



# “I Like People to Treat Me Normally”: Barriers to Type 1 Diabetes Self-Management Among Adolescents

Aaliyah M. Momani,<sup>1,2</sup> Peter Callery,<sup>2</sup> Yin-Ling Lin,<sup>2</sup> Raghad H. Abduelkader,<sup>1</sup> and Heba Khalil<sup>3</sup>

Adolescents with type 1 diabetes face barriers that can have a negative influence on self-management behaviors. This study was an analysis of semi-structured interviews with adolescents, parents, and health care providers to better understand these barriers among adolescents in Jordan. Adolescents with type 1 diabetes reported individual-level barriers including feeling labeled, pitied, and stigmatized for having type 1 diabetes. They also discussed the system-level barrier of an education system that does not adapt to meet their needs. Individual- and system-level barriers are interrelated and could influence adolescents' decisions regarding whether to disclose their condition to others.

Type 1 diabetes is the most common endocrine condition among children and adolescents, and its rate has been increasing globally by 3–5% annually over the last half-century (1). Individuals with type 1 diabetes need to adhere to a strict and labor-intensive daily regimen (2). Coffen (2) described 600 steps to manage type 1 diabetes, which include, but are not limited to, daily insulin intake regardless of the type of insulin and the method of delivery; daily frequent blood glucose monitoring; nutritional planning that includes carbohydrate counting and must be tailored to an individual's preferences, age, weight, stage of development, culture, and lifestyle; insulin dose adjustments based on blood glucose levels, physical activities, and carbohydrate intake (with some types of insulin); avoidance and management of hypo- and hyperglycemia; screening for and treatment of diabetes-related complications such as retinopathy; and, finally, attention to the psychological and psychosocial well-being of the person with diabetes,

including issues such as depression and eating disorders. Adolescence is a crucial life stage, as it is a time of various developmental processes involving the brain, identity, and cognitive, emotional, and social functioning (3–5), all of which can be challenging. Having a chronic condition that requires adherence to a complex management regimen can make adolescence even more challenging (6,7).

## Diabetes Self-Management During Adolescence

Diabetes self-management is important because poor glycemic control is associated with the development of both short- and long-term diabetes-related complications. Short-term complications include hypoglycemia, hyperglycemia, and diabetic ketoacidosis, whereas long-term complications include retinopathy, nephropathy, neuropathy, and macrovascular disease. These complications can lead to devastating consequences and are associated with increased mortality rates (8). Thus, appropriate diabetes self-management is essential to attain and maintain glycemic targets and thereby prevent, delay, and/or slow the progression of complications (9,10). Poor glycemic control can also affect the quality of life of adolescents with type 1 diabetes (11).

Nonetheless, diabetes control may be poor during adolescence (6). For example, among 4,499 adolescents aged 13–18 years in the United States, only 32.4% achieved good glycemic control (A1C <7%, based on American Diabetes Association recommendations for this age-group) (12). In Jordan, little research has been conducted on adolescents with diabetes. In one published study of 145 adolescents, two-thirds of the

<sup>1</sup>Applied Science Private University, Amman, Jordan; <sup>2</sup>School of Biology, Medicine and Health, University of Manchester, Manchester, U.K.; <sup>3</sup>Faculty of Health Sciences, Higher Colleges of Technology, Fujairah, United Arab Emirates

Corresponding author: Aaliyah M. Momani, a\_momani@asu.edu.jo  
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participants had an A1C level  $>6.2\%$ , and the average A1C level was  $9.4\%$  (13).

There are two possible explanations for the generally poor glycemic control among adolescents. The first is physiological; hormonal changes during puberty affect insulin sensitivity, which can lead to poor glycemic control (14,15). The second is a combination of behavioral, psychosocial, and emotional factors, which can influence diabetes self-management (16).

This study aimed to understand how adolescents and their parents manage type 1 diabetes in Jordan.

## Research Design and Methods

### Design

Constructive grounded theory principles were used to guide this study (17). These principles are discussed in more detail below.

### Sampling

Two approaches to sampling were used—purposive and theoretical sampling. First, a purposive sample of adolescents (a variety of ages and sexes considered) and their parents were included, as they could inform this research. Table 1 summarizes the adolescents' demographics. Health care providers (HCPs) were purposively sampled based on their roles in providing care for adolescents with type 1 diabetes. Theoretical sampling was the second approach used and was a process of data collection based on emerging categories, allowing researchers to choose and add new participants and to modify the interview topic guide as new themes emerged (18). The aim was that theoretical sampling would continue until a theoretical saturation point was reached.

HCPs introduced potential participants to author A.M.M., who explained the study to them. Adolescents aged 10–19 years (based on the World Health Organization's age range for adolescents [19]) who were diagnosed with type 1 diabetes, parents of adolescents diagnosed with type 1 diabetes, and HCPs who care for adolescents with type 1 diabetes were eligible to participate if they could communicate in Arabic or English. Exclusion criteria included diagnosis with other chronic conditions, pregnancy, and inability to perform self-care because of their condition(s) based on their parents' or their HCPs' judgment. In total, 48

**TABLE 1** Demographic Data of Adolescent Participants

| Adolescent Participant Identifier | Sex | Age, years |
|-----------------------------------|-----|------------|
| A1                                | F   | 18         |
| A2                                | F   | 10         |
| A3                                | M   | 15         |
| A4                                | M   | 18         |
| A5                                | F   | 16         |
| A6                                | F   | 12         |
| A7                                | F   | 11         |
| A8                                | M   | 15         |
| A9                                | F   | 18         |
| A10                               | M   | 16         |
| A11                               | F   | 13         |
| A12                               | F   | 19         |
| A13                               | F   | 13         |
| A14                               | F   | 14         |
| A15                               | F   | 19         |
| A16                               | F   | 19         |
| A17                               | F   | 14         |
| A18                               | F   | 10         |
| A19                               | M   | 19         |
| A20                               | F   | 18         |
| A21                               | M   | 15         |
| A22                               | M   | 17         |
| A23                               | F   | 13         |
| A24                               | M   | 14         |
| A25                               | M   | 12         |

F, female; M, male.

participants were recruited, including adolescents, their parents, and HCPs.

### Ethical Considerations

Ethical approvals to conduct the study were obtained from relevant research ethics committees. Written assent and/or consent forms were obtained prior to

data collection, and participants were assured of confidentiality. All participants were given pseudonyms.

### Data Collection

Data were collected and analyzed concurrently. Participants were recruited from a university hospital in Jordan. Thirty-eight semi-structured and audio-recorded interviews were the main method of data collection, and these interviews were contextualized by field notes of the setting and interactions between adolescents and their parents. The interviews were conducted in a conversational manner to help adolescents and their parents respond as openly as possible, thereby helping them to concentrate on their perspectives while topic guides helped to maintain focus on the interview topic.

The topic guides were developed based on the literature. Three topic guides were developed as flexible tools to guide interviews (17)—one each for adolescents, parents, and HCPs. The topic guides for adolescents and parents were gradually developed over the process of data collection and analysis. Adolescents and their parents were interviewed either separately or jointly according to their preferences on the hospital premises, which explains why only 38 interviews were conducted with 48 participants. Another 13 follow-up interviews were conducted with 12 adolescents and 1 mother either face-to-face or over the phone. Follow-up interviews were used to clarify, further understand, and explore adolescents and/or parents' perspectives after the initial interviews, as well as facilitate investigation of gaps that came up during the course of data collection and analysis. This is an essential part of grounded theory methodology and assisted in reaching saturation of the categories (17). The lengths of interviews varied from 10 to 80 minutes, with shorter interviews conducted with HCPs and longer encounters with adolescents and their parents.

HCPs were interviewed to understand the context of providing diabetes care at the hospital and their views on the service provided for adolescents. The HCP interviews were conducted in their offices. Data were collected between October 2016 and April 2017.

### Data Analysis

Data analysis was achieved using the following measures: transcribing and translating the interviews; coding the data; performing constant comparative analysis; and writing memos.

Interview transcription was considered the first step in data analysis (20). All the recorded interviews were transcribed verbatim, and nonverbal cues such as sighs and laughs were incorporated into the transcribed text. At this stage, the participants' anonymity and confidentiality were ensured. Transcribing the interviews was an important part of the analysis, as it helped author A.M.M. become familiar with and understand what was happening in the interviews, raised questions from the data about the data, and helped to pinpoint what topics required further exploration in upcoming interviews.

Different levels of coding were used, and it was not a linear process. After conducting the first few interviews, line-by-line coding was performed. Then, patterns were identified, and the coding process moved to another level (i.e., focused coding), which resulted in identifying categories. Subsequently, axial coding was used, which helped researchers explore these categories in more depth, and this level of coding included constant comparative analysis, memo-writing, and identification of relationships between categories and subcategories, as well as theoretical sampling. Finally, theoretical coding helped to explain and connect the categories on a more conceptual level and was facilitated by memo-writing, diagramming, and constantly comparing this study's findings to the existing literature. An example of the coding process is presented in Table 2.

Memo-writing is fundamental to grounded theory research (17), and these memos helped in understanding the data at a deeper level. New ideas raised during the act of memo-writing assisted in distinguishing between categories and subcategories, experimenting with possible explanations of the data, and identifying new connections within the data, which then led to a more conceptual understanding of diabetes self-management among adolescents and their parents. Memo-writing was a continuous task throughout the process of data collection and analysis. The constant comparative analysis did not end when data collection was complete; rather, it continued by making comparisons with data from existing literature. NVivo, v. 11, qualitative analysis software was used to manage the data.

### Rigor

Rigor was enhanced by having more than one researcher involved in analyzing the data. Furthermore, credibility was enhanced by prolonged engagement in the field, negative case analysis, and critical and

**TABLE 2** An Example of the Coding Process

| Initial Codes                      | Axial Codes  | Categories               | Implications  |
|------------------------------------|--|--------------------------|---|
| Labeling, pitying, or stigmatizing | Attitudes of others (not immediate family members) that made adolescents feel different in social settings                                 | Individual-level barrier | Disclosing or hiding the condition from others → health implications in terms of managing the condition around others |
| Not understanding needs            | Within the educational setting (schools and universities), a lack of understanding regarding the needs of adolescents with type 1 diabetes | System-level barrier     |   |

Individual- and system-level barriers are interrelated.

reflective memo-writing. Moreover, theoretical sampling maximized the range of information obtained.

## Findings

Adolescents with type 1 diabetes discussed two sets of barriers: individual-level and system-level barriers. Individual-level barriers included attitudes some individuals within society have toward type 1 diabetes. These attitudes lead to labeling, pitying, or stigmatizing adolescents because of their type 1 diabetes. System-level barriers were identified within the education system. Individual- and system-level barriers were interrelated and can both influence adolescents' decisions regarding whether to disclose their diabetes to others, as adolescents typically wish to feel and be treated as normal among their peers. These findings reinforced the idea that adolescents wanted to be treated like any other person by individuals in the wider society and to not be subject to pity, sorrow, or stigmatization for their diabetes. As one participant put it:

*“This is what I like. I like people to treat me normally. This is exactly what I like, to be treated normally. I do not really like when somebody says . . . like, [not] to annoy her because she has diabetes.”* (Tala, 19-year-old female)

Adolescents saw the attitudes of some individuals in the wider society as a barrier to diabetes self-management because they made adolescents feel different for having the condition. These attitudes could be from adolescents' relatives, but never from their immediate family members, and they led to either labeling, pitying, or (less commonly) stigmatizing adolescents for having diabetes. Adolescents perceived themselves as labeled by diabetes and felt that others might pity them for

having the condition. This made the adolescents feel different, which is something adolescents do not like. As one participant stated:

*“. . . it was not nice, you know, the society's views about illnesses and things. I did not like telling [people], even my friends. I did not like telling them [about my diabetes], but I felt afraid that [if] something happens to me and that the people around me need to know, . . . I started to accept that. I feel like they feel, ‘Oh, we are sorry for her.’ They pity me. It is like this, and I do not like this, when they pity me. I do not like it.”* (Asal, 19-year-old female)

Some other individuals in the society had the belief that adolescents developed diabetes as a punishment for previous sins. This attitude made adolescents feel different, as they seemed to be stigmatized by others because of their condition. Perceiving diabetes as a punishment from God was never an idea that adolescents and their parents supported; however, sometimes, a few individuals within the society held views and beliefs of diabetes that were different from what the adolescents and their families believed. As one adolescent remarked:

*“I don't know. I feel like the society thinks in a retarded way. Like, if I tell my friends, I feel they will not treat me normally. I like people to treat me normally, so I did not tell them. Look, even my family—only my immediate family members know [about my diabetes], but [for] my older sister [who also has diabetes], everyone knows—like all our relatives, our uncles and aunts, everyone, all the relatives, and the neighbors . . . But when my sister got [diabetes], all the people gloated over [her diagnosis], like it is not a thing, but I feel the society somehow is retarded, for real. They started to say things. So, when I got it, I felt*

like, 'No, I am not telling anyone. My family is enough . . . .' When [my sister] was diagnosed, I remember that time . . . . It was my uncle's wife, actually. She was really mean. She is despicable and low. She started talking and telling all the people that it is because of sins . . . . The society is very retarded. Like, my sister, she gets so annoyed when she meets our relatives, like, when they greet her, they . . . pity her, and this is not nice at all. It is normal; I am a human [the same] as you, yeah, and something is better than other things [meaning that diabetes is better than some other conditions]. But you know how the society views not just us, [but] . . . anyone who has anything special. You feel that they look at them in a bad way." (Tala, 19-year-old female)

Tala's sister (who was diagnosed with diabetes before Tala was diagnosed) was stigmatized for her diabetes because one of her relatives believed that she developed diabetes as a punishment for her family's previous sins and that the family had, in essence, caused her diabetes. This type of attitude by others toward adolescents with type 1 diabetes is considered to be an individual-level barrier.

The main system-level barrier identified was with the education system. Some participants mentioned that some teachers in some schools did not allow adolescents with diabetes to leave the classroom when they needed to. As one participant said:

"Yes, the teachers did not understand [diabetes]. Like, if I needed to go out [for insulin], they would not always allow me." (Loia, 18-year-old male)

This barrier was not limited to adolescents in schools, but was also found in colleges and universities, with some of the participants reporting similar behaviors from their instructors. This kind of barrier could be considered an "individuals-within-systems" barrier. However, it suggests that the system did not adapt to the needs of adolescents with diabetes and that individuals within the system also acted as a barrier to adolescents' diabetes self-management, possibly because of a lack of guidelines for dealing with individuals with special needs such as individuals with type 1 diabetes.

Being labeled or stigmatized by having diabetes influenced adolescents' decisions regarding whether to disclose or hide their diabetes from others. Tala, for example, decided not to disclose her diabetes to others outside of her immediate family. During the interviews, adolescents acknowledged the important role their

friends and other individuals around them might play in case of an emergency, which they and their endocrinologists had discussed previously. However, some said they decided not to disclose information about their diabetes to others as the responses they received might have been negative. This finding suggests the potential for further difficulties with diabetes self-management (e.g., when deciding how to respond to invitations to share food, staying away from home when injections are required, informing others about the need for support, and responding to threats to safety such as severe hypoglycemia).

Adolescent participants expressed wanting to be treated like any other person by individuals in the wider society and to not be subjected to pity, sorrow, or stigmatization because of their diabetes. One participant described what he wanted, saying:

"To treat me like a normal human being, me just like the others, like, not in a special way, just like the others . . . ." (Ameen, 15-year-old male)

Individuals in the wider society can support adolescents simply by treating them like they would any other person. Adolescent participants said this would help them to integrate into society and not feel different. Being an adolescent is challenging, and having diabetes and being labeled by others can make adolescence even more challenging.

## Discussion

To our knowledge, this is the first study introducing barriers to type 1 diabetes self-management among adolescents in Jordan. In this study, adolescents reported facing both individual- and system-level barriers. These barriers can make adolescents feel different from their peers, which can influence their decisions regarding whether to disclose their type 1 diabetes to individuals around them. Choosing not to disclose the diagnosis can be risky in the event of a hypoglycemic or other emergency. Despite the availability of type 1 diabetes therapies, many adolescents with type 1 diabetes experience poor glycemic control (7,12), which is associated with the development of both short- and long-term complications (10), poor quality of life (11), and even premature death (8).

Individual-level barriers to diabetes self-management among adolescents may be explained by beliefs about diabetes, which in turn could be linked to culture, and specifically cultural beliefs about diabetes (and possibly

other conditions). In contrast, system-level barriers can be explained by limitations within systems that can affect diabetes self-management among adolescents.

Our findings indicate that the experience of living with type 1 diabetes is culturally constructed. Illness and health are socioculturally constructed concepts (21), meaning that social and cultural factors shape the experience of illness and health within a given culture. Moreover, as Napier et al. (21) wrote, “well-being is increasingly recognized as both biological and social, [and] health care providers can only improve outcomes if they accept the need to understand the sociocultural conditions that enable people to be healthy and make themselves healthier—i.e., to feel well.” This suggests the importance of culture in experiencing illness and in understanding how illness is experienced among individuals of a specific culture and around individuals with different beliefs. In our study, this concept was indicated by the differing beliefs regarding type 1 diabetes held by adolescents and by some other individuals in Jordanian society.

Adolescents did not like it when others pitied them because they wanted to feel “normal” and like their peers, which is expected during this developmental stage. One study showed that normalization was the core theoretical concept for adolescents with type 1 diabetes and was defined as “the ability of the adolescents to integrate diabetes into the background of their daily life by creating routines to make diabetes ‘part of me’” (22). Our study findings mirrored the findings of a Canadian study exploring stigmatization of adolescents with type 1 diabetes by Brazeau et al. (23). Their cross-sectional study involving 380 participants found a stigma prevalence of 65.5% (95% CI 60.7–70.3%). Furthermore, stigma was associated with poor glycemic control (odds ratio 2.25, 95% CI 1.33–3.80) after adjusting for age, sex, and treatment type.

Stigmatization of adolescents with diabetes may be explained by a lack of knowledge about diabetes and its causes, which may make others fear the condition. Feeling different was one of the identified challenges that adolescents with diabetes encountered in the United States, as well (24). In a descriptive qualitative study involving 16 individuals with type 1 diabetes aged 6–18 years, participants reported feeling different because of diabetes-related routines such as checking blood glucose levels and taking insulin injections, leading them to fear losing their friends and being alone because of diabetes self-management (24). Furthermore, Mulvaney et al. (25) showed that some barriers to diabetes

self-management can predict A1C levels among adolescents with type 1 diabetes. These barriers include stress, time pressure and planning, lack of social support, lack of parental autonomy support, and stigma.

Making adolescents feel different or stigmatizing them results in some adolescents choosing not to disclose their condition to the wider society for the reasons discussed above. Although not all adolescents and their parents experience negative views on diabetes from others, such responses, when they do occur, have the capacity to disempower adolescents, making them more cautious and inhibited because of the variability in the responses they receive from others.

The significance of this study’s findings is the potential impact of the identified barriers on adolescents’ diabetes self-management behaviors. Not disclosing their condition to others may negatively affect adolescents’ management of diabetes when they are around others such as their friends or in a school setting. In turn, in the event of an emergency such as a hypoglycemia event when away from home, the lack of knowledge of diabetes on the part of others may lead to serious complications or even life-threatening events.

Importantly, the adolescents did not have to experience negative views on diabetes by the wider society firsthand to feel the need to hide their condition from others; some of them had learned from their siblings’ earlier experiences that such negative views existed. Three reasons may explain the negative views of diabetes within the wider society. The first is that there are different cultural beliefs about the condition, including that the development of diabetes is an individual’s destiny as a punishment for previous sins. The second reason reflects a general lack of knowledge about diabetes, its management, and the role of others in diabetes self-management. The final reason is an absence of policies designed to help adolescents with diabetes integrate and manage their condition outside their homes, which could specifically explain the system-level barriers adolescents with type 1 diabetes faced in school settings.

## Implications

### Future Research

This study raised a question for future research, which is whether similar barriers hinder individuals’ diabetes self-management beyond adolescence and into the period of emerging adulthood (26). Managing diabetes while away from home can be difficult for emerging adults because self-management is complex and

intensive. Emerging adults might face difficulties adapting to new environments such as new educational institutions and workplaces. Additionally, they may face problems taking on their diabetes self-management completely independently, which can be stressful (27–29). The specific stresses can vary and may include decreased involvement from parents or other caregivers, poor eating habits, lack of life routines caused by the irregular nature of their school or work lives, and others (28,30). Therefore, exploring diabetes self-management among emerging adults in the context of Jordanian culture will be important in assisting HCPs and family members of young people with diabetes in understanding their needs and providing appropriate support during this life stage.

### Public Policy

Adolescents' reports of their interactions with others in wider society suggest that the public needs more education in terms of understanding diabetes, its causes, and how important their role is in assisting adolescents in managing their condition. This type of public education is important because adolescents who choose not to disclose their diabetes to others could face significant risks such as when emergency situations arise. Educating the public might be accomplished in various ways and on different levels, including engaging organizations interested in diabetes, which are already working to improve diabetes and its management in Jordan. Furthermore, policymakers are encouraged to develop policies to adapt for the needs of adolescents with type 1 diabetes in schools, colleges, and universities.

### Conclusion

Adolescents with type 1 diabetes in Jordan faced numerous barriers to diabetes self-management, both at the individual and system levels. These barriers have an important influence on adolescents' diabetes self-management and particularly may affect their decisions regarding whether to disclose their condition to others. Efforts are needed to allow adolescents with diabetes to make that disclosure without being treated as different or stigmatized.

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### DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

### AUTHOR CONTRIBUTIONS

A.M.M. designed the study, collected and analyzed data, and wrote the manuscript. P.C. and Y.-L.L. contributed to the study design and data analysis. R.H.A. and H.K. contributed to the manuscript writing. A.M.M. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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