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Invisible Struggle: Diabetes Self-Management Through the Eyes of Diabetic Individuals With Retinopathy

Tuğba Bilgehan[1] | Münevver Sönmez[2] | Hülya Türkçapar[3] | Meleknur Göktaş[3]

[1]Department of Internal Medicine Nursing, Ankara Yıldırım Beyazıt University, Faculty of Health Sciences, Esenboga, Ankara, Türkiye | [2]Gülhane Faculty of Nursing, University of Health Sciences, Ankara, Türkiye | [3]Department of Internal Medicine Nursing, Ankara Yıldırım Beyazıt University, Institute of Health Sciences, Esenboga, Ankara, Türkiye

Correspondence: Münevver Sönmez (munevverunlu@gmail.com; munevver.sonmez@sbu.edu.tr)

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ABSTRACT

Individuals diagnosed with diabetic retinopathy may experience difficulties in performing daily life activities and maintaining diabetes self-management due to vision problems. This study aimed to conduct an in-depth investigation into challenges and needs experienced in diabetes self-management by individuals diagnosed with diabetic retinopathy. This study employed a descriptive phenomenology study design. Data were collected from 13 diabetic patients through a questionnaire and semi-structured interview form, and were analyzed using the NVivo 12 program. When the qualitative data in the study were analyzed, two main themes were identified for diabetic individuals with retinopathy: daily struggles experienced during diabetes self-management and supportive requirements required for diabetes management. The daily struggles theme included the subthemes of psychological, treatment monitoring, physical activity, and nutrition, while the supportive requirements theme consisted of the subthemes of social support, diabetes technologies, lifestyle changes, and coping methods. Findings indicate that diabetic individuals diagnosed with diabetic retinopathy experienced significant difficulties in the areas of psychology, nutrition, treatment monitoring, and physical activity. They emphasized the need for coping methods and supportive resources for effective diabetes management.

1 | Introduction

Diabetic retinopathy (DR) is one of the most common and severe microvascular complications of diabetes mellitus, which, if not properly managed, can lead to vision loss and blindness (Shi et al. 2023). DR is a leading cause of visual impairment and blindness for 3.9 million people worldwide and is the most significant cause of blindness among individuals aged 20–74 in developed countries (WHO 2023; TEMD 2024). In Türkiye, there are 215076 visually impaired individuals registered in the National Disability Data System, with visual impairment ranking fourth among all disability groups, accounting for 9.53% of the total (T.C. Ministry of Family and Social Services 2023). A study conducted in Türkiye in 2020 among individuals aged 40 and above determined that the prevalence of DR was 21% among individuals with diabetes and 2% in the general population (Erdoğan et al. 2020). Additionally, another study conducted in 2022 reported a DR prevalence rate of 36% (Yıldırım et al. 2022).

The visual impairment caused by DR is irreversible and significantly affects patients' quality of life, as well as their physical

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Summary

- Diabetes education programs should integrate DR awareness and management strategies, emphasizing the promotion of self-management practices for individuals with visual impairments.
- Healthcare professionals should receive specialized training to deliver comprehensive care, including psychological support and tailored interventions for individuals with DR, addressing the unique challenges they encounter in diabetes management.
- Enhanced support systems, involving family members, healthcare providers, and social networks, are essential to empower individuals with DR in managing their diabetes and maintaining a high quality of life.
- Future studies should focus on evaluating the effectiveness of diabetes technologies and lifestyle interventions for individuals with DR to optimize disease management and improve clinical outcomes.

and mental health (Shi et al. 2023). Vision loss due to DR leads to dependence in daily living activities, reduced physical activity, and social isolation, ultimately resulting in a significant decline in quality of life (Cooper et al. 2020; Roberts-Martínez Aguirre et al. 2022; Zayed et al. 2024). Additionally, individuals with DR are reported to experience anxiety and depression symptoms more frequently and to have poorer overall health outcomes. Given the negative impact of DR on physical and psychosocial well-being, effective diabetes self-management and the prevention of complications emerge as critical necessities (Al baiuomy et al. 2021).

Diabetes self-management plays a critical role in achieving glycemic control, preventing additional complications, and improving overall health outcomes for individuals with DR (Al baiuomy et al. 2021). In this context, essential components include maintaining appropriate levels of physical activity, following a balanced diet, adhering to prescribed medication regimens, regularly monitoring blood glucose levels, and engaging in activities aimed at reducing the risk of further complications. Additionally, social support and coping skills are key components of self-management, contributing to better disease control and enhancing overall well-being. In this regard, adherence to diabetes self-management is of great importance in preventing diabetes-related complications, particularly severe conditions such as DR, which can lead to vision loss (Yang et al. 2017). Several studies have investigated self-management and challenges associated with diabetes (Bener et al. 2017; Zamani-Alavijeh et al. 2018; Guo et al. 2022; Tuobenyiere et al. 2023). However, research specifically highlighting the difficulties experienced during diabetes self-management and the essential components required for individuals diagnosed with DR remains limited (Coyne et al. 2004; Devenney and O'Neill 2011; Kaminsky et al. 2014). This study aimed to conduct an in-depth investigation into the difficulties and needs experienced during diabetes self-management by individuals diagnosed with DR.

1.1 | Study Questions

- What are the challenges experienced during diabetes self-management by individuals with DR diagnosis?
- What are the needs in diabetes self-management for individuals with DR diagnosis?

2 | Materials and Methods

2.1 | Study Design

This study employed a descriptive phenomenology study, which emphasizes patients' lived experiences and encourages their reflections on daily life (Lopez and Willis 2004). This approach is particularly suitable for gaining an in-depth understanding of patients' experiences and emotions. Given that the study aimed to explore patients' authentic experiences during their illness, descriptive phenomenology study was chosen as the study method.

2.2 | Study Population and Sample

The population for the study comprised diabetic individuals with DR diagnosis attending internal diseases, endocrinology metabolic diseases, and eye diseases clinics in a state hospital located in Ankara and allowing the study.

The inclusion criteria were voluntary participation, being 18 years or older, and having a diagnosis of DR in addition to type 1 or type 2 diabetes. The exclusion criteria included the presence of chronic complications other than DR and a history of visual disability prior to diabetes diagnosis. The study employed criterion sampling, a type of purposeful sampling (Patton 2014). In qualitative study, sample sizes are typically determined based on the concept of "saturation," which refers to the point at which no new information or themes emerge from the data. The saturation stage, indicating the repetition of data, signifies that an adequate sample size has been reached (Hennink and Kaiser 2022). So, data saturation was considered reached when participants provided similar responses to the questions and no new differing answers were obtained. The study was completed with 13 diabetic individuals who met the inclusion criteria.

2.3 | Researchers

TB, an assistant professor (PhD) in internal medicine nursing science, MS, an associate professor (PhD) of fundamentals of nursing science, along with HT and MG, both Master's students in internal medicine nursing, comprised the study team. The interviews were conducted by Academician TB, Nurse HT and Nurse MG under the guidance of Academician TB, who had previously received training in qualitative study methods.

2.4 | Data Collection Tools

The data collection method in this study was designed based on the literature related to the topic. Data were collected with a questionnaire and a semi-structured interview form.

TABLE 1 | Semi-structured interview guide.

1. Can you describe the period when you were diagnosed with retinopathy?
2. How does having vision impairment due to retinopathy affect your diabetes self-management? (e.g., blood glucose monitoring, nutrition, medication, insulin management, and exercise)
3. What lifestyle changes have occurred since your retinopathy diagnosis?
4. What general challenges do you face in managing your diabetes alongside retinopathy? (e.g., engaging in exercise and monitoring blood glucose levels)
5. What do you do to cope with these challenges? What are your coping strategies?
6. How does your social environment support you in managing retinopathy and diabetes?
7. What do you need to manage your diabetes effectively while living with retinopathy?
8. What steps have you taken, or do you plan to take, to achieve these goals?
9. What would you like to improve in diabetes management with retinopathy? What kind of support would help you?

2.4.1 | Questionnaire

The questionnaire consisted of a total of 22 questions, covering sociodemographic data and information related to DR. The sociodemographic section included 12 questions, addressing participants' age, gender, marital status, and employment status. The section on DR contained 10 questions, covering aspects such as diabetes type, duration of diabetes, treatment method, HbA1c level and the stage of retinopathy. Both forms were developed by the researchers based on the existing literature (ACCORDION 2016).

2.4.2 | Semi-Structured Interview Form

This consisted of nine open-ended questions aimed at exploring the diabetes self-management of individuals with DR. While a review of the literature (Devenney and O'Neill 2011; Shi et al. 2023) provided a general framework for understanding the context of diabetes self-management, the questions themselves were not directly derived from the literature. Instead, they were developed by the research team to ensure that the focus remained on the participants' lived experiences. The researchers made deliberate efforts to maintain bracketing, ensuring that the questions were crafted without direct influence from existing theories or findings. The questions are presented in Table 1.

2.5 | Data Collection

Researchers who had no prior connection with the participants scheduled and conducted face-to-face interviews. Participants were made to feel comfortable while sharing their experiences, and all interviews were conducted in a quiet and secure environment in an unoccupied room of the hospital, with only the participant and the researcher present. Before the interviews, the purpose, significance, and confidentiality of the study were explained to the participants, and their informed consent, including consent for voice recordings, was obtained. The interviews were conducted in April 2024 and recorded digitally. In-depth interviews were conducted using probing questions and follow-up questions based on participants' previous responses. Two pilot interviews were conducted with individuals diagnosed with DR. These interviews were carried out by HT and MG under the supervision of TB (the first author), who had received training in qualitative research methods. During the pilot interviews, participants did not suggest any additional modifications to the semi-structured questions. Therefore, these two participants were included in the final sample. The first two interviews, initially conducted as pilot interviews, were included in the analyses. The interviews lasted an average of 35–55 min.

2.6 | Analysis of Data

The descriptive characteristics of the participants were analyzed using SPSS v.27 software. Content analysis of the qualitative data was conducted using NVivo 12 software. The authors met repeatedly to discuss emerging themes and underlying patterns in the data. First, the audio-recorded interviews were carefully transcribed verbatim to prepare the data for analysis. Second, all transcriptions were thoroughly reviewed. Next, initial codes were generated and grouped into relevant themes, followed by the development of themes, subthemes, and codes. The researchers developed codes exclusively based on the information emerging from the participants' responses. Subsequently, each initial code and theme was revisited. Data analysis followed Colaizzi's seven-step process: (1) thorough initial reading of the transcripts to become fully acquainted with the data; (2) extraction of significant utterances; (3) interpretation of these utterances to discern underlying meanings; (4) organization of these meanings into themes and subthemes; (5) comprehensive description of all emergent themes; (6) elucidation of the phenomenon's underlying structure; and (7) presentation of findings to participants for validation (Morrow et al. 2015). All participants were outpatient clinic patients, and therefore, following the interviews, the findings were sent to participants via email (visual thematic diagram including patient statements and explanatory audio recording containing this information) for validation, with their consent, to confirm the accuracy of the findings. Participants provided confirmation, ensuring that the findings accurately reflected their lived experiences. Analyses were conducted by researchers with PhDs as well as other team members. Themes and subthemes were identified based on the data, and subthemes were systematically linked to their corresponding themes. To enhance the credibility of the study, selected participant statements were directly quoted (Houser 2015). A critical auditor, MS, independently reviewed the thematic structure and its alignment with the raw data. Participants were assigned numerical identifiers (e.g., Participant 1: P1) to protect confidentiality.

2.7 | Validity and Reliability Rigor

Guba and Lincoln emphasized that, in qualitative study, trustworthiness should be prioritized over validity and reliability, and they established specific criteria for ensuring it (Houser 2015; Merriam 2013). These criteria have been recognized in the literature as the gold standard. In 1982, Guba and Lincoln categorized the criteria for trustworthiness under four main components: credibility, dependability, confirmability, and transferability. In this study, appropriate methods were employed to ensure trustworthiness, considering key factors: credibility (reducing researcher bias, participant confirmation), transferability (purposeful sampling, inclusion criteria, detailed descriptions of the setting and participants), dependability (comprehensive literature review, detailed presentation of study methods, review of processes and findings by an independent researcher), and confirmability (minimizing researcher bias) (Creswell 2003). To enhance credibility, the lead researcher engaged in regular discussions with the study team to refine the study design, methods, data collection, and analysis. These collaborative exchanges provided external validation and enriched the study with diverse perspectives. Transferability was supported by providing rich, contextualized descriptions of participant responses, enabling applicability to similar populations or settings (Farrelly 2013). Auditability was ensured through systematic documentation of data collection, coding, and theme development (Daniel 2019). A detailed audit trail was maintained in a deidentified and structured format, enhancing transparency and replicability. Additionally, the researchers employed bracketing techniques to set aside preconceived notions and assumptions during data collection and analysis. The researchers conscientiously avoided presuming any preconceived relationships between self-management performance and external factors. This approach ensured that the findings remained grounded in the participants' lived experiences, free from bias or influence by previous theoretical assumptions.

2.8 | Ethical Aspect of the Study

The study was approved by the Ankara Yıldırım Beyazıt University Health Science Ethics Committee (Decision date: 16.01.2024, Decision no: 01-528). After receiving ethics committee permission, study permission was obtained from the hospital where the study would be performed. Voice recordings were encrypted and stored on a computer. The potential risks and benefits of the study were explained to the participants. Additionally, they were informed that they could withdraw from the study at any time without any consequences. All personal data were kept confidential, and the anonymity of the participants was maintained throughout the study. Participants had the purpose of the study explained to them and provided both written and verbal informed consent. The research was performed in accordance with the principles of the Declaration of Helsinki. The study has been reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist (Tong et al. 2007). Additionally, the COREQ checklist has been included as a Supporting Information S1: File.

3 | Results

The distribution of sociodemographic and diabetes-related features of participants is given in Tables 2 and 3. The mean age of individuals participating in the study was 54.61 ± 13.61 years, and the mean HbA1c was 6.93 ± 1.09. Of participants, 38.5% were in the third stage of retinopathy (severe non-proliferative DR), while 30.7% were living with full blindness (Tables 2 and 3).

When data gathered from participants are analyzed, two themes of (1) daily struggles and (2) supportive requirements were identified. These themes were later divided into subthemes and codes (Figures 1 and 2).

3.1 | Daily Struggles

The first theme is related to daily struggles experienced during diabetes self-management by diabetic individuals with DR. Four subthemes of psychological, treatment-monitoring, physical activity, and nutrition were determined under this theme (Figure 1).

Among these daily struggles, “psychological” struggles stand out. The psychological subtheme was identified to include three codes of fear of additional complications, give my eyes back, and stress.

The majority of participants have intense anxiety about “fear of additional complications” that may develop in the future, which directly affects their daily lives. This fear was not only rooted in their current struggles but also in the uncertainty of what might come next:

> ...I try to ensure that I do not experience more serious problems. I am afraid... For example, it is crucial to control diabetes to avoid kidney disease and heart disease... (P11)

Among the many challenges reported, vision loss emerged not merely as a medical issue but as a deeply emotional rupture in participants' lives. Participants expressed a strong desire to halt or even reverse the progression of their visual impairment. The plea to “give my eyes back” echoed through multiple narratives, encapsulating their desperation and sadness:

> ...I want to be healthy so that the problem with my eyes does not worsen, and I won't go blind. I am sad. I struggle with my eyesight, and I want it to improve ... (P3)

> ...I make every effort to prevent my eyes from going blind. I go to my check-ups every three months, and I never skip them... (P8)

TABLE 2 | Distribution of sociodemographic and diabetes-related characteristics of participants.

Sociodemographic characteristics	*n*	%
Gender		
Woman	13	100
Age		
43–54	7	53.8
55–65	6	46.2
Marital status		
Married	5	38.5
Single	8	61.5
Education status		
Primary school	3	23.0
High school	4	30.8
License	6	46.2
Employment status		
Not working	9	69.2
Part time	1	7.7
Full time	3	23.1
Income level		
Income less than expenditure	4	30.8
Income matches expenditure	8	61.5
Income more than expenditure	1	7.7
Family members providing care at home		
Mom and dad	5	38.5
Husband	3	23.0
Child	5	38.5
Cigarette use		
Yes	3	23.1
No	10	76.9
Frequency of health check-ups		
Once every 3 months	7	53.8
Once every 6 months	5	38.5
Irregularly (less than every 6 months)	1	7.7
Frequency of internal medicine/endocrine controls		
Once every 3 months	8	61.5
Once every 6 months	4	30.8
Once a year	1	7.7
Frequency of eye check-ups		
Once every 3 months	5	38.5
Once every 6 months	3	23.0
Once a year	5	38.5

TABLE 3 | Distribution of data on diabetes.

Diabetes type		
Type 1	5	38.5
Type 2	8	61.5
Duration of diabetes (years)		
5–10 years	2	15.4
11–20 years	4	30.8
21–30 years	2	15.4
31–40 years	4	30.8
41–50 years	1	7.6
Treatment method		
Oral antidiabetic	1	7.7
Insulin	8	61.5
Insulin + oral antidiabetic	4	30.8
HbA1c value		
7.00% or less	8	61.5
7.01%–8.0%	3	23.1
8.00% or more	2	15.4
Family history of diabetes		
Yes	2	15.4
No	11	84.6
Family history of retinopathy		
No	13	100
Duration of retinopathy (years)		
1–10 years	7	53.8
11–20 years	6	46.2
Retinopathy stage		
Stage 1 (mild NPDR)	2	15.3
Stage 2 (moderately severe NPDR)	3	23.1
Stage 3 (severe NPDR)	5	38.5
Proliferative stage (PDR)	3	23.1
Current eye complaints		
Redness and swelling of the eyes	2	15.4
Blood supply and vascularization	2	15.4
Blurred vision and photosensitivity	2	15.4
Partial blindness	3	23.1
Total blindness	4	30.7

“Stress” emerged as a psychological challenge in participants' narratives, revealing how DR complicated not only physical routines but also psychological effects. They described how DR diminished their confidence in self-care tasks that were once routine, particularly insulin administration:

> ...I used to be confident in the past. I knew exactly how much I was injecting. Now, I struggle daily with

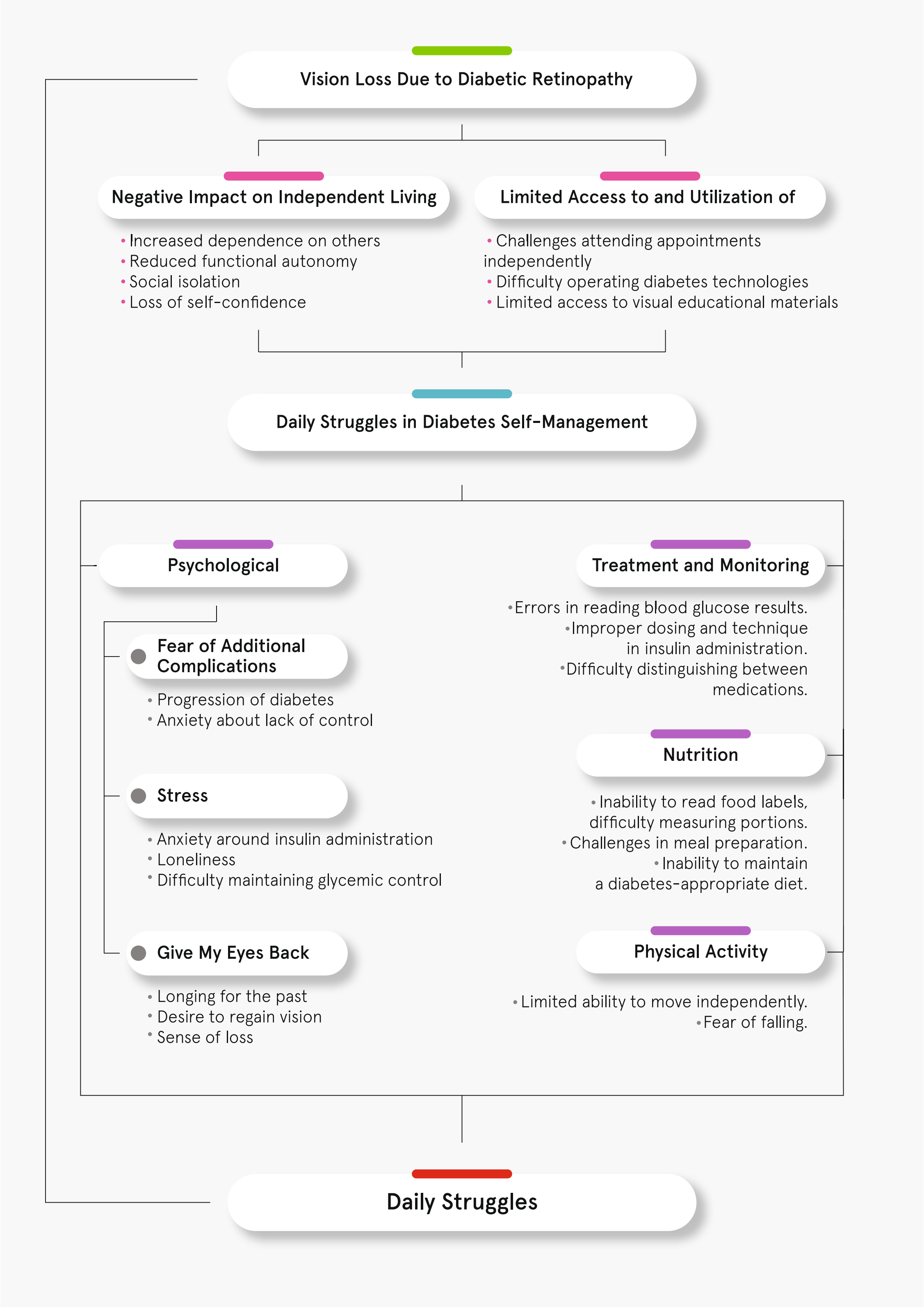

FIGURE 1 | Thematic analysis flowchart of daily struggles.

> questioning how much I've injected. I'm not sure, and then I get stressed, which causes my blood sugar to spike… (P6)

Living with DR created a state of constant alertness and vulnerability, especially when participants were alone:

> …At home, I walk while holding onto the walls and doors; I'm always on alert. If there is no one with me, managing my diabetes is almost impossible. Sometimes, I fixate on it, and I get stressed… (P9)

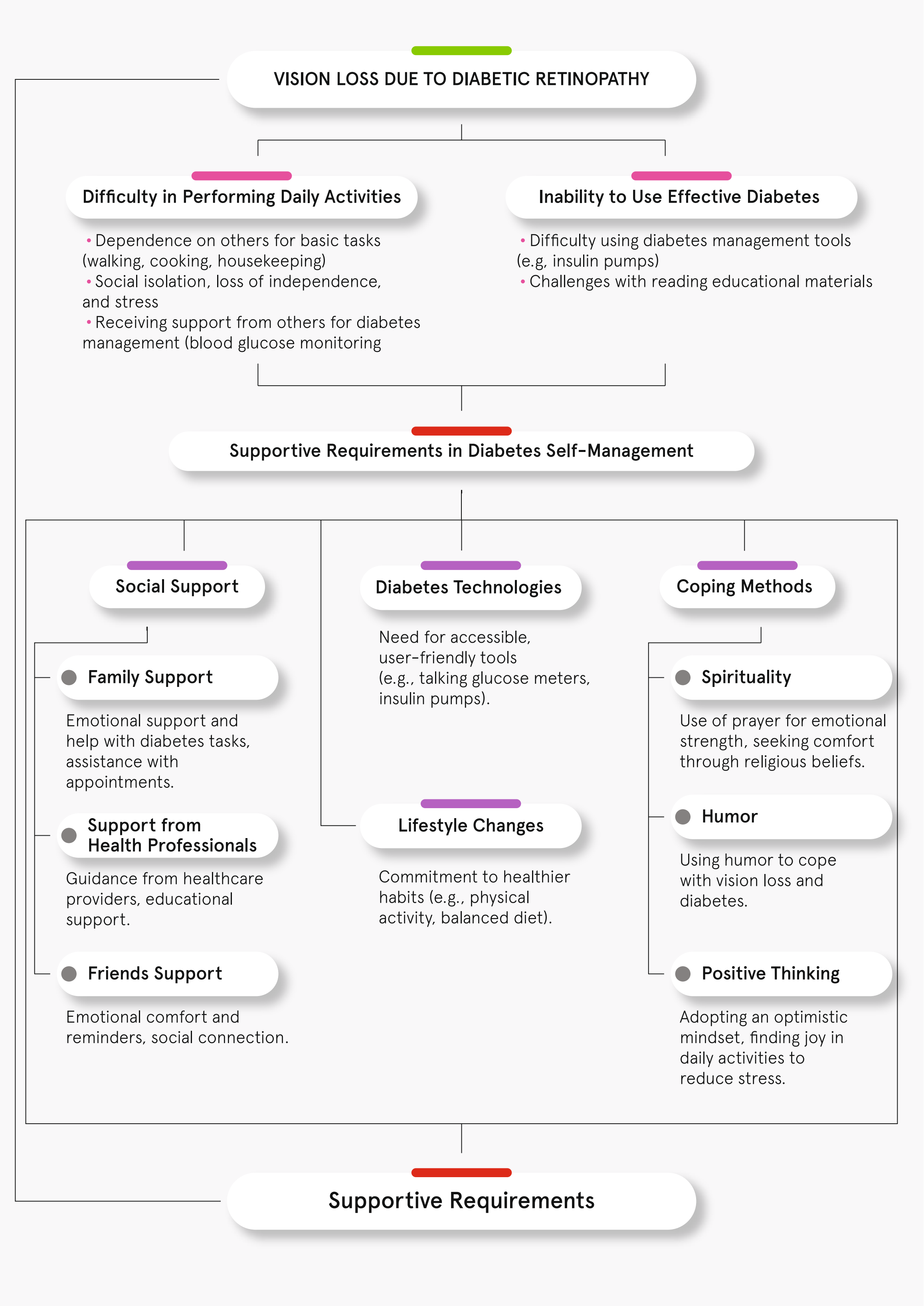

FIGURE 2 | Thematic analysis flowchart of supportive requirements.

Managing diabetes became increasingly complex for participants as their vision deteriorated, making routine "treatment and monitoring" tasks vulnerable to errors. Visual impairment not only slowed them down but introduced a degree of uncertainty that directly affected their safety:

> ...Without glasses, I can't see, so I struggle daily to set my insulin by counting. When I measure my blood sugar, I might misread the result. Sometimes, I hold it upside down. If it displays 411, for example, I might read it as 114. This poses a risk... (P4)

"Nutrition" emerged as a significant challenge among participants, particularly as visual impairment interfered with their ability to prepare appropriate meals and maintain dietary control. For many, the inability to read food labels, recipe books, or even distinguish ingredients became a significant challenge that led to compromised food choices. As one participant emphasized, even the intention to cook a nutritious meal could be thwarted by the inability to read recipes or see ingredients clearly:

> ...Sometimes, I want to cook and prepare a nice meal. But when I pick up the recipe books, I struggle because I cannot read them. Glasses don't help. So, I end up eating breakfast items with bread. Bread then increases my blood sugar. Or, I struggle by eating a lot of bread because there is no proper meal available... (P5)

Another participant described how the act of preparing and serving a meal—something once automatic—had become a nearly impossible task:

> ...Since I can hardly see at all, this naturally affects me significantly. Think about it—it's very difficult to prepare a plate of food for myself. In fact, doing many things on my own is almost impossible, difficult... (P9)

Visual impairment also significantly hindered participants' ability to engage in "physical activity", often disrupting routines that had previously supported their diabetes management. Many shared that vision loss led to reduced mobility and limited their confidence in navigating public spaces, ultimately resulting in sedentary lifestyles. Activities they once enjoyed—such as cycling or walking—had become unsafe or unfeasible due to diminished visual capacity:

> ...My blood sugar doesn't decrease due to immobility. My active lifestyle is over. I can't ride a bicycle. I used to in the past, but I don't go out much anymore as I can no longer see well... (P4)

Another reflected on the fear and instability caused by poor night vision, which made outdoor activity especially difficult:

> ...Maybe if I exercised, my blood sugar would be more balanced, but my vision is very poor, and streetlights at night appear blurry. I struggle with tripping over pavements and walking in fear. As a result, I don't go outside... (P5)

3.2 | Supportive Requirements

The second theme related to diabetic management of participants was related to what their supportive requirements were. Within this theme, four subthemes of social support, diabetes technologies, lifestyle changes, and coping methods were identified (Figure 2).

Participants emphasized the importance of receiving support from others in navigating the complex challenges of diabetes self-management while living with DR. "Social support," in particular, was considered essential for emotional well-being in daily life. Within the social supports, there were three codes: family support, support from health professionals, and friends support.

For many, "family supports" played a vital role in facilitating treatment tasks and providing encouragement. One participant shared how her daughter and son stepped in to assist with critical daily responsibilities, such as insulin injections and making dietary adjustments:

> ...My daughter injects me with insulin and measures my blood sugar—I am grateful to her because I can't do it myself. My son has started to care for me more. He buys me whole wheat rye bread, saying, "Don't eat regular bread..." (P5)

Another participant described the lifelong presence of her family in supporting her diabetes management:

> ...Since I was a child, my mother, father, and siblings have been a great support to me. I've had diabetes since I was two, and they have been with me throughout my journey. Even now, my mother continues to support me despite her age... (P13)

"Support from health professionals" was also highly valued. Nurses and dietitians were viewed as critical supportive healthcare professionals who provided both technical assistance and emotional motivation. One individual noted the sense of security that came from having professional support readily available:

> ...I can't change the insulin pump; the nurse does it for me. The dietitian suggests supplements. It is reassuring to have nurses; they help with everything... (P2)

Another participant emphasized the relational dimension of healthcare support, highlighting the encouragement and continuity provided by a diabetes nurse:

> ...Our diabetes nurse is very kind and always smiling. I visit her often. She motivates me and tells me what I'm missing... (P4)

In addition to family and professional support, “friends support” as informal yet meaningful sources of encouragement. Spending time with loved ones contributed to participants feeling socially supported and less alone:

> ...When I get bored, I go and sit with my neighbors to distract myself. I spend time with people I love; I visit my children. In those moments, I forget my illness and feel a little better... (P8)

Another described how friends offered practical reminders and emotional backing in managing diabetes-related routines:

> ...I receive a lot of support from my friends regarding retinopathy. They generally encourage me to eat properly or remind me to measure my blood sugar before eating... (P13)

Many emphasized the importance of access to “diabetes technologies” that could reduce the physical burden of routine tasks and compensate for visual impairments. For some, repeated finger pricks had caused damage to their fingertips, while others expressed the need for systems that could help them manage their condition more independently. One participant, for instance, described the value of sensor-based technologies that rely on audio feedback rather than visual input:

> ...Measuring my blood sugar has caused damage to my fingertips. There are calloused areas. A sensor and a diabetes pump are necessary. These would make things easier for us. If there were a sensor, it would have an alarm, it would beep—I can't see, but I can hear. Do I have one? No. It is a luxury product, and the state won't cover it... (P1)

Another individual reflected on the potential of automated systems to alleviate the daily demands of self-care:

> ...The blood sugar measuring device should be automatic and have voice prompts, so I wouldn't have to handle it myself. Ideally, sensors should provide verbal feedback. I wish insulin delivery could be automatic too—I could just live my life, and the insulin would inject itself. Technology is so important; it would be wonderful if machines were designed for people like us... (P5)

In addition to technology, participants spoke of necessary changes in their “lifestyle changes” to better manage their condition. Adjustments such as increasing physical activity, maintaining hydration, carrying emergency snacks, and following strict routines around medication and meals were commonly mentioned:

> ...This is a new life for me... I try to exercise, or at least stay active. For example, I keep my water bottle beside me; I don't drink from a glass. I also keep snacks with me in case my blood sugar drops... (P6)

> ...Of course, my lifestyle has changed significantly. For one thing, I pay much more attention to my health compared to before. I generally go for walks once or twice a week; I make sure my blood sugar doesn't drop or rise too much. Because of this, I have adjusted my lifestyle. I try to maintain my current health. I don't skip my insulin doses, nor do I skip meals. From now on, I plan to continue living this way... (P13)

Participants were determined to have another need for coping methods. The subtheme of “coping methods” included three codes: spirituality, humor, and positive thinking.

“Spirituality” emerged as a key resource, providing strength and comfort in the face of uncertainty. For some, prayer was an essential daily ritual that fostered resilience and hope:

> ...I always pray to Allah for strength to cope. Only He helps me... (P7)

> ...I am thankful for my current condition. I can see 10%, and I am grateful for that. Inshallah, I won't lose it—I take care to preserve it... (P8)

“Humor” also played a valuable role in helping participants deal with the psychological burden of vision loss. It allowed them to navigate difficult situations with lightness and reduced the social discomfort of discussing their condition.

> ...I joke with my friends, saying, “Don't get under my feet.” They are surprised at first, and then I add, “Because I can't see.” When I bump into things, I make jokes. But life goes on. In the beginning, I avoided crowded places so that I wouldn't have to explain my condition or draw attention to it... (P1)

For others, maintaining a “positive thinking” was a conscious and strategic way of coping with the long-term nature of diabetes. Reframing routine tasks as enjoyable or meaningful helped reduce emotional fatigue and preserve motivation.

> ...You could say I look at the bright side. For example, when walking, I try to see it as a hobby because if I thought I was doing it for an illness, it would feel exhausting. For this reason, I try to find enjoyment in everything I do... (P13)

4 | Discussion

DR, a long-term complication of diabetes, is one of the leading causes of vision impairment in individuals (Eroğlu 2018; Safwat et al. 2021). Vision impairment due to DR significantly impacts daily life and social activities, increasing individuals' dependence on others (Devenney and O'Neill 2011). Individuals with DR may encounter various challenges in diabetes self-management, which can negatively impact their quality of life (Kaminsky et al. 2014; Roberts-Martínez Aguirre et al. 2022). This study found that individuals with DR face many struggles in their daily activities, particularly in the areas of psychological well-being, treatment and monitoring, nutrition, and physical activity.

In this study, individuals experienced psychological challenges most closely associated with vision impairment in diabetes management. Participants expressed a strong need for their vision and a deep fear of further vision loss. Additionally, they reported concerns about developing complications beyond retinopathy. When diabetes self-management is not maintained over an extended period, the likelihood of microvascular complications increases. If individuals with DR do not effectively manage their blood glucose levels, the severity of retinopathy may progress, increasing the risk of additional complications (Shi et al. 2023). DR is already a challenging process, and the progression of vision loss or the development of additional chronic complications can be expected to further negatively impact individuals with DR. Effective diabetes management is essential to halt the progression of complications and prevent the onset of additional complications. A multidisciplinary approach is required to achieve this. Diabetes nurses play a key role in patient education, particularly by informing individuals about the importance of regular medical check-ups, including eye examinations and other routine screenings. Physicians oversee medical treatment, pharmacists provide guidance on insulin management, and dietitians play a crucial role in developing and optimizing medical nutrition plans. Additionally, caregivers provide essential support in medication administration and dietary adjustments, contributing to overall diabetes care.

In this study, stress was identified as one of the psychological challenges faced by individuals with diabetes and retinopathy. Individuals experienced stress due to the significant impact of vision impairment on their daily lives (such as being unable to read or feeling uncertain about administering the correct insulin dose), and they stated that this situation affected their blood glucose levels. Another qualitative study conducted with individuals with DR by Devenney and O'Neill (2011) revealed that the personal and social losses experienced by individuals had negative effects on their psychological well-being. Additionally, another study found that nurse-led mindfulness-based stress reduction interventions reduced HbA1c levels and improved diabetes self-management (Guo et al. 2022). Diabetes nurses can implement various stress management techniques (such as meditation, yoga, and cognitive behavioral therapy) to mitigate the negative effects of stress on diabetes and provide education to individuals.

As part of the daily struggles of diabetes management, individuals with vision loss reported facing significant challenges in treatment adherence and monitoring routines, particularly with tasks such as taking oral antidiabetics, administering insulin, and conducting blood glucose monitoring. This places them at a high risk of medication errors. A similar qualitative study found that participants often failed to complete essential diabetes treatment procedures due to vision loss, particularly struggling with insulin injections and reading numerical values (Coyne et al. 2004). As a result, all these difficulties in the treatment and monitoring process due to vision impairment in individuals with diabetes may hinder glycemic control. This situation may lead to the development of life-threatening complications, the emergence of comorbid diseases, and a decline in quality of life. Diabetes nurses are advised to provide up-to-date education on diabetes technologies, including continuous glucose monitoring devices, artificial pancreas systems, wireless insulin pumps, and generative artificial intelligence applications. Additionally, diabetes nurses should encourage individuals to use magnifying glasses and develop effective strategies to support medication adherence and prevent potential medication errors. These struggles in diabetes treatment also negatively impact individuals' ability to maintain lifestyle changes. In this study, individuals were found to experience difficulties with nutrition and physical activity. Studies have shown that individuals with DR face challenges not only in preparing meals but also in consuming them, due to the limitations imposed by vision loss (Coyne et al. 2004; Shi et al. 2023). Studies has also revealed that medical nutrition therapy is effective in achieving glycemic control and significantly improving HbA1c values (van Zuuren et al. 2018). Nutrition is one of the cornerstones of effective diabetes management (Evert et al. 2019). Therefore, it is important to find solutions to the nutritional issues that individuals with DR face in their daily lives. For diabetic individuals to receive support from their social surroundings and community, local health centers, support groups, and activities should be organized by municipal councils and non-governmental organizations. Since vision impairment significantly affects meal preparation, diabetes nurses should provide individualized guidance. The use of adaptive kitchen tools, such as talking measuring cups, high-contrast kitchen utensils, and large-print food labels, should be encouraged. In addition to nutrition and medication therapy, exercise plays a crucial role in diabetes management. Increasing physical activity and engaging in regular exercise enhance the body's sensitivity to insulin in diabetic individuals, thereby aiding in better blood sugar control (Taşkın Yılmaz 2015; Colberg et al. 2016). However, in this study, individuals stated that they stopped exercising due to vision impairment and avoided going outside due to a fear of falling. Another study found that the dependence associated with vision loss made outdoor walking and exercising challenging (Devenney and O'Neill 2011). Maintaining regular physical activity is essential for effective diabetes management (ADA 2023). Individuals with DR should be encouraged to engage in physical activity within safe and familiar environments to promote both safety and adherence (Ren et al. 2019). They may also exercise at home using resistance bands, lifting weights, utilizing treadmills, or cycling on stationary bikes. Additionally, smartphone applications and audible guidance systems can assist visually impaired individuals during exercise. With the help of trained guide dogs, they may also walk outdoors. Diabetes nurses, in collaboration with physical therapy and rehabilitation specialists, should educate individuals on exercises that can be performed independently, particularly in the home environment.

Individuals with DR reported a need for various supportive services to cope with the challenges they face in managing diabetes. In particular, they emphasized the importance of social support, including family support, support from health professionals, and support from friends. Family members play a crucial role in providing support in various aspects, including assisting with daily care needs, medication management, blood glucose monitoring, offering emotional support, and accompanying individuals to medical appointments (Busebaia et al. 2023; Mphasha et al. 2022; Sa et al. 2024). Similarly, support from healthcare professionals, particularly nurses, is essential for developing appropriate treatment plans, monitoring patients, preventing diabetes-related complications, and promoting behaviors that enhance diabetes self-management and overall health (Pasambo et al. 2024; Sørensen et al. 2020). Support from friends contributes to emotional well-being by ensuring that individuals feel they are not alone in coping with the disease (Higa et al. 2021; Sa et al. 2024). From this perspective, the findings of this study align with previous studies indicating that social support from family, friends, and healthcare professionals facilitates coping with challenges, promotes socialization, and helps individuals regain independence (Devenney and O'Neill 2011; Sa et al. 2024). Individuals with DR expect to receive support from their families, friends, and healthcare professionals in order to manage their diabetes self-management effectively (Sa et al. 2024). Healthcare professionals should communicate with individuals in a timely manner, deliver supportive educational activities, and provide guidance on relevant knowledge and skills. They should also assist patients in alleviating negative emotions, making autonomous decisions, enhancing their ability to cope with emotional and life-related stressors, and developing personal goals and positive action plans to actively explore self-management strategies that are suitable for them.

Although diabetes technologies enhance individuals' quality of life and significantly contribute to diabetes management, they pose a considerable financial burden in Türkiye (Gülen et al. 2023). In the study, individuals stated that they primarily needed diabetes technologies for effective diabetes management, yet they experienced difficulties in accessing them due to their high cost. The perception of diabetes technologies as luxury items limits individuals' equitable access to healthcare services (Gülen et al. 2023). However, these technologies have the potential to significantly facilitate daily life activities and diabetes management, reduce individuals' level of dependence, and enhance their overall quality of life (Naranjo et al. 2016; Polat and Avdal 2021). Therefore, it is crucial that health policymakers, researchers, and technology firms work toward advancing diabetes technologies and making them more affordable and accessible to a broader population.

Certain healthy lifestyle modifications are required for effective diabetes management (ADA 2023; IDF 2023). In this study, it was revealed that individuals with DR needed to make lifestyle modifications in order to better manage their diabetes. Participants took an active role in disease management by making significant changes in their lifestyles following the diagnosis. They developed strategies to increase physical activity, carefully regulate their dietary patterns, and manage insulin therapy effectively. The fact that individuals recognize the connections between lifestyle, physical health, and diabetes-related complications, actively manage their diabetes, and make efforts to control their health represents a positive outcome. Additionally, participating in training programs to gain knowledge about diabetes management and utilizing social support mechanisms by joining diabetes-related communities indicates that individuals are making proactive efforts to self-manage their diabetes effectively. In this process, diabetes nurses should provide personalized guidance by offering tailored nutrition and exercise recommendations, developing individualized treatment plans that meet patients' specific needs, and educating individuals on appropriate dietary habits, exercise routines, blood glucose monitoring, and insulin administration. Such nursing interventions will support diabetic individuals in effectively managing their condition and enhancing their quality of life.

Diabetes is a chronic condition that affects not only individuals' physical health but also their psychological well-being (Kalra et al. 2018; Greene et al. 2020). Individuals with vision impairment may face challenges in maintaining their daily routines and require diverse coping strategies. Individuals participating in the study used spirituality, humor, and positive thinking methods to coping method they encountered. In this study, spirituality emerged as a key resource that provided participants with strength and comfort in the face of uncertainty. Prayer functioned not only as a religious ritual but also as a coping mechanism that enhanced resilience and sustained a sense of hope. In the literature, individuals with strong spiritual beliefs have been shown to adjust better to medication treatment, and religious coping strategies have been found to positively influence diabetes care and management (Sukarno and Pamungkas 2020; Onyishi et al. 2022). Humor can serve as an important buffer against the physical and psychological threats experienced by individuals (Greene et al. 2020; Greene and King 2023). Indeed, in this study, humor helped participants reframe potential social barriers caused by vision loss, alleviating the psychological burden associated with their condition. Through humor, they were able to normalize their experiences and establish more comfortable and socially acceptable communication with others. Previous studies have also reported that humor strengthens individuals' social connections, reduces stress levels, and enhances emotional resilience (Crawford and Caltabiano 2011; Falkenberg et al. 2011; Greene et al. 2020; Greene and King 2023). In addition, positive thinking emerged as a key coping mechanism among participants. It was observed that individuals gave meaning to their daily diabetes-related tasks by reframing them through a lens of positive thinking. Similarly, in the study conducted by Sturrock et al. (2018), it was reported that when faced with stressors, individuals remained hopeful about the future, attempted to normalize DR, and this approach contributed to perceiving the condition not as a catastrophe but as a manageable health issue. As a result, diabetes nurses should educate individuals about coping methods and encourage participation in group therapy sessions to help them navigate the difficulties associated with diabetes management and daily life activities.

5 | Conclusion and Recommendations

This study determined that individuals with DR experience challenges in the areas of psychological, treatment, monitoring, nutrition, and physical activity, which hinder effective diabetes self-management. Additionally, the findings revealed that these individuals require support in the areas of social support, effective management of diabetes, and coping methods. Diabetes nurses should provide personalized self-management education for individuals with DR, considering their vision impairments. Educational materials should incorporate audio-based guides, large-print formats, and Braille resources to enhance accessibility. For blood glucose monitoring, the use of talking glucose meters, continuous glucose monitoring systems, and artificial intelligence-supported insulin infusion pumps can be recommended. Additionally, smartphone applications with voice-activated commands and wearable technologies should be suggested to facilitate diabetes management. Diabetes nurses should collaborate with ophthalmologists, endocrinologists, pharmacists, dietitians, and physical therapy and rehabilitation specialists to ensure a comprehensive and coordinated approach to diabetes care.

5.1 | Limitations

This study has three main limitations. First, the experiences and recommendations shared by the participants were based on their perceptions. Second, the study focused on a specific geographical area, which may limit the generalizability of the findings. Third, the fact that only female participants took part in the study may have influenced the diversity of perspectives.

Author Contributions

Tuğba Bilgehan: conceptualization, data curation, formal analysis, investigation, methodology, project administration, resources, software, supervision, validation, writing – original draft. **Münevver Sönmez:** conceptualization, investigation, resources, software, validation, writing – original draft. **Hülya Türkçapar:** data curation, formal analysis, visualization, writing – original draft. **Meleknur Göktaş:** data curation, formal analysis, visualization, writing – original draft.

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Ethics Statement

Necessary ethics committee permission to be able to perform the research was obtained from Ankara Yıldırım Beyazıt University Health Sciences Ethics Committee (16.01.2024/01-528). After receiving ethics committee permission, research permission was obtained from the hospital where the research would be performed. Voice recordings were encrypted and stored in a computer.

Consent

Participants had the purpose of the research explained to them and signed written volunteer consent forms.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.