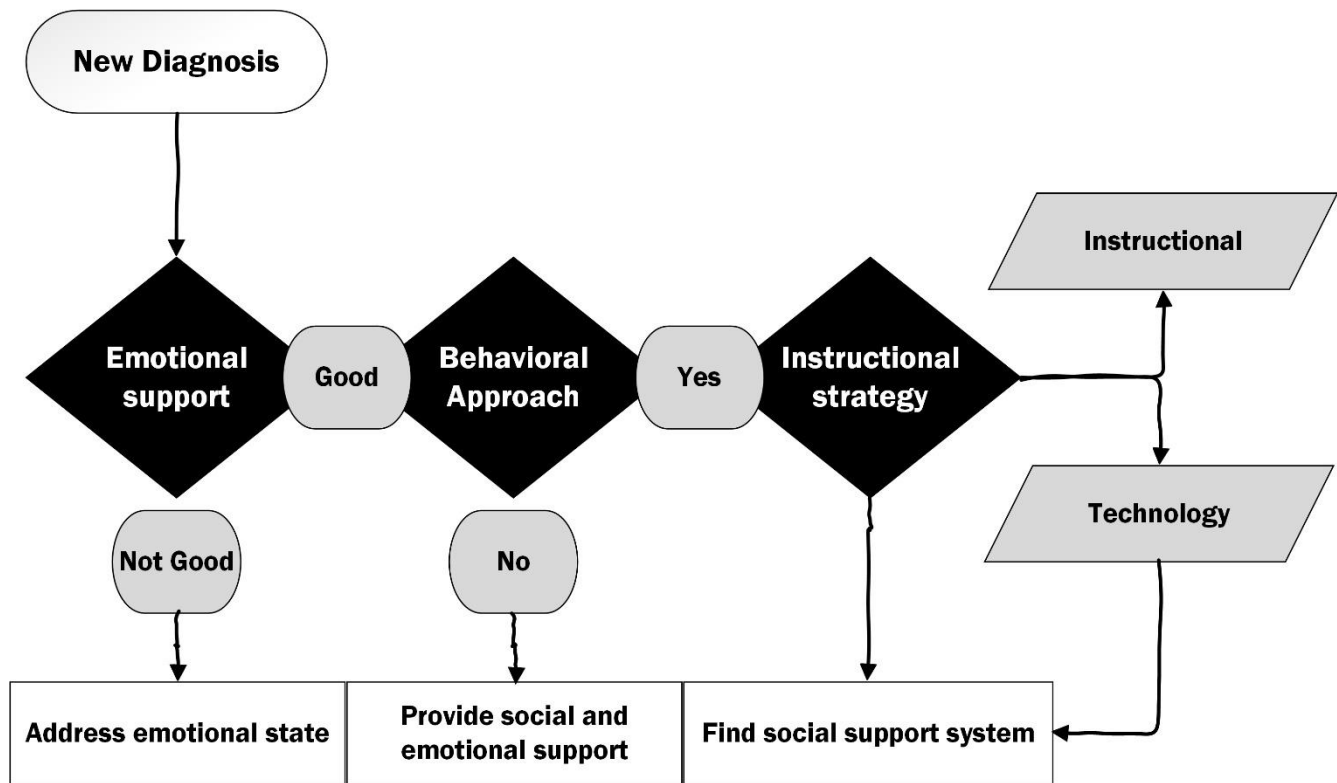

Figure 3. Health literacy Instructional Model

The second step in the health literacy model is a behavioral strategy (Dunn, Margaritis, & Anderson, 2017). The behavioral strategy is designed to engage and motivate the patients to make lifestyle changes, ranging from weight loss, dietary modifications,

increasing physical activity, cessation from tobacco, and taking medications as prescribed. The support structure of the patient, including friends and family, connections with other patients, access to trusted information, and access to healthcare providers was a key driver in building a behavioral strategy. Patients that were more isolated and lacked a support system had a very difficult time acquiring the knowledge and skills necessary to manage their health.

Finally, once the emotional state of the patient is addressed and a behavioral strategy is in place an instructional approach can be implemented. If the first two steps are ignored, however, the perception among patients and healthcare professionals is that an instructional approach has very little chance of success. Instructional strategies include the use of technology, including apps and devices, video and print materials, and direct patient educational approaches. Patient education included informal methods, including conversations between patients and healthcare professionals, patients' other patients, and the patient's own experiences. These informal methods resulted in incidental learning opportunities where patients could build their own experiential knowledge base. Formal educational methods included discharge instructions, group education and health coaching. In the case of cardiovascular disease and diabetes, programs, such as cardiac rehabilitation, diabetes self-management, and therapeutic lifestyle change programs, and online support networks were perceived by patients to provide the best learning opportunities.

The key theme that runs through all three of the steps in the health literacy instructional model is the social and emotional support system. Patients that did not have a support system, and were managing their health by themselves, did not appear to be developing the knowledge and skills as easily as those patients that had good support systems.
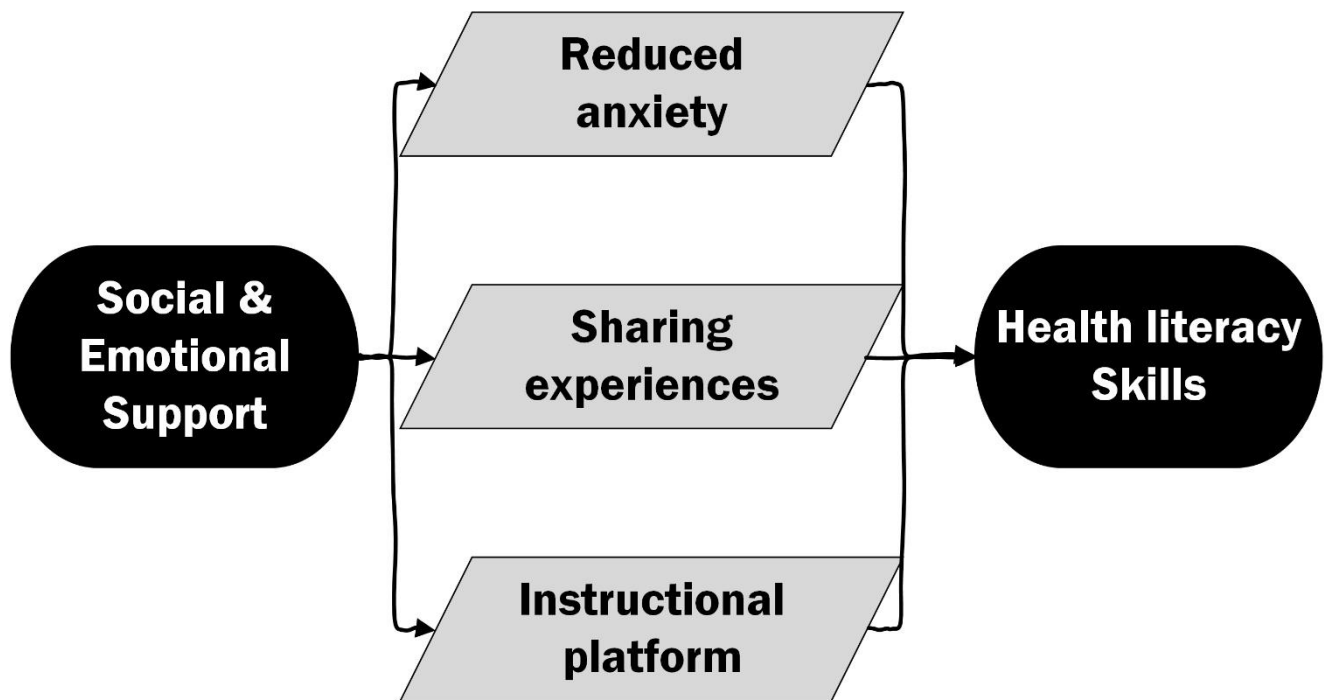
Figure 4. Relationship between social and emotional support and health literacy skills

But how does social and emotional support relate to health literacy? Insights from the health literacy instructional model were that the support system seemed to reduce the anxiety level of the patient enough to make learning possible (Dunn, Margaritis, & Anderson, 2017). Many the support systems, including cardiac rehabilitation programs and online support systems, such as the American Heart Association's Patient Support Network, provide an opportunity for patients to share their experiences. Since patients that have just been diagnosed with a chronic condition do not have their own experiences to draw from, they use other people's experiences to fill in their own gaps. Finally, the support system itself becomes an instructional platform. While some patients learn from reading brochures and watching videos, it appears that a significant number of patients learn by interacting with other patients. This can be as simple as sharing recipes, but can go much deeper into their approach to their own health.

Chapter 2

Approaches to building health literacy

Despite the National Action Plan to improve health literacy, research on the health impact of strategies designed to build knowledge, health literacy, and self-management skills is mixed (Taggart et al., 2012). In quantitative studies, health literacy is usually the independent variable, defined as either a dichotomous variable (low literacy vs. not low) or an ordinal variable, below basic, basic, intermediate, and proficient (Kutner, Greenberg, Jin, & Paulsen, 2006), or insufficient, problematic, sufficient, or excellent (Sorenson et al., 2015). In most these studies, the dependent variable is either self-management skills, such as medication adherence, or health outcomes, such as glucose, blood pressure, or weight readings (Taggart et al., 2012; Berkman et al., 2011). Qualitative studies have focused on barriers encountered by patients with low health literacy skills, and the attributes necessary to build self-management skills, such as communication, navigation, and decision making (Easton, Entwistle, & Williams, 2013; Edwards, Wood, Davies, & Edwards, 2012; Jordan, Buchbinder, & Osborne, 2010). Neither quantitative, nor qualitative studies have addressed how health literacy skills are developed in patients with cardiovascular disease or diabetes.

This approach reveals a gap in the literature regarding how the development of health literacy skills leads to the improvement in health outcomes. In fact, very little is known about the extent to which health literacy skills can be improved. The most common strategies, including the use of plain language with clear and concise messaging, and avoiding jargon, are not educational, skill building strategies. Teach-back, which is the most common method used by healthcare professionals serves the same function as a post-test, but does not distinguish between new and existing knowledge. Finally, writing educational materials at a 5th grade level is a communication strategy, not an instructional approach. The emphasis on reading level has led to a debate about the definition of health literacy, beyond linguistics, to include numeracy, navigation, communication, and decision making (D'Eath et al., 2012).

These strategies are designed to accommodate patients with low literacy, and for that reason, they are justified. They should not, however, be thought of as the answer to building new health literacy skills. If these strategies were used in our educational system

to improve reading literacy, many children would never learn to read. Instead, we would build a culture that did not require reading, and certainly not encourage reading anything that used "big words" or "big ideas". I think we would agree that approach would be unacceptable.

While health literacy is associated with access to health-related information and actions, it is closely associated with general literacy, focused on reading and comprehension. Health literacy goes beyond the linguistic domain to include the related concept of numeracy, which is the ability to understand and manipulate numbers. In the case of a patients with diabetes that is taking insulin, the practical skill of determining the insulin requirements, based on the number of carbohydrates consumed requires numeracy skills. Higher order skills include navigating the healthcare system, communicating with healthcare professionals, and both shared and unilateral decision making (Ishikawa & Yano, 2008). While this broader definition makes sense, it makes health literacy interventions, and measurement more challenging, especially in patients with good language skills, but may still lack essential navigation, communication, and decision making skills (Easton et al., 2010). Furthermore, there are a significant number of patients that have a very good understanding of their condition, but still lack the skills necessary to make the appropriate self-management decisions (Peerson & Saunders, 2009).

The key elements of andragogy, or adult learning theory, such as self-directedness and drawing upon a reservoir of personal experiences to not seem to explain how information is initially gained (Grace, 2011). The gap is in the basic understanding of how patients with cardiovascular disease and diabetes learn the information they need to manage their condition. Additionally, there is a gap in how digital tools and technology are used to build health literacy skills.

Health care approaches

Healthcare professionals have little training in educational methods, and limited time for education, so have difficulty in building health literacy skills in their patients (Macabasco-O'Connell & Fry-Bowers, 2011). To focus on health literacy in a healthcare setting requires integrating health literacy into all aspects, including planning and operations, decision support, and technology, and partnership with community health settings (Koh, Brach, Harris, & Parchman, 2013). The Health Literacy Toolkit was

published by the Agency for Healthcare Research and Quality to help healthcare professionals improve spoken and written communication, and promote empowerment and self-management (Dewalt, 2010). Two key principles of the Toolkit include the use of plain language, and clear and concise messaging (Stableford & Mettger, 2007), and teach-back (Dewalt, 2012). The use of plain language does not explain how an individual that is recently diagnosed with a chronic condition can find and use health information to build their knowledge and skills. A patient with cardiovascular disease or diabetes must eventually confront long, complicated, and unfamiliar terms, such as cholesterol, saturated fat, carbohydrates, and insulin resistance. Simply avoiding these terms and concepts to stay aligned with reading level recommendations will not result in better health. *Teach to Goal* is a health literacy educational intervention for heart failure patients, but there is no empirical data (Baker et al., 2012). Teach-back is a well-established method of having the patient repeat back what they just heard. Teach-back, therefore, only assesses what has already been received, and does not address how new information is acquired.

Educational approaches

According to the Merriam-Webster Dictionary (2017) and educator is one who is skilled in teaching, and is a student of the theory and practice of education. The providers of 'patient education' include doctors, nurses, ancillary healthcare providers, such as pharmacists, social workers, and dietitians, and health educators, including health coaches. The question is how much awareness and training in education methods to these professionals have?

Traditional educational methods start with foundational skills that build to mastery. This is true in reading, beginning with letters, then words, then sentences, leading to mastery, however that is defined (reading, writing books, etc.). Learning a musical instrument starts with sounds, then notes, then scales, leading to songs. Athletic skills work the same way, such as stand, walk, run. In healthcare, the "simplify, simplify, simplify" approach goes in the opposite direction. For example, explaining a lipid profile may break down to cholesterol, then to fats. If reading level requirements are strictly enforced, however, they may prevent the educator from pivoting the patient on the road to mastery. Figure 5 is an illustration of this point.

Common educational approaches
Building from foundational skills to
mastery

Mastery

Sentances

Words

Scales

Letters

Notes

Foundational skills

Sounds

Healthcare   Lipoproteins

Does the 'simplify' approach lead to mastery?

Simplify → Cholesterol

Simplify → Fats
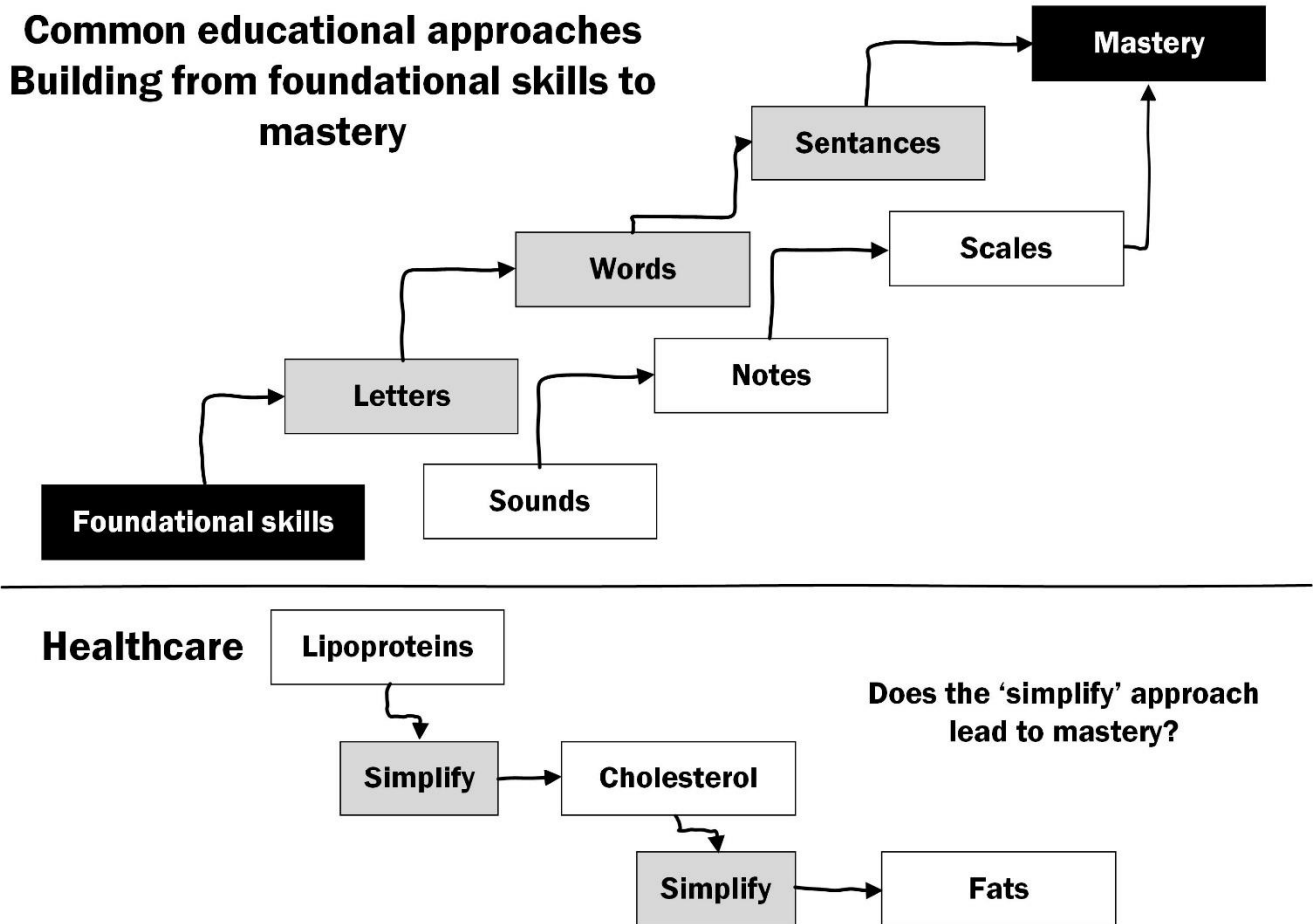
Figure 5: Comparison of education approaches

Most of the research on building literacy skills has been done in children and adolescents (Lesgold & Welch-Ross, 2012). Educational models, designed for the classroom, have been used in adult education programs, such as English as a second language (ESL), but not specifically in adult health education. These educational models include Bloom's Taxonomy (Krathwahl, 2002), Vygotsky's Zone of Proximal Development (Shabani, Khatib, & Ebadi, 2010), and Gardner's Theory of Multiple Intelligences (Gardner, 2002).

Bloom's taxonomy is a hierarchical framework for teaching children to read, beginning with foundational skills that build to mastery (Krathwahl, 2002). The revised taxonomy is much broader and can be applied to many other applications of teaching and learning, including mathematics, music, and athletics, and have been applied to adult learning, such as financial, digital, and health literacy (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016). The revised taxonomy domains include remembering,

understanding, applying, analyzing, and learning (Krathwahl, 2002). This educational approach can be applied to the progression of health literacy (Table 1).

Table 1: Comparison of the revised Bloom's taxonomy to the progression of health literacy

Bloom's taxonomy	Health literacy skills
Remembering	Navigation
Understanding	Communication
Applying	Decision making
Analyzing	Numeracy
Learning	Reading comprehension

All three educational theories are combined into a model for building health literacy skills (Figure 6).

Remembering I Understanding I Applying I Analyzing I Learning

Learning Zone

Higher level complicated skills

Lower level basic skills

Progress from low level understanding to higher level knowledge
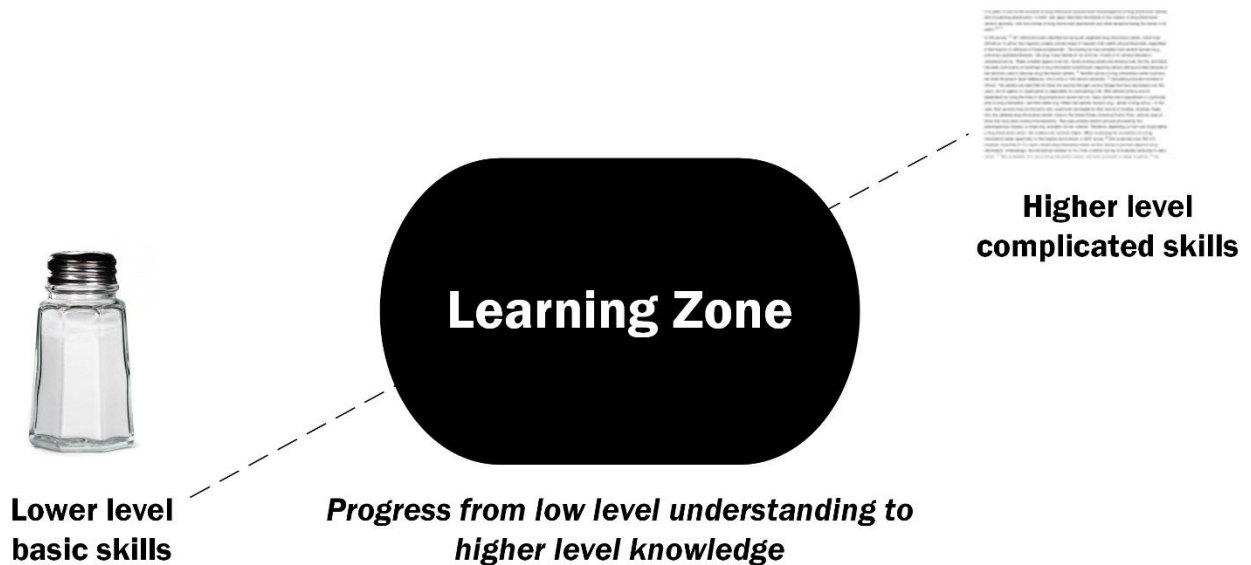
VISUAL I SOCIAL I AUDITORY I EXPERIENTAL

Figure 6: Model for incorporating educational theory into health literacy

The theory of multiple intelligences uses different style of learning, such as visual, auditory, and kinesthetic to build knowledge (Gardner, 2002). This opens the door to the use of digital tools, offering multimedia formats for the delivery of information, as well as the ability to segment groups and curate content based on the motivations and world view of the individuals. Rather than applying a one-size-fits-all approach, providing multiple educational formats, such as one-on-one, group, informal, digital, and social, may reach and engage a larger number of patients. Additionally, while some patients prefer to follow the directions of their healthcare provider, other patients want to be provided with choices, or alternatives, and others would prefer to do their own research.

Vygotsky's zone of proximal development and problem based learning theories use the metaphor of a scaffold, to support the individual's learning needs (Richard-Amato, 2003). Just like a scaffold is built around a building as it is being constructed, a support system is built around the learner. The key is finding the learning zone and building through the zone. Simplifying the message too much runs the risk of being below the zone, and not engaging to the patient, while using jargon and complicated concepts runs the risk of being above the zone and overwhelming the patient.

An integrated conceptual model of health literacy, using multiple conceptual models, and a multilevel approach was developed by Sorenson (2012), including four dimensions – access to information, understanding of the information, appraisal, and application. Using grounded theory, Jordan, Buchbinder, and Osborne (2009) identified the key abilities necessary to find and understand information as the knowledge of when and where to seek information, verbal communication skills, assertiveness, application skills, and the ability to process and retain information. Edwards et al. (2015) identified a progression health literacy from knowledge to skills and actions, and finally to decision making.

The development of health literacy skills is a process that moves from knowledge, to skills, to decision making. Patients with higher levels of education, knowledge, and skill are more likely to advance into critical health literacy, including communication and decision making (Smith, Dixon, Trevena, Nutbeam, & McCaffrey, 2009). Socioeconomic factors can play a large role in the progression to critical health literacy (Heijmans, Waveijin, Rademakers, van der Vaart, & Rijken (2015), and those in most need of health

information have the least access to it (Rowlands, Protheroe, Winkley, Richardson, Seed, & Rudd (2015).

Applying these models and educational approaches to broader definition of critical and functional health literacy as described by Nutbeam (2008) and D'Eath (2012) is depicted in Figure 7. This results in a progress of health literacy skills from reading and comprehension to numeracy, to navigation, to communication, and finally to decision making. In practical terms, using blood pressure as an example, the patient can understand blood pressure and why it is important, then can good and bad blood pressure readings, then know what to do with a blood pressure reading, such as rechecking, or calling 911; then know what information to share with their physicians, such as side effects from the medication, and finally to make good, well informed decisions, such as lowing sodium intake.
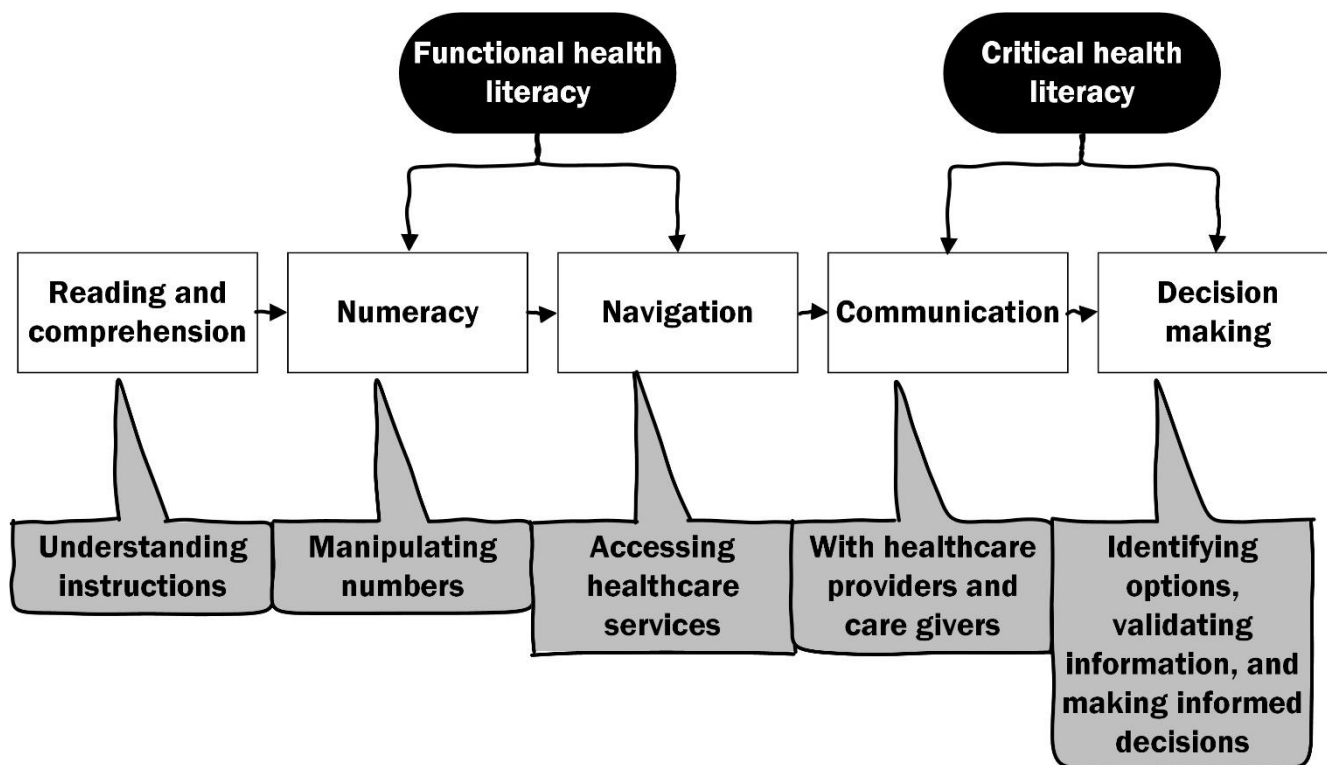
Figure 7. Progression of health literacy skills in chronic disease

Health impact of health literacy interventions

Qualitative studies, cross sectional studies, prospective observational studies, and randomized controlled trials have been conducted on patients with diabetes, coronary artery disease, hypertension, high cholesterol, heart failure, and obesity. While low health literacy is associated with greater healthcare utilization for readmissions and emergency visits, and is associated with lower utilization of preventive measures, including, the results of interventions to build health literacy skills, the research findings have been inconsistent (Berkman, et al., 2011). Most of the research on literacy interventions has been conducted in the adolescent population. Due to challenges in measuring health literacy, research on health literacy in the adult population has primarily used utilization measures, such as readmission, or biometric, such as blood pressure and blood glucose as the dependent variable, with health literacy as a dichotomous independent variable. There is, therefore, very little research on how health literacy knowledge and skills are developed in patients with new diagnosis of a chronic health condition, such as cardiovascular disease or diabetes.

Cardiovascular disease and diabetes are similar in that they are complex chronic conditions that can become acute and life-threatening if uncontrolled, and have a strong lifestyle component (Smith et al., 2011). Cardiac rehabilitation is a program of secondary prevention for patients following a cardiovascular event, as is an ideal setting for building knowledge, health literacy, and self-management skills (Gallagher et al., 2012). A scientific statement from the Heart Failure Society of America recommended the use of health literacy principles in the management of patients with heart failure (Evalgelista et al., 2010). A substantial body of evidence exists in the role of self-care skills in the management of high blood pressure, including medication adherence, dietary and physical activity interventions (Appel et al., 2006). A series of studies led by Hayden Bosworth have demonstrated greater confidence, improved medication adherence, and better blood pressure control (Bosworth et al., 2005; Bosworth et al., 2008; Bosworth et al., 2009). Diabetes, like hypertension has a strong health literacy and numeracy component. Protheroe, Rowlands, Bartlam & Levin-Zamir (2017) emphasize the importance of health literacy in achieving diabetes control. Diabetes health literacy interventions have demonstrated improve behavior change, better adherence to diet, self-glucose

management, better foot care, (Kim, Live Quistberg, and Shea, 2004; Wallace et al., 2004).

Not all studies have shown positive outcomes (Kandula et al., 2009). Even more concerning, is the reality that in many of these intervention studies, the patients with good health literacy skills have significantly better outcomes that patients with low literacy skills. Table 2 is a summary of the health impact of health literacy instructional approaches. The table is organized by the instructional approach, application, and patient population. These studies are a representative sample, but do not include all studies conducted on health literacy. Review articles by Berkman et al., 2011 and Taggart, 2012 provide a more comprehensive list.

Table 2

Health Literacy Instructional Approaches

Instructional approach	Application	Population	References
Individual counseling	Self-management skills	Heart failure	Baker et al., 2011; DeWalt et al., 2009.
	Intensive training with pharmacist and diabetes educator	Diabetes	Rothman et al., 2004
	Counseling and educational materials	Diabetes	Wallace et al., 2008
Group education	Nutrition (low fat)	Apparently healthy	Howard-Pitney et al., 1997
	Heart attack warning signs	Cardiac rehabilitation	Gallagher et al., 2012
	Self-management skills	Diabetes	Kim et al., 2004

Print materials	Educational materials	Diabetes	White et al., 2010
Digital media	Diabetes education	Diabetes	Sarkar et al., 2010
Multimedia	Nutrition (food labels)	Apparently healthy	Jay et al., 2009
	Diabetes education	Diabetes	Kandula et al., 2009
	Slide presentation on symptoms and risk factors	Coronary artery disease	DeVon et al., 2010
Telephonic	Daily monitoring, education, follow up	Heart failure	DeWalt et al., 2006
	Nurse administered telephone intervention	Hypertension	Bosworth et al., 2009, 2008, 2005

Chapter 3

The Health Literacy Instructional Model

Methods

While there has been considerable research on health literacy, much of this work has centered around identifying groups that are high risk for low health literacy, and interventions designed to mitigate the impact of low health literacy. Medical research is dominated by quantitative, hypothesis driven research methods, but the inductive nature of qualitative methods can be used to gain greater insights in areas where there are significant knowledge gaps (Krumholz, Bradley, & Curry, 2013). Qualitative and mixed methods research designs can be used to develop better tools and hypotheses, that can be tested statistically (Curry, Nembard, & Bradley, 2009). Very little research has been done on how knowledge and skills are developed. To gain deeper insights into how health literacy skills are developed in patients with cardiovascular disease and diabetes, a qualitative methodology was selected. Using a mixed methods model, inductive and deductive approaches can be used together for gain greater insights and test hypotheses (Figure 8).

Deductive
Hypothesis driven
Quantitative
Based on logic and fact
Good when a lot is known
Common in medical research

Inductive
Used to form explanation or theory
Qualitative
Based on observation
Good when little is known
Rare in medical research

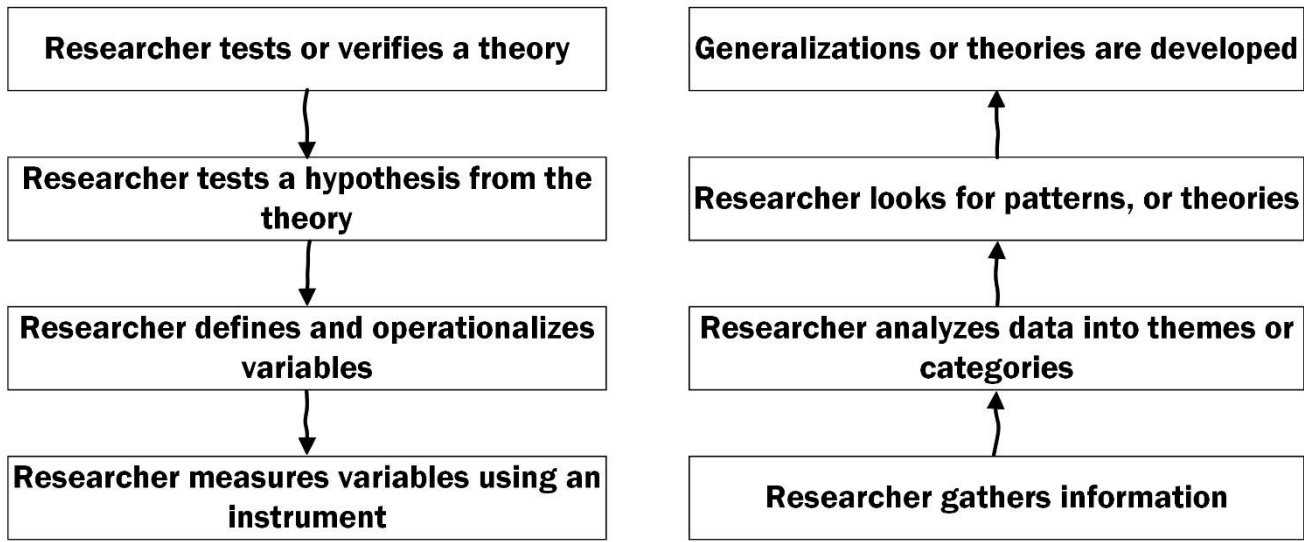| Researcher tests or verifies a theory | Generalizations or theories are developed |
Researcher tests a hypothesis from the theory	Researcher looks for patterns, or theories
Researcher defines and operationalizes variables	Researcher analyzes data into themes or categories
Researcher measures variables using an instrument	Researcher gathers information

Figure 8. Inductive and deductive research approaches

Dunn, Margaritis, and Anderson (2017) conducted a qualitative study, using grounded theory to gain a better understanding of how patients that have recently been diagnosed with cardiovascular disease or diabetes acquire the knowledge and learn the skills necessary to manage their health. The gap in the literature and practice is the need for greater insights into how healthcare professionals assess and build health literacy skills, and how patients find and use health information. The patients included those with a diagnosis of coronary artery disease, heart attack, heart failure, hypertension, a lipoprotein disorder, a heart rhythm disorder, or diabetes within the past 12 months. Patients were recruited from a primary care and a cardiology medical practice, from patients centered programs provided by the American Heart Association, and social networking. Patient centered programs included the Patient Support Network, a social support network for patients and caregivers developed and managed by the American Heart Association; Heart360, a digital platform for monitoring blood pressure; and Connected Heart Health, a care management platform for patients with cardiovascular disease; and the Game of

Health, a lifestyle change program focused on the metabolic syndrome. Social networking sites included Facebook and Twitter (Figure 9).
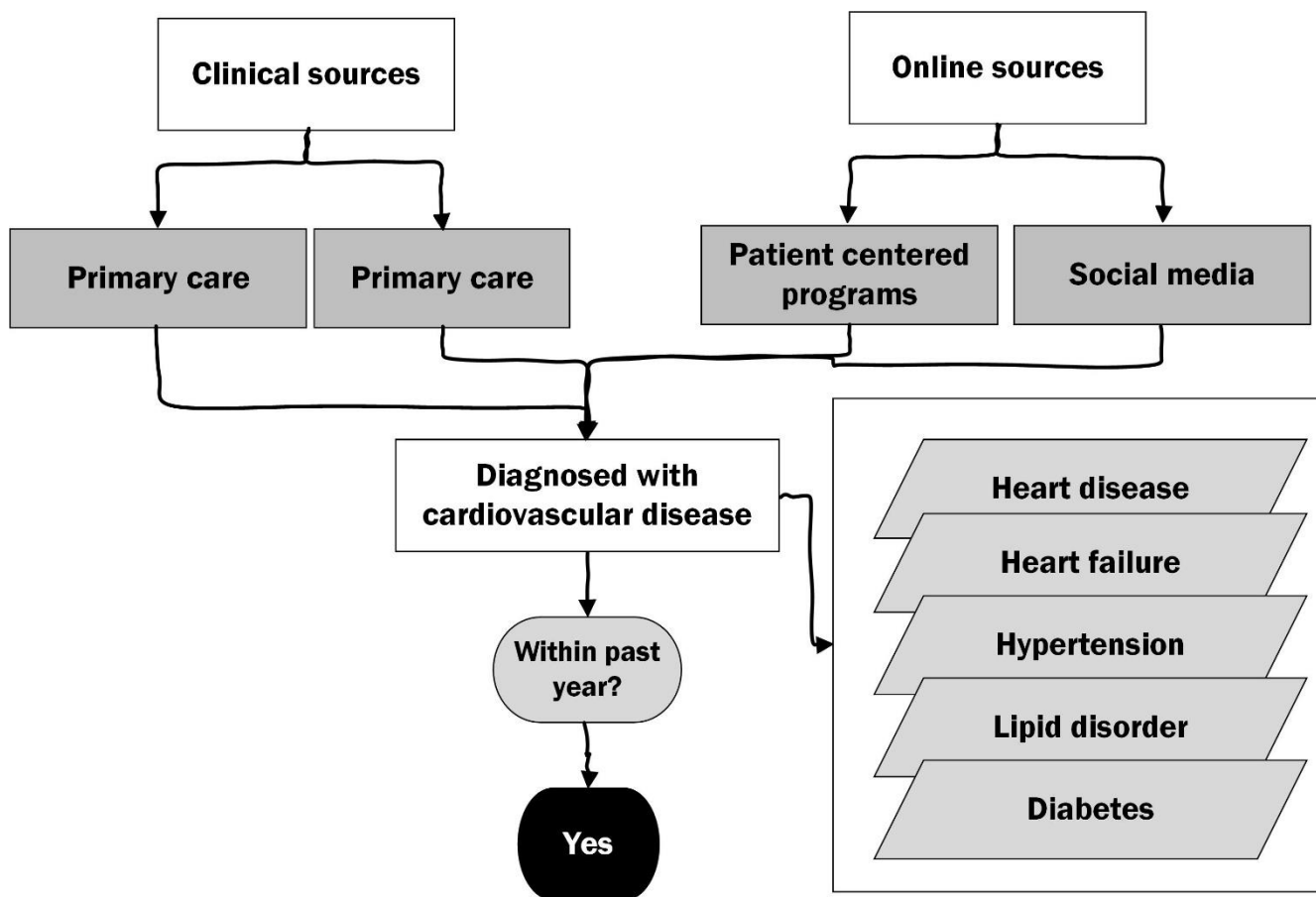
Figure 9. Participant selection process.

The healthcare professionals included individuals that provide medical care or education to patients with cardiovascular disease and diabetes, including physicians, nurses, physician assistants, nurse practitioners, dietitians, pharmacists, exercise physiologists, social workers, medical assistants, and health coaches. This group also included individuals that design print and digital educational products.

Each participant was interviewed for 30-45 minutes, using semi-structured questions. Interviews were recorded, and were transcribed, and coded immediately. Analytic and methodological memos were written following the interviews. Memoing was a critical component of linking categories and themes, resulting in a unified theoretical explanation of how health literacy skills are developed in patients with cardiovascular disease and diabetes. Using constant comparison, process and evaluation coding was conducted

(Miles, Huberman, & Saldana, 2014). Open coding began by identifying the core actions and processes, including who, what, when, and how of knowledge and skills development. Axial coding was used make connections among the codes, leading to a description of the core phenomena, causal conditions, strategies, intervening conditions, context, and consequences. Selective coding was the final step and was used to generate the theory and establish a better understanding how health literacy skills are developed.

A grounded theory approach was used because it goes beyond a description of the phenomenon to a theoretical explanation of the process and action (Corbin & Strauss, 2015). While grounded theory is rooted in social science research, it is rarely used in medical research, but that trend might be changing (Watling, 2012). The grounded theory research design is shown in Figure 10 and Table 2. Key elements of grounded theory include the use of theoretical sampling, constant comparison, and theoretical saturation.

Grounded theory is based on the seminal work of Strauss and Glazer, 1967. Since then several methods of grounded theory have emerged, based on the philosophical worldview of the researcher (Glazer, 1992; Corbin & Strauss, 2015; Charmaz, 2014). Grounded theory involves simultaneous data collection and analysis, using inductive and deductive methods, using theoretical sampling, constant comparison, and theoretical saturation (Corbin & Strauss, 2015; Charmaz, 2014; Bryant, 2016). A theoretical explanation, or theory emerges from the data. Since the audience for this research are healthcare professionals, who are trained in the scientific method, the approach described by Corbin and Strauss (2015) was selected for this study because it most closely aligns with the worldview of healthcare professionals.
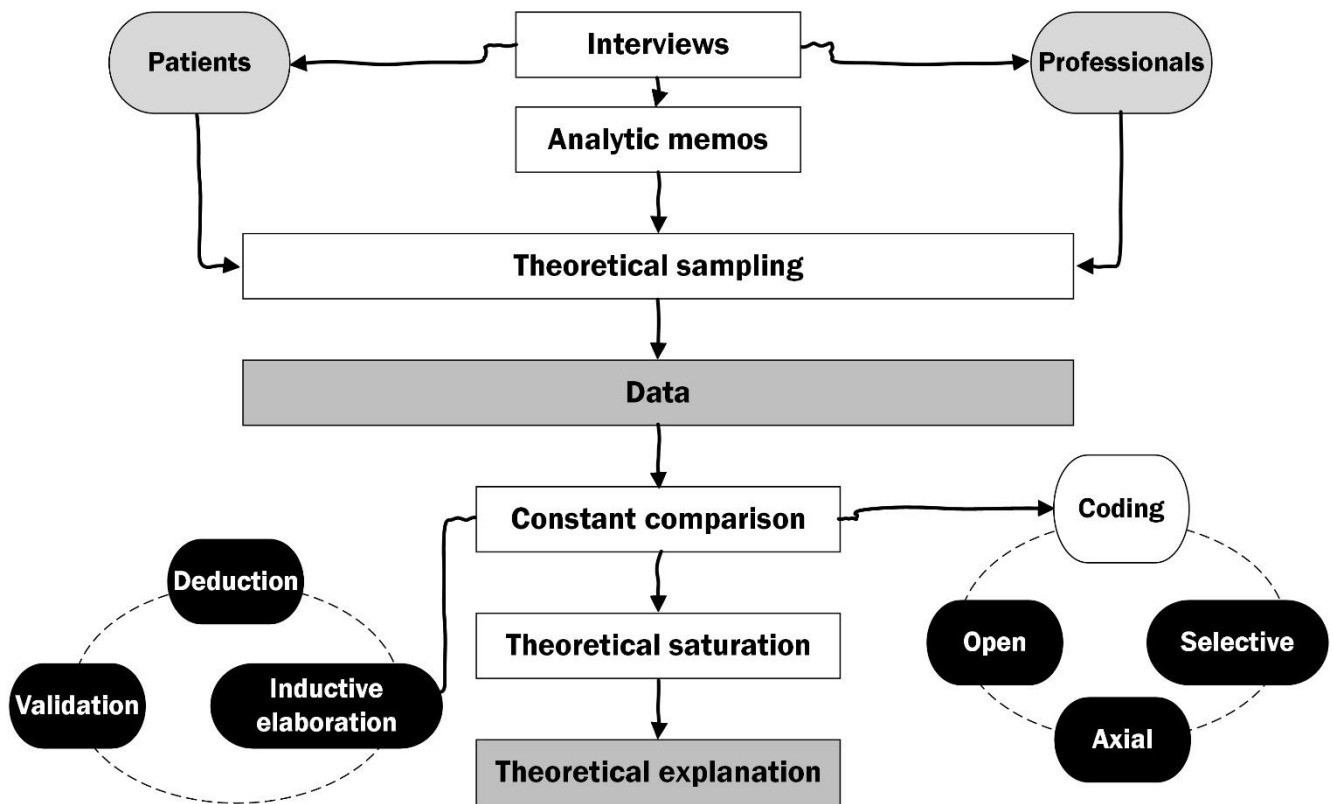
Figure 10. Data collection and analytic methods.

Table 2

Summary of Data Collection and Analysis Methods

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

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

The intent was to go beyond the description of low health literacy groups, the challenges, or the motivational issues, to a greater focus on factors related to health literacy instruction to explore the process of learning and how new resources that are now available to patients are used.

The central phenomenon in this qualitative study was the process and actions from the perspectives of both patients and healthcare professionals in the development of health literacy skills. This central phenomenon included the use of instructional and motivational strategies by healthcare professionals, and use of search engines, social networks, digital tools, including apps, wearable devices to track physical activity, and connected devices to monitor blood pressure, weight, and blood sugar by patients.

The research questions included, (1) what are the perspectives of patients and healthcare professionals in the development of health literacy skills; (2) what are the perspectives of patients and healthcare professionals in the use of new technologies to build health literacy skills; (3) how to healthcare professionals and health educators assess and build health literacy skills in their patients; and (4) how to the instructional strategies used by healthcare professionals align with the learning need of the patients. These research questions were explored through semi-structured interviews of patients that have been diagnosed with a cardiovascular condition or diabetes within the past we months and the healthcare professionals that care for or educate these patients.

Adult learning theory, the health belief model, the transtheoretical model and the social ecological model have all been used in health literacy research (Sallis, Owen, & Fisher, 2008). Health literacy is mediated by individual, social, and environmental factors, and is at the crossroads between the healthcare system, the educational system, culture, and society (Nielsen-Bohlman et al., 2004). This multilevel approach to health literacy instruction includes the learner's knowledge, education, and linguistic background, the cultural and environmental context of the learning experience, the teaching methods, activities, and tools, and the purpose of the educational strategy (Lesgold & Welch-Ross, 2012).

Results

The results of the health literacy instructional model are described by Dunn, Margaritis, and Anderson (2017). To make the results more personal, one patient and one healthcare professional from the original study have agreed to be identified and be the subject of a case study. These two individuals were selected because they provided very deep insights in the initial interview.

Patients

Jennifer Volland is a 53-year-old female that lives in Spokane Valley, Washington. At age 50 experienced a heart attack, and later had coronary artery bypass surgery. The following is an excerpt from her interview, conducted on January 28, 2015.

On May 30, 2015 I got up and was having my Chi Tea, and checking my Facebook, when all of a sudden, my arm started hurting, and when I stood up, I was dizzy, which turned out to be a heart attack, followed by coronary artery bypass surgery. After discharge from the hospital I began cardiac rehabilitation at my local hospital.

What was your prior knowledge of heart disease?

My understanding was virtually zero. I could not have told you what a good cholesterol or bad cholesterol was, and I could not have told you what the top and bottom number of a blood pressure meant. I did not have high blood pressure or diabetes, and I go in for an annual physical, but that's it. I did start smoking when I was 42, and my last cigarette was that morning.

How did you learn how to manage your condition?

For the first 30 days I was scaring myself because I was trying to take it all on myself. I think cardiac rehabilitation was the biggest impact for me, because you are going through a lot of emotional stuff. Emotionally, I was a mess. I didn't die, but I had a lot of fear. Having the cardiac rehab staff monitor me while I was pushing my limits on the treadmill helped me to build confidence. I also received a lot of education. I learned a lot about nutrition. I am not obese, but I ate a lot of fast food and pizza. Learning how to cook, using the right oils, and reading labels was huge for me. I am now on the American Heart Association's Patient Support Network and we started a discussion

called 'you gotta go to rehab.' I know I am a survivor so it is part of my personality to do everything I can to control my outcome, and not just be a victim.

It was a nurse in the hospital when I was discharged that got me into cardiac rehab. I was very lucky because my insurance paid for me, and it was worth every dime. In cardiac rehab they would take 15 minutes and talk about different topics. I was directed to the AHA Support Network through cardiac rehab.

From whom did you get your information?

The doctors are really good, but they are overworked, and really busy. You need to follow your doctor's advice, but you also need to be your own advocate. I started posting on the AHA Support Network, and people started responding. I realized that what I was feeling was perfectly normal. I realized my emotions were out of control and discussed that with my doctor.

What technologies did you use?

Oh my goodness, the first blood pressure device I used was a wrist device and it did not work worth a darn. My doctor recommended a blood pressure device and it is spot on. I have a treadmill and bike in the basement, and I learned from cardiac rehab to use the rating of perceived exertion, because it would say to get your heart rate to 150 or 155, but if you are on blood pressure medication, that is not going to work. I use an app that records my heart rate using the camera on my phone. I exercise 5 days per week and take my blood pressure before and after I work out. All of this, I learned in cardiac rehab. I am not longer on blood pressure medications so when I am working out I grab my phone and stick my finger on the camera. Even the app was something I learned about at cardiac rehab. I didn't know anything like that existed. You have to find a way to validate, and correlate with things you already know, because it is hard to weed through everyone's opinions.

What are your preferred learning methods?

I don't think it is the internet, because you must flush through a lot of junk. The internet has some really good stuff, but it is a wonderful, and dangerous place. So for me it has to be more personal. Either the nurse sitting with me, or the cardiac rehab staff showing me how to read a nutrition label.

How long did it take you to feel confident with the knowledge of your condition?

It took me 6 months. I am now more tuned into my body than I was before. You get pains, but instead of ignoring them, I really analyze, but you can drive yourself crazy. I am 51, so things are going to hurt occasionally.

What additional information do you wish you had that would have helped you manage your condition?

I joined Mended Hearts and was trained to talk to other patients. I wish I would have had someone to talk to when I was in the hospital. To sit in the hospital, feeling fine, but not knowing if you are going to die was a very scary time. It was not until I went to cardiac rehab and they gave me a flyer. Also, it would be nice if all of the information was in one place, rather than going to the internet for information.

Healthcare professionals

Scott Conard, M.D. is a family practitioner in Dallas, TX, and has practiced for the past 30 years.

Can you describe any training you received in educational methods in general, or health literacy specifically?

In my residency, we had a psychologist that taught us the "softer side" of patient care for 3 years. I also went on to receive training and continuing education in stress management, anxiety, depression and so forth. In 2000 I became a Certified Diabetes Educator that has an excellent focus on the diabetic mindset and experience of being diagnosed and living with diabetes. Additional training included behavioral sleep medicine and board certification in holistic and integrative medicine which included hypnosis, acupuncture, visual imagery, and mind-body medicine.

What is the process of learning for a patient newly diagnosed with diabetes or hypertension?

In the practice, we talk about winning the "Game of Health." A five-step process that all of us must go through to overcome a health challenge;

1. *Awareness – discovering the problem like diabetes, hypertension, hyperlipidemia,*

2. *Education – learning what the diagnosis mean and why it would be worth doing something about. The education must be personalized and individualized, so that it is relevant. It is important to believe worth the effort do the work to change*

3. *Response-ability – Acknowledging that their actions have contributed to the challenge and identifying the habits and behaviors that increase risk*

4. *Accountability – Setting up external support to maintain the effort when will power runs out, and*

5. *Sharing – Letting others know about the challenge, success, and communicating with others about the journey.*

Where do patient get the information, they need to manage their health?

The most common source of information is the Internet, but there is a plethora of information in the market place. How they learn best – reading, listening to books, lectures, TED talks, or experiential learning for example determines where reliable and safe information can be found. But I often find the problem is not finding good information, the problem is the ability to put all of the new learning into practice. People tend to do well for 4-6 weeks, but then tend to fall off, because there is no structure to the environment to evolve or adapt to their new situation. I think the most exciting next step in how this will all occur is with mobile devices, and smart phones that will be the way of the future, but I don't know that right now we have that figured out.

What would they be doing with that information to help them manage their health?

I don't think there is one answer to that question. I think you must go to where the person is, meet them where they are, and figure out what works for them. In the future, I fully expect technology will be developed that identifies what has worked or not worked in the past and will develop and action they are capable of accomplishing, at that moment in their life. It will have a lot of change management technology built into it, which includes intellectual understanding, emotional desire, and practical application of making what is the right thing easier than what you have been doing.

How do you assess the level of knowledge and health literacy in your patients?

We do not have a structured process. One of the challenges in family medicine is that when you have long-term relationships you assess them and their health literacy, but we

have not put a formal science to it. My informal assessment of the patient's health literacy skills starts by the assessing questions they ask. It may also manifest in how well the patient can navigate the healthcare system. We use an outside company that will help the patient select the right specialist, or imaging center, based on their insurance, the cost, and the quality profile of the provider. In my practice I would try something, and if it didn't work, I would try it another way, until I found something that worked, but it was very inefficient and it took a tremendous amount of time, and even then, often I never got there. I look at their biometrics. If their numbers are improving, I assume they are getting it.

What is your approach when you have a highly engaged patient, but their numbers are not ideal?

In all frankness, it depends on how much time I have. If I have 7 minutes to get it out, I might ask "what is working and not working" and I will focus on where they are failing to meet their objectives, and what we can do to help. I would focus on 3 things they could do, and focus on how that would look. If I had more time I would focus on why they think it is important to get those numbers over the finish line. I would then ask them, "now that you have chosen what you really want to accomplish I request you go through the Game of Health, including the books The Seven Numbers and The Seven Healers."

What is the Game of Health and how did it start?

While I received great training as a doctor early in my career I had 3 patients die suddenly of massive heart attacks. I realized that some patients feel fine one moment, and are gone the next. The Game of Health is a therapeutic lifestyle change program that created to help patients better understands their numbers, such as blood pressure, cholesterol, glucose, and weight, and the behaviors that lead to these numbers. This program was conducted in a group setting, and it became so popular that some of my patients went to their employers and asked that it be brought to their work, thus we began offering at the worksite. Over the past 15 years' thousands of patients have "played" the game of health, improving their health and outlook on life.

How do you know that they are being successful?

Their numbers get better! Also, a significant part of this program is "mindset management." Are they experiencing life as though it is happening to them, where they

feel like a victim, or are they happening to their challenge - taking response-ability and doing things to manage their risk. This is an important paradigm shift that is taught in the Game of Health. Until they shift their mindset making progress is a significant challenge.

There are some common themes between Jennifer and Dr. Conard. Both emphasize the importance of stress and emotions in the patient's ability to process and retain information. While both mentioned the potential role for digital tools and technologies, neither believes that the current form of technology can be the total solution. Also, both mentioned programs that allow patients to interact with other patients, in both face to face, and virtual settings, as key to helping patients develop their health literacy skills. While these are only 2 cases, they represent the key themes that emerged in the health literacy instructional model.

Of course, this qualitative study is only the first step in the development of the health literacy instructional model. By conducting a qualitative study, deep insights were gained in how health literacy skills are acquired in patients newly diagnosed with cardiovascular disease and diabetes. By using the grounded theory methodology, those insights are the basis for a theoretical explanation.

Another insight from healthcare professionals was that assessing health literacy in a clinical setting is not easy. The literature also indicates that while there are standard tests for assessing general health literacy, there are no assessments of cardiovascular or diabetes specific health literacy. An individual may understand the importance of immunizations, or wearing seatbelts, but may still lack the skills needed to manage cardiovascular disease and diabetes. The next step in the health literacy model will be to develop a series of condition specific health literacy assessment, and validate those assessments with standardized assessments of health literacy and used in a clinical setting. This portion of the health literacy model will be quantitative and will be used to determine which interventions result in the greatest improvement in health literacy and health outcomes.

The final stage of the health literacy instructional model will be to design an intervention focused on building health literacy skills in patients with cardiovascular disease. This stage will require a mixed methods approach, using qualitative methods to gain greater insights into the specific instructional strategies, and quantitative methods to measure the impact.

Chapter 4

Health literacy assessment

The National Assessment of Adult Literacy (NAAL) was first measured in 1992, and again in 2003 (Kutner, Greenberg, Jin, & Paulsen, 2006). The NAAL is an assessment of literacy, not health literacy, including sections on prose, document, and quantitative literacy. While the quantitative section addresses numeracy, the NAAL does not address functional or critical health literacy domains. Several assessments of health literacy have emerged. The Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) have been the most researched (Baker, 2006). The REALM and TOFHLA and difficult to apply in a clinical setting and are not specific to cardiovascular disease or diabetes.

In addition to evaluating the health literacy of individuals, there are tools designed to assess the readability and health literacy demands of health education materials. The Roundtable on Health Literacy has established guidelines for the development of materials, including keeping documents at less than a 5th grade reading level, keeping sentences to less than 15 words, and avoiding multi-syllabic words. Multiple studies (Hill-Briggs, Schumann, & Dike, 2012; Taylor-Clarke et al. 2012) have shown that most educational materials, especially related to cardiovascular disease and diabetes, do not meet these guidelines. On a practical note, however, eliminating multi-syllabic words in cardiovascular disease would exclude cholesterol, triglycerides, saturated fat, hypertension, insulin resistance, carbohydrates, and many others.

Condition specific health literacy assessments have been developed as part of the Health Literacy Instructional Model. These assessments are based on the 5 domains of health literacy progression shown in Figure 7. These assessments are currently being validated and are shown in Appendix 2. The health literacy assessment begins with a general assessment of health literacy, followed by a lifestyle assessment for health and wellness. Disease specific assessments have been developed for diabetes, high blood pressure, cholesterol, cardiometabolic, and heart failure.

The components of health literacy, as described in Figure 7, include knowledge, numeracy, navigation, communication, and decision making. Much of the focus on health literacy, at least in the United States, is on linguistic factors, such as reading level. The Europeans and Australians, however, take a broader view of health literacy and include functional and critical health literacy factors. While efforts to simplify the message, and reduce jargon are worthwhile, these efforts should not be at the expense of functional and critical health literacy. While definition vary, for simplicity, functional health literacy includes numeracy and navigation, which critical health literacy includes communication and decision making.

No studies have been conducted looking at these 5 levels of health literacy as a progression. They do, however, seem to be related, and have the potential to build from one to the next. Using blood glucose as an example, being able to calculate insulin requirements based on the current glucose reading, carbohydrate intake and activity level is an example of numeracy, that would not be possible without understanding how glucose, insulin, and carbohydrates are related, which is an example of knowledge. If a patient with heart disease was given nitroglycerin for chest pain, they would be instructed to place the nitroglycerin under their tongue and wait 5 minutes. If the pain persists, they would be instructed to take another nitroglycerin and wait another 5 minutes. If the pain continues, the patient is instructed to call 911 (navigation). When the ambulance arrives, the patients will be asked to describe the pain (communication). At the hospital, the patient and the cardiologist might have a conversation about having a percutaneous coronary intervention (PCI), coronary artery bypass surgery (CABG), or a change in medications (shared decision making), and the patient may decide to finally enroll in cardiac rehabilitation (decision making). The functional health literacy factors (numeracy and navigation) seem to be the connecting points with knowledge and critical health literacy factors seem to be the highest level of health literacy.

Knowledge and linguistics. The first level of health literacy is knowledge, or understanding the concept. This includes reading, speaking, writing, and understanding health content and directions from healthcare professionals. It is measured with linguistic markers, including word length, number of syllables, and reading level. While is does no good to use jargon, and speak over the head of the patient, note that many of the key terms and concepts listed below are large, multi-syllable words. Avoiding these terms is as

much a disservice and using jargon. For example, it is very difficult for the patient to understand cholesterol, triglycerides, hypertension, atherosclerosis, angina pectoris, saturated fat, insulin, and carbohydrates without using these terms. They are common, albeit large, terms, that are used routinely by healthcare professionals that are necessary to understanding medications, diagnostic tests, laboratory results, foods and nutrition, and side effects. In fact, a new diagnosis of cardiovascular disease or diabetes results in a new language with new terms, new numbers, and new rules. Assessment of knowledge in cardiovascular disease and diabetes should be based on applied knowledge with actionable steps that lead naturally to the higher levels of health literacy. In other words, knowledge alone is not enough to result in behavior change and improved outcomes.

Examples of knowledge for patients with cardiovascular disease include:

- Understanding the heart and how it works, including arteries and veins, atria and ventricles, and electrical activity (heart rate and ECG)
- Understanding diabetes, including the pancreas, insulin, and glucose
- Being able to recognize signs and symptoms of a heart attack or stroke
- Being able to recognize symptoms of a high and low blood sugar
- Understanding systolic and diastolic blood pressure, and how to take or get a blood pressure reading
- Understanding cholesterol, triglycerides, HDL-cholesterol, and LDL-cholesterol
- Understanding glucose and hemoglobin AIC, and how to measure blood sugar
- Understanding medications, including effects and side-effects
- Understanding nutrition factors, including calories; fat, saturated, mono-unsaturated, polyunsaturated, and trans-fat; carbohydrates; sodium; vitamins and supplements
- Understanding the key components of safe and effective exercise and physical activity
- Understanding how stress and emotions affect cardiovascular disease and diabetes
- Understanding how obesity affects the risk of cardiovascular disease and diabetes

Numeracy. Numeracy is the numerical equivalent to literacy. Numeracy is classified as functional health literacy, because it requires not only an understanding of the topic,

but also the ability to apply that information, expressed as a number. Numeracy involves not only understanding the numbers, but also the ability to manipulate them. Numeracy is tied to literacy in other applications, such as finances. For example, being able to calculate a payment based on the balance, the due date and the interest rate is an example of numeracy. Knowing how much to tip a waiter, or taxi cab is another example. To find examples of numeracy in cardiovascular disease and diabetes you need to look no further than medications and food labels. Numeracy skills are necessary if you are taking 200 mg tablets of ibuprofen, and cannot exceed 800 mg per day. Patients taking coumadin and insulin must be able to perform mathematical equations. Calculating sodium intake, based on the serving size is an important skill for a patient with hypertension or heart failure.

Numeracy in diabetes is especially important in managing blood sugar. The blood sugar is a function of carbohydrate intake, physical activity, and medications. This is especially true for a patient taking insulin. For example, if the blood sugar is low, the patient needs to know how many carbs will be required to get the blood sugar into the normal range. If the blood sugar is too high, the patient will need to know how much insulin will be required to get the blood sugar into the normal range. An example, a diabetic patient would need the numeracy skills to answer the following question, "if your blood sugar is 160, and your goal is 90-130, and you are estimating that your meal contains 25 carbohydrates, how much insulin is required?"

Patients will use numbers, such as blood sugar, blood pressure, and weight to validate their plan. Ironically, healthcare professionals also will use these numbers, as well as cholesterol, to measure the health literacy of the patient. In both cases, this method is not perfect, and may cause the patient or healthcare professional to under-estimate or over-estimate the knowledge and health literacy of the patient. Like knowledge, assessment of numeracy should be applied and related to actionable steps that relate to knowledge, as well as the other functional and critical factors.

Examples of numeracy in cardiovascular disease and diabetes include:

- Able to determine what range a blood pressure reading is in
- Able to determine the range that cholesterol, HDL, LDL, and triglycerides are in
- Able to determine the range that a blood glucose is in

- Able to determine the range that an ejection fraction is in
- Able to determine the range that a heart rate is in
- Can calculate insulin needs based on carbohydrate consumption and activity level
- Can calculate sodium intake
- Can calculate caloric intake
- Can calculate fat intake
- Can calculate carbohydrate intake

Navigation.   The other functional health literacy domain is navigation. Navigation is a building block stage that incorporates their knowledge and numeracy, and applies this information to critical health literacy domains, including communication and decision making.   Without health-system navigational skills, the patient will not know what questions to be asking, which is necessary to good decision making skills. The patient should be asking themselves:

- Who should I see?
- Where should I go?
- What should I expect?
- What will happen if I don't act?
- How much will it cost?

Patients need to understand not only the concepts and how to manipulate the numbers, but also what to do with the information. In the case of cardiovascular disease and diabetes this involves knowing how to access the healthcare system. From decisions about doctors and health plans, to the mode of access (911, emergency department, physician's office, or non-medical sources), these decisions will impact the type and quality of care that the patient receives. The disposition of the patient, and mode of arrival at the time they need to access the healthcare system (in cardiac arrest, in an ambulance, in a car, on the phone). If the patient is unconscious, arriving in the emergency department on a gurney, their ability to decide which facility, physician, or medications are quite limited. Patients can communicate certain needs through advanced directives, and many decisions are determined in the health plan. Health literacy navigational skills, therefore, can be built before, during and after a medical encounter. Some hospitals have patient navigators

that will help the patient work through this complicated process. Once the acute phase has passed the patient can also become a more active participant in decisions related to price transparency, quality, service, and ultimately value. Assessment of navigation tends to be specific and personalized. There are, however, key navigational areas that all patients with cardiovascular disease and diabetes should know, such as how to access the EMS system in the case of an emergency, and how to respond to critical numbers, such as blood pressure and blood glucose.

Examples of navigation in cardiovascular disease and diabetes include:

- Understanding when to go to the emergency department, when to dial 911, and when to call the doctor's office
- Knowing how to select a physician, imaging center, or cardiac rehab program
- Able to determine of services, such as cardiac rehabilitation, or diabetes self-management are covered in the health plan
- Able to fill medication prescriptions

Communication: The final two domains of health literacy are classified as critical health literacy skills, and include communication and decision making. Much like navigation, communication itself is a skill that sets up the decision-making process. This includes questions, clarifications, filters, and validation. For example, the patient is filtering the information they are getting from their healthcare provider, as well as other sources, and attempting to validate that information. Since the patient does not have a personal history to draw from, the patient is looking at multiple sources and determining which source is the most trustworthy.

In the case of cardiovascular disease and diabetes a key communication skill is knowing what information to share with the healthcare team, especially the physician. Key information includes an accurate and precise description of symptoms and side-effects. If the patient is experiencing symptoms, the doctor will try to determine whether the symptoms is heart-related. If the patient is unable to describe the symptom effectively to the doctor, this key opportunity might be missed. Patients should be instructed to communicate with the healthcare team if they are having trouble with the cost of medications, if they have transportation issue, or other issues that might affect their care. In addition to sharing vital information, a good communication skill is the ability ask

questions and to seek clarifications from the healthcare team. For example, the patient should clarify with the healthcare team about when to communicate signs and symptoms and how to access the healthcare system. Many patients will drive themselves to the hospital when they are experiencing chest pain, rather than calling 911. Assessment of the communication domain of health literacy is based on knowing what information to share and what questions to ask. In cardiovascular disease and diabetes, key information to share includes any symptoms or side-effects. Assessment can also focus on knowing what information might need clarification. Examples of clarifications might include the best way to contact the healthcare team.

Examples of communication in cardiovascular disease and diabetes include:

- Knowing how to get information to the doctor, including the primary care physician
- Knowing what information to share with the healthcare team, such as symptoms and medication side-effects
- Knowing what questions to ask the healthcare team; and how to ask

Decision making – shared decision making: The final, and ultimate level of health literacy is decision making. Decision making can be unilateral, such as losing weight, eating better, increasing physical activity, and smoking cessation. For example, if the patient is experiencing chest pain, they need the literacy-decision making skills to determine whether to: call their doctor's office, call the cardiologist, go to the emergency department, or call 911. Shared decision making is when the patient and the physician jointly make choose the treatment path, such as PCI vs. CABG. Shared decision making can also be used in choices of medications, based on cost, risk, and side effects.

Shared decision making is gaining traction as part of the conceptual model for patient engagement in healthcare settings, such as the emergency department (Blackwell et al., 2016). Tools and interventions have been developed to help bring the patient into the conversation regarding the course of action, such as the selection of imaging, evaluating the risk of radiation exposure to the benefit of a more accurate diagnosis (Melnick et al., 2016). A decision tool, using a pictograph depicting the pre-test probability of acute coronary syndrome, for patients presenting to the emergency department with chest pain resulted in greater knowledge and engagement, and fewer hospital admissions (Hess et

al., 2012). The American Heart Association has published a scientific statement on decision making in advanced heart failure (Allen et al., 2012). Unilateral decision making is more difficult to measure, but is as important as decision making. It is easy, however, to mix up goal achievement with the actual decision making process.

Examples of decision making in cardiovascular disease and diabetes include:

- Able to select a cardiologist, surgeon, primary care physician
- Able to determine a self-management plan
- Able to select a cardiac rehabilitation program
- Part of the conversation regarding having a PCI vs surgery

In addition to assessing the progression of health literacy skills, the health literacy instructional model must address how and when health literacy is measured. Figure 10 is an illustration of a model for how health literacy can be assessed. This assessment format begins with an initial assessment of general health literacy issues, including infectious disease, acute, and chronic diseases/conditions. These are generally preventive measures including immunizations and screenings. The next step is an assessment of lifestyle factors, including physical activity, nutrition, weight management, stress management, and smoking cessation. If there are no chronic conditions, the assessment is complete, but if there are chronic conditions, then disease specific health literacy, using the 5 domains, should be assessed.
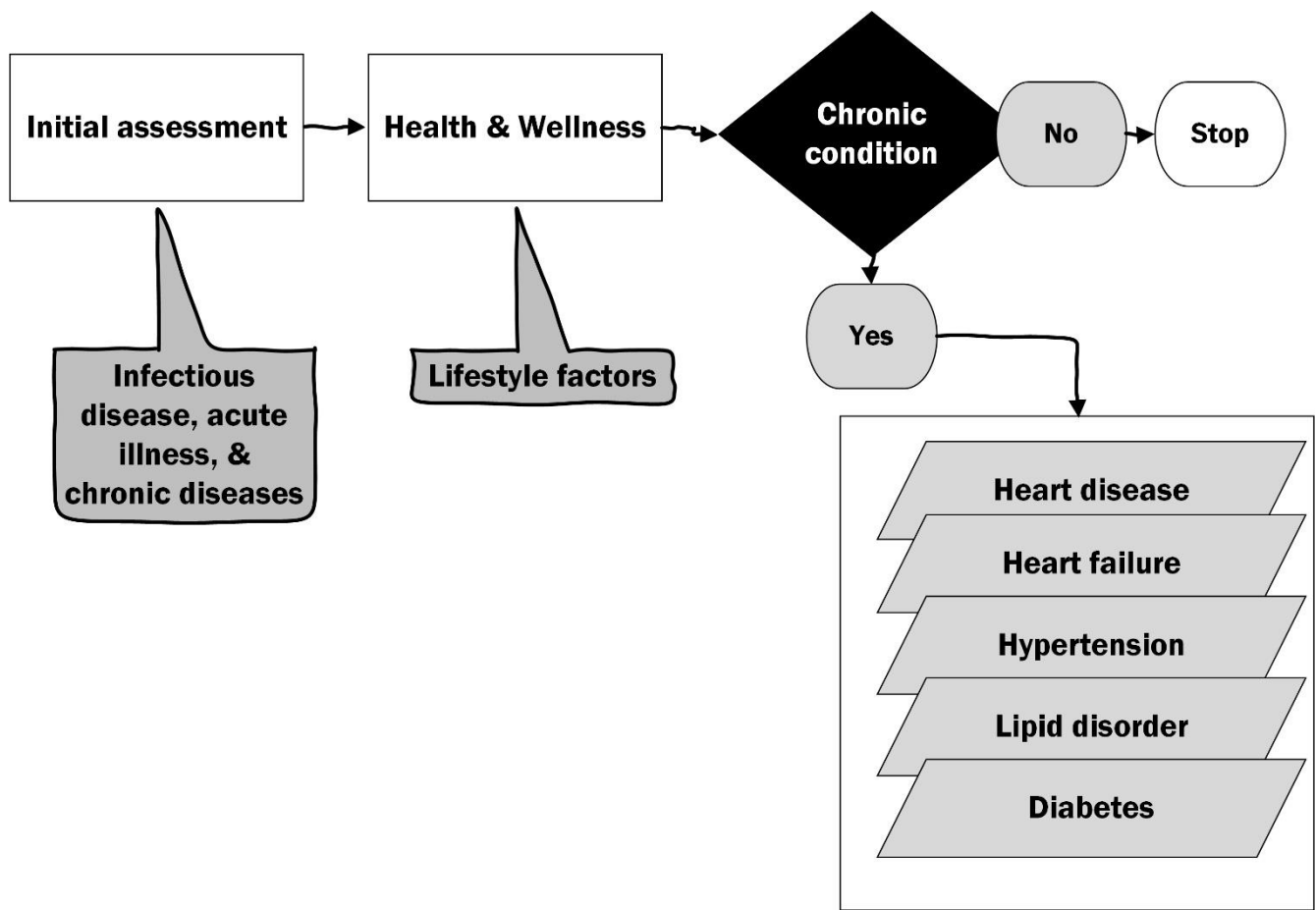
Figure 11. Health literacy assessment format

Chapter 5

Building health literacy skills

The first step in the achievement of a culture of health literacy is to comply with standards identified in the National Action Plan (Department of Health and Human Services, Office of Disease Prevention and Health Promotion (DHHS, 2010) and strategies contained in the Universal Precautions Toolkit (Dewalt, 2010). In both documents, there is an emphasis on using plain language, with clear and concise messaging, and eliminating jargon. The best practice is to write documents at a 5th grade reading level. Another strategy is to improve communication skills between healthcare professionals and their patients. This is more than simply reducing jargon and writing at a 5th grade level. It also includes verbal and non-verbal communication skills that build trust between the patient and the healthcare team.

Use of plain language and low reading levels are great strategies for patients with low health literacy. Since cardiovascular disease and diabetes are complex conditions, with a high level of patient involvement, there are times when polysyllabic words are required. Using big words and concepts, in fact, are necessary, at times, to convey the correct meaning. For example, teaching a patient with high cholesterol about saturated fat is very challenging if word length, and number of syllables are used. Eliminating the words cholesterol and saturated fat will invariably change the meaning. These words might be considered jargon, but are common terms. Rather than eliminating the terms, making the terms more familiar, not less, and should be the goal. The risk is that if the message is too simple, patients with higher literacy skills may not be engaged, but if the message is too complex, patients with low literacy skills may be overwhelmed. One solution is to change the emphasis from communication to education. If a culture of health literacy can be achieved, and knowledge and health literacy skills across the spectrum of health literacy, then higher level communications can be used. The result is that the patient with a high cholesterol level will be able to identify foods that are high in saturated fat.

To build a culture of health literacy requires not only establishing better ways to communicate with those with low health literacy, but also to find methods for building health literacy skills for all. In addition to strategies to improve communication between healthcare professionals and patients with low health literacy skills, the DHHS (2010)

National Action Plan is also a call to action for more research into innovative solutions for building health literacy skills. Since much of the research on health literacy interventions has not measured improvement in health literacy skills, an inductive approach has been taken to determine the best strategies for building health literacy skills. This grounded theory approach has resulted in a theoretical explanation of how patients with cardiovascular disease and diabetes acquire the knowledge and skills to manage their health. This theoretical explanation is called the Health Literacy Instructional Model. This inductive approach has revealed some areas that should be explored with additional research. Some of these areas present opportunities for achieving a culture of health literacy not only in the United States, but around the world. An area that has emerged as a key throughout the spectrum of health literacy is that social and emotional support is a learning opportunity. The use of digital tools, including apps, devices, websites, and search engines hold the promise that technology can result in better health, but this promise is yet to be fulfilled. Finally, there are several behavioral and instructional strategies that hold promise to building knowledge and health literacy in patients with cardiovascular disease and diabetes.

Social and emotional support is a learning opportunity.

The key theme that ran across all levels of health literacy and was mentioned by virtually every patient and healthcare professional was the importance of a support system. For patients with cardiovascular disease and diabetes, the support system included participation in cardiac rehabilitation programs, diabetes self-management programs, therapeutic lifestyle change programs, and face to face and online support systems. In her interview, Jennifer mentioned cardiac rehabilitation, Mended Hearts, and the American Heart Association's Patient Support Network as keys to being able to better understand the information that was presented to her by her physician.

Comprehensive cardiac rehabilitation programs provide a multi-level intervention, including exercise therapy, risk factor modification, education and group support, demonstrating positive clinical outcomes (Haskell et al., 1994; Ornish et al., 1990; Koertge et al., 2003). It is very difficult, however, to tease out the incremental impact of education and support from other benefits of cardiac rehabilitation. Cardiac rehabilitation is conducted in a group setting for a minimum of 12 weeks, but for many patients, they will continue attending for the rest of their life. Patients will, therefore, bond with other

patients because they share a common experience. Cardiac rehabilitation programs meet all the criteria for how support is related to health literacy. Interaction with other patients and healthcare professionals trained to care for patients with heart disease can reduce the anxiety of the patient, it provides the patients with an opportunity to share their experiences with one another, and it provides an effective platform for informal teaching and incidental learning. As patients witness other patients getting stronger, it gives them confidence that they too can, and will regain much of their independence and functional capacity that they had prior to their cardiovascular event. Face to face support, such as Mended Hearts, and online support, such as the American Heart Association's Patient Support Network, diabetes self-management courses, and therapeutic lifestyle change coaching programs provide similar opportunities for building health literacy (Gordon et al, 2017; Courtney, Conard, Dunn, & Scarborough, 2011; Richards, Wicks, & Coulter, 2015).

The first step in building health literacy skills is to address the emotional state of the patient. Most health literacy interventions have focused on building knowledge, and most stress management interventions have not focused on building knowledge and literacy. There are good examples of studies that have been designed to manage stress and emotions in patients with cardiovascular disease, and it is very difficult to tease out the impact of health literacy on improvement in health outcomes (Blumenthal et al., 2005; Surwit et al., 2002; Dunn, Conard & Kirschner, 2017).

Behavioral strategy

Programs designed to manage patients with cardiovascular disease and diabetes emphasize motivation and engagement. Motivation and engagement, by themselves, are not instructional strategies. Patients can be motivated to engage in behaviors that are not beneficial. Examples are programs that focus on nutrition, fitness and weight loss. According to the health literacy instructional model, a behavioral strategy is a key element in the development of health literacy skills, once the emotional state of the patient has been addressed, and before the instructional strategy begins. A common method to engage patients is through health coaching, conducted in a live or virtual setting (Gordon et al., 2017; Conard et al. 2017). The health coaches typically comprise of nurses, dietitians, exercise specialists, and other health and wellness professionals. The most common behavioral strategy is the transtheoretical model and the health belief model

(Scales, 2013). It is unclear, however, how much training health coaches, and other healthcare professionals received in basic teaching and learning methods. In the study conducted by Dunn, Margaritis, and Anderson (2017) only 1 of the 19 healthcare professionals that participated in the study had any kind of formal training in educational methods. The one professional only had the training because she had been a high school English teacher prior to changing careers.

The transtheoretical model (Beckie, 2006) and the health belief model (McCorry et al., 2009) have been used to build self-management skills in patients with cardiovascular disease and diabetes. These behavioral models help to explain the patient's motivation, readiness for change, and self-efficacy, but do not explain how the information, knowledge, skills, communication, and decision making skills are obtained for an individual with no prior experience with their condition.

General keys to effective health mentoring include reinforcing how important it is to manage health, always be positive, acknowledge participation, be a good role model, and an active listener. In a scientific statement from the American Heart Association, (Artinian, 2010) keys to promoting lifestyle changes to reduce the risk of heart disease, including high blood pressure include:

- Setting goals
- Self-monitoring
- Frequent contact
- Feedback
- Self-efficacy
- Relapse prevention
- Communication

Setting Goals. Setting goals at the outset is important in achieving the desired behavior change. Goal setting should be measurable with a realistic timeline and each goal should have an action plan that addresses barriers and is checked and updated on a regular basis. Goals can be general, based on pre-selected recommendations, such as blood pressure, cholesterol, glucose, obesity, physical activity, or nutrition guidelines, but can also be highly personalized. Attending a grand-daughter's wedding might be more

meaningful to the patient than managing heart failure symptoms, and can achieve the same results.

The action plan is just as important as setting the goal. The plan should be assessed by the patient and the healthcare professional on a regular basis. For the healthcare professional, the action plan might be the choice of medication or other therapy. For the patient, the plan might be compliance to medication and non-pharmacological therapy. The action plan should be evaluated on a regular basis. In fact, with technology, the healthcare professional no longer must wait until the patient schedules the next visit. If the action plan is not effective, a course correction should be made, by either modifying the goal or the action plan.

Self-Monitoring. Self-monitoring includes biometrics from wearables and connected devices, as well as self-reported data. Self-reported monitoring can include biometric data or subjective data, such as medication adherence, symptoms, and behaviors, including nutrition and smoking.

Example of a self-monitoring goal with a timeline and action plan
Goal: 2 blood pressure readings per month

Timeline: 4 consecutive months

Action Plan: Reduce sodium intake to 1,500 mg daily, exercise at moderate intensity for 30 minutes per day and upload a blood pressure reading 2 times per month for 4 consecutive months. Self-monitoring of blood pressure and other goals, such as weight will increase awareness. It also provides direct feedback on how well the action plan is working. It is good for the mentor to affirm that the monitoring is being done, even if results are not yet achieved.

Example: *"I see that you have uploaded your blood pressure. Good job! I know you are not where you want to be, but keep up the good work."*

Frequent contact. Regular contact between the educator and the participant are important. This contact helps to establish trust. Contact can be in various modes, including face to face, telephone, and email/messaging. The educator and the participant should discuss and agree upon the frequency and type of contact. If contact is withdrawn, achievement of behavior change decreases.

Feedback. Feedback from the educator can be a powerful reinforcement of the desired behavior. The should focus on the level of effort regarding behavior changes. Stay positive and let the participant know that the educator understands the challenges they are facing and appreciate their efforts, even if results are not always positive. If there are any concerns about data coming from self-monitoring, the participant should he encouraged to follow up with their healthcare provider.

Example: *I know you have had a difficult time keeping your blood pressure under control. I know you are working hard. Don't give up!*

Feedback to participant is in one of the following categories

- Blood pressure uploaded and blood pressure is good: Congratulate the participant on their success;

- Blood pressure is uploaded, but is higher than they hoped: Thank them for uploading the reading, and stay positive, encouraging them to continue;

- Blood pressure is not uploaded: Encourage them to continue to upload their blood pressure, even if it is not where they want to be. Do not criticize, blame, or in any way be negative because you will get the opposite results of what you hoped for.

Self-Efficacy. Self-efficacy is the belief that if you try to make a change you will succeed. In other words, it is the confidence in yourself that you can do what you set out to do. Understanding the importance of a problem and believing that you will succeed is a major determinant of performance. For many, this is a two-part question, "can I succeed?" and "should I try?" People, in general, will choose to do things that are good for their health, but may be indecisive regarding what to do. This indecision is normal, not pathological, and helping people resolve that indecision is a key to change. With most things, we weigh the cost of the change and benefit of not changing to the benefit of the change and cost of not changing. The goal is to tip the scale in favor of the change, by focusing on the reasons that "I can" and "I should" rather than "I can't" and "I shouldn't." Tipping the scales in favor of changing simply by being there, being a good listener, and, at all costs, staying positive is the best strategy (Figure 12).
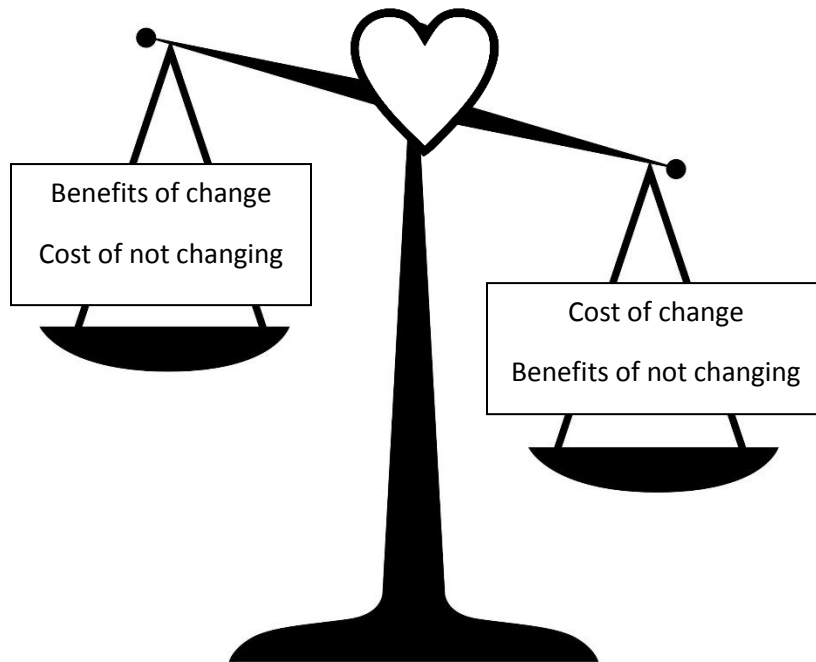
Figure 12. Balance of cost and benefits of change vs. no change

Stages of change. Stages of change, or readiness for change refers to where the patient is in the decision-making process. The stages of change were first identified by Prochaska and DiClemente (1983) in a smoking cessation program. Stages of change, or readiness for change is a very popular health behavior strategy. The stages include *pre-contemplation*, which means that patient has not even considered making a change; *contemplation*, which means the patient has considered making the change, but has not made the decision to change; *preparation*, which are the activities that occur prior to the behavior change; *action*, which is the process of making the change; *maintenance*, is designed to maintain the change; and *relapse prevention*, which are the actions necessary to keep from reverting back to the old behavior. Using blood pressure as an example, a pre-contemplator is someone that is unaware that they have high blood pressure, or is aware, but has not even considered doing anything about it. If they have considered it, but not made a decision they are a contemplator. If they have decided to start making some changes to manage their blood pressure, but not yet begun they are in preparation. If they actually start making some changes, such as monitoring their blood pressure, they are in the action phase. Finally, if they are trying to stay engaged they are in maintenance. These stages are not static. It is possible to move from one stage to the next, either forward or backward very quickly.

Relapse Prevention. Relapse prevention is a component of the stages of change. People frequently cycle from action to maintenance to relapse. The key is to not be discouraged and help the participant get back into the action phase as quickly as possible.

Communication skills. The process of educating involves using active listening skills, helping the participant to set their goals and action plans and achieving success to fostering compliance, accountability and engagement. The educator is a powerful determinant of resistance and change. Avoiding confrontation, arguments and rolling with the resistance you are increasing the participant's chance of success. Motivation can be increased by a variety of strategies. Even relatively brief interventions can have a substantial impact on problem behavior. Motivation emerges from the interaction and relationship with the participant.

Personalization - Psychographics

The newest trend that just might be a game changer as a behavioral strategy is the use of segmentation, or psychographics. There is not a 'one size fits all' approach. Segmentation has been used in consumer products for decades. All one needs to do is take a tour of your local grocery store to experience the impact of segmentation. Segmentation can be applied to health behavior just as it is in consumer behavior. By figuring out what it important to a person, messaging can be targeted to that individual, providing a more personalized and relevant experience (Hardcastle & Hagger, 2016).

The next level is likely to be the use of artificial intelligence and machine learning to not only identify the values and motivation of the individual, but also the ability to act on that information on a continual basis. While the emphasis of segmentation, psychographics, artificial intelligence is on engagement and behavior change, they also present an opportunity to build health literacy skills by having a more motivated learner.

Instructional Strategy

Educational methods. Adults are self-directed learners. According to adult learning theory, known as Androgeny, adults are self-directed, experiential learners (Knowles, 1970). To be motivated to learn, the material must be relevant and personal to the learner. Also, the content must be practical and used to solve the problem. The problem, in the case of health literacy, is the chronic health condition. Formal, structured educational methods are challenging because they need to be broad enough to account for different backgrounds and experiences, while still being personalized and relevant to the individual.

Patients are also social learners. Social cognitive theory was developed by Bandura (2002) and is based on earlier work that is concerned with the social context of learning. Social Cognitive Theory is applied at the interpersonal level and involves the ongoing and dynamic process by which personal, environmental, and behavioral factors influence each other. A key element of the social cognitive theory is self-efficacy.

So, for the adult learners reading this section, what are the practical take-aways for building health literacy skills, using adult learning theory and the social cognitive theory? First, the information presented to the patient must be personalized, relevant, social, and interactive. There are two solutions, one is high tech, and one is low tech. The high-tech approach is to leverage technology, especially psychographic segmentation, artificial intelligence, and machine learning to curate content specific to the individual patient. The low-tech approach is to build informal methods that result in incidental learning.

The teaching methods most closely aligned with building health literacy skills appear to be Bloom's taxonomy (Krathwohl, 2002), Vygotsky's zone of proximal development (Shabini, Khatib, & Ebadi, 2010), and Gardner's theory of multiple intelligences (2002). Figure 5 is an illustration of how all three can be incorporated into a health literacy building model. Bloom's taxonomy of remembering, understanding, applying, analyzing, and learning fit with the progression of health literacy skills of reading and comprehension, numeracy, navigation, communication, and decision making. In fact, Table 1 reveals virtually a one-to-one relationship between the two models. Again, what is the practical significance of Bloom and Vygotsky to Health literacy? In both models, the key is to build foundational skills, such as reading or math. This is where there seems to be a difference in how patient education is delivered. In healthcare, complicated

concepts are simplified by reducing jargon and replacing big words with smaller ones (see Figure 5). That is not the same as building foundational skills. The argument is that there is no time for teaching foundational skills. While that might be true, that is only because the priorities of the healthcare delivery system demand that there is no time.

Gardner's theory of multiple intelligences (2002) can be operationalized in today's environment using psychographics. Communications, and educational strategies have become more nuanced than in the past. While older generations are more comfortable with a 'prescriptive' relationship between the doctor and the patient, in today's world more options and different pathways of communicating are critical to success.

Formal vs. Informal Approaches. Healthcare professionals can provide patient education using formal or informal methods, or a combination. Formal methods for cardiovascular disease and diabetes include offering patient education classes. These classes are commonly conducted in a cardiac rehabilitation, diabetes center, or in a community center. In a hospital setting, a formal method might include discharge instructions, with the nurse following a checklist of areas to cover, showing the patient a video, or providing a brochure. For patients, additional formal methods might include reading books or magazines, watching videos, or attending lectures. Informal methods might include the period in the medical encounter when the physician asks the patient if they have any questions, or conversation with the nurse as they are interacting with the patient. For the patient, informal methods might include conversations with other patients and participation in social networks. Frequently formal and informal methods are combined. Showing the patient a video, but then asking if they have any questions is an example of a combined method. Dr. Conard and Jennifer used both formal and informal methods, but both seems to favor informal methods.

Informal instruction, using quick delivery, resulting in incidental learning is common health the healthcare setting (Dunn & Milheim, 2016). Informal methods have emerged as convenient ways to deliver key information in a cost-effective manner. Informal methods also appeal to many patients who like to explore information on their own time, and at their own pace. Informal approaches, however, have the potential to be less structured, incomplete, and delivered without attention to a curriculum, basic learning objectives, and may lack basic concepts of teaching and learning. While patient education is frequently informal, quick, and incidental, it does not need to be unstructured.

Educational methods can still be designed, and delivered informally, but in ways that are aligned with the learning needs of the patient. This may include beginning the educational process earlier, allowing for more encounters. Also, these methods can be standardized, practiced, and even simulated, just like other medical skills.

The healthcare setting is frequently not conducive to formal methods due to time, setting, and the priorities and skills of the healthcare professionals. The delivery of informal methods allows the healthcare professional to balance other priorities. While informal methods are easier for healthcare professionals to deliver, they can still be structured with a curriculum, learning objectives, a checklist of topics to discuss, and teaching methods such as teach-back, should still be delivered with a minimum of jargon.

Cognitive vs. Experiential Approaches. While the overwhelming majority of patient education in the healthcare setting uses a cognitive approach, applying key principles of adult learning would indicate that much of the patient learning is experiential. The most practical way to provide experiential learning is to get patients to interact with other patients. While the patient might not have a personal history of a heart attack, they will fill in knowledge gaps by learning from other patients. This is where cardiac rehabilitation and social support programs come in.

Cognitive approaches are much more practical, and should still be thought of as a key part of the educational process. Examples include the choices given to the patient and the participation of the patient in the development of goals and action plans. There is a natural tension between being too prescriptive or allowing too many choices. Ultimately, organizations and individuals are much more likely to achieve their goals if an action plan, with measurable objectives, a timeline, and accountability system is in place (Burt et al., 2012). Key elements of the engagement plan include making it as user/patient friendly as possible, and making the content interesting so that the patient continues to use the system. To make the care plan more interesting it needs to be highly personalized, relevant, interactive and social.

Experiential approaches go beyond just interacting between patients. They also have to see it from a perspective they can understand, something they can relate to, and make a well informed decision. The value of education is much higher when the patient reaches the right conclusion by him/her self. For example, in a group of patients newly diagnosed with diabetes, a good approach would be to give them examples they can see, and not just an image, related to foods with high sugar content, or how insulin works in the body.

They will experience the impact of their disease by testing its limits, as defined by how food, activity and medicine impact blood sugar levels. A way to do this is by starting with something everybody knows, like a common cold, learning how to identify it, possible treatment ways, possible triggers, indications that they are getting better. Questions can be asked to determine how well the patient is understanding the information.

Gaps. While the healthcare professionals, starting with the physician are the most trusted source of information, many patients still have a healthy distrust of the information they receive from their healthcare professionals and seek to validate it with other information. Also, while the instructional strategies used by healthcare professionals are perceived to be effective for patients with proficient health literacy and numeracy skills, they are not effective for patients with low literacy and numeracy skills.

Healthcare professionals, including physicians are not trained in educational methods. Medical students are told they need to explain the medical conditions, diagnostic tests, and treatments to patients, but are not given the tools necessary to communicate this information effectively. The result is that many health professionals avoid giving advice to their patients on modifying behavior because they consider traditional approaches to be time consuming and difficult for the patient to implement. Additionally, reimbursement for taking extra time with a patient is usually non-existent. Better teaching methods may result in more efficient use of time and result in better health outcomes.

Role of Digital Tools

Facebook, Google and FitBit have been disruptive influences on how patients receive and track information about their health by making access to information and social networks as close as the nearest internet connection. Artificial intelligence systems, such as IBM Watson have the capacity to place structure to unstructured information. Formal patient education practices such as brief, one time educational sessions and hand-outs do not engage patients the same way that they did in the past. Instructional strategies that enhance the patient's ability and desire to learn, provide hands-on experiences, and allow the patient to reflect and share their experiences with others are idea for informal learning. Digital tools with live health coaching and or the use of artificial intelligence have the capability of providing informal learning in a way that is highly personalized, interactive, social, and relevant.

The use of digital tools and mobile technology has fundamentally changed how individuals with chronic conditions find and use health information (Beatty, Fukoaka, & Wholley, 2013). The tools include smartphones, tablets, and wearable devices that measure physical activity, blood pressure, heart rate, and calories. The technology has moved beyond basic communication to artificial intelligence, and virtual reality. Increasingly, patients of all age and ethnic groups are using web-based tools to find information on diseases and conditions, treatments, track results, and communicate with their healthcare team (Lefebvre & Bornkessel, 2013). Of adults living with a chronic health condition, 72% use the internet to gather information about their medications, conduct research on alternative approaches, or read about other people's experiences (Fox & Duggan, 2013). There is, however, a digital divide, with patients with low health literacy being much less likely to use technology (Levy, Janke, & Langa, 2015). Even for users of digital tools, it difficult to determine the health impact.

Research agenda

To validate the health literacy instructional model, a mixed methods approach will be needed. This study will use a hybrid type 1 trial design as defined by Curran, Bauer, Mittman, Pyne, & Stetler, 2012. Using this model, the trial design will determine the clinical effectiveness, while also better understanding the context for implementation (Curran et al., 2012). The design, therefore, will have a quantitative as well as qualitative components with the intervention adapting through several cycles of learning. Additionally, this research must determine the effectiveness of these methods across the spectrum of health literacy. Qualitative methods will be used to continue to gain deeper insights into how health literacy skills are developed from the perspective of both patients and healthcare professionals. These perspectives will be gained using grounded theory and will include a diverse group of patients with cardiovascular disease and diabetes, as well as a diverse group of healthcare providers, including critical care professionals and educators. These different patient types and professionals all have different perspectives. Quantitative methods will be necessary in several ways including:

- Validating the condition specific health literacy assessments listed in appendix B;
- Establishing the progression and relationships among the 5 levels of health literacy described in Chapter 4;
- Validating the health literacy assessment model described in Chapter 4.

- Demonstrating statistical relationships between 3 steps described in the Health Literacy Instructional Model described in Chapter 5.

There are unanswered questions that will need to be explored for this model to work, including:

- The relationship between social support and health literacy;
- The role of digital tools in building health literacy;
- The role of psychographics in health literacy;
- The impact of teaching methods in health literacy

Recommendations

Health literacy is a diverse and complicated topic, which is much more nuanced than maintaining a 5th grade reading level, avoiding jargon, and using the teach-back method. Using a social ecological approach, becoming a more health literate culture, especially in cardiovascular and diabetes health must be multi-level and system wide (Pearson et al, 2013). Recommendations for becoming a more health literacy culture, therefore, are specific to the setting, including the community, the worksite, the healthcare setting, and the educational setting (Table 3).

Table 4. Recommendations for becoming a more health literacy culture

Community health	Comply with established health literacy standards
	Partnerships with healthcare, corporate, and educational setting
Worksite	Provide benefit plan incentives aligned with health optimization
Healthcare	Encourage the use of support systems, such as cardiac rehabilitation, diabetes self-management programs, and therapeutic lifestyle change programs, as well as social support systems
	Provide formal education on teaching and learning methods to healthcare professionals
Education	Provide adult education resources and encourage life-long learners

Technology	Establish standards for health technology apps, devices, and platforms that follow health literacy standards

Finally, healthcare professionals must need to become better educators. Physicians, nurses, and other healthcare professionals take pride in their chosen profession and seek to achieve excellence in patient care. If patient education is anywhere within the job description of a healthcare professional, this excellence cannot be achieved without dedication and commitment to the art of teaching. To do so requires finding ways to engage patients in the process of learning how to take better care of themselves by creating the context and providing the content conducive to learning. Paying more attention to the patient's learning needs, by providing an effective learning environment, and by assessing both the gaps and growth in knowledge and skills, the healthcare professional and health educator is likely to find even greater professional satisfaction.

The problem of health literacy, however, cannot be solved solely by healthcare professionals and educators. Individuals with and without chronic health conditions must be a greater commitment and effort in achieving optimal health. While there are many flaws in the healthcare system, especially in prevention and education, the primary beneficiary of improved health literacy is the patient. To achieve this, however, we need a commitment to a more health literate culture, leaving no patient behind.

Appendix 1: Key terms

Cognitive approaches: Educational approaches that rely on the passage of knowledge from the instructor to the learner.

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

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

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

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

Incidental learning: The result of informal instruction, where the patient is learning information that is not structured (Dunn & Milheim, 2016).

Informal instruction: Teaching opportunities that are unplanned and unscheduled, such as conversations with healthcare professionals, care givers, and other patients (Dunn & Milheim, 2016).

Learning zone: The range of information that the patient can absorb. In an educational setting this is known as the Zone of Proximal Development (Harland, 2003).

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

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

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

Psychographics: A segmentation strategy that is focused on behaviors, motivations, and communication style (Hardcastle & Hager, 2016).

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

Appendix 2: Assessment of health literacy

General

The best way to prevent the spread of germs is?

1. Taking anitbiotics

2. Avoid sneezing

3. Hand washing

Answer: Hand washing

Signs of an infection include

1. Redness

2. Swelling

3. Fever

4. Pain

Answer: Redness; swelling; fever; pain

If your prescription says to take 2, 20 mg tablets, 3 times per day, what is your daily dose?

1. 60 mg

2. 90 mg

3. 120 mg

Answer: 120 mg

Match the nutrient, of food item, that is most closely associated with each risk factor

1. Carbohydrate – cholesterol

2. Saturated fat – blood pressure

3. Sodium – blood sugar

Answer: Carbohydrate – blood sugar; Saturated fat – cholesterol; Sodium – blood pressure

If the food label says there are 40 calories per serving and there are 4 servings per container, and you consume three-fourths of the container, how many calories have you consumed??

1. 40

2. 120

3. 160

Answer: 120

Rank the sources of medical information?

1. Your personal physician

2. Medical professional organizations, such as the American Diabetes Association, the American Heart Association, or the American Cancer Society

3. Wikipedia

4. Bloggers

5. Friends and family

Answer: Your personal physician; Medical professional organizations, such as the American Diabetes Association, and American Heart Association, or the American Cancer Society; Friends and family; Bloggers; Wikipedia

If you are experiencing chest pain, you should?

1. Call 911

2. Go to the emergency department

3. Call your doctor

Answer: Call 911

You should have a physical exam?

1. If you are at high risk

2.   At least every 5 years

3.   If you are experiencing symptoms

Answer: If you are at high risk; At least every 5 years; If you are experiencing symptoms

Your doctor has just recommended that you have an expensive medical procedure. Rank the order in which you would decide to have the procedure, or not?

1.   Your out of pocket cost

2.   The likelihood of success

3.   The outcomes reported by the doctor and the facility in which the procedure will be performed

4.   The total cost of the procedure

5.   The personality of the doctor and his or her staff

Answer: The likelihood of success; The outcomes reported by the doctor and the facility in which the procedure will be performed; Your out of pocket cost; The total cost of the procedure; The personality of the doctor and his or her staff

What are some ways to effectively communicate with your doctor?

1.   Write a letter or email your doctor

2.   Call your doctor's office and ask to speak with her or her nurse

3.   Send a secure message through the doctor's electronic health record

4.   Call the doctor's home number

5.   Call the insurance company

6.   Send a text message to the main number listed for your doctor

Answer: Call your doctor's office and ask to speak with her or her nurse; Send a secure message through the doctor's electronic health record; Write a letter or email your doctor; Call the doctor's home number; Call the insurance company; Send a text message to the main number listed for your doctor.

Diabetes

Knowledge: Diabetes is the result of your body not being able to produce enough

1.   Carbohydrates

2.   Glucose

3.   Insulin

Answer: Insulin

Numeracy: A fasting glucose of 135 is

1.   Normal

2.   Borderline

3.   High

Answer: High

Navigation: You should get your A1C measured

1.   Once per year

2.   At least twice a year

3.   Once per month

Answer: At least twice a year

Communication: If you are experiencing symptoms, such as blurred vision, or numbness or tingling in your hands and feet, you should discuss this with your doctor

1.   Immediately

2.   At your next office visit

3.   Only if it continues for more than 7 days

Answer: Immediately

Decision making: If your blood sugar is too low, you should

1.   Consume 15 grams of carbohydrates

2.   Consume 15 grams of carbohydrates and recheck in 15 minutes

3.   Take an additional dose of your diabetes medication

Answer: Consume 15 grams of carbohydrates and recheck in 15 minutes

High blood pressure

Knowledge: Sources of excess sodium in your diet include

1.   Breads

2.   Processed foods

3.   Water

4.   Fresh fruits and vegetables

Answer: Breads

Numeracy: A resting blood pressure of 132/86 is

1.   Normal

2.   Borderline

3.   High

Answer: Borderline

Navigation: In managing your blood pressure, check the statements that are true

1.   You only need to worry about your blood pressure if you are having symptoms

2.   Over the counter medications, such as antihistamines may elevate your blood pressure

3.   You should avoid using blood pressure medication that has gone generic

4.   Exercise causes your blood pressure to rise, but lowers your blood pressure in the long term

Answer: Over the counter medications, such as antihistamines may elevate your blood pressure and Exercise causes your blood pressure to rise, but lowers your blood pressure in the long term

Communication: In discussing your blood pressure treatment with your physician

1.   Report any side effect you may be having

2.   Report blood pressure measurements that you have taken at home or in a community setting

3.   Discuss the use of supplements, over the counter medications and stimulants

4.   Report symptoms you are experiencing, even if you are unsure that they are related to your blood pressure

5.   Discuss non-medication related issues, such as diet, exercise, and stress management

Answer: Report any side effect you may be having; Report blood pressure measurements that you have taken at home or in a community setting; Discuss the use of supplements, over the counter medications and stimulants; Report symptoms you are experiencing, even if you are unsure that they are related to your blood pressure; Discuss non-medication related issues, such as diet, exercise, and stress management

Decision making: Treatments for high blood pressure include

1.   Taking medications as prescribed

2.   Dietary approaches (DASH diet)

3.   Stress management

4.   Weight lifting

Answer: Taking medications as prescribed; Dietary approaches (DASH Diet); Stress management

Cholesterol

Knowledge: The lipoprotein component that is good, and by increasing reduces your risk of a heart attack is

1. HDL

2. LDL

3. Triglycerides

Answer: HDL

Numeracy: An LDL cholesterol of 135 mg/dl

1. Normal

2. Borderline

3. High

Answer: High

Navigation: To prepare for lab work, fasting means

1. No food for the past 8-12 hours

2. No food, or water for the past 8-12 hours

3. No food, water, or medications for the past 8-12 hours

Answer: No food for the past 8-12 hours

Communication: Symptoms you should report to your doctor if you are taking cholesterol medications are

1. Muscle pain

2. Indigestion

3. Weight gain or loss

Answer: Muscle pain

Decision making: You should begin lipid lowering medications if

1. Your LDL is greater than 160, or 100 if you have heart disease

2. Your HDL is less than 40

3. If you and your doctor agree that it will reduce your risk of a heart attack or a stroke

Answer: If you and your doctor agree that it will reduce your risk of a heart attack or a stroke

Heart failure

Knowledge: Weight gain for patients with heart failure is likely an indication of

1.   Eating too much

2.   Not getting enough physical activity

3.   Fluid retention

Answer: Fluid retention

Numeracy: You should limit your daily sodium to

1.   1500 mg

2.   2 g

3.   2300 mg

Answer: 1,500 mg

Navigation: You can reduce your chance of a readmission to the hospital by

1.   Monitoring your weight and symptoms

2.   Taking your medications as prescribed; Staying connected to your physician

3.   Monitoring your fluid intake

4.   Reducing your sodium intake

Answer: Monitoring your weight and symptoms; Taking your medications as prescribed; Staying connected to your physician; Monitoring your fluid intake; and reducing your sodium intake

Communication: Symptoms you should report to your physician include

1.   Shortness of breath

2.   Swelling in your ankles

3.   Heart failure has no symptoms

Answer: Shortness of breath; swelling in your ankles

Decision making: What rate of weight gain should you report to your physician

1.   No reason to report changes in weight

2.   3 pounds in 3 days

3.   More than 5 pounds in a week

Answer: 3 pounds in 3 days.

Cardiometabolic

Knowledge: Cardiometabolic risk includes

1.   Blood pressure

2.   HDL Cholesterol

3.   Triglycerides

4.   Waist circumference

5.   Blood glucose

Answer: Blood pressure; HDL cholesterol; Triglycerides; Waist circumference; and Blood glucose

Numeracy: The fat content of the food you are consuming has 5 grams per serving and there are two servings, how many calories have you consumed?

1.   10

2.   45

3.   90

Answer: 90

Navigation: Healthcare professionals that can help you reduce your risk include

1.   Diabetes educators

2.   Dietitians

3.   Health educators

4.   Nurses

5.   Exercise physiologists

Answer: Diabetes educators; dietitians; health educators; nurses; exercise physiologists

Communication: Effective solutions for reducing cardiometabolic risk you should discuss with you doctor include

1.   Therapeutic lifestyle change

2.   Stents and bypass surgery

3.   Treatment of cholesterol, blood pressure, and glucose

4.   Pacemakers

Answer: Therapeutic lifestyle change; Treatment of cholesterol, blood pressure, and glucose

Decision making: A BMI of 29 classifies you as

1.   Underweight

2.   Normal weight

3.   Overweight

4.   Obese

Answer: Overweight

Lifestyle

Knowledge: How many hours of sleep should you get per night?

1. 6 to 7

2. 7 to 9

3. 9 to 10

Answer: 7 to 9

Numeracy: If you walk 1 mile per day, how many days will it take you to burn 1 pound of fat?

1. 3

2. 14

3. 35

Answer: 35

Navigation: Items that you should consider when developing your lifestyle plan

1. Immunizations and vaccinations

2. Preventive screening tests

3. Establishing a good support system

4. Establishing a relationship with a primary care physician

5. Following dietary and activity guidelines

Answer: Immunizations and vaccinations; preventive screening tests; establishing a good support system; Establishing a relationship with a primary care physician; Following dietary and activity guidelines

Communication: Blood pressure can be measured

1. Only by a healthcare professional

2. At home, using a blood pressure device

3. Accurately with an automated device

4.   Accurately with a wrist cuff

Answer: At home, using a blood pressure device; Accurately with an automated device

Decision making: The optimal rate of weight loss is

1.   1-1.5 pounds per week

2.   2-5 pounds per week

3.   5-7 pounds per week

   Answer: 1-1.5 pounds per week

<center>Appendix C</center>

Motivational Interviewing: Practicing and Role Playing

Appendix C is an excerpt from a training program on motivational interviewing and reflective listening with specific examples of exercise, medication adherence, and dietary change. Motivational interviewing is a population behavior change strategy that fits very well with the health literacy instructional model (Miller & Rollnick, 2002). The key to motivational interviewing is getting the participant on the right side of the argument. If the participant is the one making the case, it is much easier than having to convince them that they need to make the change. The key skills are effective listening strategies. What happens when you tell your kids to clean their room? Their natural tendency is to take the other side of the argument. "My room does not need to be cleaned", "I am too busy", "and Why don't you do it." The same thing happens in mentoring. If you say, "You need to lose some weight" the participant may respond with "No I don't", or "Yea, and you need to lose a few pounds yourself." The key is to turn it around so that the participant is the one making the argument for the change.

You should be aware of signs that the individual is ready to make a change. They include decreased resistance, resolve, making self-motivational statements, increased questions about change, envisioning what it would be like to make the change, and even experimenting with making the change.

Effective approaches include removing barriers, increasing choices, practicing empathy, providing feedback, clarifying goals and being an active helper. The FRAMES model is an effective strategy using in motivational interviewing (Miller & Rollnick, 2002).

Examples of effective motivational approaches include:

Feedback: *I see that you have not been uploading your blood pressure every week.*

Responsibility: *For best results, we need you to upload your blood pressure readings 2 times per month for 4 consecutive months*

Advice: *One of the keys to managing your blood pressure is to get regular blood pressure readings.*

Menu: *Let's discuss some ways to get those readings uploaded each week.*

Empathy: *I know it has been hard for you to find the time*

Self efficacy: *Do you feel that this program will make a difference for you?*

Principles of motivational interviewing include: resisting the temptation to fix the person; understanding and helping the person explore their own motivation; listening with empathy; and empowering the person, encouraging hope and optimism. You should avoid arguments. Arguments are counter-productive and breed defensiveness. If you meet resistance you should change strategies. Also, labeling is unnecessary. Some examples include:

Staying positive, avoid arguments:

Exercise: Let's start with something you can do

Med compliance: Your medications cost too much, maybe there are alternatives that your doctor can recommend.

Diet: We are all humans, so "cheating" occasionally, is normal, do not be discouraged.

If you encounter resistance you should roll with it. The momentum can be used to your advantage and can help the participant shift their perspective. These new perceptions can be invited, but should not be imposed.

Rolling with Resistance:

Exercise: Tell me more about the things you enjoy about exercise

Med compliance: You should discuss some alternatives with your doctor

Diet: What would you be willing to try?

Always listen with empathy. This means you understand where they are coming from. It does not mean that you agree or that you have a common experience with them. If they feel accepted they will be more likely to change. The key is skillful listening. Also, indecision is normal.

Listen with Empathy:

Exercise: I know it is a struggle for you, it is for me too, but you have really made good progress

Med compliance: I understand the cost of your medications is an issue

Diet: I can see that reducing salt in your diet is really hard for you.

Motivation involves being aware of the consequences. If the participant sees the discrepancy between their behavior and their goal they will be more likely to change, but they need to be the one that sees it.

Dealing with Discrepancy:

Exercise: So exercise makes you feel better, but you have a hard time finding the time

Med compliance: You have indicated that you are worried about your blood pressure, but have a hard time paying for your meds

Diet: You are trying to lose weight, but really love having desert.

Belief in the possibility of change is an important motivator. The participant is responsible for choosing and carrying out personal change. There is hope in the range of alternative approaches available

Another key to building motivation is avoiding traps. Some common traps are:

Avoiding Traps:

Question-Answer Trap: "Did you exercise today?"

Confrontation-Denial Trap: "Why didn't you exercise today?"

Expert Trap: "You should exercise today"

Labeling Trap: "You are non-compliant with exercise"

Premature focus Trap: "We need to figure out why you are not exercising"

Blaming Trap: "You are not exercising because your treadmill does not work"

Early strategies should include asking open ended questions, listening reflectively, affirming, summarizing and eliciting self-motivational statements.

Early Strategies:

Ask open ended questions: How has it been going since our last visit?

Listen reflectively: You are concerned about the cost of your medications

Affirm: I can see that it has been hard for you, but you are really making good progress

Summarize: You have been taking your medications, but are not sure if you can continue to afford them

Elicit self motivational statements:

How much importance do you place on taking your medications?

Listen for self-motivational statements:

Problem recognition: *I know high blood pressure is bad for my health*

Concern: I am worried that I might not be around to provide for my family

Intention to change: I plan to get my blood pressure under control

Optimism: I know I can do it if I try

Some strategies for eliciting self-motivational statements include: asking evocative questions, exploring pros and cons, asking for elaboration, imagining extremes, looking forward and looking back.

Motivational Statements:

Ask Questions: Do you think blood pressure has been a problem for you?

Exploring pros and cons: What are the best and worst parts of exercising?

Ask for elaboration: Tell me more about your concerns regarding your blood pressure?

Imagine extremes: What is the best that you could hope for if you lower your blood pressure, worst?

Looking forward: How would your life be different if you got your blood pressure under control?

Looking back: If you did not have high blood pressure, how would things be different for you?

Look for signs of resistance. These include:

- Arguing: Challenging, Discounting, Hostility

- Interrupting: Talking over, cutting off

- Denying: Blaming, disagreeing, Excusing, claiming impunity, Minimizing, Pessimism, Reluctance, unwillingness to change

- Ignoring: Inattention, Non answer, No response, sidetracking

Resistance is best handled through reflection, shifting the focus and reframing.

Reflection:

Simple reflection: You really do not like to exercise

Amplified reflection: You have had some bad experiences with blood pressure medications.

Double sided reflection: You don't enjoy exercise, yet it makes you feel better

Shifting focus: Let's go on and talk about your diet

Reframing: Do you have any active hobbies or interests?

Listening skills:
Since listening skills are fundamental, it is good to know what listening is not. Listening is not:

- Ordering, directing or commanding,
- Warning or threatening, giving advice, making suggestions, or providing solutions,
- Persuading with logic, arguing, or lecturing, Moralizing, preaching, or telling clients what they "should" do,
- Disagreeing, judging, criticizing, or blaming,
- Agreeing, approving, or praising; Shaming, ridiculing, or labeling, interpreting or analyzing;
- Reassuring, sympathizing, or consoling;
- Questioning or probing;
- Withdrawing, distracting, humoring, or changing the subject

Pair up with a partner. Select one behavior change you plan to do. If you cannot think of anything, use starting a blood pressure program.

Exercise 1:

Listening roadblocks:

Aim: To raise awareness of common responses that are examples of poor listening and block the speaker's expression. Have one person describe what they are going to do. The other person may only use nonverbal cues to communicate. Talk for 5 minutes, and then switch roles.

Discussion: What were some examples of poor listening skills?

Exercise 2:

Nonverbal skills:

Aim: To increase awareness and skillfulness in the use of non-verbal cues to communicate empathetic listening. With the same partner, again describe your behavior change. The other person may only use nonverbal cues to communicate. Talk for 5 minutes, and then switch roles.

Discussion:

Speakers: What did the listeners do to communicate?
Listeners: What did you want to say?

Exercise 3:

Reflective listening:

Aim: To raise awareness of reflective listening skills

Have the same discussion with your partner. This time, the listener can speak, but may not ask any questions. Instead, you will need to use reflective listening skills, such as repeating, rephrasing, paraphrasing, or reflecting your feelings. Talk for 5 minutes, and then switch roles.

Discussion: How did it feel, to not ask questions? Did you feel like you got the same information?

Exercise 4:

Asking open ended questions:

Continue your conversation. This time you can ask questions, but they must be open ended questions and for every question, you must use a reflection. Talk for 5 minutes, and then switch roles.

Discussion: How did it feel to use open ended questions rather than closed ended questions? How did it affect the conversation?

Overall discussion: How do you think these skills affect the relationship between you and the participant?

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