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Explanatory Model of Diabetes Management; An Experience from Iran

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ABSTRACT

Background: Managing diabetes requires changes in the patients' life style and health habits which in turn need the comprehensive understanding of the disease and its impact.
Objectives: To understand the explanatory model of diabetes in Iran, a qualitative study was performed using the grounded theory method.
Patients and Methods: Thirty persons were interviewed: fifteen patients, eleven nurses, three physicians and one dietitian. The semi-structured interviews were transcribed and analyzed in three stages of open, axial and selective coding.
Results: The findings showed that patients' personality can shape their self-care behavior; however, curing, caring and supporting systems are also necessary. The interactions between personality, curing, caring and supporting systems and society makes the outcome, which is the core variable in the designed explanatory model of diabetes.
Conclusions: This paper reflects an explanatory model of diabetes management. Understanding the factors that affect self-management behavior is important for nurses as key providers in the health care system.

Implication for health policy/practice/research/medical education:
The explanatory model of diabetes management might help health care providers to understand the circumstances that may influence patients' self-care behaviors. This acquaintance can lead to a better assessment and restored services in diabetes management.

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1. Background

The prevalence of diabetes is rapidly increasing all over the world. Diabetes is one of the major causes of morbidity and mortality in middle aged people and is the seventh leading cause of death (1, 2). It is estimated that 5.5 percent of Iranian population suffer from diabetes mellitus (3). Diabetes mellitus is one of the leading causes of renal failure, retinopathy and neuropathy and increases the risk of cardiovascular and cerebro-vascular diseases (4). A study done on 101 patients with a diabetic foot ulcer in Iran showed that 34.7% had eventually undergone amputation (5). Another research in Iran showed that 24.7% of diabetic patients had never gone to a physician, 80.9% had never had a foot examination, and 45.2% had never had any education (6). As the incidence of diabetes mellitus increases and its mortality and morbidity reach

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epidemic proportions, it becomes more and more important to implement additional effective models of health care delivery in order to reduce the complications associated with this disease (7). Diabetes management is a challenging issue. Successful self-management of diabetes needs a wide range of life-long activities which must be carried out on a daily basis in different situations (8). Diabetic patients require support in changing their lifestyle and need appropriate therapy to ensure glycemic control and reduce the risk of chronic or acute complications. Support from diabetes specialist nurses and family caregivers are necessary in self-managing diabetes (8). Several models have been used in diabetes care. The effectiveness of these models has been diverse. A research study in Belgium showed that Chronic Care Model (CCM) based program could improve the diabetes care moderately. The HbA1C and cholesterol levels were better in a group that received CCM but micro-albuminuria and ophthalmologist visits were not different in the intervention and control group (9). Other research showed that the Health Belief Model positively influenced the use of diabetes-related pharmaceutical care services (10). In Trinidad, the implementation of Trans-Theoretical Model did not improve the glysemic control and medication use. The researchers concluded that the harsh social conditions overrode the clinical intervention (11). It seems that social and cultural factors can influence the effectiveness of caring models. Health professionals, especially nurses, can facilitate the changes and teach patients how to manage their diabetes. To do this efficiently, they require a model of caring based on the views and experiences of other afflicted patients and health professionals. Current knowledge about the basic caring processes in diabetes mellitus is limited in our country (6).

2. Objectives

The main object of the study was to introduce an explanatory model for diabetes management in Iran.

3. Patients and Methods

A qualitative research study was conducted using the grounded theory method.

3.1. Participants

The participants in this study were adult patients (above 18 years old) who all suffered from diabetes for at least one year. The participant selection process deliberately chose patients at different ages and with varying physical conditions. Each patient referred to the Iranian Diabetes Society (IDS) in Tehran was given a form to write specifications, age, type of diabetes, related diseases, complications, as well as contact details. Later they were contacted for a comprehensive interview. Fifteen patients, seven females and eight males were interviewed. Thirteen patients had diabetes type 2 and two patients had diabetes type 1. Eight patients were being treated with insulin injections, and the other seven patients were under the treatment of anti-diabetic oral medications. The average age of the participants was 52.6 years (range 19-75) and the average duration of diabetes was 10.6 years (range 1-25). After collecting data from the patient group, fifteen health professionals who had at least five years' experience working with persons with diabetes were selected. Participants in this group were working in the IDS or were key persons who were well-known for their work with diabetes. In the health professional group, eleven nurses, three physicians and one dietitian were interviewed.

3.2. Data Collection and Analysis

Following ethical approval from the ethical committee of Tarbiat Modarres University and after obtaining the participants' informed consent, the researcher made appointments to conduct in-depth, face-to-face, semi-structured interviews with participants. The interviews underwent at the patients' houses or the IDS, whatever the patients preferred. Open-ended questions were asked regarding the patients' experiences in living with diabetes, its effects on their everyday life, their feelings about diabetes, and the problems that diabetes may have caused for them. Some of the open questions are, "How has diabetes affected your life?", "How is your everyday life with diabetes?", "How do you cope with your illness?", "What are your expectations from others?", "How you manage your diabetes?" "How do you solve your health-related problems?", "What are the support resources for you?" and "What is the meaning of success when managing your diabetes?" Interviews took 20 to 60 minutes. In the health professional group, the interviews were semi-structured with open questions. Most of the questions were about their experiences with persons with diabetes and the ways the health professionals thought these patients could be helped. Some of the open questions are: "What are the most important and common problems that diabetic patients complain about?", "Which are the most common self-care behaviors among diabetic patients?", "How do you think patients can be helped?", and "What are the patients' expectations?" The interviews were performed at the participants' work place. The interviews took 30 to 50 minutes. The data analysis began subsequent to the first interview. The audio taped interviews were written down to serve as the content for the data analysis by the first author of this manuscript. The other authors listened to each tape completely to verify the accuracy of the content and analysis. The collected data were analyzed in three phases of coding: (a) open coding; (b) axial coding and (c) selective coding. In open coding, every detail of the data was reviewed to identify and code units of data. Significant points were extracted and recorded; this step was repeated several times to validate the information and ensure nothing were missed. At the end of this phase, 395 primary conceptual codes were

extracted from both patients' and health professionals' interviews. In the second phase of coding or axial coding, the primary codes were divided into nine main categories and 26 subcategories. These categories and subcategories are shown in table 1. In the third phase or selective coding, the relationships between categories were determined and a core variable was identified. Three experts who had published articles in qualitative research confirmed the reliability of the process, following listening and recoding three interviews. The results were referred to all participants to get their opinion. Four patients indicated that they had more to clarify. A subsequent interview was arranged and their views were considered in the final report. The participants agreed that the results showed their genuine views.

4. Results

In this section, the main categories: 1) disease, 2) character, 3) society, 4) problem, 5) coping, 6) cure, 7) care, 8) support, and 9) outcome are going to be explained. These main categories are also the main concepts which shaped the explanatory model of diabetes.

4.1. Physical Dimension of Diabetes (Disease)

Patients mentioned three features in physical aspect of diabetes: 1) The signs and symptoms that they experienced, such as fatigue, polyuria and mouth dryness ; 2) problems related to long term complications, such as loss of vision and 3) problems related to acute hyper and hypoglycemia. Suffering from pain and loss of vision were among the disturbing problems reported by some patients: "When pain comes, other problems seem nothing; you forget them all" (A 47 year old woman with diabetes) "If I cannot see, then how can I live? I can't even come for dialysis anymore. I will be completely dependent on others." (A 65 year old woman)

4.2. Psycho-Spiritual Dimension (Character)

Trust in God, hope, love of life, being loved, self-confidence, thoughtfulness and resistance are among factors which seemed to impact patients' self-care behaviors. Some patients believed that diabetes had positively influenced their life style. A 19 year-old girl said: "Diabetes has had positive effects on my life; so many times it has made me think more about myself, about God, about the

Table 1. Categories and Subcategories in Axial Coding

Physical dimension of diabetes	Physical Complications, Signs, and Symptoms
Spiritual and mental dimension	Attitudes, views and feelings in people with diabetes
	The effect of patient's personality in diabetes
	Positive effects of diabetes
	Views about the cause of disease
The influence of socio-cultural, political and economic factors	Social effects on diabetes
	Expectations from health system
Problems related to diabetes	Social effects of diabetes
	Effects of diabetes on family
	Psychological influences of diabetes
	Challenges for people with diabetes
Coping in diabetes	Life Adjustment for people with diabetes
	Hobbies in diabetes
	The factors effecting coping
Curing in diabetes	Obstacles against treatment
	Expectations from treatments
	Insulin therapy in diabetes
Caring in diabetes	Education
	Presence of nurse
	Nursing process
Support in diabetes	The role of diabetic support groups
	The role of family in diabetes
Outcomes in diabetes	Glycemic control
	Quality of Life
	Self-management

universe. I have always faced lots of difficulties compared to my friends but this gives me a feeling of being stronger and superior in some ways." The participants in the health professional group had opinion similar to what the patients expressed and believed in the importance of character in patients' self-care behaviors. A nurse said: "I know a student that has diabetes; he has isolated himself completely and can't tolerate the situation. We also have diabetic patients that are completely successful in their lives and in controlling the disease."

4.3. Socio-Cultural and Economic Situation (Society)

The influence of socio-cultural, political and economic circumstances society with its economic, cultural and political components could affect patients. A nurse said: "In Iran, we don't have any national program for the prevention or control of diabetes; all are sporadic efforts here and there. If patients are educated and rich, they can get access to everything; if not, they are really miserable." Many social factors could affect diabetic patients directly or indirectly. A 55 year-old man said: "In all situations, at work, in the bank, in the streets, when you are driving, there is something that makes you nervous. How can someone control his blood sugar with these numerous stresses in the environment?" These kinds of sentences showed the stressful environment in Iran which could influence patients and health professionals' behaviors.

4.4. Contextual Problems (Problem)

Mental, social and economic problems were of great concern to many patients. Some experts and patients believed that diabetes and its related problems might cause depression. A 43-year-old woman with diabetes said: "Whenever I see my diabetic card and imagine a situation where someone might find me unconscious and takes me to the nearest hospital, I start crying and feel miserable." Another patient said: "I know someone who doesn't have a job. His wife and children nag him all the time. They are almost right, because of life expenses and they have to pay the rent at least. I saw him lately and he said 'I prefer to die sooner'. Such a person doesn't have any motivation to control his disease. I know diabetic patients that don't have enough money to buy Insulin." Young patients were very concerned about finding jobs and said that diabetes limited their opportunities for even marriage. Social stigma was another problem. Many patients expressed difficulties in working, studying, traveling and going to parties gathering. A patient who worked as a teacher said: "Sometimes when my blood glucose goes down, I can't remember words and it is a very bad situation in front of the students." Nurses and physicians recalled incidents where many patients tried to hide their disease, especially among those with Type 1 diabetes. A nurse said: "I was working at the emergency department, when they brought in a young woman that was unconscious. Her husband said she just felt down for no reason. Her blood glucose was 550. She had married five days before and she had hidden the fact that she had diabetes from her husband and his family."

4.5. Coping with Diabetes (Coping)

According to interviews, three coping stages were recognized in the patients: 1) Following diagnosis stage, 2) Trying or ignoring stage and 3) Stabilization stage. As patients pointed out, the post diagnosis stage was accompanied by fear and uncertainty. According to the health professionals, the patients and their families require a great deal of attention during this period. The participants pointed out that during the second stage which could be called the stage of trying or ignoring, many patients and families tried to cope with the situation. They began to acquire more information and make an effort to overcome the problems. A physician said: "I call the time following diagnosis, the golden time, because patients are very susceptible to their new situation and you can prepare them for change more easily." At the same time, some patients ignored or denied the problems and did nothing or very little to control the situation. Participants believed the patients got used to their situation by the third stage which could be called the stage of stabilization. In this phase, it is difficult to change the patients' life style. Earlier experience, a supportive environment and access to health resources were among the open codes, which could have a positive effect on coping with the situation. Gender was also an important factor. Most of the women interviewed complained about situations that could interfere with successful coping: "My husband doesn't want to change his diet and it is difficult to make two kinds of food for a family. If I make healthful food with vegetables and a small amount of fat, he doesn't eat or says he is still hungry.

4.6. Treatment in Diabetes (Cure)

All participants agreed that physicians were the key persons in the process of treatment. Lack of physicians specializing in diabetes, difficulty in contacting physicians, expensive treatments and equipment and insufficient treatment were some problems related to the process of treatment. A dietitian said: "We have physicians that still prescribe one daily injection of insulin for patients. This treatment does not control blood glucose and we are unable to do anything." Patients believed that a good effective relationship between patients and physicians was another important factor in the treatment process. A 36 year-old- man with diabetes said: "Physicians are like kings in their palaces, you don't dare to ask any question about treatment. You are supposed to just obey their orders. They are very reluctant to talk to you or explain the treatment."

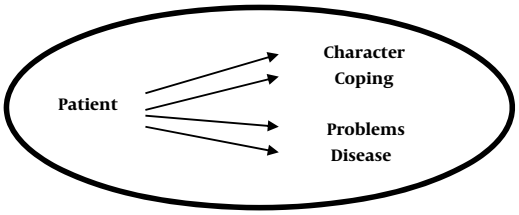

Figure 1. The Personal System in Explanatory Model of Diabetes Management

4.7. Caring in Diabetes

Nurses are key professionals in the caring domain. Education is the main responsibility of the nurses. Many patients did not have enough knowledge about their treatment. A woman with diabetes said: "I used to take my medications before sleep for four years and nobody told me I should take them before a meal!" The presence of the nurse on the side of the patients has a significant role in controlling the diabetes. Patients should have an easy access to the nurses. Telephone counseling was a suggestion that could provide support for the patients. The nursing process can help patients solve or control their health related problems.

4.8. Support in Diabetes

Family seemed to be the most important upkeeping source for patients and had the key role in influencing patients to accept, cope and change their habits when necessary. Participants in both groups agreed that family plays a strong role in supporting the patients. A 19 year-old patient said: "I accepted my new situation very well, because of my mother, she helped me a lot and even now after 15 years, she comes to see whether I am all right at night." Most patients believed diabetic groups and social security systems were other possible sources of support.

4.9. The Outcomes of Diabetes

It seems that health, quality of life, metabolic control, satisfaction with treatment and self-care were the concepts that can be put under the category of the outcomes in diabetes management. When the patients were asked how they felt about their own health and about other people whom they considered to be healthy, their answers varied. Patients believed that healthy people are more active, have good social relationships and good friends, have a happy family life, enjoy life, feel secure, and have hope and love. A patient said: "Health is a continuous comparison, if you feel you are better off than others you feel healthy. A one-eyed man is king in the city of blind." Mental, spiritual, and social health, were as important as physical health for persons with diabetes. A 67-year-old patient said: "Assume you have a completely healthy body but your son is addicted to drugs. Can you feel healthy?"

The processes identified and core variable: In selective coding, the relationships between the main categories were identified and the explanatory model was designed. The main processes identified are listed here:

1) The character of patient, his/her coping strategies, the severity of the disease, and the other problems that patient may encounter can affect his or her performance. These four concepts reflect the personal system of the diabetes management (Figure 1).

2) Patient can be helped by care, cure and support sys-

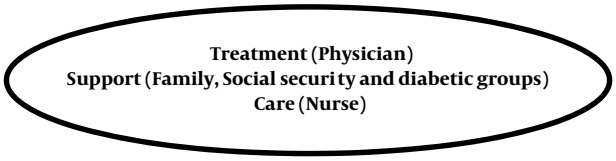

Figure 2. Cure, Care and Support System in Explanatory Model of Diabetes Management

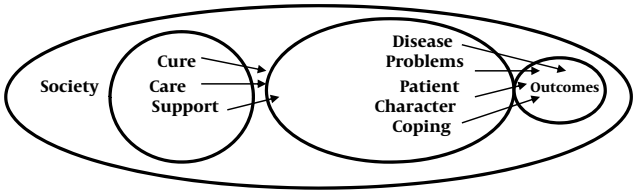

Figure 3. The Relations between Main Categories

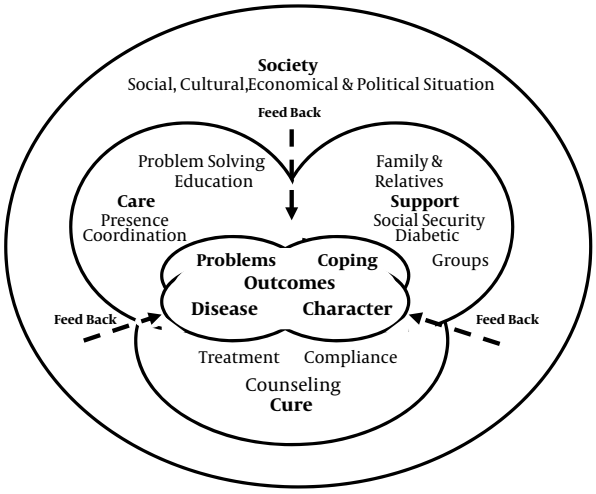

Figure 4. Outcome Based Management Model

tems. Nurses, physicians, families, diabetic groups and social security are the main helping resources (Figure 2).

3) The patient and other involved persons like family members, nurses and physicians continuously are influenced by the environment which consists of socio-cultural, political and economic factors.

4) The outcome is the criterion of success for patients and health professionals. It provides the basis of assessment, goal determination, planning, intervention and evaluation. The relationship between categories can be seen in Figure 3.

5) Core variable: Outcome is a category that can relate other categories. Therefore, this concept was considered as a core variable in this research. The outcomes such as health, quality of life and glycemic control can be evaluated in the patients. Therefore it is placed in the middle of the personal system. The patients and its personal system continuously receive the feedback from other systems. The complete picture of Explanatory Model of Diabetes Management can be seen in Figure 4.

5. Discussion

Diabetes is a self-managed disease for which patients provide 99% of their own care (12). A deep psychological acceptance is critical in order to mobilize a person's psychic energy towards good health and self-management (13). Personal characters can influence their health behaviors (14). In current research, the mental and spiritual beliefs of patients could define the behaviors regarding the disease. Dewar and Lee (2000) recognized three phase of coping in their qualitative study; they say: "The process of bearing illness involved three phases: Finding out, facing reality and managing reality" (15). The three phases are almost similar to coping stages recognized in our study. As we move forward with the goal of helping people to self-manage diabetes in the best possible way, it is important to follow the lead of those providing the management of diabetes (16). The importance of family as a main support system is well established in scientific literatures (17, 18). Our study showed the importance of family in supporting cases with diabetes. Patient beliefs, attitudes, and behaviors are influenced by cultural and socioeconomic factors (19). Society as a political, cultural and social environment affects patients and health providers simultaneously. The cultural factors can also influence the health behaviors (20). Understanding the factors that affect self-management behavior is important (21). In this circumstance nurses are key providers in effective self-management programs (22). If formal health services fail to provide sufficient and satisfactory nursing care, the patients will show the negative behaviors such as self-medication, which is common among Iranian diabetic cases (23). In conclusion the stressful life puts considerable pressure on patients and health professionals. Financial issues have some concerns for the patients. Some cultural characteristics of Iranian society like gender difference and leaving everything to a superior power (God) has been reflected in our study. According to the participants, there is lack of attention to primary and secondary prevention in Iran which makes the situation worse for diabetic patients. There is no community based program for diabetes in Iran and the social security doesn't provide the costs of needles, glucometers and even simple educational courses. Despite social differences, many aspects of living with a chronic disease such as diabetes seem to be universal. The way people cope with diabetes and the families as the main support system are examples of these universals. The explanatory model of diabetes management can help nurses to understand the circumstances that may influence patients' self-care behaviors. This knowledge can lead to a better assessment and better care plans in diabetes management. The outcome which is the core variable in this study has this potential to direct the team work in diabetes care. This study might provide basic information for further research in comparing diabetes in different countries and cultures. The implementation of the model and designing an assessment tool according to the concepts of the model need further study. This is a study in the culture not the study about the culture, so the cultural factors which can be interesting for the international readers might be insufficient.

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Authors' Contribution

The first author performed the interviews. All the authors contributed equally in designing the research, data analysis and writing the article.

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