Research Article

Ghana Social Science Journal
2025, Vol.22 (2): 81-100
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Publisher: School of Social Sciences **UG**

"How can I get diabetes! I want to get healed": Experiences of adolescents living with type 1 diabetes in Ghana.

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Abstract

This study explored the lived experiences of adolescents with type 1 diabetes and the challenges of self-care management. A qualitative design (interpretative phenomenological analysis approach) was employed where ten adolescents consisting of males and females, with a mean age of 16.8 years were interviewed from two hospitals. Data was analyzed using the interpretative phenomenological analysis, which generated three superordinate themes: 1) Searching for answers, 2) Adjusting to diabetes diagnosis and 3) Coping with diabetes. Adolescents described experiencing 'abnormal' symptoms which led them to seek medical attention, and the negative emotions they experienced upon diagnosis with type 1 diabetes. They reported their diabetes self-care management as demanding and exhaustive, with disruptions from school activities. Their ways of coping included receiving social support from family and friends, having faith in God, and receiving education from medical experts and diabetes support groups. Findings were evidence of an incomplete care system for these adolescents as their main model of care was biomedical care. There is therefore the need to include psychological and social interventions to constitute a holistic care system for improved wellbeing after diagnosis.

Article History: Received March 30 2025 Accepted 8 December 2025

Keywords: Type 1 diabetes mellitus, Adolescents, Diabetes self-care, Lived experiences, Qualitative.

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Introduction

Type 1 diabetes mellitus (T1DM) incidence and prevalence have increased over the years globally with a current overall figure in 2024 being 9.15 million people, of which 1.81 million are younger than 20 years (International Diabetes Federation [IDF], 2021). Although type 1 diabetes accounts for 5% (IDF, 2021) of the different types of diabetes, it is a major health concern due to its life-long complications and financial burden at both the individual and the national levels. In Ghana, for instance, the cost of diabetes-related expenditure across all ages is $258.8 per person (IDF, 2025). The diagnosis of type 1 diabetes, its chronicity, complications, and complex treatment regimen are a significant burden for affected children and their families (Gong et al., 2024; Madrigal et al., 2020). For adolescents, the diagnosis of the illness mostly comes with reactions such as shock, confusion, sadness, and anxiety as they move from living normally to making lifestyle changes and accommodating the demands and challenges of their diabetes treatment regimen (Aguiar, 2021; King et al., 2017; Montali et al., 2022).

Diabetes self-care management of adolescents is affected by psychosocial barriers inherent in growing through the adolescence stage (Gürkan & Bahar, 2020; Montali et al., 2022; Paduch et al., 2017) which includes anxiety about having diabetes, distress and frustration with treatment adherence, embarrassment and despair, feelings of isolation, poor sleep quality, and suicidal ideations (Ng, 2022; Owusu & Doku, 2024). These negatively affect glycemic control and treatment adherence, thereby increasing complication rates and impacting the overall well-being of these adolescents (Khadilkar & Oza, 2022). They have to grapple with challenges such as the lack of regular blood glucose monitoring, frequent hyperglycaemia, experiencing burnout and missing hospital appointments, and being disinterested in managing their diabetes (Aguiar, 2021; Montali et al., 2022; Ng, 2022). Meanwhile, adherence is necessary to avoid short term complications (e.g. hyperglycaemia and diabetes ketoacidosis) and long-term complications (e.g. visual impairment, foot ulcer, neuropathy, and reproductive ill-health), coupled with high levels of psychological distress (Agiostratidou et al., 2017; Ng, 2022; Tomic et al., 2023; Owusu & Doku, 2024).

Adolescents with type 1 diabetes have to deal with the changes that come with the transitional phase of adolescence while handling the self-care management regimen of the illness (Gürkan & Bahar, 2020). This twofold burden has been asserted to cause fatigue, stress, and anxiety which can have a negative impact on adherence to treatment, glycemic control, complication rates, as well as their general well-being, and quality of life (Zhao et al., 2018). They experience psychosocial distress from adjusting to and maintaining a change in their lifestyle for good self-care management and optimal glycemic control, and yet, psychosocial care for these patients may not be the focus of healthcare centers in Ghana. This study therefore sought to investigate the experiences of living with type 1 diabetes and the psychological and social challenges that arise from managing this chronic illness. The study aimed at exploring 1) incidences which led to adolescents being diagnosed with type 1 diabetes and their reactions to the diagnosis, 2) challenges adolescents encountered in self-care management of the illness, 3) psychosocial barriers to diabetes care 4) coping strategies adolescents adopted to manage the psychosocial barriers.

Methods

Research design and setting

The researchers used the Interpretative Phenomenological Analysis (IPA) approach (Smith, 2008; Smith et al., 2009) to explore the lived experiences of adolescents, with the assumption that each adolescent experienced the phenomenon differently and the meaning of the lived experiences could be subjected to interpretation. Adolescents were recruited from the National Diabetes Management and Research Center of the Korle-Bu Teaching Hospital and the diabetes clinic of the Greater Accra Regional Hospital in Accra, Ghana. These sites are major referral centers for the management of chronic illnesses. Records at the Korle-Bu Teaching Hospital showed an average of 3,000 attendances monthly. The average daily attendance at Greater Accra Regional Hospital was about 200 patients.

Participants

The target population consisted of adolescents from ages 10 to 19 years with type 1 diabetes who visited Korle-Bu Teaching Hospital and Greater Accra Regional Hospital. Adolescents were eligible to participate if they; a) had been diagnosed with type 1 diabetes for at least one year, which provided them with enough experiences that can be shared, b) lived in the Greater Accra Region, and c) had no mental health problems. Ten (10) adolescents were purposefully selected, consisting of more females (n=7) than males (n=3). The mean age of the adolescents was 16.8 years with most of them (n=6) being in senior high school. Their mean body mass index was 17.3 kg/m2 with a mean glycated haemoglobin level of 9.0mmol/mol. Nine of the adolescents were on insulin and diet management while one was on tablets, insulin and diet management (See Table 1).

Interview guide

A semi-structured interview guide was used to collect the needed information from the participants. The interview guide had six (6) open-ended questions (with probes) which focused on how adolescents were diagnosed with the illness, their reactions upon diagnosis, challenges with self-care management, the psychosocial barriers experienced, and how they coped with the barriers.

Table 1: Demographic and clinical characteristics of the participants (N=10)

Participants	Gender	Age	Education	Treatment	Duration of diabetes	BMI (Kg/m2)	HbA1c (mmol/mol)
					Mean (SD)		
					5.8(4.2)	17.3(9.4)	9.0(5.2)
Sandy	Female	15	JHS	Tablet, insulin, diet	1	21.48	12.1
Col	Male	19	JHS	Insulin, diet	3	21.22	10.7
Kobby	Male	19	University	Insulin, diet	7	17.47	10.6
Akua	Female	15	SHS	Insulin, diet	4	-	-
Chris	Male	18	SHS	Insulin, diet	14	22.02	8.3
Bless	Female	13	JHS	Insulin, diet	4	20.03	14.9
Rash	Female	18	SHS	Insulin, diet	2	21.1	14.8
Ella	Female	17	SHS	Insulin, diet	11	24.97	9.8
Nun	Female	19	SHS	Insulin, diet	8	24.61	8.8
Afia	Female	15	JHS	Insulin, diet	4	-	-

Noted:
JHS: Junior High School; SHS: Senior High School; BMI: Body Mass Index; HbA1c: Glycated Haemoglobin

Procedure

Data was collected from the hospital sites and from participants' homes. The objectives of the study were explained to the prospective participants, and they were given the opportunity to ask questions for clarity. Participants were assured of confidentiality and anonymity of their responses, and their right to withdraw from the study at any time. For minors (less than 18 years old), consent was sought from their caregivers. Assent forms were thus signed by five adolescents whereas adolescents aged 18 years old and above consented to the study independently. Permission was sought from participants to record the interviews, and each participant was given compensation of GHS 10 (equivalent to £2 at the time of the interview). Most of the interviews were conducted at participants' homes or the hospital based on their preferences and some of these interviews were conducted in a local language (i.e., Twi). The interviews lasted between 30 to 120 minutes and were audio recorded with consent from the adolescents.

Ethical considerations

Ethics clearance was obtained from the Ethics Committee for Humanities of the University of Ghana (ECH 054/18–19). Approval was also sought from the head of the National Diabetes Research Center at KBTH and the Public Health Unit in charge of research at the Greater Accra Regional Hospital. Additionally, the study adhered to the declaration of Helsinki (2013) ethical principles for medical research involving human participants

Data analysis

Data was analysed using the interpretative phenomenological analysis (Smith, 2008; Smith et al., 2009). First, audio-recorded interviews were transcribed verbatim, and those conducted in Twi were translated into English. The transcripts were read and re-read several times for familiarity and to gain a general representation of the participants' experiences. Analysis then began with one transcript at a time. Thoughts, reflections, and preliminary codes were noted and written down upon reading each transcript. Emergent themes were recorded and then clustered into groups of themes according to common features in terms of meaning. This process involved the researchers imagining a magnet, with some themes drawing others in, helping to organize and clarify them (Smith, 2008).

The emergent themes were confirmed by re-examining each transcript and then illustrated with supporting quotes from the transcript to ensure they had been adequately represented and grounded in the data. This process was then repeated for every transcript. On completion, the themes for each transcript were matched and combined into master themes to offer a merged 'picture' of participants' experiences. Being a bottom-up approach, common themes amongst the emergent themes (represented as sub-themes) were categorized into themes which then culminated into superordinate themes.

Reflexivity and trustworthiness

The second author (MP), who collected the data, had no experience with the illness, thus she easily went into the research with no biases. She sought to understand the experiences of living with a chronic illness such as type 1 diabetes, reading and gleaning knowledge from literature. Therefore, from data collection through to data analysis, each experience was seen as unique, and meanings given by the researchers to each experience were given distinctively. Lincoln and Guba's (1985) framework was used to increase the trustworthiness of the study. Thus, we ensured that there was no previous existing relationship established with participants. In developing the interview guide, care was taken to tailor the items on the guide to help answer the research questions. The participants recruited were also appropriate people to help answer the research questions and the process of data collection and analysis were also done with rigour, following the tenet of IPA.

Findings

Three superordinate themes emerged from the analysis of participants' transcripts: (1) Searching for answers, (2) Adjusting to diabetes diagnosis, and (3) Coping with diabetes. Each superordinate theme had various themes and subthemes as presented in Table 2.

Table 2: Superordinate themes, themes and sub-themes for adolescents (N=10)

Super-ordinate themes	Themes	Sub-themes
Searching for answers	Journey to diagnosis	· Symptoms of illness · Learning about the illness
	The aftermath of diagnosis	· Initial responses - "How can I get diabetes"? · Making sense of the diagnosis
Adjusting to diabetes diagnosis	Self-care challenges	· Difficulties with dietary plan · Pain from injections
	Diabetes and its effect	· "You become a different person" · Balancing school and treatment regimen · Emotional distress
Coping with diabetes	Social support and spiritual coping	· Social support from family and friends · Praying and having faith in God
	Receiving information to cope	· Receiving professional support · Joining a support group

Superordinate theme 1: Searching for answers

Adolescents were asked to describe their experiences surrounding the diagnosis of type 1 diabetes. Two themes captured their experiences: 1) Journey to diagnosis and 2) The aftermath of diagnosis.

Theme 1: Journey to diagnosis

This theme represents the circumstances that made participants seek treatment. Most of the adolescents described experiencing symptoms that aroused their curiosity.

Subtheme 1: Symptoms of illness

Adolescents experienced symptoms of ill health which could not be explained. They could not tell what these symptoms were, but they knew 'there was something wrong with their health'. These symptoms included frequent urination, frequent thirst and hunger, reduced energy and weight loss. The persistence of these symptoms alerted the adolescents' caregivers to seek medical treatment as depicted in the following quotes:

Before the diagnosis, I had frequent urination, frequent thirst, weight loss and my energy level had also reduced. I went with my mother to the hospital, and my blood and urine samples were taken to the lab for investigation. The doctor at the Government Hospital confirmed to me and my mother that I had diabetes from the results of the test (Col, 19, male).

Some parents, however, were knowledgeable about diabetes and therefore they suspected their children had diabetes when they noticed the symptoms they were experiencing. Thus, their knowledge and suspicion influenced their health-seeking behaviour. As one adolescent noted:

When we went to the hospital, my mother told the doctor that she had heard about children with diabetes and was afraid of some of the symptoms I was having. She then insisted on a lab test, and it proved it (Akua, 15, female).

Thus, these unusual physiological changes caused the adolescents to visit the hospital to get answers to questions about their health which led to the diagnosis of diabetes.

Subtheme 2: Learning about the illness

Following their diagnosis with diabetes, adolescents were educated about measures they needed to take to manage their condition, given the chronicity of the illness. Most of them indicated that doctors and dieticians provided vital information about food, exercise, injuries and medications intake. As they reported:

> I was told not to eat starchy foods. I should eat food which contains more fiber and I should exercise more. I should also be injecting the insulin, every time and also, I shouldn't hurt my body or get any sore, because it can get serious and could not heal or something (Kobby, 19, male).

> For me, they taught me it can kill your kidney, it can make the eyes go blind, when you get a sore, the sore can become big and can lead to amputation of the leg (Bless, 13, female).

The adolescents recounted the impact of their diagnosis and the negative emotions they experienced, knowing they had an incurable illness.

Theme 2: The aftermath of diagnosis

While some adolescents experienced complete denial, others merely accepted their diagnosis which caused them to experience negative emotions. Over time, they were educated by health professionals to engage in good diabetes self-care behaviours, to maintain good glycemic control and prevent complications. These are depicted in the subthemes below.

Subtheme 1: Initial responses - "How can I get diabetes"?

Some adolescents experienced shock at their diagnosis because they viewed themselves as healthy and therefore could not believe the sudden diagnosis with type 1 diabetes. They expressed intense sorrow because they believed their lives would never be the same after the diagnosis, stating:

> I asked myself 17- I was then 17- 'how can I have diabetes at 17, I don't believe it'. So, I went for Form 3 first term, and I was still eating the sugary foods. I still didn't believe I have diabetes (Rash, 18, female).
>
> For the first time I wept…at the age of six (6) knowing I was going to be piercing myself, injecting, and eating different things from what others are eating, I didn't feel good (Ella, 17, female).

As the adolescents accepted their diagnosis and experienced the emotions that came with having a chronic illness, they began to come to terms with their condition and began to make meaning of the illness.

Subtheme 2: Making sense of the diagnosis

Despite the negative emotions, some of the adolescents tried to give further understanding of their diagnosis and make meaning of it. Some perceived the cause of the illness as 'divine', suggesting that 'God had a hand in it'. This is what a couple of them stated:

> I have to accept because it is God who allowed it. Apart from that I don't know what caused it (Afia, 15, female).
>
> I didn't know the cause of it. When I asked my parents, they said they don't even know, and it is only God who knows. I think God has the answers (Sandy, 15, female).

Others ascribed the cause of the illness to genetic influences. They believed the cause of the illness was hereditary because of their family history of diabetes. This perhaps helped them to demystify their prior experience of unexplained ill health as depicted in the following quotes:

> To me personally, I think it is inheritance because my father's side [because] they have diabetes… yeah my mother's side they also have it. Ermm my grandfather was a diabetic so let's say it was through diabetes he died. My father too…his mother too was a diabetic and through diabetes she died (Rash, 18, female).
>
> My grandmother had the diabetes, but we didn't know. It was when I was diagnosed that my father said his mother died from that sickness (Akua, 15, female).

Super-ordinate theme 2: Adjusting to diabetes diagnosis

This super-ordinate theme represents the adolescents' process of adjusting to being diagnosed with diabetes. In adjusting to the illness, adolescents experienced self-care challenges and the effects of diabetes. The themes which culminated into this super-ordinate theme are self-care challenges, and diabetes and its effects.

Theme 1: Self-care challenges

Adolescents reported experiencing challenges with their self-care management as they struggled with the multiple daily self-care activities they had to engage in.

Subtheme 1: Difficulties with dietary plan

The adolescents revealed the challenges they experienced while adhering to their dietary regimen. One of them indicated how confusing the diet was since the proportions of food she had to eat were far less than what she used to eat, coupled with the arduous task of keeping up with the recommended diet. She reported:

> Very difficult…I just can't pay attention to all the things I've been asked to do…it's very complicated ... they have also added quantity, it's difficult. I was instructed to eat local (brown) rice, and the stew should be more than the rice... how? I've not seen some before aha...it's making things difficult. I can't really pay attention to it but sometimes I try but not all the time. (Rash, 18, female).

Most adolescents desired their old way of eating, which influenced them to sometimes eat non-recommended foods. They found themselves torn between adhering to their dietary regimen or satisfying their cravings. As some noted:

> I have been following it, but when I go to school, sometimes when it's break time, I will say that oh, let me have a drink because before having diabetes, I used to take them. Sometimes I eat the things I've been told not to eat. I just feel like eating them, so I eat (Afia, 15, female).

> With the diet, I don't really stick to it. Sometimes, when I feel like eating a certain kind of food, I do it. I eat them even though I know it's not good for me. My mother has been talking but sometimes I just want to eat what I feel like eating (Sandy, 15, female).

Not only were they struggling to adhere to dietary plans, but they were sometimes influenced by what friends were eating. As one participant indicated:

> When I go to school, I eat the same foods as my friends. I don't want them to be asking me why I am eating something different (Chris, 18, male).

This participant like many others was non-adherent in his bid to conceal his illness his schoolmates as he wanted to be seen and treated as 'normal' and this was likely to negatively affect diabetes management.

Subtheme 2: Pain from injections

Most adolescents complained of pain from injecting insulin to the extent that some had contemplated stopping the injections, while others yearned for a permanent solution to their illness which will end the injections. For instance, two adolescents reported:

> I ask myself why I have to take an injection every day. Won't I rest for a while? Initially I felt like stopping the injection because of the pain I was feeling (Bless, 15, female).
>
> I don't like… [injections] … I think that am I always going to be injecting the insulin? I want a solution to stop injecting it. I feel pains in my body (Kobby, 19, male).

The distress of injecting themselves everyday made the adolescents express the desire to stop. They felt pain and discomfort with this routine, but they had to continue injecting themselves.

Theme 2: Diabetes and its effects

The realization that the condition was chronic further took a toll on the adolescents both socially and psychologically. They talked about how diabetes made their lives different, the challenges of maintaining their regimen in school and the emotional distress experienced.

Subtheme 1: "You become a different person"

Having type 1 diabetes caused a change in the adolescents' personal lives and their lifestyle, which made them feel different. They felt entrapped and alone as their caregivers tried to 'shield' them from likely temptations of straying from their treatment regimen. Some adolescents cried or sobbed as they recounted how they felt, as reported below:

> I feel something like I'm being isolated. I have now become a different person. Sometimes too, I don't know why I am not meeting with my friends, I feel like maybe I'm being now a social outcast (Nun, 19, female).
>
> I'm not like the way I used to be. At first, I used to go out but now I have to be indoors. My mother will not let me go out, she will tell me that like when I go, I'll take in drinks and all that so she wouldn't let me go (Rash, 18, female).

Subtheme 2: Balancing school and treatment regimen

There were reports of experiencing academic challenges by most of the adolescents since they were still schooling. They complained that the illness disrupted their academic life, stating:

> I was diagnosed in JHS and during that time, whenever the symptoms of hypo[hypoglycaemia] start, I have to come home, and my studies will be left behind, and I can't cope with them. (Nun, 19, female).
>
> Sometimes I forget to take my insulin shots before going to school. It happened several times and they had to bring me home. I was sent to the school clinic one time when I was vomiting and feeling weak, and the nurse asked me if I had any illness and I told her yes 'I have diabetes' Also, sometimes I have to go for a review, so I've been skipping school a lot and it has affected me [academically] (Chris, 18, male).

These accounts showed that the adolescents were not incorporating their treatment regimen properly into their daily activities. It also suggested that there was a limited exchange of information between their school and the adolescents and their families and so their condition was not known to school authorities.

Subtheme 3: Emotional distress

The adolescents reported that they sometimes experience sadness because they were socially isolated by their peers following an episode in school, suggesting some form of stigmatisation. As two adolescents recounted:

> Sometimes I go hypo in school and collapse. When you come back it's like nobody wants to play with you...I became lonely and sad (Afia, 15, female).

Living with type 1 diabetes also evoked negative emotions and kept the adolescents on edge every time. They had uncertainties about their future and expressed negative emotions about the long-term implications of having diabetes:

> I just feel sad like, having this sickness. I have been thinking that they say this kind of diabetes when you are a man you can't be giving birth, so I have been thinking about it most often. I don't know what will happen (Kobby, 19, male).
>
> I fear the future. I am scared that I'll get sick and be admitted at the hospital. I don't like being admitted at the hospital (Rash, 18, female).

Despite the challenges and effects of diabetes on their lives, the adolescents learned to cope with this long-term illness as highlighted in the following superordinate theme.

Super-ordinate theme 3: Coping with diabetes

Although these adolescents faced challenges with the illness, they learned to adjust and manage the illness by employing strategies and receiving support that enabled them to address the emotional challenges associated with the illness. They had social support, engaged in spiritual exercises and received information about the illness to help them cope with it.

Theme 1: Social support and spiritual coping

Encouragement and support from family members helped the adolescents to navigate the emotional and practical challenges from the complexities of their treatment regimen. They had social support from family and friends.

Subtheme1: Social support from family and friends

This form of support came from family members most especially with their physical presence, their solidarity, and open communication. Family members avoided foods that the adolescents were supposed to stay away from to ensure the adolescents adhered to their dietary regimen. They also provided an enabling environment for open conversations to foster better management of adolescents' condition. Two adolescents indicated that:

> Because of me there are certain things the whole family is not eating. Like I've been asked not to take in this margarine and spices but first when we cook, we used to add it but because of me, all of them don't take it. (Rash, 18, female).
>
> My parents and my siblings, we sometimes talk about the illness like (pause) um…they say um I don't take instruction so it's making me lose weight. They also think about um…some complications later so we will be talking about it (Kobby, 19, male).

Other adolescents reported that their friends sometimes helped them to manage their illness by giving them advice. One reported that she received support from her friend who also had diabetes:

> I have a friend who is older than me who also has type 1 diabetes. She checks on me and advises me on how I should take care of myself (Akua, 15, female).

Thus, when support was not sought from parents due to the lack of intimate relationships with their adolescents, friends were a good source of social support.

Subtheme 2: Praying and having faith in God

This theme depicts how adolescents coped spiritually. While some engaged in prayers to God, others expressed their strong faith in God that they will be healed. They communicated their illness to God, believing that he can cure them for their diabetes to disappear, as exemplified by the following quotes:

> I want to get healed and I know God will heal me. Every day I use it to pray and meditate on it. I know I will wake up one day and it is gone (Akua, 15, female).
>
> I believe that one day God will speak for me, and I will be healed. That is what I believe. Though they said you cannot get healed, I know God can do it (Nun, 19, female).

These adolescents believed God could cure their illness, despite being told that it was incurable. Having this belief that all hope was not lost implied Chris was not going to give up. He had come to accept that his illness could not be wished away but he had faith that God was dependable, and God would see him through the challenges of managing type 1 diabetes. These quotes reflect the level of confidence some of the adolescents had in their faith in God as their healer, which helped them cope with the distress of having and managing type 1 diabetes.

Theme 2: Receiving information to cope

The adolescents had some form of education from the health professionals after diagnosis, which also gave them a better understanding of their illness and how to cope with it.

Subtheme 1: Receiving professional support

Most adolescents reported they had some education from the medical experts. This was especially about their dietary regimen and the long-term complications that may arise from poor self-care management. Only one adolescent reported seeing a psychologist who helped him to manage his illness as depicted below:

> The nurses and doctors told me diabetes is a sickness you shouldn't joke with. It's not a curable disease. You can manage it. You may get blind and a lot of things, so you should be careful about it especially with the diet (Sandy, 15, female).
>
> Previously, I used to cry, cry, and cry almost every day until just recently I went to see a psychologist for help (Rash, 18, female).

The education and cautions about diabetes management and likely diabetes complications made participants aware they were not to take the illness lightly.

Subtheme 2: Joining a support group

Some adolescents mentioned that they had joined a support group organized by a non-governmental organization that focused on providing them with support such as access to information about their illness, as depicted in the following quotes:

> Sometimes with the help of the diabetes group, I feel that I'm not alone. Even some of them are nurses and all these encourage me. I got to learn a lot there (Nun, 19, female).

> The Diabetes Youth Care has helped me. They educate us on how to take care of ourselves (Ella, 17, female).

These support groups educated the adolescents and gave them encouragement, so they did not feel alone. This serves as a form of emotional support that helped the adolescents to navigate the care associated with their condition.

Discussion

This study aimed at exploring the lived experiences of adolescents with type 1 diabetes in Ghana, challenges encountered in the self-care management of the illness, psychosocial barriers to care, and how these challenges and psychosocial barriers are managed by the adolescents. Findings showed that for the adolescents and their caregivers, their experiences with the disease began with a search for explanations for their symptoms as these were unusual physical manifestations. This suggested that they believed the biomedical model of health could address their concerns, which is consistent with previous findings, where caregivers had expressed the need for an explanation for their children's illness as they made hospital visits (e.g., Holmström & Söderberg, 2022; Iversen et al., 2018; Usher-Smith et al., 2015). Holmström & Söderberg, (2022) for instance reported that for the young people with diabetes, the journey of being diagnosed with type 1 diabetes began with them noticing unfamiliar sensations and emotions in their bodies.

Having been diagnosed with diabetes, the adolescents experienced negative emotions in the form of denial and feelings of sadness, consistent with previous findings (e.g., DeCosta et al., 2020; King et al., 2017; Montali et al., 2022). DeCosta et al., (2020) for instance described a state of denial where children deliberately ignored their diabetes management as they described the illness as an unwelcome intruder, until over time, they accepted their diagnosis. Similarly, in the present study, it took some time for the adolescents to make sense of and come to terms with their diagnosis.

In accepting their new condition, some of the adolescents acknowledged their family history of diabetes, while other just simply accepted the diagnosis as "the will of God". These religious and hereditary perspectives have also been reported in existing literature (e.g., Abolhassani et al., 2013; de-Graft Aikins et al., 2019; Wallin & Ahlström, 2010). Ghanaians are known to be religious (71.2% Christians) in every aspect of their lives, especially in relation to their health. Thus, it is not surprising that the adolescents in the present study gave a spiritual meaning to their diagnosis, which further reflected in how they coped with their illness.

The adolescents found the treatment regimen difficult to adhere to due to the many activities they had to perform daily, and of which they lacked the motivation and endurance. Having diabetes and engaging in school activities for instance posed a challenge for the adolescents consistent with Holmström and Söderberg's, (2022) report that young people found the school environment stressful in relation to their diabetes management. In the present study, some adolescents reported skipping their insulin injections before going to school, which often resulted in hyperglycaemia, and other time they experienced hypoglycaemia in the course of the day. The pain they experienced with their daily injections made them want to give up or skip injecting themselves. This supports a previously study that indicated that people with diabetes sometimes wanting to take a 'diabetes holiday' where they would forget about being a diabetes patient (Polonsky & Anderson (2017).

The adolescents further reported that their friends' actions sometimes hindered their ability to adhere to their dietary regimen corroborating previous findings of adolescents engaging in negatively health behaviours for fear of losing their friends or in a bid to fit in among their peers (e.g., Chao et al., 2016; Holmström & Söderberg, 2022; Lou et al., 2024). This suggests the vital role that peers can play in the lives of these adolescents with diabetes. It also suggests that perhaps the adolescents had not incorporated the illness into their self-concept and hence they seemed to detach themselves from their illness when they went to school and were therefore likely to be non-adherent.

The adolescents expressed sadness about feeling isolated because their caregivers restricted their social activities out of fear of neglecting their diabetes care. Some also expressed experienced sadness because they were socially isolated by their peers following an episode in school such as collapsing from hypoglycaemia, suggesting some form of stigmatisation. Other challenging experiences reported by the adolescents were their own desire not to feel restricted with their dietary intake and missing out on schoolwork because of clinical appointments or falling ill while in school, which undoubtedly affected their academic performance. They also expressed fear of being hospitalized, developing diabetes complications and dying from diabetes. These findings are consistent with existing literature of adolescents experiencing the many fears of living with diabetes (e.g., Epp et al., 2019; Gürkan & Bahar, 2020; Holmström & Söderberg, 2021; King et al., 2017; Silveira et al., 2019).

Despite all the distress from having diabetes, the adolescents learned to cope with their illness which they had come to accept as incurable. Their coping strategies included religious coping and receiving social support from family and friends. They also received information from medical experts and other peers who had diabetes. Literature has shown the positive effect of social support in lessening the burden placed on adolescents (e.g. Holmström & Söderberg, 2022; King et al., 2017). Thus, adolescents in the present study who were receiving support were likely to cope better with diabetes. Religious coping is not a new phenomenon, because in the Ghanaian context, most people tend to ascribe spiritual meaning to chronic illnesses (Atobrah, 2012). For instance, Nyarko et al. (2014) found that religiosity cushioned the effect of psychological distress in diabetes. This coping mechanism provided relief from the burden of living with diabetes. Furthermore, in the present study, education from medical experts helped the adolescents to understand their illness and engage in good self-care activities and maintain a healthy life (Jönsson et al., 2012).

Limitations and recommendations

Despite the contributions of this study, findings are limited to the lived experiences of adolescents with type 1 diabetes. Future studies could explore an in-depth understanding of their experiences regarding the number of years they have lived with the illness. This study did not set out to understand the lived experiences of adolescents diagnosed with diabetes as a basis to plan an intervention. However, the findings undoubtedly show there is the need for further studies aimed at designing an intervention that would help newly diagnosed adolescents deal with the emotional distress during diagnosis and thereafter. An intervention study can also be designed to ultimately help family members of such adolescents to learn how to support their children and manage the psychological impact the family members themselves experience, while trying to be a good support system.

Clinical implications

The findings of this study was evident that the care for these adolescents was not holistic/ biopsychosocial, since the main model of care for them was biomedical care. Receiving professional psychological intervention upon diagnosis was near to none. Therefore, there is the need for interventions from clinical and or health psychologists to address the psychosocial needs of adolescents with type 1 diabetes, from accepting the illness, to adjusting to it, and learning to live with it in perpetuity.

The adolescents' narratives suggested there was a lack of disclosure of their health conditions to school authorities, indicating limited exchanges between their families and the school authorities. When schools are aware of their students' health conditions, they would be more likely to make the needed arrangements for such adolescents to comply with their diabetes self-care activities in school regularly and more religiously. This would limit how often they miss/ skip school, and subsequently, their academic performance would improve.

Conclusion

This study provides valuable insights into the lived experiences of adolescents with type 1 diabetes in Ghana. It highlights the challenges and barriers these adolescents face, including adjusting to lifestyle changes, experiencing emotional distress, and disruptions in their academic work resulting from hypoglycaemic and hyperglycaemic. Despite these challenges, the adolescents employed various coping strategies, such as religious coping, social support, and information seeking, to manage their illness. Findings are evidence of an incomplete care system, suggesting the need for a holistic and comprehensive approach to care, which incorporates biopsychosocial support, particularly from clinical and health psychologists, to improve adolescents' diabetes care. Additionally, collaboration between families and school authorities is crucial to ensure they receive the necessary support to boost their diabetes self-care and to thrive in their academic and social environment.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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