



Patients' and Health Professionals' Views on Caring in Diabetes Disease

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ABSTRACT

Background: Diabetes is a common problem with severe complications. The control of diabetes needs a close and honest relationship between patients and health professionals. The views of these two groups might influence the professional relationship.

Objectives: The purpose of this study was to identify the views of diabetic patients versus the views of diabetic care professionals on the content of caring.

Patients and Methods: This qualitative study was conducted with the content analysis method. The participants consisted of adults who had suffered from diabetes for a minimum of one year, and health care professionals working in diabetes care centers. Fifteen patients and fifteen health professionals participated in the interviews.

Results: The findings present four main themes which are as follows: what caring is and what means to care, the obstacles in providing care, the outcomes of caring, and specialist community-based care as a crucial intervention in diabetes care, the themes were identified and based on the data analysis, It appeared that patients were more outcome centered, while health professionals were more process- centered in the context of caring.

Conclusions: It appeared that patients were more outcome centered, while health professionals were more process -centered in the context of caring.

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► Implication for health policy/practice/research/medical education:

This research gives an idea to policy makers that how much the views of the professionals and patients in the fields of diabetes care, are different and tries to close these views.

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1. Background

Diabetes mellitus (DM) is a common chronic disease and one of the leading causes of mortality (1). It is estimated that 6% of the population in Iran has diabetes mellitus (2). According to the research, 27.4% of the diabetic patients in Iran had not seen any physician, 80.9% had never had their feet examined, 92% had never heard

of the Hemoglobin A1c (HbA1c) test for the assessment of glycemic control, and 45.2% had never been provided with any education on diabetes (3). This research showed that there was a lack of awareness and focus on diabetes care in Iran. The concept of caring has been the central element of nursing since the 1980s (4). Leninger defines care as the essence of nursing and the central, dominant

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and unifying focus of nursing (4). Watson describes nursing as a human science with the major focus upon the process of human care for individuals, families and groups (5). Current definitions of caring primarily focus on the clinicians' perspectives. The patients' perspectives on caring are not often considered in scientific literature (6). Managing diabetes mellitus is a difficult task for both patients and clinicians. Unawareness of the different conceptions and views about caring and its goals that might be held by the patients and health professionals can exacerbate the problem, which might result in unsatisfactory health outcomes for the patients (7). In chronic conditions such as diabetes, where the focus of care should be placed on the patients' empowerment and self-care improvement (8, 9), the patients' views are important. It is difficult to understand patients' self-care behavior without understanding her / his health beliefs, feelings and views (10). In a study that investigated how nurses and diabetic patients viewed certain aspects as being the highest priority in diabetes care; the report showed that diet was one of the highest priorities for both groups. For patients, disease progression and complications were just as important as diet. However, nurses did not regard these as high-priority issues. Physical signs and symptoms were noted as the highest priority issues for 28.4% of patients while only 10.2% of nurses considered them to be important (11). The research showed the differences existed among the nurses' and the patients' perspectives, which could create different caring goals and expectations. Patients' views can affect their care behaviors. Research conducted with diabetic patients in Sweden showed that patients that considered the disease less serious and had a fatalistic view of the disease, external locus of control, and a passive attitude, had a lower self-care efficacy (12). It is difficult to address patient-centered care without considering the patients' views about their care and comparing these with the views held by the health professionals. Understanding the similarities and discrepancies in patients' and health professionals' views of caring may result in more practical and user friendly caring plans and interventions.

2. Objectives

The purpose of this study was to illuminate the meaning of caring and to identify the views regarding the subject of caring as perceived by diabetic patients and diabetic care professionals.

3. Patients and Methods

This qualitative study was conducted by utilizing the content analysis method. The participants consisted of two groups, adult diabetics (aged over 18 years) and health care professionals in diabetes care. All the participants with diabetes were members of the Iranian Diabetes Society (IDS) in Tehran city. IDS is a Non-Governmental

Organization that provides education for people with diabetes in Tehran, so people with different conditions and backgrounds are referred to this center. In this study, it was planned to interview patients who were referred to the IDS during a three-week period. The inclusion criteria consisted of being over 18 years, having diabetes mellitus for at least one year and no hospitalization in two weeks before the time of the data collection. The volunteers who fulfilled the inclusion criteria were asked to fill in a form containing their name, age, type of diabetes, type of treatment, duration of the disease, complications, address and telephone number. Out of the total number of 32 volunteers, fifteen were interviewed. Purposeful sampling was used in the study. Sampling included choosing participants from volunteers with various types of diabetes, treatment modes complications, gender and age in order to enrich the categories of data as they developed. The health professionals who participated in this study were selected from staff with at least five years' experience with diabetic patients or those who involved in research on diabetic patients in clinics or universities in Tehran city. There was an announcement in clinics and universities and the volunteers who fulfilled the criteria were invited for interview. The process continued until the data saturation. Nurses, due to their role in creating a caring plan, were key participants in this group and participants from other professional groups were also involved in order to enrich the data variation. After obtaining approval for the research from Tarbiat Modarres University Ethics Committee and also taking the participants' written consent for the interviews and audiotape recording, the first author made an appointment to conduct semi-structured interviews with the participants. The interview meeting was planned at the patients' house or at the IDS building, according to the patients' preference. The interviews in health professional group were done in participants' workplace. The interview questions explored the meaning of caring for participants. The open questions in the patients' group included: "What does care and caring mean to you?" "What are your expectations from nurses?" "What are your expectations from other clinicians, e.g. physicians?" "What is your opinion of the care you are receiving?" "What is your ideal caring situation?" "Can you give an example or recall a situation that involved good or bad caring?" The open questions for those who were in the professional group included: "What does care and caring mean to you?" "What is your opinion on the care for diabetic patients?" "What is your ideal caring situation?" "Can you give an example or recall a situation involving good or bad caring?" The first author conducted the interviews. The interviews were recorded and transcribed into their full length to ensure transparency, and content analysis was used to analyze the data. The interviews and questionnaires were coded using the categories for the different topics that were revealed in the data. The categories subsequently were or-

ganized into core themes describing Patients' and health professionals' views on caring in diabetes disease. Finally, all the interviews and the analyses were reviewed and confirmed by the second author. The analyses were sent to all participants via mail and later on; their views were collected through telephone calls or personal contacts. Based on their feedback, some changes in the categories were made. All the interviews and the analyses were carried out in the Persian language. The quotations and themes in this article were translated into English by the authors. Three additional English language experts confirmed the translations.

4. Results

Fifteen patients, seven females and eight males were interviewed. Thirteen patients had diabetes type 2 and two had diabetes type 1. Eight patients were being treated with insulin injections while seven were being treated with oral anti diabetic drugs. 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). Three patients had End-Stage Renal Disease and were under dialysis; three had severe loss of vision; six had hypertension, and nine reported the signs of neuropathy while six didn't have severe complications. In the health professional group, eleven nurses, three physicians and one dietitian were interviewed. The interviews lasted between 20 to 60 minutes and the average time was 40 minutes. At the end of the analysis process, a total of 150 codes were extracted from the transcripts as open codes, then they were categorized into four main themes that will be presented in our findings.

4.1. What Caring is and What Means to Care

Patients and health professionals discussed caring in different ways. Health professionals usually tried to explain what caring was as a central concept in the health care profession. Patients were more eager to point out what caring meant to them. The following descriptions of caring were made by the health professionals:

"Caring as helping people to cope better with diseases or new situations" (Physician)

"Caring as a god-given power in every human being, from a mother who cares for her baby to nurses who provide care professionally" (Nurse)

"Caring as a dynamic concept which changes through the time" (Nurse)

"Caring as a process of assessment, planning, implementation and evaluation as it exists in the nursing process." (Nurse)

"Caring is in the nature of human beings, when you wash your hands you care for yourself, when you obey driving rules you care for yourself and others so every human being has a nurse inside her or him." (Nurse)

As a response to the question about what caring was,

patients were more focused on trying to express their expectations from the health professionals. They focused on their relationship with nurses and physicians. Respecting patients and families, being friendly and kind, having a helping attitude, talking to patients clearly and listening to them carefully, being patient, having creativity and being skillful were some descriptions of the patients' expectations. "If a nurse forms a trustful relationship with me, I feel she is caring for me, and I will listen to her." (A 37-year-old man with diabetes). "Nurses should be like angels; they should be kind and do their best to help patients." (A 52-year-old woman with diabetes)

4.2. The Obstacles in Providing Care

According to participants, there were some obstacles when providing professional care for people with diabetes. The patients themselves did not seem to expect a great deal from the nurses providing professional care. They did not seem to be aware of the different roles that the nurses could play in their recovery and therefore did not expect more than very basic care. A 54-year-old woman with diabetes said: "I am not ill enough to need a nurse; I can wash myself and move. I don't need caring for." It seems that some patients were not aware of the nurses' professional responsibilities in diabetes care. The patients' awareness/unawareness of the nurses' role in diabetes care meant that they had different expectations about care from the nurses'. Some patients viewed education as something that interfered with their personal lives. A 37-year-old man with diabetes said: "So many people don't feel comfortable when others tell them what to do and what to eat. It is just like that they are interfering with one's personal life." One of the issues that almost all the patients worried about was economic problems. However, only a few health care professionals addressed this issue. A 64-year-old woman with diabetes said: "Diabetes is an expensive disease; you have to buy insulin and injection devices; you have to go to a physician and have tests regularly. All of these require money, and if they provide people with free caring services, then that is good, but if you are expected to pay for it, it is only good for rich people." According to one health professional, some of the obstacles that prevented satisfactory diabetes care were: a poorly functioning professional relationship between nurses and physicians, a lack of time and a lack of competence among nurses to provide community-based care. One nurse said: "Physicians don't believe in nurses' competence and at the best they regard nurses as their hands and eyes, they don't believe that nurses have brains to think with or that they can be creative in caring." Some nurses mentioned low motivation for the task at hand as an obstacle for providing good diabetic care. A nurse said: "Caring is a very individual matter .if you are a good person with great dedication and high motivation, you will be a good nurse and if not you will only carry out the minimum of duties that are expected

of you.” In the interviews, patients were more interested in talking about the obstacles they met with diabetes in their everyday lives while clinicians were more focused on the deficiencies existing within the system of caring and the health system.

4.3. The Outcomes of Caring

The outcomes of caring were widely described in the interviews. According to the participants' descriptions, concepts such as health, quality of life, patients' satisfaction, self-care performance, controlling blood glucose, and family support were some examples of the concepts that were related to the outcomes of care. In the patients' interviews, the concepts of the outcomes were highly considered and reflected upon when compared to the health professionals. Below are some statements: “I have changed my physician several times because I don't feel I am getting better.” (A 52-year-old woman with diabetes). “I was in hospital and they gave me twice drugs but my blood sugar reached 440; I don't know the reason for this.” (A 64-year-old woman with diabetes). “Physicians just pay attention to the results of my blood sugar and when I tell them that I don't feel well, it does not seem to be important to them.” (A 64-year-old woman with diabetes). Health professionals were, however, more interested in talking about the process of caring or the problems they met when trying to provide care. A nurse said: “We don't have enough time at the wards to provide an adequate amount of education, we say things to patients, but we don't know whether they understand it or not.” Although the nurses believed that educating the patients was an important aspect of caring and a part of their duty, they paid less attention to the outcome of this education. Inadequate treatment was another important example that was commonly pointed out in the health professionals' interviews. A physician said: “Physicians have their patients and these patients come and go regularly and both patients and physicians are happy, but when you see the laboratory results you realize that most of patients don't have proper blood-glucose control”. A dietitian said: “We have so many patients coming here and when we see their treatment we discover that they only inject NPH insulin once a day, which cannot control their blood glucose.” In their interviews, the health professionals expressed that their concern was more focused on their everyday work demand, which left little time for reflecting more thoroughly upon the results of their interventions and for each patient. For the patients, it was extremely important that they would spend time with the health professionals if a positive change was to be achieved.

4.4. A Need for Community-Based Care

The participants suggested and agreed that specialistic community-based care was crucial and the most ap-

propriate one for people with diabetes. “Diabetes is a chronic disease and patients may get tired and just neglect their situation, there should be nurses who go to the patients' homes so that they can find tired patients and help them.” (A 45-year-old man with diabetes). “We have patients who come and take drugs and disappear for a long time and later on they come back with severe complications; community-based care can prevent these problems.” (Physician). “When nurses go to visit patients, they can see their real living situation, so they can create a more practical care plan and also, most patients feel more comfortable in their own homes.” (Nurse). Participants expressed their opinions on how they thought that community-based care could function. According to all the participants, providing education for people with diabetes and information on the provision of care was a high-priority issue in an intervention such as this. They emphasized the fact that a lack of knowledge about the disease and its treatment was common among people with diabetes. “For four years, I used to take my pills before I went to bed, and nobody told me that I should have taken them before meals.” (A 64-year-old woman with diabetes). A 55-year-old man who had suffered from diabetes for 25 years did not know that he could keep insulin in room temperature for a period of time and he said: “Carrying insulin packed in ice is very difficult for me; I have to take a thermos with me wherever I go”. According to the participants, structuring a diet plan, regular education and regular follow up were other important elements that they felt ought to be included in specialistic community-based care. The most important factor for all participants was the fact that they needed to follow a diet and all of them described this as a continuous struggle, which ought to be considered in the caring plan. “When I go to my friend's house, it is not pleasant to bring your own food and they serve food very late there, so I prefer to stay at home.” (A 52-year-old woman with diabetes). “I think eating is one of the greatest joys in life, so when you restrict it in any way, it will become difficult for so many people.” (A 45-year-old man with diabetes). Health professionals stated that the patients' diet plans should be clear, practical, and easy to follow. “Some of my colleagues tell patients not to eat rice, potatoes and bread. Since these are our main foods and no one can exclude them, so patients don't listen.” (Physician). “Patients should be given detailed information about the carbohydrate ingredients of different foods so that they can choose between them and eat with fewer limitations” (Dietitian). Other important factors that were referred to as important elements in appropriate diabetes care were the significance of the team-work in caring, encouraging patients to be physically active, strengthening diabetic non-governmental organizations, providing individual care plans for each patient, planning for an increase in motivation among patients and stress management.

5. Discussion

This research showed that there are some differences between patients' and health professionals' views on the subject of caring, while health professionals mostly tended to view care as what it really is, patients considered caring from the viewpoint of what it means to them. Patients had personal views about the obstacles when receiving care but health professionals were more interested in discussing these obstacles as deficiencies that existed in the health system. Regarding the care that was provided, patients were more outcome-centered while the health professionals were more process-centered. Both groups shared the idea that community-based care was crucial in the context of diabetes care. They also expressed the value of education, a diet plan and the importance of physical activity in the care plan. This study revealed that patients believed that the relationship between patients and health professionals was an essential part of caring. This is also strongly supported in literature (13-15). In one study (16), the patients were asked what they considered to be proper caring. From the interviews, the researchers identified eight themes as the characteristics of proper caring. The importance of the relationship between the nurse and the patient was recognizable in five themes as attentiveness, cooperative action, individuality, informal talking and attention. In another study (17) that focused on how diabetic patients with foot ulcers perceived their care; the ideal nurse was described as engaged with the patients and someone who tried to understand their situations. This study also showed that there is the same tendency among nurses to relate the deficiencies to the health care system when explaining dissatisfaction among patients. The risk of such a simplified explanation may prevent health professionals from reflecting more critically upon their own roles in the caring situation and/or to trying to find strategies for problem solving with the available resources. The lack of time is one of the obstacles in providing care (18). In another study, according to nurses, the obstacles for providing good care were an inadequate health budget, a lack of coordination, a lack of time, rapid discharge of patients from wards and a shortage of nursing personnel. At the same time, the patients suggested that the obstacles arise from an unfamiliar caring environment, a feeling of powerlessness in the caring process, and inadequate relationships (19). In our findings, it was indicated that participants considered education and information dissemination as crucial components in diabetic care. Tanakova (20) found that education improved Quality of Life (QOL) and glycemic control. According to a meta-analysis conducted by Norris (21), it has been estimated that per 23.6 hours of education, the glycoside hemoglobin decreased by one percent. This study also pointed out the advantages of continuous care and the presence of community health care nurses during the caring actions. The nurses' presence within the context of caring provided an opportunity for holistic

nursing care (22). If patients don't receive caring that they expect or if they feel that caring doesn't provide the positive outcomes, they might practice the negative behaviors such as self-treatment and self-medication (23). Hirsch (24) believes that the burden of care in diabetes should be taken away from the physicians and moved to the advanced experienced nurses and clinical nurse specialists. This research has focused on patients' views together with nurses' and other health professionals' on the meaning of caring in order to make a contribution to the development of a more holistic concept of care in the context of diabetes care. Our findings may help to provide an understanding of patients and their expectations and viewpoints regarding care. An understanding such as this can motivate planning for patient-centered caring in diabetes care.

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Authors' Contribution

All the authors were responsible for the study conception and design, data analysis and writing the article. Negin Masoudi Alavi conducted the interviews.

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The authors declare that they have no competing interests.

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