Original Article

From Negligence to Perception of Complexities in Adherence to Treatment Process in People with Diabetes: A Grounded Theory Study

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What's Known

• The rate of adherence to treatment in Iranian diabetic patients is shown to be poor, but its cause is not stated.
• The rationale for the process of treatment adherence in patients with gestational diabetes had been described.

What's New

• Main reasons for poor treatment adherence are the lack of serious symptoms at disease initiation, age requirements (resistance to change), cultural habits, and religious beliefs (divine determinism)
• Main strategies to help such patients are positive treatment feedbacks, proper training in early disease detection, visual warnings, and peers helping.

Abstract

Background: Poor adherence of patients with type 2 diabetes to treatment is one of the most complex and important clinical concerns. It is the main issue of the present decade and acknowledged as a challenge to control and treat diabetes. This study was carried out to explore and understand how adherence to treatment process occurs among Iranian patients with type 2 diabetes.

Methods: The present study is qualitative with grounded theory approach. The data were collected from December 2015 to July 2016 in Tehran (Iran) through individual semi-structured in-depth interviews, field notes, and memos from 21 patients with type 2 diabetes; combined with two members of their families and a healthcare professional. The data were analyzed based on Corbin and Strauss constant comparative analysis (2008).

Results: Adherence to treatment is a transitional, interactive, and continuous process. For patients with diabetes, this process includes unperceived threat in diagnosis time (poor knowledge and skills, bottleneck of dependencies, superficial understanding of the new situation), bitter belief (downhill quality of life, physical and emotional treatment feedbacks), and adaptation to treatment (self-care dominance, regimen integration in daily activities). The process of adherence to treatment was influenced by knowledge and skill, social support, beliefs and values, psychological characteristics of people, and the nature of diabetes.

Conclusion: Adherence to treatment in Iranian people with diabetes depends on the family and social context, which is challenging for the patient and leads to the negligence of health behaviors. It is vital for healthcare providers to identify these factors to encourage patients to adhere and commit to treatment in order to prevent irreversible complications of diabetes.

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Introduction

Diabetes is one of the most common and important metabolic disorders in the world and it is one of the major causes of death in most communities.[1] The influence of diabetes is multidimensional

and its influence on daily life, occupation, and social relationship shows a justifiable disorder in the quality of life.[2] Diabetes largely affects the quality of life of the patients due to the cardiovascular complication, retinopathy, nephropathy, neuropathy, psychological, and behavioral side effects. Therefore, diabetes treatment needs permanent and regular changes in patients' life, such as changing diet, regular dependency to medicine, controlling the short-term or long-term side effect, and bearing the costs.[3] Considering the importance of permanent care in diabetes, one of the main concerns and clinical issues that often healthcare providers are facing is the non-adherence of patients to the prescribed treatment.[4] Poor adherence to the prescribed treatment is one of the causes of treatment failure, increased disease side effects, prolonged treatment time, and higher healthcare costs.[5,6] The importance of adherence to treatment is to the extent that if a patient does not adhere to the recommendations of healthcare providers, even the best treatment regimens could be valueless and endanger the patient's health and quality of life.[7] In other words, chronic diseases such as diabetes largely depend on the extent of patient's adherence to treatment.[8] However, according to WHO reports, the extent of adherence to treatment in patients with chronic illness is about 50% in the developed countries and to a lesser extent in the developing countries.[5,9]

Recognition of the experience and perception of this group of patients regarding adherence to treatment could lead to the identification of a specific treatment adherence process and self-care in such people. It also helps healthcare providers to facilitate treatment adherence and enhance patient's quality of life. Considering the particularity of the Iranian culture and background as well as the lack of research in the field of adherence to treatment in patients with type 2 diabetes in Iran, the present research was performed to explore and understand how treatment adherence process occurs among Iranian patients with type 2 diabetes.

Patients and Methods

A qualitative methodology using grounded theory was used to conduct the present study since the adherence phenomenon is complex, multidimensional, and interactive. Furthermore, to some extent, it is personal and influenced by social and cultural context and different factors.[10] The present study was performed in December 2015 to July 2016 in Tehran, Iran. Purposive sampling was used and patients with type 2 diabetes who were able to share their life experiences related to diabetes were selected as the main participants. The collected data forced researchers to continue sampling by the theoretical sampling method such as grounded theories. Therefore, the subsequent participants were selected from diabetics with different courses of diabetes, age, family history, adherence, career, and education; combined with two family members and one member of the treatment team. Interviews were conducted in locations such as endocrinology ward of hospitals, diabetes association, doctor's office, clinics, or diabetic patient's residence.

Data were collected by semi-structured interviews using open questions such as "talk about your disease and treatment" and gradually pitched up to specific subjects. The interviews were recorded and transcribed verbatim immediately and analyzed. The duration of interviews ranged from 40 to 120 minutes. In addition, the use of field notes and memos for the elaboration of the data was performed.

Data analysis was performed using constant comparative analysis (Corbin and Strauss; 2008) and consisted of four stages, namely analyzing data for concepts, analyzing data for context, bringing a process into the analysis, and integrating categories.[11] In the first stage, data analysis was focused on preparing data concepts. Data collection and data analysis occurred concurrently and the researcher began the analysis by coding. The recorded interviews were transcribed and reviewed carefully several times. The researcher reviewed the data line by line, examined the main sentences and concepts of each line or paragraph, and assigned a code to it. Coding was done using participants' or researcher's wording. Then, based on similar properties and dimensions of the codes, they were put together to develop categories (concepts). In the second stage, the classification of data was continued until the researcher was able to identify conditions and problems that had an impact on participants (context). In the third stage, the researcher used continuous comparison to define the relationship between categories and search the underlying process in the data. Categories were linked to each other and the main themes were identified. Both memos and the constant comparative method were useful in all stages of the analytic process.

In order to determine rigor and trustworthiness, based on Corbin and Strauss (2008) criteria, fitness of the findings was reviewed and evaluated by the research team. Additionally, some participants were asked to

review the findings to ensure consistency with their perception. A peer researcher, familiar with qualitative research, was asked to evaluate the logical procedure of findings. In cases where the findings were not confirmed, the concepts and the findings were reviewed again. The research team aimed at enriching the study by addressing descriptive details of how patients with type 2 diabetes adhered to treatment, providing in-depth findings, determining complexities of the studied phenomenon meticulously, and exploring various aspects of the data.

This study was authorized by the Research Ethics Committee of Shahid Beheshti University of Medical Sciences (Tehran, Iran). The objectives and methods used in the study were explained to all participants. The participants were ensured about confidentiality and anonymity. Moreover, the participants were ensured that their participation was voluntary and they could withdraw at any stage of the study. Time and place of interviews were determined in agreement with the participants according to their preference.

Results

Data were collected from 21 men and women (aged 36-67 years) with diabetes diagnosed since 2-16 years, together with two members of their families (one wife and one daughter) and a health professional (endocrinologist).

Adherence to diabetes treatment is a continued development from negligence to perception of complexities. During this process, patients try to achieve a relatively normal life, but feel that they have been caught between the efforts to achieve therapeutic goals and their dependency on old habits. Dependency on unhealthy habits and false beliefs was the main problem of people with diabetes that could be eliminated through adherence to treatment. Adherence to treatment is a lifelong process for achieving a new lifestyle consistent with treatment goals and integrating treatment with daily life.

The findings deduced from the perception of patients regarding adherence to treatment were classified in three main themes:

- Unperceived threat (poor knowledge and skills, bottleneck of dependencies, superficial understanding of the new situation)
- Bitter belief (downhill quality of life, physical and emotional treatment feedbacks)
- Adaptation to treatment (self-care dominance, regimen integration in daily activities

Unperceived Threat

In this study, unperceived threat (i.e. negligence) describes the factors and conditions that influence patient outcomes and adherence to treatment; leading to the behavioral reaction of patients. Although people with diabetes are aware of their disease, they do not consider it as a serious health threat, do not accept it as an illness, and ignore self-care. Patients with poor knowledge and skill regarding the disease and health behaviors were challenged with unrealistic beliefs. They were dependent on bad habits and unhealthy lifestyle. These factors influence adherence to treatment in the cultural and social context of Iran.

Poor Knowledge and Skill

The patients repeatedly noted that they had poor knowledge of their disease at the time of diagnosis. A 36-year-old woman stated, "*As a matter of fact, I do not know what the disease is. The doctor said that I am diabetic. He said that I should not eat specific foods. He prescribed medications and mentioned that I should visit again in three months* (P_{12})." Moreover, patients noted that they do not have the required skill and experience to manage diabetes under different circumstances. A 47-year-old man stated, "*I ate diet food at home and everything was under control. However, I had to quit the diet when I went to work or parties due to the unavailability of diet food. The food on the table was greasy and sweet and I did not know what to do. Everyone told me to eat that food only for this time; which I did. But then, my blood sugar rose* (P_{13})."

Bottleneck of Dependencies

A diabetic is trapped in unrealistic beliefs regarding diabetes. These beliefs, which depend on family and social backgrounds, challenge the patients and make it difficult to adhere to treatment. A 44-year-old woman stated, "*My doctor told me that I have to inject insulin. However, I will not accept it as long as possible. I feel insulin injection is a nightmare, it is too extreme, and I am disappointed* (P_{10})." Moreover, unhealthy lifestyle and dependence on bad habits lead to negligence of proper health behaviors. A 52-year-old man stated, "*I used to eat everything, I never had a regimen, I did not exercise as I had no time for it. I was always distressed, overweight, and obese* (P_2)."

Superficial Understanding of the New Situation

Participants claimed that the lack of a correct understanding of the new situation and denial of illness at the time of diagnosis led them to neglect the treatment. A 58-year-old man stated,

"When I found out about my disease, I was made aware of the treatment. I did not realize what was happening to me and it was all new. Then I ignored my treatment and my health condition (P₁)." A 49-year-old man stated, *"Except for some minor health problems, in general, I felt that I was healthy. Thus, I did not consider myself as a patient (P₇)."* A member of the treatment team (endocrinologist) also noted, *"Patients would not choose to adhere to treatment as long as they are not distressed (P₁₇)."*

Bitter Belief

In making the efforts to control the disease and adhere to treatment, all patients come to the belief that the new situation would threaten their health and influence their lives. In fact, gradual exposure to outcomes, reaction of the body to disease control, and interaction with the body lead patients to grow with the course of the disease, understand its complexities, and recognize the need to adhere to treatment.

Downhill Quality of Life

Participants claimed that they noticed drastic health change when they did not control their disease. This followed by hospitalization, prolonged treatment, additional financial burden, exhaustion, dissatisfaction, and even limited their professional capabilities. These conditions declined their quality of life in all aspects. A 40-year-old man mentioned, *"I was hospitalized several times and I felt uncomfortable in the hospital. I could not work and had no income for which I blamed myself for not controlling my illness (P₁₁)."* The spouse of one of the patients stated, *"In addition to financial problems, our lives became disastrous. When he was hospitalized, the whole family was on the edge (P₁₆)."*

Emotional and Physical Feedbacks

The patients become aware of the advantages and effects of treatment by receiving positive feedbacks through laboratory results, body reaction to parameters such as reduced glycosylated hemoglobin, reduced blood cholesterol, weight loss, and reduced frequency of shock. Such positive feedbacks would encourage them to adhere to treatment. A 46-year-old woman stated, *"Since I check my blood sugar at home, I do not get a shock anymore. I used to get shocks several times in the past (P₃)."* Moreover, they realize that the new situation can threaten their health and influence their lives by receiving negative feedbacks. These feedbacks are alarming to patients as they realize the need for disease

control. A 55-year-old man stated, *"I had foot ulcers and doctors had to amputate my leg. I was distressed until doctors told me that amputation was not necessary. Thank God, I did not lose my leg. I blamed diabetes for this and should not have ignored it (P₈)."*

Adaptation to Treatment

Adaptation to treatment refers to the need for the management of requirements related to disease and continuous follow-up of treatment by patients. Patients can use proper problem-solving techniques to eliminate their problems. Moreover, self-care activities to improve their health are performed independently by the patients.

Self-Care Dominance

The ability to control the condition and independent self-care are realized through personal knowledge and experience, efforts of the patients to acquire skill as well as family and social support. This can increase self-confidence, life expectancy, and self-efficacy of the patients. A 47-year-old woman stated, *"One would not face problems if the consumed carbohydrate is counted. At a party, work, or restaurant you know how much you have eaten and how much you can eat. Based on this, you can choose your food (P₆)."* A 38-year-old man noted, *"I check my fasting blood sugar every morning and late at night as I know how important these periods of the day are. In doing so, my blood sugar level does not drop during sleep or elevate during the day (P₉)."*

Regimen Integration in Daily Activities

This refers to full adaptation to treatment. Only some patients can integrate their treatment with daily activities. By using the acquired knowledge and experience as well as continuous interaction with healthcare providers, patients can use health behaviors on a routine basis without objection. A 50-year-old woman stated, *"I never stop taking my medications; I take them as a lifestyle similar to other daily duties. They are a part of my life and I take them routinely without thinking about it (P₄)."* Moreover, internalization of health behaviors helps the patients to believe that they do not need encouragement or supervision of others on health behaviors and do not need to view it as an obligation. A 63-year-old man mentioned, *"I regulated my life based on changes that I made due to my disease. I know almost everything that is required for my treatment. I get distressed if I miss a session. However, I feel relaxed when I do everything correctly. I cannot quit my diet*

even for one night. It is not hard for me to resist temptations. I prefer to have my routine (P$_{21}$)."

Discussion

The three-stage process (unperceived threat, bitter belief, and adaptation to treatment) does not mean that all people experience these stages and the process necessarily ends with adaptation to treatment. Instead, most people are continually wandering between these three stages. Meleis believes that considering any changes in patient's health condition, the patient passes stages in order to pass this change and tries to keep his stability. The patient knows this stage as a pathway between two stable stages, which its steps are integrated.[12] Some researchers believe that the steps and the stages, due to their dynamic nature, are constantly changing and they include fluctuations and movements backward and forward.[13,14] In a study, Kneck et al. explained that patients, after involving with diabetes, pass through stages in order to keep their health, which includes initial stage, experience stage, and integration stage. In the initial stage, the patient follows the advice of the healthcare team member without any question due to feeling insecure and suspension of disbelief. In the experience stage, the patient tries to have an active role in the process of treatment and also tries to find ways to improve his/her health condition. In the integration stage, which is the final stage, the patient accepts the disease and is able to set his/her life program according to the new conditions.[15]

In the present study, the participants demonstrated that they had no realization of the threat when dealing with the disease. Therefore, accepting the role of a patient and the treatment was unacceptable to them. Their poor knowledge of the disease and health misperceptions was the reason for such reactions. Williams et al. mentioned that patients repeatedly doubt about what happens to their health due to their physically complex condition. Becoming aware of their physical condition can persuade them to accept the treatment to upkeep their health.[16] Some patients neglect or overlook the disease as if their disease has no signs, is tolerable, or even prefer to continue with their usual social activities (e.g. job).[17] The findings of the present research show that the process of adherence take place at the time that a patient feels threatened. The fear leads to motivation and subsequently to awareness towards accepting medical recommendations.

Heydari and Vaghee believe that a person's perception of the threat affects adherence to treatment.[18] Many studies have shown that misunderstanding and lack of knowledge about treatment and the disease side effects are the basis for poor adherence to treatment.[19,20] Lewis and Newell showed that the practice of healthcare system and failure to provide adequate information and quality care to patients, as the context and factor affecting adherence to treatment, especially in developing countries is a common phenomenon.[21] While, according to many studies, patients need and want to gain health information and to learn self-care skills.[22-27] Therefore, educating patients and their family members, through free and available programs in health centers, before involvement with the disease complication can develop a positive view of the treatment, suitable response to the disease, and would develop changes in the lifestyle of people.

Poor attention to self-care and treatment finally led patients to a bitter belief that diabetes can seriously threaten their health and affect their lives, including involvement with the side effects of the disease, difficulties of frequent hospitalization, disorders in the life course of the patient and his/her family, and physical and mental problems. Nair et al. also explained that many of diabetics do not have a clear understanding of the disease risks and advantages of treatment in the initial encounter with the disease for correct decision making. It seems that they will be aware of the advantages of treatment and the risks of poor attention to treatment while they experience the side effects and limitations caused by the disease in their lives.[28] In a study by Ghafari et al., the patients also experienced feelings such as anger toward themselves, hospital staff and their family, fear from the future of the disease, frustration and stress due to expenses, and being far from family, work, and daily activities.[29] Tewahido and Berhane pointed that many patients experience lack of control and vulnerability and thus they will be dependent on hospital staff and others to do their daily activities, which cause them to try to gain their independence and control their lives.[30] There are many ways to prevent frequent hospitalization of these patients, follow-up treatment, regular visits to a practitioner, and increase the availability of healthcare services in all districts and regions. If these factors are strengthened in such patients and in the Iranian society, it could decrease hospitalization and side effects of the disease.

In the present study, some of the diabetic patients established optimum interaction with their body through positive physical and implicit feedbacks. They understood the advantages

of treatment and its effects on their body and thus acquired the ability of self-regulation. In comparison with other studies, this is a new finding of the present study. In other studies, in the course of dealing with the disease, patients had experienced the understanding of the disease threat and treatment adherence through negative physical feedbacks.[31,32] Of course, this process is unconscious, which requires continuous collaboration with the healthcare system in order to access the medical information and make a correct decision.

Based on the findings of the present study, adherence to treatment is experienced just by some patients. In this stage, the self-care activities are done independently by the patient in order to improve health, which, according to the participants' statements this ability was acquired through knowledge, personal experiences, and the person's attempt to cope with the present condition. Then, by mastering self-care behaviors, they increased self-confidence, life expectancy, and self-efficacy in order to cope with their challenging duties. On this topic, Rostami et al. stated that empowering patients with chronic disease in disease management could result in life satisfaction and enjoying a normal life.[33] Evidently, self-management takes place in social context and interpersonal interactions. The present study, using qualitative approach, attempted to discover psychosocial processes and clearly justified diabetics' interactions, perceptions, and lifestyle. Patient's knowledge and awareness of the disease and their attempt in self-care, in addition to right beliefs and perceptions about the disease, treatment, and social support can lead to diabetes self-management.

The absence of multiple data collection methods, which is limited to patients' interviews, was the limitation of the present study. However, extensive involvement of researchers with patients with diabetes, to some extent, minimized the effect of this limitation.

Conclusion

This study noted an important part of healthcare. Poor adherence to treatment is a major public health problem. It can be helpful to understand why patients with diabetes do not adhere to their treatment; how they think and feel about social and cultural contexts; how they can change their beliefs and attitudes and act differently by developing thoughts and interacting with others. The findings of the present study can be used to design inclusive programs for empowering patients with diabetes and promoting adherence

to treatment. In addition, the study identified different aspects for future research, such as curriculum development for diabetes, nurse education, and exploring the process of treatment adherence in other chronic diseases.

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