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Barriers to health information seeking in Iranian patients with cardiovascular disease: A qualitative study

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ABSTRACT

Objective: Providing patients with health care information is a critical component of the process of cardiovascular disease (CVD) management. The purpose of this study was to explore obstacles to seeking health care information among cardiovascular patients from the perspectives of patients, their family caregivers, and health care providers.

Methods: This study was conducted with a qualitative approach using conventional qualitative content analysis. The study included 31 Iranian participants including 16 cardiovascular patients, 5 family members, and 10 health care providers (multidisciplinary). Data were collected with semi-structured interviews and continued to the point of data saturation. Analysis of the data was performed continually and concurrently with data collection of using a comparative method.

Results: Five themes emerged including ‘poor quality of information provision,’ ‘mutual ambiguity,’ ‘beliefs, faith, and expectations,’ ‘from routine life to obtaining information,’ and ‘conditions governing information seekers.’ Seven sub-themes indicated participants’ experiences and understandings of obstacles in health care information seeking.

Conclusion: Health care information seeking in cardiovascular patients and their family members occurs as a result of the influence of beliefs, interaction with numerous information sources, and in the context and structure that the care and information are provided. Understanding the nature of obstacles to health information seeking will help health care policy makers to provide evidence-based, reliable, and patient-centered information to encourage cardiovascular patients’ involvement in treatment decisions.

Introduction

Cardiovascular disease (CVD) is the leading cause of death and disability in Iran and worldwide.[1] In spite of a 45% mortality rate due to cardiovascular diseases,[2,3] the increasing growth of coronary artery bypass graft (CABG) surgery,[4] and rising hypertension levels in Iran,[2] the health care system in this country has mostly focused on the control of communicable diseases and the development of primary health services.[2,3] Despite utilization of information technology in other sectors of the health system, there are few information technology resources for cardiovascular patients in Iran,[5] and patients may acquire self-care information from non-accredited sources.[6] Although there are non-governmental organizations (NGOs) and charities to support other chronic diseases such as diabetes and cancer patients,[3] there are still no government or public societies to support cardiovascular patients.[7] Thus, there is a need to address the information needs of cardiovascular patients in Iran.[2]

Patient involvement in health care decisions[8] and active patient engagement to seek relevant information includes obtaining information on treatment options, choice of physicians, management of symptoms, and dealing with the social and emotional aspects of the disease.[9] However, in Iran cardiac patients and their families often fail to acquire relevant information[10] with resulting negative consequences, such as problems enhancing quality of life,[11] feeling alone with physical/mental setbacks,[10] uncertainty in the management of their disease,[6] non-compliance with exercise and low sodium diet and delay in treatment seeking.[12]

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Iranian studies have revealed non-collaborative organizational cultures governing hospitals[13] and poor inter-sectorial cooperation as barriers to obtaining cardiovascular information.[14] Many are readmitted due to deficient self-care knowledge.[5] A qualitative study revealed that acquiring information could be a method for regaining control over one's own situation.[15] Evidence-based and tailored information could also provide key strategies for the successful management of heart failure.[16] Also obtaining health information can help the patient to seek out the meaning of illness experience, develop coping strategies,[17] and make informed decisions.[8] Despite the useful outcomes of information seeking, some studies have shown that cardiovascular patients are exposed to challenges in information seeking, despite the desire to find information relevant for self-management strategies, and practical advice.[16,18]

In a study by Alavi et al (2012) in Iran, access to unreliable, outdated and non-systematic rehabilitation sources were obstacles in gaining quality information for cardiovascular patients.[19] A review of previous studies about health information seeking behavior has shown[16,18–20] that understanding the phenomenon and its obstacles is defective in cardiovascular patients. Limited studies have been conducted on health information seeking; however, they mostly deal with cancer patients,[21,22] parents, women in rural areas, the general public,[23] African-American men and women,[24,25] diabetics,[26] and AIDS patients.[8] In these studies, variety of social, cultural, economic, physical, cognitive, and affective factors have been cited as barriers to seeking health information.[24–26] The role of the patient's social network and background in information seeking has rarely been addressed.[21,26] Some other studies have investigated the pattern of information seeking and the association of social determinants with information seeking in mass media and the Internet,[9,24,26] using mainly unreliable questionnaires.[9,27]

Most non-Iranian studies have focused on information needs of cardiovascular patients, with particular emphasis on prognosis and medication information, and also on patient-health care professional communications.[28,29] In Iranian studies, the focus has been on interventions associated with information support,[5] investigation of information needs through non-native questionnaires, and the role of the patient and family in searching for information from various sources has been less considered.[13,14]

Information seeking is a behavior dependent on the social context and structure of the health care system.[8,9] Given that the majority of patients are Muslims, with a diversity of religious minorities (e.g. Shia and Sunni) and ethnicities (e.g. Fars, Turkish, Kurdish, and Gilak), and also the uniqueness of the health system in Iran,[30] studying information seeking in the Iranian community has been recommended in other studies.[13,14] However, to date, there has not been any study focused purely on information seeking in the Iranian cardiovascular patient. Furthermore, a review of the existing literature lacks a naturalistic orientation,[20] while patients' stories provide a basis for understanding how information is sought in areas with little knowledge.[31] Therefore, the aim of this study was to examine barriers to seeking and obtaining information among Iranian cardiovascular patients, their families, and professional caregivers.

Methods

Design

Qualitative content analysis used for the interpretation of the content of the text data, and through a process of regular classification, implicit and explicit themes or patterns in the text can be identified.[32] This method concentrates on life experience, interpretation, and concepts to which patients have been exposed.[33] This study presents the results of conceptual ordering produced by constant comparison analysis. The aim of conceptual ordering is developing categories in terms of their properties and dimensions by the process of content analysis as called in GT open coding. Conceptual ordering is classifying events and objects along various explicitly stated dimensions, without necessarily relating the classifications to each other or developing an overarching explanatory scheme.[34]

This study is a component of a larger study that explored the process of health information seeking in patients with cardiovascular diseases. Conventional content analysis was used to address the aim of the current study. The study was approved by the Research Ethics Committee of the Welfare and Rehabilitation Sciences University and Tehran University of Medical Sciences. All participants provided written informed consent.

Sample and setting

A criterion sampling technique[35] was used to identify and select patients from two sub-specialty heart hospitals, rehabilitation centers and clinics affiliated with the Tehran University of Medical Sciences. These centers are the major referral centers for the treatment of CVDs in Iran.

Included patients had a diagnosis of CVD and were aged 18 years or older. Health care professionals had at least one year's experience in the treatment and care of cardiac patients. Family caregivers had experience living with and caring for these patients. All had the ability to understand and speak Persian and a desire to take part in the study.

The first author was available during morning and afternoon shifts at the above mentioned hospitals to conduct the interviews. Face to face contact with potential participants was strategic to ask them to participate in study. Then, based on good rapport established with the participants and with the cooperation of nurses in these centers, first, patients and their family members who had greater experience with seeking health information, and also health workers that had the necessary experience of training and interacting with cardiac patients were identified. Considering that the patients were the key participants in this study, as the study developed and in order to have maximum variation, attempts were made to select cardiovascular patients from different socio-economic and demographic backgrounds (such as age, marital status, education level, occupation, ethnicity, etc.), as well as patients in various stages of illness and treatment (diagnosis to rehabilitation). A total of 31 people including 16 patients, 5 family caregivers, and 10 professional care providers from various disciplines, over 12 months (May 2012 to May 2013) participated in this study.

Data collection procedure

The semi-structured interview began with an open question based on the main question of the study such as: 'How do you obtain cardiac related information? What are the challenges for you in seeking health information?' Then, based on the analysis of this data, more probing and follow-up questions were asked with respect to the subjects' daily experience of seeking this information. First interviews were conducted with cardiovascular patients. However, given the role of family members and health care professionals in the process of information seeking, after consultation with the research team, interviews were conducted with family caregivers and professional care providers for greater clarity and accuracy of the conceptual categories. Based on saturation of data in the qualitative study, a total of 31 interviews were conducted with 31 individuals, in the Persian language, each lasting between