

## Perceptions of Type 2 Diabetes Patients for Starting Insulin: A Qualitative Content Analysis

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### ABSTRACT

**Aim:** Examining perceptions about insulin may provide a deeper understanding of initiation to insulin therapy and guide healthcare professionals to develop suitable strategies to increase patient adherence. This study aimed to deeply elucidate perspectives of Turkish insulin-naive type 2 diabetes patients who were recently scheduled to receive insulin therapy.

**Material and Methods:** A descriptive qualitative study design was utilized. The patient questionnaire and interview guide were used for data collection. Individual face-to-face interviews were performed (n=14). Mean, standard deviation, and percentages were utilized to define sample characteristics. A qualitative content analysis approach was employed to identify the key themes. Consolidated criteria for reporting qualitative research checklist were used as a guideline to report the study.

**Results:** The mean age of the participants was 51.71 ± 9.78 years. Most participants were male (71.43%). The mean duration from diabetes diagnosis was 8.02 ± 5.06 years. The emerged themes included (i) facing the reality of insulin, (ii) attributions to dependence on insulin therapy, (iii) coming changes with the insulin in all aspects of life, and (iv) positive consequences of insulin.

**Conclusion:** Patients had heavily negative perceptions regarding insulin and stated significant worries related to working and sexual life changes. On the other hand, starting insulin triggered patients to act for maintaining life in a healthier, better, and safer way. Investigating the expectations of patients with type 2 diabetes from health care providers at the beginning of insulin therapy is needed to better manage all aspects of the treatment process.

**Keywords:** Insulin, Type 2 diabetes mellitus, Qualitative research, Content analysis, Nursing

## Tip 2 Diyabetli Hastaların İnsülin Tedavisine Başlamaya Yönelik Algıları: Nitel İçerik Analizi

### ÖZ

**Amaç:** İnsülin tedavisine başlama konusunda hastaların algılarını incelemek sağlık profesyonellerine daha derin bir anlayış sağlayabilir ve hastaların tedaviye uyumunu artırmak için uygun stratejilerin geliştirilmesinde rehberlik edebilir. Bu çalışma, insülin tedavisine başlama kararı verilen, daha önce hiç insülin tedavisi almamış tip 2 diyabet hastalarının insüline yönelik bakış açılarını derinlemesine incelemek amacıyla yapılmıştır.

**Gereç ve Yöntemler:** Bu çalışmada tanımlayıcı nitel araştırma tasarımı kullanıldı. Verilerin toplanmasında hasta soru formu ve görüşme formu kullanıldı. Yüz-yüze derinlemesine bireysel görüşmeler yapılarak araştırma verileri toplandı (n=14). Araştırma örnekleminin özelliklerini tanımlamak için ortalama, standart sapma ve frekans dağılımı kullanıldı. Ana temaları belirlemek için nitel içerik analizi yaklaşımı kullanıldı. Araştırmanın raporlanmasında nitel araştırmalar için birleştirilmiş kriterler kontrol listesi kullanıldı.

**Bulgular:** Katılımcıların yaş ortalaması 51,71±9,78 yıl idi. Hastaların çoğunluğu (%74,3) erkekti. Diyabet tanı alma yılı ortalaması 8,02 ± 5,06 yıl idi. Araştırmada (i) insülin gerçeğiyle yüzleşmek, (ii) insülin tedavisine bağımlı hale gelme (iii) insülin ile birlikte yaşamın her yönüyle değişmesi ve (iv) insülinin olumlu etkileri şeklinde dört ana tema belirlendi.

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**Sonuç:** Hastaların çoğunluğu insüline yönelik olumsuz algılara sahipti ve özellikle çalışma hayatı ve cinsel yaşamla ilgili önemli endişeler dile getirdiler. Diğer taraftan insülin tedavisine başlamanın, hastaları yaşamlarını daha sağlıklı ve daha güvenli bir şekilde sürdürme konusunda harekete geçirdiği belirlendi. İnsülin tedavisinin başlangıcında tip 2 diyabetli hastaların sağlık profesyonellerinden beklentilerinin araştırılması, tedavi sürecinin tüm yönleriyle daha iyi yönetilebilmesi için gereklidir.

**Anahtar Sözcükler:** İnsülin, Tip 2 diyabet, Nitel araştırma, İçerik analizi, Hemşirelik

## INTRODUCTION

Insulin therapy is an essential part of diabetes treatment and is initiated in type 2 diabetes (T2DM) to provide better glycemic control. Several trials have reported that early initiation of insulin therapy may help treat T2DM patients by achieving better glycemic control, preserving beta cell function, improving endogenous insulin secretion, and delaying disease-related complications (1,2). However, despite the benefits of insulin, many patients do not believe in the advantages of insulin therapy in improving glycemic control and health status (3-5).

Patients are often reluctant to insulin therapy at the beginning of the treatment due to a complex set of beliefs and misconceptions about the insulin, fear of self-injections and complications related to insulin therapy, loss of control over one's life, and social stigma associated with insulin therapy (6-8). Various factors may be influential on perspective about insulin therapy including age, gender, education status, social roles, self-perceived body image, co-morbid conditions, previous hospitalization history, presence of diabetes complications (9-12). Besides, familial, social, and cultural contexts, the structural organization of the health system may affect individuals' beliefs and attitudes (13,14). Therefore, assessing perceptions and expectations of diabetes patients related to insulin therapy from a wide perspective is essential.

Considering previous qualitative studies, a few studies were conducted in the diabetes population and examined patients' perspectives regarding insulin therapy (4,13,15-19). In these reports, mainly emphasized themes were ordered as emotional reactions, perceptions about insulin, perceived consequences of insulin treatment, and influencing factors of insulin acceptance (4,15,16,18). To the best of authors' knowledge, till date, a limited number of quantitative studies investigating influencing factors on negative perceptions of insulin therapy in the Turkish population (8, 10, 20). However, no qualitative study has been performed to reveal individual perspectives on all aspects of starting insulin therapy in Turkish T2DM patients. Turkey is a state with a disproportionately high burden of diabetes. During the last decade, Turkey has consistently ranked among the highest diabetes prevalence and diabetes-related mortality

all over the world. A cross-sectional, population-based survey, TURDEP-II, reported the prevalence of diabetes as 16.5% (21).

Given the high prevalence, symptom burden, and mortality, define thoroughly the perceptions about starting insulin therapy and plan care services considering these perspectives are necessary. Therefore, this study aimed to elucidate perspectives of Turkish patients who are currently scheduled to receive insulin therapy in a deep manner. Study authors anticipated that the outcomes may provide insight regarding diabetes patients' perceptions about insulin therapy that adds to the holistic and national/international understanding of beliefs and thoughts related to insulin.

## MATERIAL and METHODS

### Study Design

This study used a qualitative content analysis approach as it enhances to gather in-depth information about individuals' perceptions and experiences related to a phenomenon (22,23).

### Setting and Participants

The study was conducted between February 2019, and July 2020 in the endocrine disease and metabolism outpatient unit of Ankara University School of Medicine İbni Sina Hospital, located in Ankara. A purposive sampling method was employed to recruit participants. The inclusion criteria were (a) age 18 years or above; (b) who had a documented diagnosis of T2DM; (c) who did not have a previous training history about insulin therapy; and (e) who have recently been prescribed insulin for the first time. Exclusion criteria were (a) history of severe psychiatric disorder; (b) recently undergone amputation; (c) cognitive and communication problems; and (d) not volunteering to participate in individual interviews. The sample size was determined based on the theoretical saturation principle that recommends stopping sampling when no new themes emerged (24). Accordingly, the data saturation was established at the 12<sup>th</sup> participants in this study. Two additional participants were also included to test whether data saturation was achieved or not. Thus, the study was completed with a total of 14 participants.

## Data Collection Tools

### Patient Questionnaire

The patient questionnaire, developed based on the literature, included five questions on socio-demographic (age, gender, educational level, marital status, and employment status) and five questions on disease-related characteristics (disease duration, presence of chronic symptoms, medications, current treatment protocol, and comorbid conditions) (5-8,13-15).

### Interview Guide

The interview guide was designed by the researchers, considering the guideline for in-depth interviews by Kvale (25). This guideline consists of seven steps of structuring in-depth interviews: thematizing, designing, interviewing, transcribing, analyzing, verifying, and reporting (25). Considering these steps, the interview guide was generated to elicit the perspectives of patients starting insulin therapy. Open-ended questions used in this study were presented in Table 1.

### Data Collection Procedure

Data were collected via face-to-face individual interviews with patients. The information on the presence of diabetes complications and co-morbid conditions was obtained from the patient records. The second co-author who is a female nursing academician with a PhD degree and who is experienced in qualitative studies. Interviews were conducted in a separate room when the patients came to the clinic to attend insulin therapy training. Each interview lasted for 30-50 minutes and was audio-recorded to ensure clear and accurate transcription.

### Data Analysis

The SPSS software version 23.0 (IBM Corp., Armonk, NY, USA) was used to analyze the quantitative data. Means and standard deviations were utilized for continuous numerical variables including age and diabetes duration. Percentages were used to define categorical variables such as gender, marital status, educational level, and presence of diabetes-related complications. The qualitative content analysis approach, consisting of four main components

including the decontextualization, the recontextualization, the categorization, and the compilation was utilized for qualitative data analysis (22). Firstly, the second co-author carefully transcribed all audio recordings and repeatedly reviewed them to ensure their accurateness. Following transcription, the principal investigator (PI) checked the transcripts by comparing them with audio recordings. In the decontextualization step, the authors carefully read the transcripts to obtain the sense of the whole and to determine smaller meaning units containing aspects related to each other, trying to answer the question set out in the aim. Both authors labeled identified meaning units with codes that should be understood in relation to the context and generated an open coding list. The researchers used colorful pencils to distinguish each meaning unit. After the meaning units were specified, the authors checked whether the content covered all aspects of the study, in the recontextualization step. To ensure it, the transcripts were re-read to decide whether the unmarked text would be included or not. As for the categorization step, firstly the meaning units were condensed which means reducing the number of words without losing the content of the unit. Subsequently, mean themes were generated and then checked numerously to reduce the number of themes that have a similar meaning to another one. Once the themes were established, the analysis and writing up process was started. In the compilation step, the researchers chose appropriate meaning units as quotations and placed them under the related theme (26).

### Study Rigor

The authors assured the rigor of this study by adhering to the criteria of dependability, transferability, confirmability, and credibility (27). All interviews were performed in similar settings using the same interview guide by the second co-author and all audio recordings were transcribed by the same researcher to guarantee dependability. All the study procedures were recorded precisely to ensure transferability. The PI verified the accuracy of the transcripts by listening to the audio recordings to provide confirmability and prevent bias that may arise from the interviewer's prior knowledge, feelings, and thoughts (27). The translation of quotations from Turkish to English was made by the second co-author

**Table 1:** Interview guide.

1. What were your feelings when your physician decided to start insulin therapy for you?
2. What do you think about people who use insulin therapy?
3. What is the meaning of insulin therapy?
4. What would be impacts of insulin therapy in your life?
5. What do you think about the changes in your life related to starting insulin therapy?

who speaks English as a native speaker, after completion of all the interviews. The credibility of the results was provided by verifying the interview data with the confirmation of the patient's accuracy. To ensure this, a member-checking approach was utilized, and the verbatim transcripts were given to participants to check them about the truth and accuracy. All participants confirmed their transcripts. Additionally, both authors read each transcript once and again independently from each other and performed a blind analysis. And then, the authors came together to reach an agreement on themes (27).

### Ethical Considerations

The study was approved by the Non-Interventional Clinical Trials Ethics Committee of Hacettepe University (Decision Number: GO18/600-28). All participants were adequately informed about the study protocol and their written informed consent was obtained. Interview recordings were anonymously coded, randomly evaluated, and stored in a password-protected computer to ensure data security. The participants had the right to withdraw from the study at any time without stating a reason.

### RESULTS

The participants' age ranged from 38 to 69 years ( $51.71 \pm 9.78$ ). Most patients were male (71.43%) and graduated from high school (57.14%) and all of them were married. Duration from diabetes diagnosis varied between one month and 15 years ( $8.02 \pm 5.06$ ). Forty-six-point eighty-five percent of the patients had long-term complications related to diabetes including diabetic neuropathy (21.43%), diabetic nephropathy (7.14%), retinopathy (7.14%), and diabetic foot (7.14%) (Table 2).

Four main themes emerged from the transcripts including (i) facing the reality of insulin, (ii) attributions to dependence on insulin therapy (iii) coming changes with the insulin in all aspects of life, and (iv) positive consequences of insulin (Figure 1).

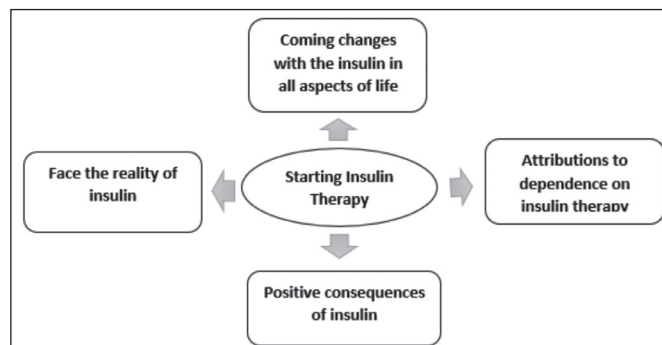
#### Theme 1: Facing the Reality of Insulin

One of the most important parts of the interviews was that all the participants had interrogated themselves to receive a decision to start insulin therapy. They also thought that why they need insulin in their life, what their faults from the beginning of the disease were: "I have not followed my diet plan and not taken my oral medicine regularly. It's all my fault."

Almost all of them expressed negative emotions regarding insulin involving unclarity, anxiety, blame, guilt, fear, sadness, and helplessness. One participant expressed his

**Table 2:** Descriptive characteristics of participants (n=14).

Characteristics	Findings
Age (years $\pm$ SD)	51.71 $\pm$ 9.78
Gender [n (%)]	
Female	4 (28.57)
Male	10 (71.43)
Marital status [n (%)]	
Married	14 (100.0)
Single	-
Educational level [n (%)]	
Primary	5 (35.72)
High school	8 (57.14)
University	1 (7.14)
Diabetes duration (year $\pm$ SD)	8.02 $\pm$ 5.06
Presence of long-term complication related to diabetes [n (%)]	
Peripheral neuropathy	3 (21.43)
Nephropathy	1 (7.14)
Retinopathy	1 (7.14)
Diabetic foot	1 (7.14)



**Figure 1.** Key themes of the study.

feelings as follows: "Yesterday! When the doctor said [you need to use insulin], I felt scared. I wondered whether I may have to use insulin for the rest of my life. However, when he said I can change insulin to oral drugs in the future, I breathed a sigh of relief." Another participant said: "Insulin was a nightmare for me, and now I found myself in this nightmare."

They reported having fears because of repeated self-injections, hypoglycemia risk, losing independence, social limitations, and ignorance. One of the participants also associated her feelings and fear related to insulin with her mothers' experiences and death following insulin therapy: "My mother became bedridden after initiating insulin therapy."

*I am not saying that she got worse due to insulin, or insulin is directly associated with the disease severity. However, she fell ill soon after initiating insulin therapy and finally died.”*

Moreover, some of the participants have highlighted that to make connections between insulin therapy and diet restrictions related to T2DM. The participants were still thinking about continuing their treatment using only oral antidiabetics and carried numerous concerns to start insulin therapy resulted from uncertainty about the efficacy of insulin therapy, determining the right dosage, administering insulin at the right place, by the right technique, and at the right time even after learning instructions on insulin application: *“I am not sure whether I can continue my insulin injections as the doctor recommended or, make insulin injection on my own.”*

### **Theme 2: Attributions to Dependence on Insulin Therapy**

The participants commented on insulin therapy as an advanced stage of the disease, the last resort, the end of life, and death. Most of the participants were under the influence of their previous experiences of relatives or friends about insulin, physicians' or nurses' reactions, common beliefs on disease, and insulin in the community. They also emphasized that being dependent on insulin to survive.

One participant said: *“For me, insulin is the last resort! If someone must use insulin, he/she will lose the meaning of life. In other words, an individual initiating insulin therapy will appear extremely sick and there will be no hope for him/her to live a healthier life except for insulin.”*

On the other hand, some of them expressed their perspectives on the meaning of insulin feeling such as a grandfather, sicker, and being close to death: *“When you ask the meaning of insulin, I can say only a single word: death. For me, insulin means the end of life.”*

Insulin was also attributed to a heavy burden, non-healing wounds, extremity amputations, and prolonged hospitalizations. Even, one participant expressed that receiving insulin equal to living with cancer: *“Insulin brings a feeling of a serious disease. You are diagnosed with cancer, or you must use insulin. In my opinion, both are the same.”*

### **Theme 3: Coming Changes with the Insulin in All Aspects of Life**

The participants specified that starting insulin may induce several changes in their daily life. They reported that they will have to leave deep-rooted habits, change their daily routines, and stop working due to the fear of hypoglycemia after the initiation of insulin therapy. One patient stated: *“I have been working as a driver. But now, it seems impossible. I do not want to be the cause of a traffic accident by insulin shock and coma.”*

Some narratives also highlighted the fact that participants have attributed body image changes such as gaining weight, possible skin problems following multiple insulin injections. A few participants also expressed concerns about sustaining healthy and normal sex life after initiating insulin therapy: *“One of the most frightening things about insulin therapy is the change in sex life. I am worried about the problems that will arise in my sex life.”*

Another important change due to starting insulin was associated with the social aspects of life. Participants shared their hesitations about insulin using “social isolation”, “embarrassment”, “social stigmatization”, and “major restrictions in social activities”. They reported that they could not imagine making multiple injections on their body in public areas, workplace, must carry insulin flacons and injectors with them, arrange their mealtimes based on their insulin doses, being vulnerable to hypoglycemia, have to change their vacation plans, and a possibility for early retirement. Below are excerpts with highlights these comments:

*“When I measure my blood glucose or inject insulin, everybody will stare at me and notice my disease.” “If you must use insulin, your social life will be restricted. In my opinion, individuals using insulin therapy represent a half-human like a half-cut apple.”*

*“Imagine you are at the beach on a vacation, and you have to use insulin at that moment. The thought will turn down all your plans. When I must go to a different place, I will have to live and breathe insulin.”*

### **Theme 4: Positive Consequences of Insulin**

In addition to the above-mentioned negative perceptions, participants also expressed their positive feelings related to insulin therapy involving better treatment, better management of diabetes, reaching targeted blood glucose, preventing multiple organ failures, and all complications. A considerable number of the participants also perceived insulin therapy as a motivating factor to keep on healthy-life behaviors such as eating more healthier, being more active, decreasing all stressors in their life, and continuing a more peaceful lifestyle, and improving the quality of life. Participants accepted insulin as a main part of the treatment, inevitable obligation, and show a willingness to use it, expressed their expectations from insulin therapy with these excerpts:

*“I think that insulin is necessary for me. I hope it will balance my blood glucose level and prevent complications. I believe that I will be much healthier after starting insulin.”*

*“I hope insulin will help me hold on to live better. I will eat healthy, exercise, and lose weight along with insulin therapy.”*

## DISCUSSION

In the current study, the most prominent theme was that facing the reality of insulin. Almost all the participants expressed negative feelings when they faced the decision on insulin initiation. Insulin therapy was perceived as a fear of losing consciousness due to hypoglycemia or hyperglycemia, socially embarrassing due to the lack of understanding by friends and family members, and feeling of uncertainty. The Chinese participants living in Canada expressed similar feelings including fear of pain, doubts about the proper use of insulin, worries related to sudden hypoglycemic episodes, and sadness when they faced the decision of insulin initiation in a qualitative study (17). Hispanic immigrants living in the Southeastern United States and Singaporeans with T2DM also expressed similar emotional reactions to insulin therapy (13,19). Morris et al (18) reported that British patients were shocked when they received the decision to start insulin therapy. Considering all these studies, regardless of cultural differences, insulin causes similar emotional reactions and feelings in T2DM patients at the beginning of the treatment. These experiences and feelings related to insulin therapy may be attributed to the lack of knowledge and experience, perceptions about insulin therapy in the community, and past experiences about insulin or injections.

The participants often considered insulin therapy to be the last option of treatment, and some of them also associated insulin with death, or equivalent to cancer. Moreover, participants reflected social consequences of insulin therapy such as social ignorance, social isolation, and stigma. Confirming our results, earlier and current reports highlighted that insulin is perceived as the last chance to survive, linked with advanced diabetes and impending death (3,9,10,13). Ho and James (17) have also emphasized that many T2DM patients provided consistent feelings such as being responsible for poor prognosis, and a factor for loss of independence in their study. The authors assumed that these negative consequences about the insulin initiation may result from as insulin is generally prescribed when the blood glucose level continues in higher levels than recommended limits, and patients may feel higher level anxiety, fear, distress, and not ready for a radical change in their routine treatment. Thus, facing the reality of starting insulin may be a detrimental effect on their lives.

Apart from previous qualitative studies focusing on individual perceptions regarding insulin therapy, one of the most important issues mentioned by the participants in this study were that significant changes in sexual life, sexual power, or sexual relation with their partners. The

participants perceived that insulin causes loss of sexual desire and has harmful effects on erection. The concerns related to sexual life reported by our participants may be due to the myths and misconceptions on insulin therapy and the meaning attributed to sex in their lives.

Regarding our last theme, the participants expressed their feelings on the positive consequences of insulin therapy. Previous studies' outcomes related to insulin therapy revealed that most T2DM patients expressed negative attitudes including concerns about the need for insulin, incorrect medical decisions, increase in complication frequency, side effects of insulin, and lack of sureness about the regulatory effects of insulin (3,9,10). On the other hand, our participants reported beneficial effects of starting insulin therapy on the regulation of blood glucose, prevention of complications including nephropathy and neuropathy, and improvement in the quality of life. This finding corroborates that the insulin-naïve Turkish T2DM patients who have been recently prescribed insulin have ambivalent thoughts on the effects of insulin therapy. Consistent with our findings, insulin was perceived as beneficial to achieve better glycemic control, prevent complications, and improve health outcomes by T2DM diabetes patients, in a few previous reports (3,9,13).

Although the participants had contradicting thoughts about insulin, they expressed a tendency for healthy lifestyle behaviors following insulin therapy. Most of our participants said that they will adopt healthy life behaviors, including regular exercises, daily walks, compliance with dietary recommendations, losing weight, avoiding fast food, and attending regular appointments with physicians, after receiving the decision on integrating insulin into their existing treatment. These reflections from our participants may be associated with reconsidering all experiences from the diagnosis to the decision time of starting insulin therapy and expressing the willingness to compensate for what they must do; therefore, they may feel self-motivated. This may be because when people take their fears seriously, they tend to change their life with a higher level of willingness and motivation (28).

This study has some limitations. The duration of diabetes was relatively shorter in our study, and we did not assess the glycosylated hemoglobin value. Additionally, the study sample mostly consisted of males. Therefore, the findings could not directly be transferred to females and those with T2DM for a longer period. Based on these limitations, similar studies should be conducted in a heterogeneous sample to reveal the impacts of gender and disease duration on insulin perception.

This study concluded that Turkish T2DM patients have ambivalent and complex perspectives composed of negative and positive consequences regarding insulin initiation. Apart from the previous studies, participants stated significant worries related to changes in working and sexual life. As everyone may show different reactions to starting insulin therapy, health care professionals should pay more attention to how T2DM patients feel when they face starting insulin and provide a more understanding approach to patients in clinical practice.

Individualized training programs are needed to reduce negative perceptions on starting insulin therapy and to help patients adapt to insulin therapy easily. Further research should focus on examining the expectations of T2DM patients from health care providers at the beginning of insulin therapy to better manage all aspects of the treatment process.

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### Authorship Contributions

All authors contributed to equally to the manuscript.

### Conflicts of Interest

The authors have no conflicts of interest to disclose.

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### Ethical Approval

The study was approved by the Non-Interventional Clinical Trials Ethics Committee of Hacettepe University (Decision Number: GO18/600-28). All participants were adequately informed about the study protocol and their written informed consent was obtained.

### Peer-Review Process

Extremely peer-reviewed and accepted.

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