

The Motivations of Iranian Patients With Cardiovascular Disease to Seek Health Information: A Qualitative Study

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Abstract

Background: Cardiovascular patients need information to preserve and promote their health, but not all of them have the necessary motivation to seek relevant health knowledge.

Objectives: The present study analyzed experiences of patients, family caregivers, and healthcare providers to explore the motivating factors that cause cardiovascular patients to seek important health information.

Patients and Methods: This study was conducted using a qualitative approach and conventional qualitative content analysis method. Thirty-six people, including 18 cardiovascular patients, 7 family caregivers, and 11 healthcare providers (from multidisciplinary backgrounds) participated in the study. The data were collected through semi-structured interviews and purposeful sampling and continued until data saturation. Data collection and analysis proceeded simultaneously and with constant comparison; this study was carried out from May 2012 to May 2013.

Results: During the analysis process, three main themes were extracted that characterized participants' experiences, perceptions, and motivations to seek health information. The themes were "Optimizing quality of life," "Desire for personal rights to be respected," and "Gaining confidence through consultation."

Conclusions: Our findings showed that, through seeking information, patients try to achieve well-being and realize their personal rights as well as their right to security. They should also be encouraged to enhance their quality of life by using the Knowles' learning theory to formulate their needs and learning priorities.

Keywords: Health Communication, Information Seeking Behavior, Cardiovascular Diseases, Motivation, Qualitative Study

1. Background

In line with healthy heart promotion in developing countries, one of the main areas needing attention is health information communication programs (1). Moreover, today, in the paradigm of patient-centered care, the importance of chronic patients like cardiac patients becoming experts (2) and self-motivated participants who seek information about their disease from different sources (3) has been emphasized by researchers. Cardiovascular patients need long-term healthcare throughout their lives, including at home, at work, and in broader society. The provision of optimal self-care requires the ability and willingness to seek relevant health information (4). Obtaining up-to-date factual information can play a key role in managing chronic diseases and can be useful for dispelling uncertainty, adjusting to the disease, and developing self-management strategies (5).

One study in Australia showed that cardiovascular patients sought relevant information and practical advice about physical activity, diet, and local rehabilitation programs on the Internet (6). Other studies have indicated that cardiac patients and their family caregivers ask questions about managing symptoms, disease progression, (7, 8) end-of-life issues (7, 9), and sources of social support when they meet with their healthcare providers (10). Some researchers believe that patients who ask their healthcare providers proactive questions about their condition are likely to have more control over their health (11).

Overall, the fact that cardiovascular patients seek information from multiple sources, especially healthcare providers, raises the question: what are the motivations of patients to seek health information? Studies on other categories of patients have shed light on useful factors. Some studies describe the motivations of patients to gain infor-

mation as follows: confirming information received from doctors; better perceiving their condition; doing something about their health; playing a participating role in treatment decision-making; becoming prepared and completing consultation; (12) and maintaining autonomy and successful aging (13). Studies show that seeking information is a logical strategy and a decision adopted by patients to achieve logical goals. Perception of goals and motivations of patients to gain information may result in a vision about the meaning of seeking information (12).

Most studies on heart health have been designed to assess cardiovascular patients' need for information and have produced results showing patients' and their families' lack of adequate information for decision-making about surgery, post-discharge care (14, 15), cardiac pathophysiology, physical activity, compatibility with physical and psychological implications of the disease, preventive lifestyle modifications (16, 17), learning technical and situational skills (18), and medication information (19). However, few studies have been conducted on the motivations of cardiac patients to seek necessary information. Motivations have been studied mostly in regard to Internet searches, patients suffering from diseases like cancer and AIDS, and patients from Anglo-Saxon countries (12, 20). No studies specific to health information seeking by cardiovascular patients have yet been conducted (10, 14, 18, 21). In studies conducted in Iran, researchers' focus has been on barriers to providing information or training patients, and the role of the patient and family in seeking health information has been less considered (22, 23). Information seeking is a behavior that is dependent on social context and the structure of the health care system (4, 24). Given that the majority of Iranian patients are Muslims, with a diversity of religious minorities (such as Shia and Sunni) and ethnicities (such as Fars, Turkish, Kurdish, and Gilak), and also given the exclusivity of the health system in Iran (25), studying this behavior in the Iranian context seems imperative. Furthermore, a review of existing literature shows a dearth of natural-oriented observations and interventions (26) despite the fact that patients' stories provide a basis for understanding how information is sought in areas with little knowledge (27). Thus, our literature review suggests that a qualitative study is needed to provide a deeper understanding of the dynamics of healthcare information seeking (26).

2. Objectives

Given that information gathering is a key factor in promoting the health, coping, and self-management of cardiac patients, this study was designed to explore motivations for Iranian cardiovascular patients to seek health in-

formation based on analysis of the experiences of patients, their families, and professional caregivers.

3. Patients and Methods

3.1. Design

The study was conducted using conventional content analysis. The analysis of qualitative content as a research methodology aims to subjectively interpret the content of textual data. The data are identified through systematic categorizing of themes or implicit and explicit patterns within the text (28). The method focuses on life experiences, interpretations, and meanings faced by individuals (29, 30).

3.2. Ethics

Prior to collecting data, the ethics and research committees of Tehran University of Medical Sciences and the University of welfare and rehabilitation sciences approved the study (No: 6291). The study was designed according to research ethics codes including informed consent, confidentiality, and participants' free-will to leave the study. The authors of this manuscript have certified that they comply with the principles of ethical publishing.

3.3. Recruitment and Participants

In this study, participants were selected from two subspecialty heart hospitals affiliated with Tehran University of Medical Sciences and from rehabilitation centers and clinics affiliated with these hospitals in a purposeful sampling method using a criterion sampling technique (30). These two hospitals are the major referral centers for the treatment of cardiovascular diseases (CVDs) in Iran. Participants in the study were cardiovascular patients who were at least 18 years old, personnel with at least one year experience providing healthcare for cardiovascular patients, or family caregivers who had experience of caring for, or living with, a patient. Other inclusion criteria were the ability to speak and understand Persian; good physical, psychological, and cognitive condition; and willingness to participate in the study. Patients with a primary diagnosis of stroke were excluded. To gain access to participants, the first author approached nurses working at the cardiovascular wards to identify patients and family caregivers with experience in seeking information (e.g., inquiring with the nurses). The first author also approached personnel who were experienced in providing necessary instructions for, and interacting with, cardiovascular patients. After acquaintance with participants, plans were made for interviews and data collection. Considering that patients

were key participants in this study, to have maximum sample variation, attempts were made to select patients with different socioeconomic and demographic backgrounds (such as age, marital status, education level, occupation, level and source of income, geographical location, ethnicity, etcetera), and also patients in various stages of illness and treatment (diagnosis to rehabilitation). A total of 36 people, including 18 patients, 7 family caregivers, and 11 professional care providers from various disciplines participated in this study over the course of 12 months (May 2012 to May 2013).

3.4. Data Collection

Semi-structured interviews began with an open question based on our main study question, such as: "What importance do you give to seeking information about the heart?" or "What are some reasons that lead you to seek information?" Based on analysis of participants' answers to these open questions, more probing follow-up questions were asked with respect to subjects' daily experience with information seeking. Interviews were first conducted with cardiovascular patients; however, given the central roles played by family members and healthcare professionals in the process of information seeking, interviews were conducted with these two groups for greater clarity and accuracy of the conceptual categories after consultation with the research team. Before saturation of data in the qualitative study, a total of 36 interviews were conducted in the Persian language, each lasting between 25 and 80 minutes. The majority of interviews were conducted by participants' bedsides, at their workplaces, and at their homes according to their comfort and preferences. A brief, personal details questionnaire was also completed by participants after each interview. All interviews were performed by the first author and recorded by a digital recorder with the participants' agreement; interviews were then transcribed verbatim and imported into Word software to facilitate coding and analyses.

3.5. Analysis

In line with our study objectives and based on participants' explanations, the data were analyzed using conventional content analysis in eight stages: preparing the data; determining semantic units; encoding the text; re-comparing the codes with the texts; classifying and expanding the categories based on similarities; comparing the categories with the data to ensure the rigor of the codes; accurately identifying themes and comparing classes with each other; and reporting the findings (28).

3.6. Rigor

To ensure accuracy and reliability of the qualitative data and scientific method, Lincoln and Guba criteria such as credibility, dependability or accountability, transferability, and confirmability were employed (31). To enhance the credibility of the data, the researcher worked with the data for the entire one-year study period. The text of interviews and list of categories were reviewed by other researchers with qualitative research experience, and the interviews were controlled by the members of primary encoding team and then returned to the interviewee in the first stage of analysis to confirm their accuracy. The data were then verified by two faculty members familiar with qualitative research, and their assessments agreed closely with one other. For auditing purposes, the researcher carefully recorded and reported all study stages so that others could follow them. For transferability of findings, efforts were made to quote participants' statements as accurately as possible. In conjunction with native English-language professionals, the first author translated the categories, subcategories, and participants' quotations from Persian into English.

4. Results

Participant characteristics: A total of 36 individual interviews were performed. Of the 18 patients, nine were female (50%). Mean age of the patients was 56 years. The youngest patient was 21 and the oldest was 82. The majority of subjects were married (72.2%), and education levels ranged from no formal schooling to PhD level though almost half had received a high school diploma (44.4%). The least duration since diagnosis was one month and the most was 36 years. The highest number of patients had heart failure (27.8%) and CABG (27.8%), while the remainder had arrhythmias, coronary syndrome, stroke, and congenital heart disease. The seven family care providers (all spouses, mothers, or children of patients) had a mean age of 40 years and included five women, four of whom were housewives. Most had high school diplomas. The 11 professional care providers (4 nurses, 3 physicians, 1 dietician, 1 physiotherapist, 1 pharmacist, and 1 psychiatrist) included seven women (63.7%), with a mean age and work experience of 39.4 years (range 29 to 52 years) and 9.4 years (range 4 to 20 years), respectively.

Interview analysis: From the detailed descriptions of participants, 880 codes were initially extracted. After analysis and comparison of the data, three main themes optimizing quality of life, respecting personal rights, and reassurance through consultation and four sub-themes were conceptualized. Table 1 shows the development of these themes.

Table 1. Theme, Sub-Theme, and Comments by Participants About Their Motivations to Seek Health Information

Theme	Participants' Statements
Optimizing Quality of Life	
Playing one's role (n = 20)	"Doctor and I spoke a lot about the treatment course because I lecture university classes; I love my teaching; I didn't want to lose it... Can I do my job properly?" "That means that their main concern is their working life. Their job is their life"
Avoiding imposing healthcare burden on family (n = 16)	"If I'm supposed to be bedridden and become a burden on my family, I don't like that kind of life; I won't think of making it longer; what matters is life's quality, not its length"
Maintaining and promoting physical-mental well-being (n = 22)	"I attended a medical seminar of Academic Center for Education, Culture and Research. I love medical and psychological seminars. I wanted to calm down myself psychologically I wanted ...my symptoms to disappear. I'm not feeling well. I want to feel comfortable physically"
Planning for the future (n = 8)	What should I do or shouldn't I do later in my life? Obtaining this information helps me plan for timing motherhood, can I have a baby or not?
Desire for Personal Rights to be Respected	
Self-determination and Freedom from restrictions (n = 9)	I read books a lot. I read the Health Magazine, too. I like to know everything because I finally say I have free will to decide. I know, but I make the decision myself.
Gaining Confidence Through Consultation	
Verification and clarification of information (n = 15)	I knew about the study. I knew what coronary is and what its symptoms are. But I thought it would better to talk to a couple of doctors. I liked them to share the same view. Have I changed my drugs correctly?

The first theme consisted of four sub-themes, described in detail below.

4.1. Optimizing Quality of Life

Experiences of participants showed that the motivations behind satisfying the needs of cardiac patients and their families for health information included: (1) playing one's social-personal role, (2) avoiding the imposition of a healthcare burden on family, (3) maintaining and promoting well-being, and (4) planning for the future. These four sub-themes were conceptualized as "optimizing quality of life" and can be explicated as follows:

4.1.1. Playing One's Role

Many participants' strategies to gain information were aimed at playing their individual, family, and social roles. Patients had a sense of responsibility vis-a-vis themselves, their family, and society and said they sought information to play an active role for a range of reasons, such as: willingness to fulfill responsibilities, love for professional and personal life, hatred for being seen as useless, children's dependence on parents, and expectations of the family. Regarding the individual-social role, one patient said that she was a social worker and explained why she asked about the function of the implantable cardioverter-defibrillator (ICD) device: "I want information. I also want to gain the information from both the Internet and doctors so I will be so healthy and be able to do my housework myself and fulfill my responsibilities toward my family. I also want to

get back to work. I haven't gone to work for a year" (Patient 7).

4.1.2. Avoiding Imposing a Healthcare Burden on Family

Many participants said that imposing healthcare responsibilities on other family members annoyed them. They tried, therefore, to reduce the burden on family by gaining information and also by leading a more active life. For example, one patient said, "For 10 years, I could not go shopping. Now I want to live by myself and stand on my own feet. I got a boy. I do not want to be dependent on him. If you are healthy, you won't take people's time. Last time, my son accompanied me to the doctor's office. The poor boy has married lately. His wife is pregnant. He is also a university student. I don't want to take his time" (Patient 29).

Seeking information was aimed largely at maintaining independence and lessening the caregiving burden. Meanwhile, lessening the burden was also important for the family caregivers. One of them explained why she had asked about her mother's condition in the emergency room: "My mom once had a stroke. She is living with my sister. I'm worried that her condition will worsen and she won't be able to walk at all. I cannot afford to employ someone for her. My sister is also weary. I don't want her to have another stroke so she will walk by herself" (Family caregiver 21).

4.1.3. Maintaining and Promoting Physical-Mental Well-Being

The Following Factors motivated patients to seek information from different sources: increasing survival time, fighting the disease, lifting the burden from one's heart, swift recovery, methods of self-care, preventing damage to other body organs, preparing mentally to manage symptoms, achieving mental peace, and reasserting sexual identity.

One participant said that she was obsessed with asking numerous questions regarding the etiology and prognosis of a disease: "What is important to me is how I can fight the disease. What should I do to make my body more resistant and to have a better life? That's what I sought. That's natural for a human being. In any fight, he needs to know the weaknesses and strengths of the other side. I'm battling the disease... I try to comfort my body without pain and hardness then I need information for comfort" (Patient 1).

For eight participants, the motive behind seeking information was to improve their physical condition. One of them said, "I should know what to do after surgery if I want to recover soon. Therefore, I asked at the classroom... how should I take a bath... how I make low-fat food?... I asked all those questions of doctors and nurses at this hospital. I was looking for information that would help improve my heart" (Patient 22).

For other participants, maintaining and promoting mental health could be achieved through reading psychology books and attending wellness seminars. One patient said, "I was looking for a way in the books to get to the destination soon... thus I went after psychology books to correct my mental condition so I'd enjoy my life" (Patient 8).

4.1.4. Planning For the Future

By developing self-awareness about working conditions, prognosis, future life challenges, and the possibility of normal living in the future, some participants tried to make plans for their future. One who had worked as strategic manager said, "I wanted to know what was going to happen after the disease. How will I go on living? Will I be an ordinary person? Can I continue my life just as I did before? From now on, what kind of a world will I be living in? What shortages will I face and what will I get? My seeking was to answer these questions so I would make plans for my future life" (Patient 34).

Verifying patients' perceptions, a healthcare provider said: "A cardiac patient has a viewpoint about the future. Can he hope that he will see his grandchildren in the next two decades? Is a cardiomyopathy patient like him going to live for another decade to marry at all? The future is important for him; therefore, he makes plans for his future through the information he gains" (Nurse 19).

4.2. Desire for Personal Rights to be Respected

Most participants said they sought information because they wanted to assert their natural rights and to maintain control over their lives through fighting restrictions, preserving their authority, and expanding their self-awareness. When confronted with diet and medicine restrictions prescribed by physicians, they tried to find a method for self-care participation through information gathering.

One way to engage in self-care was to find information about herbal, traditional, and Islamic medicine. This information helped patients balance the power dynamics between the physicians and themselves. One participant said, "The physician told me that I couldn't take another drug, I should regard his advice. But I think I should act as a physician for myself. So I studied a book about Islamic medicine... On the other hand, I believe in the method used by herbal therapist. He (herbal therapist) gave me advice several times, after that, I told my physician not to prescribe this medicine and I asked him not to consider this as an inference in his job... I don't want to be restricted" (Patient 26).

Two participants said they were themselves responsible for finding the best lifestyle for themselves. They believed that anyone is free to choose his or her healthy lifestyle. Also, the experience of some healthcare providers showed that depriving a patient of choices and limiting his diet and activity could mean depriving him of his preferences, thus leading to a failure to observe a healthy lifestyle and diet. A physiotherapist said, "If you deprive a patient of the likes, you've made life meaningless for him; therefore, he'll seek an alternative. He doesn't want his likes to be restricted. If he fails to gain information about this, he won't be able to observe the low-fat diet. He may even avoid taking his medication" (Physiotherapist 16).

Other healthcare providers said that most questions raised by patients at the decision-making stage aimed at selecting the right treatment choice. They viewed respecting the patient's right to choose as a must. A cardiologist said, "On many occasions, the patient reaches the point that he has to choose from among several treatment options. He studies other information sources. He wants to make the right choice. We need to respect the patient's choice" (Physician 12).

Developing self-awareness was conceptualized as another human right. Some participants who held university degrees said that they were entitled to seek information. They maintained that constant advancements in technology require us to seek information throughout our life span. One participant said, "My job has taught me that nothing stops in this world. Just as the earth moves, you need to move your information forward and it needs to be

updated. I as a human being have the right to know. They make a new discovery every day... Today, they (nurses) say 'eat this' and tomorrow they say 'don't eat this'" (Patient 32). Patients were aware of their rights to gain information and to point themselves in the direction of lifelong learning.

4.3. Gaining Confidence Through Consultation

Most participants said that the main motive behind seeking information was the desire to gain confidence and know the truth. To ensure understanding about their diagnosis, self-care, decision-making, prescription medicines, preventive measures, treatment options, and prognosis, patients and families consulted with numerous professional sources and even peers. One participant had a religious foundation for his belief in consultation, explaining why he had consulted with several surgeons and asked questions about the risks of surgery: "I'm entitled to know the views of two doctors. The doctor said the final decision was up to me. And I talked to several surgeons to make sure about the surgery. The Muhammad (Muslim Prophet) himself who was sent by God said consulting is necessary. I was to rest assured because that's a final decision..." (Patient 35).

Asked why his patient had consulted with several doctors about the adjustment of drugs and stem cell transplantation, one healthcare provider replied, "That's because he is well-educated. He wants to double-check to make sure about the healthcare services. He asked me about stem cells. He went and confirmed what I said to him with medical papers and other doctors. I became sure that that was it. Then, he called me and made an appointment for stem cell injection" (Physician 17).

Patients and families thought that the following factors won their trust during the consultation: friendly behavior and empathy from healthcare providers, reasoning about their condition, respecting the right to choose, and giving sincere explanations. One participant said: "The responses I received made me sure. He (the surgeon) explained to me honestly. Some doctors speak in a veiled manner so that the patient does not panic. You (the surgeon) have to tell the patient the truth. Another thing that made me sure was that the doctor was amicable" (Patient 10).

5. Discussion

Participants in this study cited three main themes as motivations behind health information seeking by patients: optimizing the quality of life, desiring that their personal rights be respected, and gaining confidence

through consultation. The study sheds light on patients' preferences to meet their needs for information. It also outlines the main concerns of patients underlying their questions. Some findings of this study like the importance of playing one's role and lessening the burden of caregiving show that patients and caregivers do not see promoting the quality of their lives as separate from the impact of their roles in family and society. These motives point to positive interactions between patients and society and to efforts of patients to adjust themselves to internalized social norms (32). For example, social norms like making a living (for men) can shape one's health behavior (33). In our study, some participants considered playing one's social role as being separate from gender and from satisfying family economic needs. Several other studies have also shown that return to work for some female cardiac patients is a source of self-esteem and financial resources and of joy, identity, and independence (34).

Meanwhile, other studies have shown that cardiac disease affects all aspects of quality of life, especially through restrictions on occupational tasks, social life, and physical performance. Hence, when some patients perceive a threat to these areas of well-being, information seeking is motivated by the intention to fight restrictions and promote quality of life (35). According to the "regulatory focus theory," people with a self-regulatory promotion-focus approach are encouraged by their need for growth. They seek information, therefore, to improve mental and other aspects of well-being (36). Some of our findings like playing one's role and autonomy, which aim to lessen the burden of caregiving and to reassert sexual identity have not been reported by other studies because they focus mainly on background (e.g., social and environmental) factors that motivate information seeking. However, studies that have investigated beyond underlying factors (internal motivations) are to some extent compatible with our study. For example, Harding et al. and Imes et al. (7, 10) have spoken of the use of prognosis information for end-of-life planning. Another study has shown that elderly Americans use the Internet to maintain their autonomy and to avoid becoming a burden (13).

One valuable finding of this study is that participants largely believed that their wellbeing lay in their playing a healthy family role. Social research also shows that the main social value for the Iranian people is family (22). In another study, diabetic patients cited social factors like enjoying family life and physical factors like fear for one's future physical health and desire for health improvement and diabetes prevention (20).

Our findings also show that freedom from restrictions the right to choose and the right to gain information are examples of respect for individuality and natural rights

prioritized in patient accounts of their reasons for information seeking. From the viewpoint of natural rights argued for by such philosophers as John Lock (37) the right of choice should be counted among basic human rights. The charter of Patient's rights also underscores the necessity of gaining proper and sufficient information and the right of choice and freedom of decision-making for the purpose of seeking health services (38).

This study shows that patients and families attempt to realize these natural rights through self-motivated perception without unilaterally receiving the information. Knowles believes that learners need to become autonomous and that their self-concept must be respected (39). The present study supports patient-centered approaches that is, respecting patient preferences, the right of patients to choose, and actively engaging them during the information gathering process (16, 40). One way participants protected their autonomy was by seeking information about herbal drugs and complementary medicine. While respecting the autonomy of patients, health experts can help them in their search for information about complementary medicine and in treatment decision-making by better understanding such motivations (20, 22).

Another significant finding of this study is the importance for cardiac patients of gaining confidence through consultation. Other studies have found that seeking security has been a concern for cardiac patients and their families in escaping tense situations (41, 42). Seeking security and seeking information can show a complex relationship. Dickson et al. showed that cardiac patients sought safe and reliable sources of information to develop their self-care skills (18). Another study found a relationship between Internet searches and mistrusting the doctor (43), while yet another study showed that patients surf the Internet to reassure themselves about a doctor's diagnosis and prescribed treatment after consulting with him/her (12). According to the "regulatory focus theory," people with a prevention-focus approach are prompted by their need for safety and security to adopt preventive measures like avoiding risks while gaining information in the process (35).

5.1. Strengths and Limitations

A major strength of this study is the inclusion of the perspectives of patients, family caregivers, and healthcare providers. This study, however, was restricted by its setting and methodology; we used qualitative methods for in-depth analysis of the motivations behind health information seeking. Our study, therefore, was restricted to Iranians with cardiovascular disease, and the results may not be generalizable to patient populations living in other parts of the world. Hence, we recommend that the goals and

motivations behind health information seeking by cardiovascular patients be studied in other communities. Meanwhile, given the key role of family in seeking information for patients, we recommend that future studies consider the experiences of family caregivers throughout the information seeking process using a larger sample size.

5.2. Conclusion

Our study shows that the following factors are highly valued for cardiovascular patients and their families when seeking information: maintaining and promoting quality of life, wishing personal rights to be respected, and gaining confidence in their diagnosis and treatment decisions. Therefore, healthcare providers should emphasize team-oriented consultations that prioritize patient values and preferences when sharing information and discussing treatment choices. Our findings also show that patients consider access to information throughout their lifetime an inalienable right, and hence, it is appropriate to use Knowles' theory of life-long learning and the role of self-direction to meet the needs of cardiovascular patients as they make themselves experts of their own healthcare.

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Footnote

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