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Research Article

Diabetes Experiences of Transition from Childhood to Adulthood Care

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Abstract

AIM: The present study was conducted to explain the perception of diabetic people about the transition of diabetes care from childhood to adulthood.

METHOD: This study with the hermeneutic phenomenology approach was conducted on 10 young people with type 1 diabetes with a history of childhood diabetes. They were selected through purposive sampling. Data were collected by semi-structured interviews until data saturation was reached. Then, data analysis was performed according to Dickelman's method. COREQ criteria for reporting qualitative research were used.

RESULTS: Three main themes of tedious marathons (laborious transition, constant do's and don'ts), unprepared transition (insufficient education, emotional exhaustion), and green sugar motivation (friendship with diabetes, beyond care, peer-seeking, freedom from dependencies) resulted from data analysis.

CONCLUSION: The findings of this study indicated the importance and necessity of planning and preparing patients with type 1 diabetes for the transition of care from childhood to adulthood, and the importance of emotional support during this transition.

Keywords: Care transition, diabetes, phenomenology, qualitative study

Introduction

One of the most important events in the life of people with diabetes is adolescence and the transition from childhood to adulthood (White et al., 2018). Cameron et al., (2014) in his study referred to irregular exercise and diet patterns, low adherence to treatment regimens, risky behaviors, and endocrine changes associated with puberty that leads to more insulin resistance as changes in adolescence that affects diabetes management.

The entry of people with chronic diseases into adolescence, along with the need for health care and lifestyle changes, is accompanied by other important changes and transitions (Iversen et al., 2019). According to Meleis (2010) theory, there are four different types of transitions in this period, such as growth transition (e.g., from childhood to adulthood), health and disease transition (from being healthy to the diagnosis of chronic disease), situational transition (feeling good about a hypoglycemic event) and organizational transition (transition from diabetes care in children to diabetes care in adults). The transition from childhood to adolescence often involves dramatic physical, hormonal, and psychological changes, and people with type 1 diabetes (T1D), in addition to the previously mentioned, also experience the transfer of childhood care to adulthood care (Meleis, 2010). This transition is a high-risk event and presents unique challenges to people with diabetes, families, and treatment teams (Lyons et al., 2014).

Based on the evidence, the risk of poor blood glucose control increases 2.46 times with the transition to adulthood (Lotstein et al., 2013), and only 14% of these individuals achieve the desired glycosylated hemoglobin (A1C) level (Miller et al., 2015), as the A1C index rises from 7.5% at the last visit in childhood to 9.2% at the first visit in adulthood (Lotstein et al., 2013). Also, the risk of developing complications from diabetes increases with the transition from childhood to adulthood, so that one-third of these people would develop early complications of diabetes (Dabelea et al., 2017). There is also evidence of an increase in hospitalization of people with diabetes during the transition from childhood to adulthood (Nakhla et al., 2009), and as the results of some studies show, there is a disruption in care during this transition (Garvey et al., 2012; Shulman et al., 2020). Prevention of confusion in people with diabetes is one of the main challenges of health care providers in the transition of care from childhood to adulthood and highlights the need for transitional care during this period (Gleeson & Turner, 2012). The number of people with chronic diseases that carry the disease from childhood to adulthood is increasing, and these people need support to increase their physical, social, and mental ability (Campbell et al., 2016).

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These cases show that diabetes care is delivered in childhood and adulthood with different approaches, and this transition of care is associated with the risk of follow-up discontinuity, decreased glucose control, and increased risk of acute and chronic complications of diabetes (Shulman et al., 2020). The World Health Organization also states that adolescents experience many barriers to self-care (World Health Organization, 2015), and this highlights the importance of considering an appropriate framework for care during this transition and supporting these individuals during the transition from childhood to adulthood (Allen et al., 2011). Understanding the experiences of individuals from the transition of care from childhood to adulthood is essential for designing an appropriate program (Garvey et al., 2014).

Understanding the challenges involved in the transition of diabetes care from childhood to adulthood helps to plan appropriate programs to improve this transition. However, there is no information on how to transfer this care from childhood to adulthood in Iran. Moreover, most studies have been conducted to explain the mothers' experience of caring for their diabetic children (Khandan et al., 2018) and compare families with healthy children and diabetic ones (Hashemipour-Zavareh et al., 2020), but the experiences of people with the transition of care from childhood to adulthood have not been considered. Therefore, the present study was conducted to explain the diabetic people lived experiences of the transition of diabetic care from childhood to adulthood.

Research Question

What is the meaning of the care transition from childhood to adulthood for people living with diabetes?

Method

Study Design

The present study was conducted with the hermeneutic phenomenology approach. This study followed the guidelines specified by the consolidated criteria for reporting qualitative research checklist (Tong et al., 2007) as much as possible in reporting on aspects of study methods, context of the study, analysis, findings, and interpretation of the findings.

Sample

In the interpretive phenomenology, the participants are generally selected based on their lived experience of the phenomenon, so in this study, in order to achieve a deep understanding of the lived experiences of people with diabetes from the transfer of diabetes care from childhood to adulthood, participants were selected using purposive sampling among young people with type 1 diabetes and a history of childhood diabetes who are willing to share their experience and can enhance or add to the rich and meaningful experience of this phenomenon. The sample of the study consisted of 10 people with type 1 diabetes. Data were collected from November 2019 to October 2020.

Data Collection

In this study, data collection was performed using semi-structured and in-depth face-to-face interviews with the participants and continued until reaching depth, richness, abstraction, and relevance. The researcher conducted all of the interviews, which lasted from 30 to 60 min, and each participant was interviewed once. Interviews were audio-recorded and transcribed for analysis. The place of the interview was determined with each participant (either in a clinic or home). Interviews began with general questions, such as "describe your experiences about the transition from childhood to adult care" and continued with semi-structured questions, including ''what were the changes in your life after this transition?"

Statistical Analysis

Data were analyzed by Diekelmann et al. (1989) method, interpretive phenomenology focuses on the experience of human beings and their interpretations of those experiences. This version of phenomenology contains a belief that the researcher should be immersed within the phenomena. This allows for the researcher to have a better understanding of the experience of each participant (Speziale et al., 2011), so that after each interview, the interview text was written down verbatim, and to get a general understanding, the text was read several times. Then, a descriptive summary was written for each text and hidden meanings were extracted from them by researcher. Selected copies of the texts or interviews were analyzed in research group, and the themes were identified and extracted. Then, in order to explain, clarify, and classify the themes, the disagreements and contradictions in the interpretations were determined and presented. Team members exchanged their ideas on extracting the topics and themes, and as the interviews continued, previous topics became clearer and evolved, and sometimes new ones emerged. The interview texts were then compared to identify, determine, and describe common meanings and functions. The basic patterns that connected the themes were then identified and extracted. A draft copy of the transcripts and themes along with selected texts was presented to the members of the analysis team (Diekelmann et al., 1989). Finally, 229 initial codes were created and sorted into eight sub-themes and three main themes based on differences and similarities. The MAXQDA-10 software was used to better manage the data.

Confirmability, credibility, dependability, and transferability were considered to assure various aspects of rigor (Guba, 1981). Therefore, by selecting the appropriate context, resources, and eligible participants, close prolonged and continuous interaction with the participants, adopting a team approach using collective team discussion, doing analytical comparisons and reciprocal referral to raw data, the validity of the study was ensured (Speziale et al., 2011).

Ethical Considerations

This study was approved by the Ethics Committee of Tehran University of Medical Sciences (IR.TUMS.VCR.REC.1398.863). Verbal and written information about the researcher, study goals, voluntary participation, and recording of interviews and de-identified publication of results were provided to all participants.

Results

A total of 10 people with diabetes with maximum variation in terms of gender (six women and four men) and marital status (two married people and eight single people) with the age range

of 21-30 years and a history of diabetes between 8 and 23 years participated in this study.

The results of data analysis were classified into three main themes of the tedious marathon (laborious transition, constant dos and don'ts), unprepared transition (insufficient education, emotional exhaustion) and green sugar motivation (friendship with diabetes, beyond care, peer-seeking, freedom from dependencies).

Theme 1 Tedious marathon
The transition of care from childhood to adulthood was like a tedious marathon, full of hardship with constant dos and don'ts. Participants shared their experiences of the difficulties of this transition, the repetitive care, and permanent limitations.

Laborious Transition: The transition of care from childhood to adulthood was difficult for participants, and changes such as puberty and going to college were accompanied by unhealthy sugar imbalances that left them in despair.

Patients described sugar imbalances during puberty as follows:

> *"What I experienced during puberty was the same fluctuations in blood sugar. Certainly, when I was stressed, it had a good effect on my blood sugar, but I tried not to lose it and continued to do so." (Participant no. 7)*

> *"I reached puberty early, my blood sugar fluctuated a lot, it affected my mood a lot, and I was very aggressive and nervous." (Participant no. 8)*

Frequent fluctuations in transition were frustrating for people with diabetes.

> *"At first, when my blood sugar went up and fell, I felt a tangle of tiredness, I was angry, I thought I would be free, but this game continued and its rules and principles were the same, only this time it was on me to manage it. It is hard to deal with its difficulties and limitations, something that never ends." (Participant no. 1)*

> *"It was hard at first. I could not push my regulars too much because I could have seizures in a bad shape, very bad. It was a bitter memory, and there were no positive points in it." (Participant no. 2)*

The Constant Dos and Don'ts: For participants, the transition from childhood to adulthood was the same as old care, the same dos and don'ts.

One of the participants said:

> *"The same precautions that diabetics take to check blood sugar, inject insulin, check sugar before going to bed and these have been from the beginning until now." (Participant no. 7)*

Another one said:

> *"Well, the care has not changed and it is the same as before. The only difference is that, I was a child before and could not understand my limitations and was not taking them seriously, but now I feel the danger." (Participant no. 1)*

Theme 2 Unprepared Transition
Another major theme of this study was unprepared transition; a theme that indicated the transition of care from childhood to adulthood without emotional and cognitive preparation. This theme included insufficient education and emotional exhaustion.

Insufficient Education: People with type 1 diabetes were taking care of their diabetes without education and did not even receive education during the transition from childhood to adulthood.

One of the participants describes his ordeal as follows:

> *"For the first 6 years, my diabetes was very terrible. Let me tell you that in our country, diabetes is really terrible. I was very young, I had no mentality about diabetes, and my family was not prepared. We had no information about diabetes, very severe hypoglycemic events, hospitalization many times during the year, and the blows I received. It was very hard for the first 5-6 years." (Participant no. 2)*

Another one said:

> *"There were no training classes in our city, and I did it without training. Maybe the guard that I have against diabetes is because of the lack of education that I had. Diabetes has not been introduced to me." (Participant no. 5)*

Emotional Exhaustion: Lack of mental readiness to accept the disease along with being blamed for the inability to manage the disease and mental anxieties caused by the transition from childhood to adulthood were among the experiences that I had as an unprepared person.

One participant in this regard said:

> *"They said you can't do it, we handed you over to yourself and you harmed yourself. After every seizure, every hypoglycemia, the emergency staff were saying; he has taken too much or too little insulin, why is it out of control? The family was upset, but then they treated me badly, saying that, why you are doing less about it." (Participant no. 2)*

Another participant referred to perceived stress as follow:

> *"Psychologically, why was I affected? I mean the stress of controlling my blood sugar; I was not supported by doctors." (Participant no. 5)*

Another participant talked about distrust:

> *"My mother upset me a lot of times; for example, she knew that soda was not good for me, but I could control it. Yet*

she told me with her eyes that I should drink less, which upset me a lot." (Participant no. 9)

Disbeliefs that may have sometimes been due to a lack of awareness.

"What was bothering me was the mental aspect of it. My sugar used to fall in the classroom and I had to eat something and go out. It was unbelievable for my teacher, and they used to say he is running away from the classroom, which upset me." (Participant no. 5)

Another participant referred to future anxieties and worries:

"I used to think to myself that, this is a problem for me. When I grow up, no one will marry me or I will not be able to have children. I did not have a good understanding. I was a child. I thought, with this disease I cannot have a good appearance in society." (Participant no. 9)

Theme 3 Green sugar motivation

Another theme in the present study was green sugar motivation. The sub-themes of friendship with diabetes, beyond care, peer-seeking, and freedom from dependencies reflected the green sugar motivation.

Friendship with Diabetes: Friendship with diabetes was one of the steps to achieve green sugar and participants described it as follows:

"I realized at the age of ten that, no one can help me in my life if I want something, so I decided to help myself so that my mother would be well, my father would be well, and I won't wake up in the morning with a seizure. I decided to become friends with my diabetes, because as we were enemies and I was trying to beat it, it was useless, so I became friend with it, I was by his side, I controlled it, I paid attention to it, I met the needs of my body as much as I could, I destroyed my guard, and then, it got better." (Participant no. 2)

"I accepted diabetes and grew up with it. In a way, I learned to live with diabetes. I learned that if I am worried about my future and my life, I should accept this in my life." (Participant no. 9)

Beyond Care: The green sugar motivation in patients was an effort beyond care. In fact, green sugar-motivated participants tried harder than usual.

"But now that I became more aware and once experienced ketoacidosis as a teenager, all of a sudden all of this made me more self-conscious and more focused on myself." (Participant no. 3)

Care in which independence is rippling.

"It has been two years now since I am writing my own insulin prescription and I do not go to the doctor, except for checkup. I see the answer to my checkup myself and decide based on it. I think something is happening inside me." (Participant no. 4)

***Peer-Seeking*:** All participants referred to peer-seeking and asking for their support in their statements. They saw their peers as an incentive to achieve green sugar, the peers they could learn from and teach them.

A participant introduced his peers as follow:

"I met many others like myself, who were successful people, and that was a motivation for both my life and my self-confidence. It was very easy to express the problems I have with them; things that one might not easily say to others. I could talk to people who were like me and that was very helpful." (Participant no. 1)

One of the participants spoke about the impact of peers on his awareness and experience as follows:

"Finding diabetic friends makes you more aware than before, and your experience increases and it feels very good, because you do not see a difference between you and them." (Participant no. 3)

Another one said:

"In 2017, I met a group of diabetics who were very energetic and loving, and it made me love my diabetes more and not be upset about my diabetes. There was someone in another city that helped me a lot on how to deal with diabetes through virtual communication, videos, and photos." (Participant no. 8)

Another participant said:

"My diabetic friends are very, very helpful. I am very motivated to help them. It makes me feel good. I learn from them. If I make a mistake somewhere and I have high blood sugar, it makes me feel very bad, but they say don't worry and give me solutions and I learn from them. I enjoy them and their company." (Participant no. 9)

Freedom from Dependencies: The feeling of liberation from dependencies was a pleasurable feeling that sufferers experienced under the shadow of green sugar motivation, a sense of fatasy, success, and freedom.

One of the patients said:

"It felt like I was being let go. I could go somewhere without a company to check my blood sugar and give me my insulin, and that sense of accomplishment that I felt was good. I can do it myself now. I have a feeling that I can do everything and if I want to stay somewhere, I do not have to have my mother or my brother with me to help me." (Participant no. 6)

Another one said:

"I expected my work to be easier and it got better. I controlled my blood sugar and took my insulin and I was no longer dependent on my mother. This injection gave me a good sense of independence." (Participant no. 8)

Another person said:

"Although I did it myself from the beginning, now I think I have done a great job, at least in overcoming my illness, which accompanies me every second. Thanks to my happy and good spirit, I have been successful so far and it feels great. I think I have done a great job compared to those who do not have diabetes and cannot stand one day of my life." (Participant no. 7)

Discussion

This study examined the diabetic peoples' experiences of care transition from childhood to adulthood. Findings of this study point to the challenges associated with the transfer of care and the efforts of patients to manage the disease during the transition from childhood to adulthood, which raises the need for careful planning during this transition.

One of the themes in this study was the tedious marathon, which referred to the difficult transition and the constant dos and don'ts during the transition. In support of this finding, other studies that have examined the care transition also referred to the transition of care from childhood to adulthood as a difficult process that leads to the experience of poor blood sugar control (Dabelea et al., 2017; Lotstein et al., 2013; Lyons et al., 2014; Meleis, 2010; Miller et al., 2015 & Nakhla et al., 2009). Some evidence points out poor management during the transition, failure to follow medication instructions, poor lifestyle, hormonal changes, and insulin resistance (Cameron et al., 2014; Nikbakht Nasrabadi et al., 2021a). This finding points out the need to empower people with diabetes for a successful transition because diabetes is a self-managed condition and the person with diabetes is at the center of his/her diabetes control decisions and experiences the consequences of his/her daily decisions (Dehkordi & Abdoli, 2017)

One of the highlights of this study was unprepared transition; a transition that takes place without adequate training and with emotional helplessness. Although the theme of emotional exhaustion has not been mentioned in other studies, the need for support during the transition has been mentioned (Shulman et al., 2019). Inadequate knowledge leads to unsuccessful management (Nasrabadi et al., 2021b). One of the themes extracted in the study of Garvey et al. (2014), which aimed to explain the experience of transferring child care to adulthood in people with diabetes, is in line with the findings of the present study and refers to the unplanned transition of diabetes care from childhood to adulthood (Garvey et al., 2014). The results of other studies also confirm this result, as they too refer to the transfer of care from childhood to adulthood without awareness (Hansen & Jensen, 2017; Shulman et al., 2018; White et al., 2018). However, training is an undeniable necessity in the transition of care that affects the quality of transition experience, because the description of programs and expectations leads to the success of the care transfer process (Shulman et al. 2019). Recent findings highlight the importance of careful planning for transition and the informational and emotional support of sufferers during the transition of care. Weissberg-Benchell et al. (2007) emphasize the need to develop programs for this transfer in the presence of health care providers, patients, and families at least 2 years before the transfer.

Another theme of this study was the green sugar motivation, which included the friendship of people with diabetes, beyond care, seeking peers, and freedom from dependencies. This finding is not seen in other similar studies, which can be explained by the different areas of research and different experiences of individuals.

Patients' efforts in the shadow of green sugar motivation was one of the positive points of care transfer in this study, which can be explained by Karlsson's et al. (2008) statement about psychological maturity and psychosocial changes in adolescence in people with diabetes and their tendency to become independent. Strengthening this finding is a way to overcome the gaps in the services provided by health care providers (Fisher et al., 2012; Heisler et al., 2010) and leads to the promotion of self-management and self-esteem of patients (Karlsson et al., 2008).

Conclusion and Recommendations

The transition of diabetes care from childhood to adulthood is similar to a tedious marathon, which is accompanied by difficulties and enduring the constant dos and don'ts. Unprepared transition leads to the initiation of insufficient care that, along with perceived anxiety, leads to a sense of emotional exhaustion. But ultimately, motivated by green sugar, the diabetic people learn to become friends with diabetics and, by seeking peers and going beyond care, enjoy the experience of freedom from dependence. The findings of this study indicated the importance and necessity of planning and preparing patients with type 1 diabetes for the transition from childhood to adulthood and the importance of emotional support during this transition.

Based on findings, it is suggested that guidelines should be designed for the appropriate transfer of people with diabetes from childhood to adulthood. It is also suggested that another study should be conducted to design and implement programs that facilitate the transition of care from childhood to adulthood.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Tehran University of Medical Sciences (Approval ID: IR.TUMS.VCR.REC.1398.863).

Informed Consent: Written informed consent was obtained from all participants who participated in this study.

Peer Review: Externally peer-reviewed.

Author Contributions: Concept – A.N.N., L.M.D.; Design – A.N.N., L.M.D.; Supervision – A.N.N.; Resources – A.N.N.; Materials – L.M.D.; Data Collection and/or Processing – L.M.D.; Analysis and/or Interpretation – A.N.N., L.M.D.; Literature Search – L.M.D.; Writing Manuscript – L.M.D.; Critical Review – A.N.N., L.M.D.

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