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# Lived Experiences of Type 2 Diabetes with Irreversible Complications: A Qualitative Research

Mohammadreza Firouzkouhi[1], Abdolghani Abdollahimohammad[1*]

[1]Ph.D. in Nursing, Associate Professor, Faculty of Nursing & Midwifery, Zabol University of Medical Sciences, Zabol, Iran.

## Abstract

**Objective:** Diabetes is a major health concern worldwide. Diabetic patients experience many issues that affect their lives. Poor self-care and compliance in type 2 diabetes mellitus (T2DM) patients cause chronic hyperglycemia and irreversible complications. The study aimed to explore the lived experiences of T2DM patients with irreversible complications.

**Materials and Methods:** The qualitative phenomenology study was conducted through a semi-structured interview. The collected data were analyzed using Braun and Clarke framework for thematic analysis. Participants included 15 T2DM with irreversible complications who were selected to conduct the study through purposive sampling in Zabol, Iran.

**Results:** Research findings were classified into three main themes "past negligence, future threat", "suffering from disastrous complications" and "complicated life with diabetes". Some of the sub-themes were as follows: being sorry for previous unhealthy behaviors, fearing the future with the disease, successive challenges of the disease, losing the importance of life, poverty, losing family and social communications, gradual involvement of body organs, and life and death.

**Conclusion:** Patients with no self-confidence are defeated by the disease and have no control over the conditions in different dimensions of life, considering the irreversible diabetes complications. Besides, patients need the support and attention of care providers and families to take the health-related behaviors, embrace the disease condition and move toward dominating the present situation.

**Keywords**: Diabetes mellitus, Type 2 diabetes, Qualitative research, Complication

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**Corresponding Author:**

**Abdolghani Abdollahimohammad,** Ph.D. in Nursing, Associate Professor, Faculty of Nursing & Midwifery, Zabol University of Medical Sciences, Zabol, Iran.
**Tel:** (98) 543 222 4101
**Email:** abdalqani@gmail.com
**Orcid ID:** 0000-0002-7929-5539

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## Introduction

Diabetes is a major health concern worldwide (1). The International Diabetes Federation (IDF) Diabetes Atlas 2017 estimated that 425 million people around the world, or 8.8% of adults aged 20-79 years, have diabetes and it will be 629 million by 2045. About 79% of them live in low and middle-income countries (2). Nowadays, the spread of Type 2 diabetes mellitus (T2DM) is 7.7% in Iran, and WHO has estimated that this amount will be 8.6% in 2025 (3). A study in 2015-2016 showed that 85.5% of patients had type 2 diabetes and the majority had uncontrolled hyperglycemia, hyperlipidemia, and hypertension. The ratios of retinopathy (21.9%), nephropathy (17.6%), peripheral neuropathy (28.0%), diabetic foot (6.2%), and ischemic heart disease (23.9%) were common among them (5).

The costs of treatment have also increased in the world. In the US, the estimated cost of diagnosed diabetes was 327 billion dollars in 2017 and 237 billion of it was related to direct medical costs. Most of the health budget is allocated to treating diabetes and its complications in developing countries (6,7).

Poor control and care cause hyperglycemia and many chronic complications (8). People with diabetes and a body mass index (BMI) higher than normal are at the risk of secondary complications of diabetes (3). Diabetes affects all dimensions of life (9). Most patients have reported short- and long-term disease complications (10). Studies (11,12) reported psychological disorders such as depression and diabetes complications.

Considering the high prevalence of diabetes, and poor care levels, its side effects are increasing in Iran and around the world. Individuals have different perspectives about diabetes complications in different areas of Iran, like in other developing countries as well as health and cultural conditions. The Qualitative research methods are appropriate for subjects related to the human nature of their social behaviors and interactions. Besides, qualitative research develops insight into individual behaviors, lifestyles, attitudes, feelings, ideas, values, and experiences (13). We aimed to explore the lived experiences of T2DM patients with irreversible complications. It aimed the answering following research question: What are the experiences of diabetes with irreversible complications?

## Materials and Methods

This qualitative study used the descriptive phenomenology approach to examine the participants' experiences of irreversible complications.

A purposive sample was provided from Zabol, Iran in 2020 on diabetes patients and consisted of people aged 45–85 years who could and wanted to talk about their diabetes and irreversible complications of diabetes and to enable a researcher to visit them in their homes. The participants were 3 women and 12 men, all living in their houses with families. The individual interview was performed after obtaining informed consent from each participant. The length of time with diabetes ranged from 5 to 29 years. Ten participants had been diagnosed over the past 20 years, and five were diagnosed less than past 10 years. All had visible evidence of diabetes-related complications, and all had more than one chronic condition in addition to diabetes with heart complications (46.6%), renal failure (26.6%), foot amputation (26.8%) and retinopathy (26.8%).

Data was collected using semi-structured face-to-face interviews. The participants were asked open-ended questions to examine the individual effect of diabetes complications and living with the condition. Fifteen participants were interviewed, and the discussions continued until data saturation. Participants had no specific directions, thus, they could freely discuss any perceived experience representing their diabetes, and care with irreversible complication issues.



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Participants were asked to talk about their irreversible complications first, and then we began with the prompt: 'Please tell me how is it for you to live with diabetes complications. They should talk about the factors that caused this situation for them. Comments and questions were followed-up with some questions such as 'Tell me more about that' and 'Tell me what that is like' to clarify the discussions.

A digital recorder was used to tape each interview and the recordings were transcribed verbatim. Data collection and analysis were conducted concurrently for each interview. The interviews lasted 30–45 minutes.

### Data analysis

Braun and Clark (2006) described a framework for the thematic analysis (14).
The six phases include (1) familiarizing with data; (2) providing the initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) providing the report. In the first phase, the researchers read and re-read all responses to be immersed in the data. In the second phase, we coded data inductively using first cycle coding methods that were elemental and effective methods, which are included in software coding. We made subsequent refinements to codes through discussion. We moved to the second cycle of coding to progress to the third and fourth phases to organize the data into themes by examining the coded data and involving extensive discussion. Themes and supporting quotes were circulated to the team for further interrogation and critical reflection to move from the fourth phase to the fifth phase. The sixth phase finished with the written manuscript.

## Ethical considerations

Trustworthiness of the data was maintained using criteria outlined by Lincoln and Guba (15): Credibility (long-term involvement in the interview process and control of information obtained by non-participants and outside experts), dependability (using two auditors and three members of the audit team), confirmability (rich and deep description of the study process), and transferability (Rich and deep description of the data).

The Zabol University of Medical Sciences ethics committee (Code Num: Zbmu.1.REC. 1396.121) confirmed this study.

## Results

The results were classified into three themes including "past negligence, future threat", "suffering from disastrous complications", and "complicated life with diabetes" indicating the concept of irreversible complications in diabetes patients.

### Past negligence, future threat

This theme consists of the following subthemes: being sorry for previous unhealthy behaviors, negligence at young ages and sensitivity in adulthood, paying no attention to sympathetic people, fearing the future with the disease, and successive challenges of the disease.

Most of the patients with diabetes talked about not properly observing, exercising, controlling their weight, and unhealthy life in adolescence and before the onset of the disease. They believed that adulthood reflects adolescence and they were careless in that period of life. They think about exercise, diet, and sensitivity to different life problems in adulthood which is now late. The patients did not pay attention to the others' recommendations for better health behaviors and they feel regret now. An important point in the patients which made their minds busy is how they will face the side effects of the disease in the future. Because when they suffer from the disease, a new problem or challenge occurs.

[M]y kids read some topics about diabetes. They insisted that I observe some issues but I paid no attention. Now, I'm observing the result… (Participant 10).

Every morning you have a new feeling that an organ in the body has a problem. You suffer increase blood glucose or lipid or



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hypertension… hands and feet tingling, feet ache… well, these are new challenges… (Participant 13).

## Suffering from disastrous complications

This theme consists of the following subthemes, including gradual involvement, involvement of sensitive organs secretly, alarms in the body in a moment, and finally a painful death.

Patients stated that their fate is suffering from painful complications. After suffering from diabetes, they attempted to lose weight and control their diet as the doctor recommended. The patient faced physical weakness. Sensitive organs like the eye, kidney, nerves, and feet were involved, resulting in changes in visual acuity, hemodialysis, amputation of lower limbs, and other problems that the patients gradually felt.

When I look at myself, I have changed each year that has passed such that I have lost all my teeth, I'm very thin and weak, and even my friends don't identify me when they saw me… diabetes weakens humans… (Participant 7).

I think it passed very soon. I lost my kidneys. It was very strange for me. Now I cannot live without hemodialysis. Now all my life is in hospital…may God help me…I fear how I will die…it is very horrible… (Participant 14.)

## Complicated life with diabetes

This theme consists of subthemes, including losing the importance of life, spending all time visiting the doctors and hospitals, creating problems for others, diabetes with economic poverty and becoming retired and losing family and social communications.

Patients with diabetes have many difficulties in everyday life. The physical and mental problems, consuming many medicines, controlling the diet, and other cases have made life difficult and unimportant. They often visited the doctor and are hospitalized, such that the hospital has become the main living place for some patients. Repeated hospitalizations, high treatment costs, inability to provide healthy foods due to economic problems, and inadequate allowance have caused them to reduce their communication with family and friends and to have an isolated life with no enjoyment.

I cannot control my blood sugar. I took medicine at the start but even though I use insulin, my blood sugar wasn't controlled well and I lost my feet. The whole life of our diabetes people is spent on visiting doctors and hospitals. We can do nothing…it is our destiny. (Participant 9)

Sometimes my old friends say: come to go for recreation, but I have no feeling to go. It is like you sit here and wait for death and cannot change anything. The doctors add more medicines which destroy the spirits and have bad effects… (Participant 2)

## Discussion

This study aimed to explore the lived experiences of T2DM patients with irreversible complications. The results show three themes, including "past negligence,

**Table 1. Study results based on themes and sub-themes**

| Sub-themes | Themes |
|---|---|
| "Being sorry for previous unhealthy" | |
| "Behaviors negligence in young ages and sensitivity in the adulthood" | |
| "Paying no attention to the sympathetic people" | Past negligence, future threat |
| "Fearing the future with disease" | |
| "Successive challenges of the disease" | |
| "Gradual involvement" | |
| "Involvement of sensitive organs secretly alarms in the body in a moment" | Suffering from disastrous complications |
| "Painful death" | |
| "Losing the importance of life" | |
| "Spending all-time visiting the doctors and hospitals" | |
| "Creating problems for others" | Complicated life with diabetes |
| "Diabetes with economic poverty and becoming retired" | |
| "Losing family and social communications" | |



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future threat" suffering from disastrous complications" and "complicated life with diabetes".

## Past negligence, future threat

Patients considered the future a threat to them and were regretful for the past and conditions in which they were neglected. In this regard, the study results showed that some diseases are controllable by preventing and observing the health issues in adolescence. People who suffer a disease think about the past, but it is late. Some problems occur after the disease and the disease becomes chronic. Young age is a suitable period for preventing some diseases (16). Diabetes patients have a threatening future by considering the side effects of the disease. Patients have different challenges that change their health, behavior, and feelings about life. The multidimensional threat of diabetes affects life, work, and relationship with others. People's actions like changing diet prevent permanent and regular changes in life (17,18).

## Complicated life with diabetes

The emergence of the complications is related to the fact that the patient does not manage the disease. Gradually, diabetes complications affect physical function, development of symptoms, mental condition, and communication. Patients' lack of self-care cause complications that result in losing kidneys, eyes, feet, and finally entire life.

The results of the studies showed that one of the critical issues in diabetes patients is the chronic and dangerous nature of the disease that its side effects have high costs annually for the individual and their families. Diabetes, like other chronic diseases, has high individual, family, social and financial problems and high mortality. It also has reverse and significant effects on all dimensions of patients' quality of life due to affecting most body organs. Permanent involvement with the disease and the limitations of diabetes leads to a negative feeling, which makes them dissatisfied with life, and as a result, reduces the quality of an individual life. In addition to the chronic nature, boring treatments, and debilitating and threatening effects, diabetes affects the physical, mental and social dimensions of life, or in other words, the quality of an individual's life (19,20). Developing the complications of diabetes is very important. These effects are diagnosed late because of the patient's conditions and inattention and create problems that threaten his life (21).

Diabetes of chronic nature affects the patient's life. Isolating the patient due to the disease destroys the life importance, work, communication with relatives, and enjoying life. Many factors complicate the life of diabetes patients such as aging, treatments, mental changes, increasing individual, family social, and financial problems, the negative feeling and dissatisfaction with life (22). In addition, the results of a study showed that the complex life of diabetic patients is according to managing the disease, access to healthcare, emotional burden, and social support (23). The results of another study showed that the higher age of the diabetes patients and the progress of complications cause to provide defects in the function, sight, and lower limbs which complicate the life of patients (24). Being retired is another factor that complicates health and life. Retired persons encounter financial and social problems which increase the risks. Contrary to this, patients who suffer the chronic disease before being retired experience worse conditions later. Besides, factors like fatigue, impatience, financial problems, inattention to the physical condition, and appearance affect health. Not enjoying the retiring period results in meaningless life and indifference toward life and relatives and even early death which is consistent with our results (25).

One of the strengths of this study was the interview with diabetes patients who had complications in different aspects of life. A weakness of the study was that some patients do not like to interview and express their problems and even some of them felt thirsty



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after 10 minutes of the beginning of the interviews and they wanted to end the interviews as soon as possible. This forces the researcher to use fewer questions. Some interviews that were done in the hospital were in a busy situation which disturbs the patient's focus.

## Conclusions

This study showed some problems of T2DM patients in the themes and sub-themes extracted from the interviews. The patients have many problems in different dimensions of being informed of disease, treatment, medicines, and family, social and economic support. The treatment and support groups should fulfill their tasks towards the patients with more care to reduce their mental problems and increase their self-confidence and success in the treatment, prevent complications, and increase the longevity of patients.

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## Conflict of Interest

No known conflict of interest exists for any of the authors associated with this paper.

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