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Understanding Health Literacy through the Lens of Phronesis: The Case of Coronary Artery Disease Patients

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Abstract. In research as well as in clinical settings, health literacy is often measured using self-rated psychometric instruments. Research has, however, shown that although patients perform poorly on health literacy measures, over time, they tend to develop skills and strategies to empower themselves to manage their chronic disease conditions [1]. In this study using focus group interviews and information landscapes and phronesis as a conceptual building blocks, we tried to understand how patients acquire, evaluate, and use health information to deal with their chronic disease conditions. Phronesis is defined as the “practical knowledge and wisdom that people developed through experience and enacted by patients to make health-related decisions and engage in healthy behaviors” [2]. Results show that patients enact a number of strategies that reflect phronesis when managing their chronic conditions. Findings from this study are discussed to evaluate phronesis as an important concept for understanding successful chronic disease self-management. Implications for theory and practice are also discussed.

Keywords: Health literacy, phronesis, coronary artery disease, chronic conditions, critical health literacy

1 Introduction

Health literacy is defined as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” [4]. The predominant approach to measuring health literacy and health outcomes assume an epistemic objectivity, in other words, that health literacy skills are quantifiable and measurable [3]. This epistemic objectivity allows scholars to quantitatively measure health literacy skills and create intervention strategies for improving health literacy in low literate populations. Health literate citizens on the other hand are expected to critically appraise health information, and exhibit skills that are equivalent to competence in evidence-based medicine [10].

Current discussions on health literacy also hold that its purpose is to enable patients to use their knowledge to play an active role in managing their health and in making independent health decisions [11]. This view has expanded the concept of health literacy by including essential dimensions of medical knowledge and a number of skills that people need to find, evaluate, and apply health information to address their health issues [12,13,4]. There are two important challenges associated with this conceptualization of health literacy. First is understanding what some of these skills actually entail [14]. Second, and the more serious concern is, in the light of skills that empower a person to take independent health decisions, it is no longer clear how the competencies that patients need to acquire differ from those of physicians [3]. The research on health literature does not address this issue. However, attempting to clarify this distinction between health literacy and professional expertise leads to a paradox. On one hand, if patients' knowledge and skills (literacy) are not commensurate with those of the doctor, then the notion of attaining skills that health literacy espouses, leads to the patient being a pale shadow of the physician. In such a situation, health literacy may empower patients and make them more independent but it would result in a dangerous precedent. It might lead to a situation wherein the patients may overestimate their real competencies and may make health choices inspired by insufficient expertise. On the other hand, hypothetically, if a patient's knowledge and skills are close to those of a doctor, then health literacy is tantamount to making the patient into a health professional. However, this goal is unrealistic and cannot be achieved [3]. In this paper we argue that health literacy must be re-conceptualised in a manner such that it avoids this paradox but, at the same time, also holds value as an important skill set that helps individuals to manage their health. To do this, we draw on research in the area of information literacy landscapes to suggest that health literacy should neither be defined by its objective and skills-based characteristics, nor as a series of de-contextualized skills. Instead health literacy must be defined and explored from the patients' perspective. We must understand how patients engage with health information and make health-related decisions, and re-ground the concept of health literacy in individuals' experiences [32].

In this study we use *phronesis* as a conceptual lens. *Phronesis* is defined as the practical wisdom that is often developed through experience and is then enacted by patients. In this manner, *phronesis* can shed light on the capacities of patients to make health-related decisions and engage in healthy behaviours [2, 3, 15, 16]. This concept must be differentiated from scientific knowledge or *episteme* and must be viewed as less systematic and procedural than the habitual performance of professional practice or *techne* [17-19]. As such, *phronesis* entails experiential knowledge gained through practice and is tied to activities and reasoning skills that allow individuals to cultivate good and healthy lives. Accordingly, *phronesis* involves not only deliberative skills including self-reflection, communication with others, and situated performance [20-22], but also the "embodiment" and enactment of habits that support the creation of a healthy life [23]. In the current research work, we explore how patients enact various strategies for evaluating and using health information by drawing upon their experiences from their "patient journey," that empower them to manage their chronic conditions.

2 Method

2.1 Sampling Method

The study was conducted in Singapore. Participants for this study were patients with coronary artery disease. We chose this population because they were expected to play an active role in managing their health and therefore were more likely to engage with health information [15]. A purposive sampling method was used to recruit participants from a pool of patients who received support from a health non-profit organization. Using the database maintained by the non-profit organization, patients were contacted by phone or email with the help of the organization's staff members. Consenting participants were given detailed information about the goals and objectives of the study. Participation was voluntary and written consent was obtained from the subjects. To obtain the broadest possible range of opinions and insights, participants were recruited to ensure diversity in age, race, and gender. All 6 focus group discussions were conducted in English and Mandarin, and dated between May 2017 to July 2017. The demographic data of the participants is as follows: Patients (n=19), age range 41-50 years=3 (15.7%), 51-60 years=5 (26.3%), >60 years=11 (57.8%); Male=14 (73.6%), Female=5 (26.3%). Caregivers (n=17) age range 41-50= 3 (17.6%), age range-51-60=2 (11.7%), and age range >60=12 (70.5%), Male=14 (73.6%), Female=5 (26.3%). Therefore in total, (N=36) participants took part in the study. We chose to include caregivers in the study because many senior patients often depended on their caregivers (children, life partners) to manage their health and hence, they played an important role in the disease management process. The study was reviewed and approved by IRB of Nanyang Technological University, Singapore IRB:2015-03-042.

2.2 Data Collection and Data Analysis

Data were collected using the method of focus group discussions, which were found to be effective and useful in health behavior research [24]. A semi-structured interview protocol was used to guide the focus group interviews. Discussion topics broadly focused on obtaining patients's perspectives on their experiences with their chronic condition, information needs, information environments, challenges they encountered when trying to find and use health information, and their strategies for obtaining, evaluating and using information. Emphasis was placed on generating rich interactions among participants [25]. The group size was limited to 5-6 members per session to facilitate a productive discussion [26]. Participants were encouraged to articulate their experiences in their own terms and were encouraged to give specific real-life examples. In addition to the above, other strategies such as neutral agreement, asking for additional information, summarizing, and paraphrasing were also used to encourage discussion among participants and to seek clarification on specific issues [27]. The focus group discussions were transcribed and analysed using qualitative methodology, which involved critical reading and the examination of the texts for conformity and variation of emerging themes [28]. The primary code reflects the conception of phronesis and comprised two essential elements: (a) the participant demonstrated an experiential insight about a health or a related issue, and (b) enacted concrete steps to address the issue. It is important to note that the coders we are not so much looking to see whether there was an instance of action by the patient which was then coded as phronesis. Instead, we attach our concept of phronesis to insights that participants express in terms of episodes that resulted in the gain of experiential knowledge and the steps that they took as a result of this knowledge, [2] or if they show an instance of active involvement in his or her own healthcare (activated patient) [29].

3 Results

The results from our analysis are presented below and discussed in the context to “patients’ journeys” [30]. There was strong consistency between the distinct themes identified by the three authors. In addition, four participants, who followed up to verify results, all conveyed their agreement with the themes identified.

3.1 Identifying and Understanding their Health Condition, and Knowing How to Respond to Different Health Situations

Discussants highlighted how people are often reactive in healthcare in that, if nothing was perceived to be wrong, people often paid every little attention to their health, or take proactive steps that would, in theory, keep them healthy and or allow them to detect the onset of chronic conditions such as coronary artery disease, at an early stage. It is only when patients face a trigger event or a health crisis that they start focusing on their own health. Drawing from their own experiences, patients underscored the importance of monitoring their own health in order to detect any early warnings, along with how understanding the appropriate response to these situations and managing their health becomes a critical skill set as they progress through with the chronic condition.

“My husband was healthy all along. He never had any problems [...]. So it was a shock actually when he had a heart problem because he was a national runner and he was always very slim. Skinny rather, underweight. And he has no cholesterol problem. It is below 200. I think when he had the diagnosis of the problem, his cholesterol level was only about 160. No high blood pressure. [...] and so it was a total shock. But after this incident we realised the importance of being cautious. With age it is important for us to pay closer attention to our health, symptoms. Look out for indicators. Watch what we eat. Today we do all this together. We as a family are constantly researching, and managing our diet.”

The response highlighted an important challenge— when an individual suddenly begins to deal with a chronic problem that is inherently corporeal in nature, surfacing as a result of symptoms that start manifesting themselves unexpectedly. This results in uncertainty and confusion, thus triggering the patients into action [31]. Once patients come face-to-face with potential problems, they begin to navigate through the landscape of health and in the, process must develop specific “ways of knowing” and learning how to deal with their health condition [32].

3.2 Ability to Identify Biases in Health Information, Evaluating Health Information Objectively to Establish its Relevance to their Own Health Context

An important part of chronic disease management is education, for which navigating through the health information landscape is critical. As chronic disease patients encounter the information landscape, they face several challenges. One cardiac patient clearly outlined the problem shared by several other patients:

“There is a lot of information out there. There are a lot of information sources out there. However this information is often broad and very general. What is an important challenge is to find the information that is right for us, that is relevant and that can actually be used.”

A second important challenge highlighted by patients are the inherent subjective biases that they hold, which in turn can impede their ability to objectively analyze health information or impede their ability to make right choices. This can have an adverse impact on their health. One relatively young male cardiac patient highlighted the issue by sharing an anecdote from his own life:

“I regularly went to the gym and always ate [...] high protein diet. I always believed that high protein diets meant I won't have any problems with fat and cholesterol and that I would not be affected by these problems. However, when I went for my medical check up, it came as quite a shock to me that I am at risk for coronary artery disease and that high protein diets in fact are going to increase my risk. After this I began to do some research on Google and found information that made me realize that there is a link between high protein diets and heart disease. So, it is important for us to do research and gather evidence before we make these decisions. Now I make sure I do good research, or talk to the doctor or the nurse before I take any decisions about my health”

Here, the experience of this young cardiac patient underscored the importance of balancing patients' own knowledge with engaging with doctors and medical professionals, as well as with objective and evidence-based medical knowledge as they negotiate the health information landscape. This respondent also noted a connection between experiential knowledge and enactment of new ways of learning, evaluating and verifying information with health professionals, which is an important element in our conceptualisation of phoresis. While seeking help from doctors and other professionals is the most common way in which many respondents often verified health information, some patients also observed their own corporeal responses to make important health-related decisions, as described by the following female patient:

“I have a heart problem and diabetes problem. Then sometimes we find that things which are good for diabetes is not good for the heart. And if things are good for the heart, it is not good for diabetes and my kidneys. [...] So what we are doing now is that we take the medicine say for the heart [...] we will look at the figures (test results). When the figures are good, everything is okay. Since the heart is good, we concentrate on cutting down on the sugar. So, by looking at the test results for both the heart and the kidneys, we make decisions about what dosages of medicines I should take so that I can deal with both the problems effectively.”

This respondent's example clearly outlined a strategy wherein the person depended on her “corporeal experiential knowledge” to make decisions about whether a particular drug was right for her and developed her own drug regimen based on these embodied

experiences. In other instances, patients also discussed how they use their social networks that span fellow patients to seek out information from them about their own experiences, in order to make relevant decisions related to their health. A male cardiac patient described this strategy:

“The best way to find out if some medicine or treatment works is to find out from those who have used it or have taken the treatment. When I had a heart stroke, my wife contacted other patients we know from the Singapore Heart Center. They came up, spoke to us, and told us not to worry. You know they have gone through the same kind of treatment, the same medication they take and things like that. So, their experiences [...] helped us to choose particular medicines and treatments.”

These participants' responses clearly indicate that their own embodied experiences and that of the other fellow patients are very important sources of experiential knowledge that contributed to the understanding of their chronic conditions.

3.3 Ability to Identify Gaps in Health Knowledge and the Ability to Fill these Gaps

Chronic patients often suffer from several co-morbidities that interact in complex ways to influence their health. They have to choose specific drugs or treatments that do not interact in complicated ways to adversely impact their health. However, often patients operate with only disparate bits of information, and information gaps in their decision making process, which may in fact increase their risk. One female cardiac patient highlighted this challenge:

“I was taking a blood thinner-warfarin and also taking some TMC supplements that contained Ginseng. Someone told me that Ginseng can actually cause my blood to clot and cause blockages. This information was never revealed to me, and even my doctor did not tell me. Someone who read it on the Internet told me. So, it is important to gather all the information and connect the dots so that it can reveal some important facts. Today I systematically collect information all my problems and then carefully analyze it. I also take all this information to the doctor and discuss it with him before I take any medicine or treatment.”

The above example clearly highlights an important challenge faced by many chronically ill patients when they navigate through the health information landscape. It also brings to bear an important fact that access to the right kind of information may not simply be enough, but what is also required is the ability to fill in the gaps in the existing knowledge so that it helps patients to connect to disparate bits of information in order to get the complete picture, that would help them to make a more informed decision. The fact that the participant enacts strategies for verifying health information for filling in the gaps so that it enables her to make a more informed decision based on her experience with dealing with apparently unconnected bits of information in an earlier instance, demonstrates an instance of phronesis.

3.4 Ability to Understand Limits of Individual Competence, and Knowing How

to Address these Limitations

In chronic disease populations, patients assume an important role in managing their own health. This requires them to develop in-depth knowledge about their disease and co-morbidities, and manage a complex regimen of dietary restrictions, medications, and other aspects. In this context, one common factor that many patients outlined was the complex demands of disease self-management, and the fact that their own limited knowledge and competencies often hindered their ability to manage their health. To overcome these challenges, patients use different strategies. For instance, one common challenge that patients discussed here was gathering and managing health information. Patients revealed that they collected information from different sources and developed different strategies for validating this information. In this manner, patients constructed a bricolage of information and developed strategic ways of verifying and using this information to address their health issues. A male coronary artery disease patient described his strategy of managing information:

“I can get a lot of information but I am not sure how to judge what is accurate and what is useful for me. I maintain a notebook in which I constantly make notes about information I hear on TV programs or read in newspapers and Websites. I also collect health-related articles from magazines, and newspapers. When I go to my appointment, I discuss this information either with the nurse or with my doctor. It helps me to verify the information I find and use only that information which my doctor or my nurse recommends for me. Sometimes I also post specific questions in Facebook health forums where people who also heart problem like me, to get their opinion. People share their experiences with me, which is very useful for me.”

This participant’s response indicates that the person is functionally health literate, yet he is also aware of his limitations in terms of his inability to judge the accuracy and relevancy of the information that he is able to collect, read, and comprehend. However, he is also able to overcome this limitation by adopting specific strategies that allow him to meet his health goals. While the above example was highlighting the challenges associated with limited expertise, sometimes, psychological factors may also affect patients’ ability to deal with their health. An elderly cardiac patient described his own dilemma in the following way:

“I know I have to exercise regularly, but somehow, I often fall behind. So, I decided to fix appointment with other fellow heart patients, and so we come to Singapore Heart Center to exercise together. In that way I make an appointment and I keep it. So, I am able to exercise more regularly.”

In this response we find that the patient is clearly aware of what he needs to do in order to maintain his health. However, he also is aware of his psychological impediment that prevents him from adopting a healthy behavior. The patient is also able to overcome this challenge by adopting a strategy that helps him to accomplish his goal successfully, which shows an instance of phoresis.

4 Discussion and Conclusion

The current approaches of conceptualizing, defining, and operationalizing health literacy assumes an epistemic objectivity. However, in recent years, there has been considerable debate about how the concept is measured and what skills people actually enact when they interact with and use health information. In this study, we used two distinct concepts-information landscapes, and phronesis to understand health literacy from the patients' perspective. These concepts helped us to foreground the importance of contextual factors and their role in shaping peoples' engagement with and use of health information. The perspectives shared by our participants demonstrate that patients ability to reach their health goals depended on three important factors. First was recognizing the importance of their health goals, recognizing the challenges and barriers that impede one's ability to reach their goals through introspection and self reflection, and thereby, finding a way to overcome these barriers and impediments by coming up with effective strategies. Though these skills are not easy to measure or quantify, they play an important role in managing one's health. This also points to the importance of recognizing the limitations of the current conceptualizations of health literacy and the importance of eschewing the narrow skills-based definition of health literacy or considering health literacy as a set of decontextualized skills, and to developing a broader theoretical and operational definition of health literacy. A second important factor that is often linked to health literacy is the concept of empowerment.

Results from our study suggest that the concept of empowerment does not imply that a patient has to operate independently and take autonomous decisions and eschew medical authority and professional help. Instead, some of the anecdotal examples clearly show that patients engage in self-reflection, and equip themselves with basic knowledge and information in order to interact with health professionals and the healthcare system productively. In this way empowerment is manifested in the patients' ability to recognize what steps one must take to and actually take these steps to research their health goals. This study makes two important contributions to the literature on health literacy. In terms of theory, this study presents an alternative way of conceptualizing health literacy-predominantly from the patients' perspective and foregrounds the importance of context and its role in shaping their health literacy skills. Our findings suggest that health literacy skills must be conceptualized more broadly to include different strategies through which patients identify their health goals and find strategies to fulfill these goals. From a practice point of view, our studies helped us to identify several skills that cannot be easily quantified and measured using regular psychometric instruments. Yet, their inclusion in both, theoretically conceptualizing health literacy as well as in health literacy interventions, is of paramount importance. This, we believe, can enhance patients' ability to more effectively manage their health. One important limitation of this study is that it was conducted in a first world country like Singapore where some unique conditions exist. Health information in Singapore is mostly streamlined and screened before public dissemination and therefore people rely on government endorsed health information that is made available through online government websites, online promotional videos, mass media channels, and literature distributed by hospitals and non-profit organizations [33]. This combined with high literacy rates and an efficient healthcare system likely influences how people engage with health information, navigate the healthcare system, and address their health issues [34]. Therefore the results from our study may not be broadly generalizable.

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