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Understanding Health Literacy Skills in Patients with Cardiovascular Disease and Diabetes

Patrick J. Dunn

Walden University and American Heart Association, pat@yourheartscore.com

Vasileios Margaritis

School of Health Sciences, Walden University, vasileios.margaritis@waldenu.edu

Cheryl L. Anderson

Walden University, cheryl.anderson@waldenu.edu

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Understanding Health Literacy Skills in Patients with Cardiovascular Disease and Diabetes

Abstract

Health literacy is the ability to understand and act on health information and is linked to health outcomes. It is unclear how health literacy skills are developed in patients with complex conditions, such as cardiovascular disease and diabetes. The purpose of this grounded theory study was to gain perspectives of both patients and healthcare professionals on how health literacy skills were developed in patients with cardiovascular disease or diabetes. The research questions addressed how knowledge and skills were acquired, the role of digital tools, instructional strategies used by healthcare professionals, and how the instructional strategies of the healthcare professionals matched the learning preferences and needs of the patients. A social ecological framework was used, which underscored the importance of understanding health literacy from multiple sources.

Semistructured interviews were conducted on 19 healthcare professionals and 16 patients. Emergent key themes included: (a) social support plays an important role as a learning opportunity; (b) many patients get their information from internet searches; (c) instructional strategies should be personalized, interactive, social, and relevant; and (d) patients are self-directed learners. Linking of these themes led to the development of the health literacy instructional model, which is a 3-step approach, including an emotional support, behavioral approach, and instructional strategy. Social support was the common element in all 3 phases and was perceived to be key to developing health literacy skills, resulting in the key implication for social change. Recommendations are to consider social support in the development of health literacy instructional strategies.

Keywords

Health Literacy, Grounded Theory, Cardiovascular Disease, Diabetes

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Understanding Health Literacy Skills in Patients with Cardiovascular Disease and Diabetes

Patrick J. Dunn

Walden University, Minneapolis, Minnesota, USA

American Heart Association, Dallas, Texas, USA

Vasileios Margaritis and Cheryl L. Anderson

Walden University, Minneapolis, Minnesota, USA

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

Health literacy is the ability of a person to understand and act on instructions given by a healthcare professional on how to manage their health (Parker & Ratzan, 2012). More than assessing reading level, health literacy includes numeracy, navigating the healthcare system, communicating with healthcare team providers, and decision making (Nutbeam, 2008; Nielson-Bohlman, Panzer, & Kinzig, 2004). An estimated 90 million Americans have low health literacy skills, impacting their ability to manage their health (Kutner, Greenberg, Jin, & Paulsen, 2006). Low health literacy is linked to poor health outcomes (Paasche-Orlow & Wolf, 2007; Sheridan et al., 2011).

Cardiovascular disease and diabetes are demanding conditions requiring knowledge, skill and involvement on the part of the patient (Smith et al., 2011). Terms like cholesterol, angina pectoris, carbohydrates, insulin resistance, and the names of medications are frequently used by healthcare providers, and are important in self-management of cardiovascular disease and diabetes (Smith et al., 2011). In the case of cardiovascular disease

and diabetes, trade-offs must be made by healthcare professionals between readability, understanding, and an accurate description of the treatments, procedures, and tests that must be explained. Individuals who survived their first heart attack do not have a personal experience to rely on. Even if they are motivated and self-directed, they still need to know how and where to find the information, be able to validate it as credible information, and be able to apply the information to their specific circumstances (Smith et al., 2011).

Since the publication of *Health Literacy: A Prescription to End Confusion*, health literacy is considered a population health priority in the United States and throughout the world (Nielson-Bohlman, Panzer, & Kinzig, 2004). The *National Action Plan to Improve Health Literacy* (U.S. Department of Health and Human Services, 2010) and the *Health Literacy Toolkit* (Dewalt et al., 2010) provide strategies designed to improve communication between patients and their health care providers. Since these strategies are designed to simplify the message, it is unclear how patients with a new diagnosis of cardiovascular disease and diabetes are able to acquire and build the knowledge and skills necessary to manage their condition. There is a large body of research in the education literature on improving literacy skills, but there is little research in adults, especially in regards to the development of health literacy skills of adults with chronic conditions (Lesgold & Welch-Ross, 2012). Current strategies, policies, and interventions designed to mitigate the impact of low health literacy focus on the use of plain language and clear and concise messaging with an emphasis on improving the readability of printed and digital educational materials. With the increase in the utilization of digital tools and technologies, and emphasis on patient centered care, there is a need for a better understanding of how health literacy skills are developed and how these skills translate to better self-management skills (Beatty, Fukoaka, & Whooley, 2013). The social ecological model was used as the starting point in the theory development by considering multi-level components, such as learning methods and the social environment (Sallis, Owen, & Fisher, 2008).

The purpose of this study was to gain perspectives of patients and healthcare professionals in the development of health literacy skills in patients who have been diagnosed with cardiovascular disease and diabetes within the past 12 months. This included how healthcare professionals assess and build health literacy skills, as well as how patients find and use health information. The intent was to go beyond the description of the low health literacy groups, the challenges, or the motivational issues and instead to focus on factors related to health literacy instruction to explore the process of learning and how new resources that are now available to patients are used.

As the primary researcher of this study, I (PD) have been a health educator, teaching patients with cardiovascular disease and diabetes self-management skills for over 30 years. I am especially interested in better understanding how patients are able to acquire the knowledge and learn the skills necessary to manage their health condition. Our intention is to develop a theory for how health literacy skills are developed with the intention of developing more effective programs, leading to improved health outcomes. The two other authors (VM and CA) were the faculty members of my PhD dissertation supervisory committee who helped me narrow this topic and successfully conduct and disseminate the results of the study.

Methods

This study was approved by the Walden University IRB (01-14-15-0326016) in accordance with federal regulation. A qualitative approach, using grounded theory, was used to explore the perspectives of patients who have been diagnosed with coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes within the past 12 months, and

the healthcare professionals who treat those patients. Grounded theory was used to gain a better understanding of the actions and processes of building health literacy skills, leading to a new theory (Corbin & Strauss, 2015). Grounded theory was selected because it goes beyond a description of the phenomenon of a common experience to a unified theoretical explanation of the process or action (Corbin & Strauss). This distinction is important due to the gaps in the theoretical and conceptual frameworks that do not fully explain the process of building knowledge, health literacy, and self-management skills in the case of a new experience, such as when someone is diagnosed with a chronic health condition. Rigorous qualitative research has been proposed as an alternative to quantitative research, especially in areas where little is known, such as health literacy (Krumholtz, Bradley, & Curry, 2013). Qualitative methods are gaining acceptance, even in areas dominated by quantitative, hypothesis driven research, such as cardiovascular research (2013). Qualitative methods research should be used to investigate complex phenomena that are difficult to measure providing a deeper understanding and leading to better approaches, strategies, instrumentation, hypotheses, and outcomes (Curry, Nembhard, & Bradley, 2009). Qualitative methods can stand alone as another form of inquiry and not simply a precursor to quantitative research methods, especially in complex areas where little information is available, or where there is a high degree of variability in results from quantitative studies. The inconsistent results of quantitative studies investigating the health impact of health literacy interventions is an indication that more information is required to develop more effective instructional strategies (Sheridan et al., 2011).

From January 15th through March 18th 2015 two sets of semi structured interviews were conducted; one for the patient and one for the healthcare professional. An interview protocol for participants and healthcare professionals were designed to answer the research questions, including how patients are able to acquire the knowledge and learn the skills necessary to manage their condition, and to gain better insights into the role of digital tools, instructional strategies, and learning methods. Interviews with the patients lasted 45-60 minutes, while interviews with the healthcare professionals lasted 30-45 minutes. Patients recently diagnosed with heart disease, heart failure, hypertension, diabetes, or a lipoprotein disorder were included in the sample. The study population included a homogeneous group of patients who have been diagnosed with cardiovascular disease or diabetes within the past 12 months and healthcare professionals who treat or educate these patients. The subjects chosen were drawn from a primary care medical practice, a cardiology practice, patient centered programming offered by the American Heart Association, and social networking sites, targeting patients with cardiovascular disease and diabetes. Informed consent was completed prior to conducting the interview. Using a theoretical sampling methodology, both medical practices were provided with a flyer describing the sample, which was posted in the waiting areas. Both physicians were updated throughout the study on specific types of patients that would provide the best information, based on emerging themes. Healthcare professionals were also theoretically sampled, based on emerging themes.

Following each interview, a memo was created summarizing the interview and commenting on theoretical concepts. These memos were used to consider the types of patients and professionals that would provide the best information, within the IRB approved sampling methods. Methodological memos were created to clarify methods, direct theoretical sampling approaches, and define the dimensions and characteristics of the emerging codes. Analytic memos were created to expand on theoretical concepts. A weekly update memo was used to summarize the interviews, methodological, and analytic memos. This weekly update memo began the process of moving concepts from codes to themes and categories. Using grounded theory, data collection, and analysis occurred simultaneously, using both deduction, validation, and inductive elaboration, leading to a theoretical

explanation of the actions and process of building health literacy skills. Constant comparison was used to generate codes and analyze the data. Three levels of coding were used, including open coding, axial coding, and selective coding, designed to develop a theoretical explanation of how health literacy skills are developed in patients with cardiovascular disease and diabetes.

To ensure the validity of the data, each interview was conducted using a conferencing calling system that was recorded. The recording of the call allowed for a verbatim transcript of the interview. If the interview was done in a face to face manner and audio recording of the interview was made by the researcher. A second researcher coded a sample of the data from the interviews, and memos, to test for intercoder agreement. The MaxQDA (2014) program was used as the computer assisted qualitative data analysis software.

Results

Interviews were conducted with 16 people who have recently been diagnosed with a chronic health condition and 19 healthcare professionals and educators. By conducting the analysis concurrently with the data collection, the investigators agreed that theoretical saturation was achieved. The characteristics of the patients and healthcare professionals are summarized in Table 1.

Table 1. Characteristics of Healthcare Professionals

Characteristic	Healthcare Professionals	Patients
Male	5	6
Female	14	10
Average age	50.4	55.4
Under 40	4	2
40-65	13	10
Over 65	2	4

The patients represented a broad range of cardiovascular and metabolic conditions, including acute myocardial infarction, heart failure, hypertension, lipoprotein disorders, and diabetes. All of the patients had at least a high school education and 7 were college graduates. Seven were recruited from the medical groups, 8 were recruited from the American Heart Association programs and 1 from social media. The healthcare professionals included 5 physicians, 5 nurses, a physician assistant, a nurse practitioner, a dietitian, a social worker, and a medical assistant, and 4 non-licensed professionals that provide health education, coaching and design educational materials. A total of 566 segments were coded, resulting in 70 codes and 8 categories. Coding of each interview was conducted immediately following the creation of the interview transcript using the MaxQDA (2014) software program. The most common code was related to resources and technology, followed by teaching methods and emotions. Themes were not based just on the number of responses, but how they related to the research questions and theoretical explanation. The final themes and categories are shown in Table 2.

Table 2. Themes and Categories

Themes	Categories
Social support is a learning opportunity	Emotional support Behavioral approach Instructional strategy
Google is a health system	Self-directed, personalized experience Role of digital tools New tech confusion and the digital divide
Instructional strategies should be personalized, interactive, social, and relevant	Traits Integration Format
Patients are self-directed learners	Healthy distrust No patient left behind

Social Support Is a Learning Opportunity

Patients talked about their emotions and professionals talked about the need to address their emotional state. Comments included, “if patients are overwhelmed, they are not learning,” and “the heart attack scared the bleep out of me.” When patients and professionals were asked about the process of learning they talked about their approach to motivation and self-efficacy. Both groups recognized how important it was for this setting the stage for learning. Patients and professionals mentioned programs, such as cardiac rehab, diabetes and weight loss classes, and online support as keys to developing their health literacy skills. Several patients mentioned the program they were participating in as being important in reducing their anxiety, giving them more confidence, and providing a support system. The theme that ran through all three of these categories was the need to have a support system. This support system was used to manage their emotions, their behavior and their ability to learn.

P1 mentioned that she was overwhelmed and an emotional mess and it was not until she started to go to cardiac rehabilitation that her anxiety was reduced. Once she found her support system her anxiety was reduced enough that she was able to begin learning how to manage her condition. From the patient point of view, the statement “I was a mess” (P1) meant that their mind was not right and learning was difficult. Emotional state, therefore, means more than depression, or anxiety, it also means level of motivation, readiness for change, self-efficacy, and engagement. P2 and P14 also experienced a heart attack, but did not participate in cardiac rehabilitation. P2 wished she had, but found the Patient Support Network, an online support program provided by the American Heart Association, while P14 found support from his wife. P1, P2, P12, P13, P15, and P16 all participated in the Patient Support Network

This theme is confirmed by the healthcare professionals who care for these patients following their acute event. A primary care physician (HP1), social worker (HP2), dietitian (HP3), physician assistant (HP15), and a nurse who provides disease management (HP8) all mentioned the need to address the emotional state of the patient before introducing educational approaches. “If they are overwhelmed they are not listening or hearing” (HP3). “The first factor for everybody is to reduce their stress” (HP11). A cardiologist (HP16)

reflected on a patient encounter earlier that day, “You know, this scared the crap out of me, I was so fearful, I did not have any hope. “The dvt paralyzed him emotionally” (HP15).

According to HP1, “If the patient is not in the right state of mind, the strategy is to address the issue and provide social and emotional support.” HP2 described how the support system was an opportunity to discuss issues and be a sounding board for their concerns, making the support system far more personalized and interactive than formal channels.

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

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

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

Once the emotional state is addressed, the next step is to provide a behavioral strategy focused on increasing motivation and self-efficacy. Again, the most common intervention was the establishment of a social support system. HP4 stated that she uses a behavioral approach, addressing lifestyle changes needed to manage the patient’s health. Similar to addressing the emotional state, social support is a key strategy for implementing behavior change (HP4). Instructional methods included internal, external, and social components. The internal component included educational materials and methods provided by the healthcare professional, and included print materials and face to face interactions. The external component included referral to programs or technology platforms. The social component included establishment of a social support system, which included programs, care givers, and support groups.

Programs like cardiac rehabilitation, diabetes education, health coaching, and support groups provide a format for behavioral and emotional support. Programs also provide an

opportunity for ongoing education, and social support, both in person and online. Perspectives from patients and healthcare providers indicated that these programs are critical in reducing anxiety in patients, allowing learning to occur. P1, a heart attack survivor, stated cardiac rehabilitation was important to her success, not only because it helped with the emotional stuff, but also it was where she learned how to manage her condition. P4 was referred to a lifestyle program to learn how to manage her diabetes and blood pressure, but also helped her manage her depression and control negative thoughts due to the comradery of the group.

Patients Get Their Information from the Internet

When asked how they acquired the knowledge and skills to manage their condition, many patients said they used the internet to obtain information on their condition and how to manage it. The majority of patients reported that they get their information through search engines including Google. These searches are primarily self-directed, un-aided, and highly personalized. P10 learned about her diabetes, high blood pressure, and high cholesterol from the internet, and by reading some books. P15 said she uses a search engine and types in key words looking for information on side effects and things to anticipate. “I go online and do my own research” (P13). The purpose of these searches is to supplement and validate the information they have received, or not received from their healthcare provider. For the patients, these are simply tools, and do not replace direct interaction with professionals, educators, and other patients. “The internet has some really good stuff, but it is a wonderful and dangerous place” (P1). He received some information from the doctor, but was interested in more so he went to the internet and found some medical websites that were pretty good. P11 uses a search engine, going one by one until he finds what he is looking for. “I cross reference information with other sites to make sure it is consistent with what others are saying” (P11).

Due to limited time and resources, HP1 and HP6 recommend digital tools and technology for their patients to fill in their educational gaps. HP14, a cardiologist believed some patients go to the internet, while some rely on the doctor, or do nothing. “The ones that go to the internet go to Google” (HP14). This is not always a welcome experience. In HP4’s experience as a heart failure nurse, stated “we work with patients, provide education, and follow up with them on the phone, and they immediately go to the internet or their family members for more information.” According to HP8, a nurse who provided disease management for heart failure patients, technology provides the opportunity for a customizable tool that can support small steps forward and can provide positive reinforcement in a manner that is not possible in the current healthcare system.

The role that digital tools and technology play in the development of health literacy skills and corresponding improvement in health was unclear. The patients that used apps or wearables, like a Fitbit, use them for fitness and health, not for disease management. Healthcare professionals perceived their role to be that of validator of information. For example, the patient goes out and seeks information, brings it back to the healthcare professional, who sorts out what is accurate and what is not. From the patient’s perspective, the validation goes both ways. They seek validation of the information from their healthcare professional, but they also seek the external information to validate what they have heard from their healthcare professional.

There seems to be some confusion on what is considered new technology. While the interviewer included examples of smart phone apps, wearables, and connected devices, patients cited the internet as the predominant tool. The blood pressure units described by the patients were manual and did not send, sync, or upload information to a database. Also, there

is still a digital divide in access and use of digital technology. “The first blood pressure device I used was a wrist cuff, and it did not work, now I use one recommended by my doctor, and it is spot on” P1. This confusion extends to healthcare professionals as well as patients. Some of the healthcare professionals recommend new technology opportunities, like an app or wearable. Some only recommend older technologies, including blood pressure cuffs or hand written logs. Finally, some of the healthcare providers did not recommend any new technology. “So I think the most exciting next step 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.” HP1.

Instructional Strategies Should Be Personalized, Interactive, Social, and Relevant

Key traits of instructional strategies perceived to be effective were ones that were personalized, interactive, social, and relevant to the patient. Social support systems, therefore, provided not only the emotional support, but also the educational platform that allowed patients to share and learn from other patients, communicate in an interactive, back and forth exchange, and consisted of information that was relevant to the patient. If the patient is self-directed and engaged they will seek out information on their own, without depending on the provider (HP8). Patients will seek out other patients, not only for social support, but also to learn from their experiences (HP8).

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

Patients attempted to integrate the information they received in the instructional and support setting with the information they get from their own, self-directed research. Patients validated information by checking with their doctor, and getting confirmation from other sources. The most trusted source of information was their doctor, yet many mentioned that they get very little information from the doctor. P1 used the doctor to validate information she was hearing from other sources. “You find a way to validate. You correlate with things you already know to be true, or you go ask a doctor, and some of it is common sense” (P1). HP14 agreed with P1 that patients get information from multiple sources and use the doctor as a way to validate what they are hearing. “So we in many cases are used as the appeals court, or if you will, the Supreme Court, where we have multiple opinions and we make the ruling” (HP14).

Patients Are Self-Directed Learners

Patients and healthcare professionals were in agreement that the emotional state and the level of engagement must be addressed first. Instructional strategies, therefore, were usually left to the patients who were ready to learn. In this case the instructional strategies of the healthcare professionals seem to match the educational needs of the patients. When the emotional state and/or the level of engagement were not ideal, the strategy was to address the emotional state, including the anxiety or depression, and provide social and emotional support. It was unclear how the unmotivated/non-engaged patient developed their skills. While it is clear that they were not getting it from healthcare professionals, and in many cases

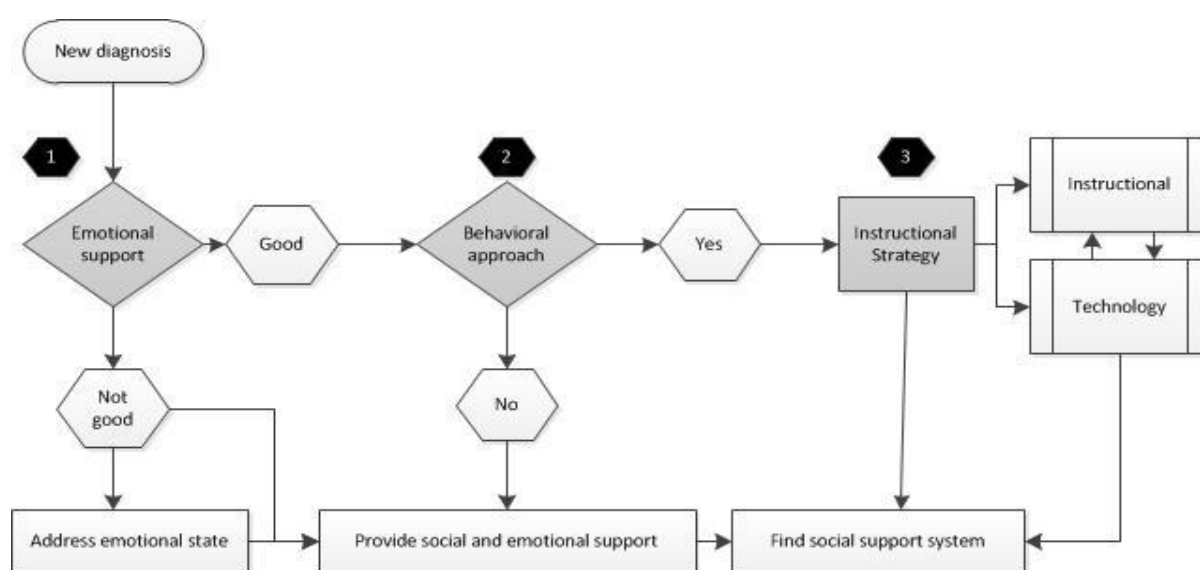
do not actively seek information, nevertheless, they must still be making decisions based on something. The current system, however, is geared to the motivated, engaged patient.

Several patients and healthcare professionals mentioned the challenges doctors face in providing education in the clinic setting. “All in all, I would say that I learn the least amount from my doctor. They were willing to share information, but I learned more on my own” (P12). “The doctor explained the medications, but not the side effects. I had to figure that out on my own” (P10). Patients seemed to have a healthy distrust of the information they got from their healthcare providers, and sought external information to validate what they heard from the providers, while the providers had it reversed; that patients sought info and went to the provider for validation. This distrust was rooted in prior experiences of being misdiagnosed, or receiving conflicting information.

Health Literacy Instruction Model

Using grounded theory, data collection and analysis occurred simultaneously, using both deduction, validation, and inductive elaboration, leading to a theoretical explanation of the actions and process of building health literacy skills. Identification of these themes and categories led to the development of the health literacy instructional model, illustrated in Figure 1.

Figure 1: Health Literacy Instructional Model



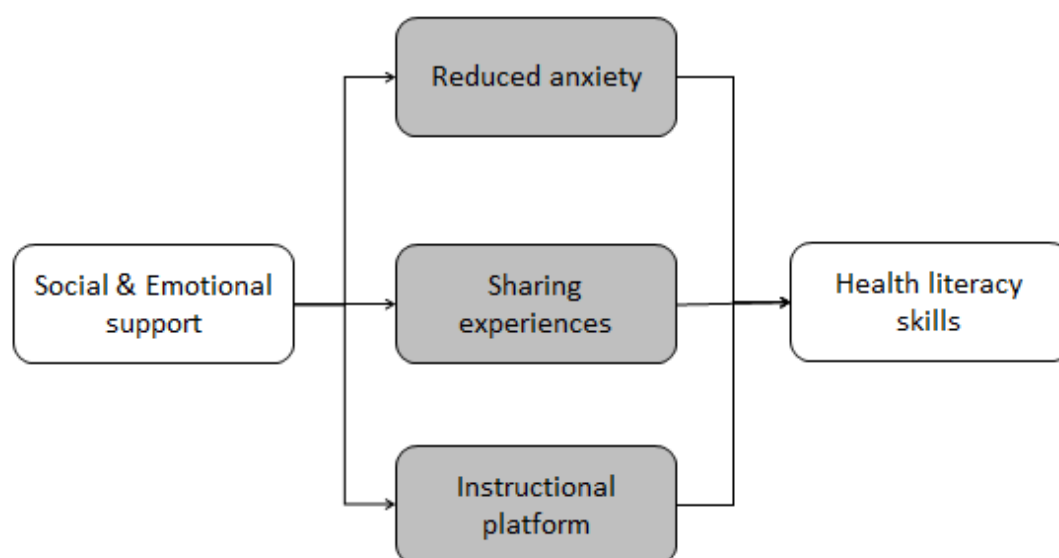
The health literacy instructional model included three steps. Step 1 was to provide emotional support for the patient. Step 2 was a behavioral approach addressing readiness for behavior change and self-efficacy. Step 3 was an instructional approach that was personalized, interactive, and relevant. Social and emotional support was a key factor in all three steps. These stages appeared to be sequential and hierarchical. For example, going directly to stage 3, without addressing the emotional support or the behavioral approach, was not perceived to be effective. The sequence of addressing the emotional support, then the behavioral approach, and then finally the instructional strategy was perceived to be the most effective.

Discussion

Social support is used extensively in other chronic conditions, such as cancer. More than one-third of cancer patients undergoing treatment report using support services (Huninghake, Dong, Hines, Adlah, & Taylor, 2014). The evidence is less clear in regards to the role of social support in cardiovascular disease (Lett, Blumenthal, Babyak, Robbins, & Sherwood, 2005). Patients described a self-directed, iterative approach to learning, using their own experiences, consistent with adult learning theory, and when they lacked direct experience, they used the experiences of others. For the healthcare professionals the process began with high emotions and a focus on immediate needs. Effective learning only occurred at the later stages.

Rather than running in parallel to the instructional model, the support system was actually part of the instructional model. Social and emotional support appeared to be key in three important ways, and are illustrated in Figure 2.

Figure 2: Role of Social Support in the Development of Health Literacy Skills



First, the support system helped to reduce the anxiety of the patient enough that they were now able to absorb the information. P1 mentioned that she was overwhelmed and an emotional mess and it was not until she started to go to cardiac rehabilitation that her anxiety was reduced. Once she found her support system her anxiety was reduced enough that she was able to begin learning how to manage her condition.

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

Finally, the support system itself became an educational platform. Several of the patients described the support system or program they were participating in as their source for learning, both through formal channels and through informal interactions with healthcare professionals and other patients. HP2 described how the support system was an opportunity

to discuss issues and be a sounding board for their concerns, making the support system far more personalized and interactive than formal channels.

There are reasons why support plays such an important role in the development of health literacy skills. The most common support systems described by the patients included cardiac rehabilitation, diabetes self-management, and online support. These support systems have common elements including the ability to interact directly with a healthcare professional, interaction with other patients, and an opportunity to access educational resources. The reasons that the support system played a role in the development of health literacy skills are illustrated in Figure 2.

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

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

The support systems became a learning platform that was personalized, interactive, social, and relevant. P12 said the online support group helped her to learn by forming relationships with other patients with a shared experience. P6 said he learned a lot in cardiac rehabilitation because he could ask questions. HP1 would start the session by answering questions, making the experience more personalized and relevant. The support system, therefore, was the unifying factor of the Health Literacy Instructional Model. As patients progressed through the model, by addressing their emotional state, their readiness for change and self-efficacy, and begin the learning progress, the support system became the scaffolding for the patient.

The results of this qualitative study suggest that support systems play an important role in the development of health literacy skills in patients with cardiovascular disease and diabetes. These support systems may include cardiac rehabilitation (Balady et al., 2011), disease specific care coordination interventions (Baker et al., 2011), and online support (American Heart Association, 2015). These findings are consistent with other qualitative studies that found emotions, behaviors, and communication skills to be important factors in the development of health literacy skills (Edwards, Wood, Davies, & Edwards, 2012; Jordan, Buchbinder, & Osborne, 2010).

A limitation of this study was that while health literacy was the topic, there was no measure of health literacy and knowledge. Improvement in the development of health literacy skills from patient and healthcare professional perceptions were taken at face value. This lack of an objective measure of health literacy prevented targeting of patients with low literacy levels. Also, the voluntary nature of the sampling procedure may have patients with higher health literacy and professionals with greater awareness of health literacy. While protecting the privacy of patients, this limitation was addressed by providing the physicians in the medical groups periodic updates on insights so that theoretical sampling could be achieved.

Conclusions

Cardiovascular disease and diabetes are complex conditions that require a high level of knowledge and skill on the part of the patient in the management of their condition. This level of knowledge and skill is generally referred to as health literacy and includes an understanding of the condition, the ability to manage and manipulate numbers, navigation of the healthcare system, communication with healthcare professionals and the ability to make decisions regarding medical and behavioral strategies. In this study, the actions and processes that led to the development of health literacy skills were investigated from the perspective of both patients with cardiovascular disease and diabetes, and the healthcare professionals who provide medical care and education to these patients. These findings illustrate the need to provide and identify the social support system of the patient. There is a need to provide information from trusted sources on the internet that can be easily accessed by the patient. Finally, no patient should be left behind in the development of the knowledge and skills necessary to manage chronic diseases such as cardiovascular disease and diabetes.

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Author Note

Patrick Dunn, Ph.D. is on the Patient and Healthcare Innovations team at the American Heart Association, and is Contributing Faculty in the College of Health Sciences at Walden University. Correspondence regarding this article can be addressed directly to: pat@yourheartscore.com.

Vasileios Margaritis, Ph.D. is Core Faculty in the Public Health program at Walden University. Correspondence regarding this article can also be addressed directly to: vasileios.margaritis@waldenu.edu.

Cheryl Anderson is Core Faculty in the College of Health Sciences at Walden University. Correspondence regarding this article can also be addressed directly to: cheryl.anderson@waldenu.edu.

To all of the patients and healthcare professionals that participated in this research study.

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