

A Grounded Theory Study on Health Information Seeking Behavior of Iranian Diabetic Patients

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Abstract

Background: Diabetes is a chronic and metabolic disease with a steadily increasing prevalence. Patients' higher level of health information has positive effect on self-care and control of conditions. The aim of this study was to investigate the information seeking behavior of patients with diabetes in Kerman through applying a grounded theory approach.

Method: This qualitative study was conducted through applying a grounded theory approach using Corbin and Strauss (2008) method. To ensure of the accuracy and reliability of the qualitative data, Corbin and Strauss (2008) criteria were used. Eighteen diabetic patients were included in the study based on a purposive sampling. Semi-structured interviews were done in diabetes and healthcare centers in June 2019.

Results: The analysis of the data resulted in 45 primary categories, 17 subcategories and 5 major categories. The five main categories were: 1) recognizing the information needs to live well with disease, 2) acquiring health information literacy (the core variable), 3) information seeking barriers, 4) supportive information directing factors 5) empowerment. The main concern of the patients was "disease management and healthcare". The main strategy to overcome it was health information acquisition. Information seeking obstacles had caused insufficient information, distrust, and information evasion; while, supportive information directing factors had facilitated the process and increased the patients' health literacy. Finally, the interaction between these variables had led to the patients' empowerment.

Conclusion: This study showed that there are various interactive factors centered on "health information acquisition" that influence health information seeking behavior of diabetic patients. The policy-makers can design optimal health information systems and effectively transmit health information to patients to increase their health information literacy, self-care, disease control and healthcare costs reduction. The findings can help diabetic patients to have access to the more proper information they need.

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Introduction

Diabetes is a chronic and metabolic disease which leads to serious damage to the blood circulation system, eyes, kidneys and nerves (1). The number of cases and the prevalence of diabetes is steadily increasing, so that about 422 million people worldwide are affected by diabetes and 1.6 million deaths are directly happened because of diabetes each year (1, 2). Diabetic patients require effective self-management besides high quality clinical care and patients' self-care plays an important role (1); in this way, the participation of informed patients in clinical interactions is emphasized. Patients with higher health information levels participate more in their care management (3), "controlling their conditions", "adapting to their conditions", "stress and anxiety", and "performing their social roles" and "hopefulness" (4). Moreover, active patients have better participation in self-care and reducing the healthcare economic burden (5).

Information behavior implies the ways in which people interact with information, seek and use information (6), including both active and passive information seeking, and information use. "Information Seeking Behavior", a subcategory of information behavior, is the purposive seeking of information as a consequence of a need to satisfy some goals (7). It is a complex phenomenon and occurs when an individual realizes the need to acquire information and deliberately takes action to meet that need (8).

"Health information seeking behavior" (HISB) studies have been widely reported in the health-related scientific literature since the mid-1990s. HISB has two dimensions: (a) the information dimension focusing the characteristics of the information sought, in terms of type and amount, and (b) the method dimension emphasizing the optional actions used by the individual to obtain health related information and sources of information (9). Some studies have investigated the information seeking behavior of diabetic patients (10-16). A systematic review was conducted by Kuske *et al.* (2017) to

identify types of information seeking behavior, information sources used, content of searched documents and the variables affecting the information seeking behavior of diabetic patients. Five types of information seeking behavior were identified: passive attention, passive search, active search, ongoing search and combined types. The Internet and healthcare professionals had been mostly consulted. Diet, complications, exercise, medications and pharmacological interactions were the contents mostly searched (17). Since preferences about variables such as information content and sources are different in terms of context (18), the present study aimed to investigate the information seeking behavior of patients with diabetes in Kerman. Health information seeking is a dynamic phenomenon with dimensions related to the individual, cultural and social context and is done in interaction with family, society and health system; therefore, this study applied the grounded theory approach to explain the unknown concepts in diabetic patients' information seeking behavior and to present a theoretical model. Previous studies studying the diabetic patients' information seeking behavior have focused on quantitative methods. The quantitative studies cannot deeply explain some realities such as information seeking behavior which is context-dependent with various dimensions and structures. The findings of this study may result in better management of the disease, more efficient involvement in disease decisions and the interventions to have information may be customized. The grounded theory methodology was adopted. It is a general methodology for developing theory that is grounded in systematically gathered and analyzed data and it is analyzing meaning instead of data. One of the advantages of grounded theory is that the researcher can gather rich data, so the data gathered through this study gives a profound view about the information seeking behavior of patients with diabetes in Kerman.

Methodology

This qualitative study was carried out based on grounded theory approach using Corbin and Strauss method (2008). A purposive sampling method, then theoretical method were applied to select the participants. The interviews continued till data saturation was achieved. Eighteen diabetic patients participated the study. The interviews were performed using a semi-structured interviews. Diabetic patients whose disease was diagnosed by the healthcare and diabetes centers and accepted to participate were interviewed. Physical, mental and cognitive favorable condition were required for participation.

Each interview lasted 15-30 min minutes. The interviews were recorded and written down at the same time. The questions asked were as follows:

1. Semi-structured questions: a) how did you informed of your disease and what were the symptoms? b) After informing, what did you do?
2. Guiding questions: a) Did you have any information about diabetes before affecting by? b) When did you need information about your disease? c) What sources did you refer to?
3. In-depth questions: a) Please explain a situation when you needed information and searched about it (with an example).

To gather data through interviews, one of the researchers attended the diabetes clinics and interviewed the patients. Participation was completely optional and the patients were given the consent form to announce their satisfaction to participate.

The researcher also used field notes and reviewed publications that included interviews and educational materials for diabetics, such as Diabetes Message Magazine, as a source of data collection.

A deductive approach using continuous comparisons method was applied to analyze the data. The stages included: grouping of semantic units including participants' statements and words during the interviews and the materials obtained from observations and field notes, coding and labeling of meaning units, revising the codes on the basis of interview texts and information gained from other sources, reviewing and comparing the codes based on the similarities and differences, combining similar codes and categorizing them, developing major categories on the basis of similarity and suitability, revision of categories and again comparing them with data, integrating the findings and ensuring of strength of codes, and ultimately, identifying and distilling the main themes. To ensure of the accuracy and reliability of qualitative data, Corbin and Strauss (2008) criteria were used. The criteria included fit, applicability, concepts, contextualization, logic, depth, variation, creativity, sensitivity and evidence of memo.

Results

The participants were 18 diabetic patients, including 10 men and 8 women, aged 38-65 years. Their education level was primary school (n=1), Middle school(n=1), high school diploma (n=7), associate diploma (n=4), bachelor (n=3), master (n=1) and PhD (n=1). The interviews were performed in diabetes clinics.

The analysis of the interviews and extracted data resulted in 45 primary categories, 17 subcategories and 5 major categories.

The five main categories were as follows:

- Recognizing the information needs to live well with disease
- Acquiring health information literacy
- Information seeking barriers
- supportive information directing factors
- Empowerment

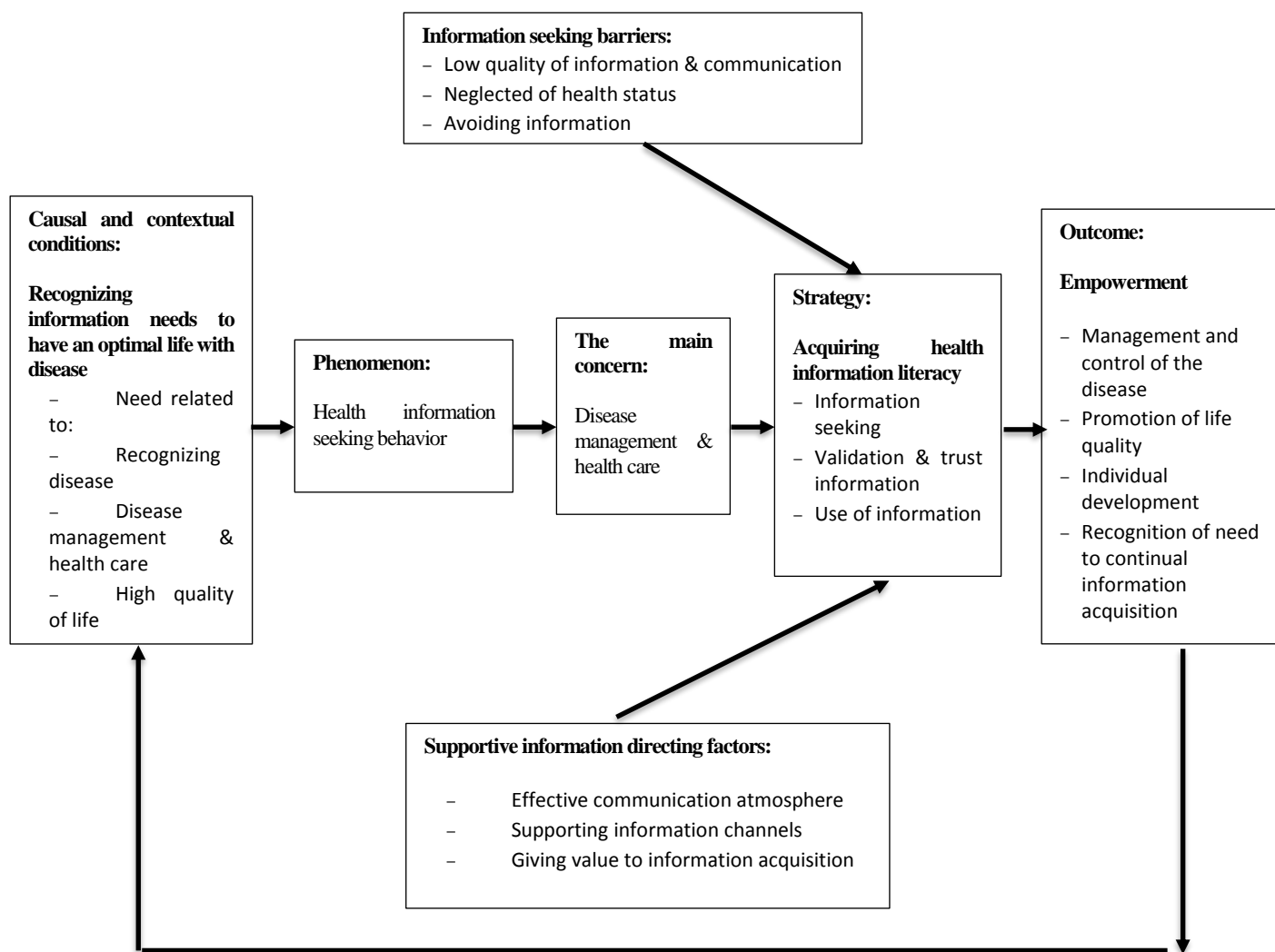


Diagram 1. The main categories extracted from the interviews on the diabetic patients' information seeking behavior

1- Recognizing the information needs to live well with disease

This need had been started at the time of patients' awareness of their disease and rooted in the participants' low health information literacy or ambiguity about their perceived problem i.e. diabetes. Recognizing this information need had motivated the participants towards health information seeking behavior. In other words, the cause of information seeking behavior was the need for information. In this way, this conceptual category was considered as a cause for information

seeking behavior. The information was related to "disease recognition", "high quality of life", and "disease management and healthcare" and was the main concern of the participants. The participant #4 expressed that "I was looking for information to prevent next problems such as wounds, or kidney diseases etc. I looked for information to avoid further problems". The participant #6 told "I needed information to change insulin intake dose. I searched internet and then consulted my doctor, and the morning and afternoon intake dosages were changed.

2- Acquisition of health information (the main variable)

The patients referred to health information to recognize their disease and to allow a healthy life style especially to overcome the main concern, i.e. disease management and health promotion and care. "Health information acquisition" was the core category which its different aspects were repeated and could be related to other categories. The patients had used different strategies for information seeking, information validation, trust and use. The main information sources were physicians, staff of healthcare centers, specialized and supporting centers and medicinal plants shops (attaries). In addition to these, the patients' friends and families were the other sources of health information. Traditional media such as newspapers, TV, radio, pamphlets and manuals presented by diabetes centers and modern media such as internet and satellite networks had been also consulted. Some patients had searched the information on diabetes actively while because of lack of health information and being unaware of information sources, some others had searched inactively. The patients had usually consulted their doctors about the retrieved information to get ensured of the validity of information and most of the patients did not trusted internet and satellite networks. A few had evaluated the information themselves.

The patients had used the information when they got ensured of the validity of information and sometimes they had shared the information. They had used the information to contribute in decision making on drugs and treatment and changes in eating habits and having active relationship with the doctors. The patient #7 stated that "I check some internet sites through google, I find the common points. The websites cannot be trusted. Everybody can make a website and insert some information. I use the information after consulting my doctor".

Patient #5: "Diabetes should be managed. I should get information and set my life. Information is needed to avoid the complications of the disease, I do exercises, take the medicine and eat according to the instructions of my doctor and the doctor advised me to follow up my eyes and kidneys and I did that".

3- Information seeking barriers

When seeking for information, the patients faced many challenges and barriers. A group of barriers between the patients and the information sources was communication problems such as ineffective communication between the patients and the physicians and the healthcare staff, lack of information sources in diabetes centers and the insufficient educational content of mass media. The other group of barriers was related to the neglect of the patients about their health status, so that the patients had not put enough time and care about their health. They had not searched the information on the disease and believed that no serious consequences would threaten them. Some other patients had avoided getting the information even passively because of destiny beliefs, mistakes, fear of receiving bad information about the disease, previous negative experiences in information seeking and contradictory and huge amount of information accessible. The participants #6 said: "I went to a doctor, he/she was busy. I asked some questions about my disease, the doctor said: which one knows better, me or you. So I stopped asking questions".

Participant #8 expressed: "I am so busy and have many things to do, so I do not think of my disease-diabetes and do not search for more information. I take the doctor's medicine. The life has become very difficult".

Participant #10: “My illness is not so serious [no serious problem]. I do not overeat food and sugar. So diabetes does not threaten me and has nothing to do with me. I take the medicine and hope to get well”.

Participant # 7: “everything that is supposed to happen, will happen, I do not look for questions and answers. What will be told, will frighten me. It’s better not to follow these”.

4- Supportive information directing factors

In searching health information and increasing health information literacy, the patients had been supported by some factors. Some factors were related to their personal characteristics such as valuing their health and having the spirit of constant attempt for information seeking. Some other factors playing a more prominent role were related to the support of physicians and healthcare staff in information giving and education. Along these factors, the social networks around the patients (such as friends and family) had also supported the patients in information seeking.

Participant #12: “It is good to have some information to save the health, i.e. the treatment becomes easier. Ask the doctors to change the medicine if it is necessary, do exercises to get healthier”.

Participant #4: “The doctor explains well, he speaks as ourselves, he/she is good-tempered. It is possible to talk alone without having others in the office. He takes time for the patients and is kind”.

In a similar study, the patients stated “These clinics are good, there are doctors there, I go there and they prescribe. We, patients, ask our questions. They give nutrition advice. They give manuals, some useful information and guidelines is presented in the classes for further follow-up (19).

5- Empowerment

After understanding the information need, passing the barriers, having information seeking facilitators and acquiring proper health information, most of patients had moved towards empowerment. This achievement had been gained due to disease management through self-care, adherence to drug-therapy and improvement in preventive behavior. After the improvement of the health information level, the patients had contributed in the disease management and made informed decisions. They had actively followed healthy life style to save their health and improve their life quality. They had tried to decrease their concerns to overcome the limitations resulted from diabetes or to cope with the illness; in other words, “to live with diabetes”.

In a similar study, the patients stated: “In my opinion, diabetes is not scary. At first, it was difficult but now [after participating in the educational classes] I have got some information and abilities that helped me to have better and healthier body and soul than before. After getting informed about diabetes, I have behaved better, my blood sugar level and nutrition have been regulated, I do exercises, follow the disease side effects. I know if I take care, no serious problem will threaten me. In my opinion, if I take care there is no difference between a diabetic and non-diabetic one. Life can be hopefully continued” (20).

Discussion

This grounded theory study explained the information need for a proper life with diabetes as causal conditions in health information seeking. This information need was usually related to the patients’ main concern i.e. “disease management and health care” subcategory which included some concepts such as “preventive behaviors”, “control or treatment of the disease”

and “self-care”. The results of a grounded study on health seeking behavior of cardiovascular patients have also indicated that the concept of “health self-care” is an essential information need of the patients (21) which is consistent with the results of our research. Another grounded theory research on the health information seeking behavior of pregnant women have mentioned information needs such as mental needs and nutritional care as the stimuli of the information seeking behavior among pregnant women (22). Most of the quantitative studies done on health information seeking of diabetic patients have pointed out that needs related to “prevention of disease complications and consequences”, “disease cause and symptoms”, “proper nutrition in diabetes”, “treatment process” and “the period of the disease” are the most important information needs among the patients (15, 23). The findings were often consistent with our findings.

The patients participating in this research, after understanding their information needs, had applied different strategies to acquire health information addressing their information needs. Information seeking strategy as an active searching or inactive acquisition of information of human resources and traditional and modern media that have been explained in this study and in other studies have been highlighted in different forms; of them, human resources especially physicians and health care personnel are emphasized on (11, 14, 16, 22). In studies on health information seeking behavior of people in rural and remote areas where access to physicians and nurses was difficult, radio and other people around the patient were mostly used resources (24). According to the findings of this study, there was a significant relationship between the patients’ active and inactive information seeking and their literacy level. Other studies also indicated that patients

with higher health literacy and more familiarity with medical terms had better health level and they mostly searched the information actively (25-27). Validation and trust on the accuracy of information was another strategy which the patients applied when searching for health information. The concept of “trust on information” has been considered in two studies applying grounded theory methodology on health information seeking behavior. According to these two studies, patients search information and get ensured of the information accuracy to take care of their life and avoid the risk to their life and health (21, 28). Some other researches have paid attention to ensuring and validation of information accuracy and mostly have specified physicians as the most valid resources of validation of health information. Our study approved the results of previous studies (10, 22, 29). The relationship between health literacy level and trust in information was the common finding between this study and Chen *et al.* study (30).

After trust in information, applied by the patients, it was information use observed as drug and treatment decision-making and information sharing. According to the previous studies, the concepts related to information use have been applying recommendations, orders and instructions by physicians and health personnel (31, 32) which is the same as the results of the present study.

In searching information, the patients faced challenges by barriers and supported by "supportive information directing factors". According to the findings of this study, low quality of information and poor communication between the patients and the healthcare system, health mass media and the people around the patients were the barriers, while effective communication environment and adequate information channels in healthcare system were facilitators which constitute the two sides of a

spectrum. In other words, their positive performance was considered as facilitators and their negative and weak performance was considered as barriers. A grounded theory conducted to investigate health information seeking behavior among cardiovascular patients has reported that the poor information performance of health care providers, inadequate responsiveness of health system, discrete information communication and inappropriate information were the barriers in the information seeking behavior process. Moreover, this study has also reported some personal barriers such as information anxiety, neglect of health and incorrect beliefs as barriers (33). These findings are consistent with our findings. Another study on health information seeking behavior among patients affected by cancer has mentioned unresponsiveness of the health personnel, high costs of health information resources and distrust in health information websites as barriers (4).

The findings showed that through understanding the information needs of patients, crossing the barriers of information seeking, having the support of "supportive information directing factors" and health information acquisition, patients had some achievements. These achievements were categorized in a major category as "empowerment". Empowerment can be achieved by disease management through self-care, drug-treatment adherence, improving preventive behaviors, following a healthy lifestyle, and reducing the worries and limitations of diabetes. The findings were in line with the findings of Hibbard *et al.* research which has considered strengthening patient management on self-care as the consequence of health information acquisition (34). Fox *et al.* also states that having information about the health status, will increase the understanding of the patient

about his/her health problems (35). Moreover, a recent research emphasizes the role of health information recommender systems on empowering the cancer patients through improvement of health information and health status (36) which is in line with the findings of the present study. Finally, it can be added that in the information seeking behavior process of the participants, the most important concern was "disease management and health care". The main strategy applied by the participants to solve this concern was "acquisition of health information literacy" which was the core variable. The "information needs for a good life with the disease" led to the adoption of a "health information literacy" strategy. The context of "information barriers" led to insufficient information and reliability or even information avoidance, but "information facilitators" facilitated the information seeking behavior and increased their health information literacy. Finally, the interaction between these variables led to "empowerment" of patients. The core category and its relation with other main categories formed the theoretical model.

Conclusion

This study showed that there are various interactive factors centered on "health information acquisition" that influence health information seeking behavior of diabetic patients. The policy-makers, having the findings of this research through grounded theory, can design optimal health information systems and effectively transmit health information to patients to increase their health information literacy, self-care, disease control and reduce healthcare costs.

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