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Psychosocial challenges of adolescents living with type 1 diabetes mellitus: a qualitative study

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Abstract

Background Type 1 Diabetes Mellitus (T1DM) is the most common endocrine disorder among young people worldwide. Living with T1DM as an adolescent can be psychologically and socially challenging. However, nursing care often concentrates on physical needs, such as treatment adherence and preventing physical complications. This study aimed to explore the psychological and social challenges faced by adolescents living with T1DM in the Ghanaian context.

Methods Using a descriptive phenomenological study, fourteen adolescents (aged 12–17 years) living with T1DM were purposively sampled from the Paediatric Endocrinology Unit of the Komfo Anokye Teaching Hospital in Kumasi, Ghana. Face-to-face individual interviews were conducted using an interview guide and data analyzed thematically.

Results The two themes; psychological challenges in living with T1DM and social challenges in living with T1DM and eight subthemes identified revealed that adolescents with T1DM expression emotional challenges such as sadness, fear, behavioural changes, and spiritual beliefs about the origin of their condition. The social challenges experienced by adolescents with T1DM included stigma, social isolation, secrecy, and disruption to schooling. The adolescents' psychosocial challenges were interrelated and often impaired their overall well-being.

Conclusion Adolescents living with T1DM face similar psychological and social challenges as their peers elsewhere. However, their belief that T1DM has spiritual causes highlights the need to enhance their understanding of their condition, while supporting their psychosocial wellbeing.

Keywords Adolescent, Psychological, Social, Type 1 diabetes mellitus, Qualitative, Ghana, Stigma

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Background

Type 1 Diabetes Mellitus (T1DM) is a chronic disease characterized by the destruction of insulin-producing β-cells in the pancreas, with its pathogenesis pointing to an interaction of genetic and environmental factors [1]. T1DM is associated with significant mortality and economic cost worldwide, with increasing incidence in children and adolescents [2]. The International Diabetes Federation [3] estimates that approximately 9 million people were living with T1DM in 2022, of whom 1.52 million were under the age of 20. Additionally, about 20,000 new cases of T1DM in adolescents are diagnosed each year. T1DM is also associated with increased risk for microvascular and macrovascular complications, including retinopathy and neuropathy, that impact the overall quality of life of individuals living with the disease, resulting in significant mortality and economic cost worldwide [2].

Individuals living with T1DM must follow a well-defined self-management plan that includes regular insulin use, blood glucose monitoring, physical activity, adaptive coping strategies, and healthy eating habits to achieve personalized glycaemic goals and prevent diabetes-related complications [4]. These daily self-management activities for T1DM can be physically and emotionally demanding, and often individuals need support from family and healthcare professionals to successfully manage the disease without overwhelming their personal resources [5], leading to a wide range of psychosocial challenges [6].

Adolescence, the period between 12 and 17 years, is a unique developmental stage between childhood and adulthood, characterized by rapid biological, mental, and social development, as well as a strong desire for independence in all areas of life [7]. Adolescents with T1DM, in addition to the normal developmental and life pressures, face several psychosocial burdens from living with a chronic illness, such as depression, stress, and worries resulting from managing a demanding long-term condition, compared to their peers of similar age without T1DM [8]. These psychosocial burdens have been linked to lower quality-of-life levels and overall well-being among adolescents with T1DM [9].

Previous studies in Ghana reveal that T1DM has a deleterious impact on young people's physical wellbeing, education [10] and mental health, leading to sadness, isolation, anxiety and suicidal ideation [11], which may transcend to their caregivers. Despite the rising incidence of T1DM among adolescents and the associated psychological and social challenges throughout the illness trajectory, in Ghana, the Ministry of Health National Guidelines for the Management of Diabetes Mellitus do not include guidelines for assessing and managing disease-related psychosocial difficulties [12]. Furthermore, hospital-based care for adolescents with T1DM often focuses on preventing physical complications, neglecting the management of the psychosocial challenges they face living with a chronic illness. This situation has led to many adolescents with T1DM struggling to manage their condition, missing follow-up appointments, and not adhering to treatment [13]. An in-depth investigation of the psychological and social experiences of adolescents with T1DM can offer healthcare providers additional insight to support adolescents with T1DM and mitigate the impact of their condition on their wellbeing. This study explored the psychosocial experiences of adolescents with T1DM who receive healthcare in a tertiary healthcare facility in south-central Ghana.

Methods

Study design and setting

A descriptive phenomenological design was employed to explore the lived experiences and challenges of adolescents living with type 1 diabetes mellitus (T1DM) in Ghana. Descriptive phenomenological design is ideal for the study as it emphasizes understanding the essence of a particular experiences to provide an understanding into the lived experiences of study participants [14, 15]. The design therefore assisted in examining contextual factors unique to the psychological and social challenges of adolescents in living with T1DM.

The study was conducted at the Paediatric Endocrinology Unit (PEU) of the Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana. KATH functions as a referral centre for all health facilities in the Kumasi Metropolitan area, as well as the Ashanti Region and the Northern and Middle belts of Ghana. Its central position and commercial significance make Kumasi an attractive destination for individuals from various ethnic backgrounds. KATH has a well-established PEU with two clinical consulting days each week, seeing 60 adolescents and young children with DM.

Study population and sampling

The study population included all adolescents diagnosed with T1DM who reported to the PEU of KATH on an outpatient basis. To ensure credibility of the study, purposive sampling was employed to intentionally select participants who could provide in-depth insights based on their lived experiences thereby facilitating a deeper understanding of the phenomenon under study [16]. The researchers therefore selected participants between the ages of 12 and 17 years, lived with T1DM for at least 6 months after initial diagnosis, who attend regular follow up visits of not less than four visits from the time of initial diagnosis and receiving formal education. Participants were however excluded in the case their parents/

guardians were unable to consent to their participation in the study.

Researcher's reflexivity

In the case of the first author as a graduate student with an academic background in social sciences and a nurse working with adolescents with T1DM in a different facility, the researcher approached the study with prior knowledge about adolescent behaviour and participation in research studies. Being familiar with the developmental stage of the participants, helped build trust during interviews. However, this required careful reflection to avoid assumptions during data collection and analysis. To address this, preconceptions were discussed before data collection and the researcher deliberately focused on participants' descriptions. A reflexive journal was also kept throughout the research process and engagement in regular discussions with the other authors was done to critically examine interpretations of the data.

Data collection and analysis

Data were collected through face-to-face interviews from February to March, 2019 using a semi-structured interview guide developed by the authors from the review of related literature and the study objectives. The interviews, led by the first author (a female MPhil Nursing candidate) were audio-recorded with participants' consent, took place in one of the consulting rooms at the clinic, as parents or guardians and their adolescent wards preferred that space. Interviews were all conducted in the English language as all adolescents could communicate in the English language. Parent or guardian presence during the interview were circumvented to allow the researchers obtain the authentic voice of the adolescents without parental influence and reduce desirability bias where adolescents may alter responses to please parents. Participants' anonymity was maintained by assigning each a unique number. Additionally, the authors' objective impressions and events occurring during the interviews were documented in a filed note.

Participants were recruited with the support of the nurses and doctors at the clinic, who introduced the researchers to the prospective participants. The researchers met with each participant and explained the study's purposes and procedures to their satisfaction. After a parent or guardian agreed to participate in the study, the adolescent was approached and informed of the purpose of the study in language they understood. For both adolescents and parents who agreed, their contact details were collected to schedule a convenient date, time, and venue for the interview. Again, a notice was placed on the notice board of the PEU for adolescents and their parents/guardians interested in the study to contact the principal investigator. Twenty-one participants and their parents showed interest to partake in the study. Three parents however later declined due to time constraint as their wards were preparing for their final school examinations. Data collection continued until thematic saturation was achieved with the fourteenth participant, at which point additional data did not contribute new themes or deepen existing categories [17]. Each interview lasted between 45 and 60 min. To ensure methodological rigour, data collection and data analysis were done concurrently. This allowed for ongoing comparison across interviews which led to the refining of interview questions and probing of emerging areas.

Data analysis

To ensure that all perspectives from participants regarding the phenomenon of interest were captured, data analysis was conducted using inductive thematic analysis following [18]. At the end of each interview, recording was listened to in full and transcribed verbatim by the first, second and third authors. Transcripts were read repeatedly to achieve familiarization and identify ideas. Initial codes from all the transcripts were manually generated inductively by the first, second and last authors through detailed, line-by-line analysis.

To enhance consistency and transparency, the first, second and last authors independently coded a subset of transcripts and collaboratively developed an initial coding framework. The framework was then applied across the dataset. Coding was then iteratively refined and compared across transcripts to support the development of coherent themes. Regular peer debriefing among the three authors were held for in-depth discussions on coding decisions, refine themes, and ensure shared understanding across adolescents' psychological and social challenges in living with T1DM. In the event of disagreement on themes and subthemes, a consensus meeting was held for a final decision to be made. Coding revisions and analytic decisions were documented throughout the process.

Ethical considerations

The study was approved by the Institutional Review Boards of Noguchi Memorial Institute for Medical Research (NMIMR) of the University of Ghana (NMIMR-IRB CPN 011/18–19) and the Committee on Human Research, Publication and Ethics (CHRPE) of the School of Medical Sciences at the Kwame Nkrumah University of Science and Technology (KNUST) Kumasi (CHRPE/RC/192/18). Before an adolescent was recruited to be part of the study, a written informed parent or legal guardian consent was obtained. The objectives, potential risks, and benefits of the research were explained in an age-appropriate language to the adolescent. Adolescents were informed that their involvement was voluntary and

Table 1 Characteristics of participants

Participant Number	Age (years)	Level of Education	Ethnicity	Religion	Period living with T1DM
P1	15	Junior High School	Akan	Christian	1 year 2 months
P2	12	Primary School	Akan	Christian	8 months
P3	17	Senior High School	Akan	Christian	4 years
P4	16	Senior High School	Akan	Christian	4 years
P5	13	Junior High School	Nanumba	Muslim	1 year
P6	14	Junior High School	Ewe	Christian	8 months
P7	16	Senior High School	Akan	Christian	1 year 6 months
P8	15	Junior High School	Akan	Christian	7 months
P9	12	Junior High School	Akan	Christian	6 months
P10	14	Junior High School	Akan	Christian	7 months
P11	13	Junior High School	Akan	Christian	6 months
P12	17	Senior High School	Nanumba	Muslim	3 years
P13	14	Junior High School	Namumba	Muslim	6 months
P14	15	Junior High School	Akan	Christian	9 months

Table 2 Table of themes and subthemes

Theme	Subthemes
Psychological challenges in living with T1DM	Sadness and suicidal thoughts
	Fear of Diabetes-Related Complications
	Behaviour changes
	Spiritual causal attribution of the disease
Social challenges in living with T1DM	Stigma
	Self-isolation
	Disease Concealment and Non-Disclosure
	Influence on Schooling

that they could withdraw from the study at any time without penalty after which a written assent was obtained.

Rigor of the study

To ensure trustworthiness of the study, the researchers followed the criterion as proposed by [19]. A purposive sampling technique was employed to select participants who could provide accurate responses to the phenomenon under study. The interview guide was kept simple yet open-ended to elicit an in-depth description of the phenomenon under study. The interview guide was further piloted using five participants to assist in refining and improving its structure and content. The interviews were engaging by asking probing questions to elicit participants experiences. All interviews were audio recorded and transcribed verbatim immediately. To reduce biases, the first author kept a reflective journal where personal experiences were reflected considering that she works with adolescents with T1DM in a different facility. Preconceptions were discussed before data collection and the researcher deliberately focused on participant's description. Peer debriefing among the authors were held to ensure agreement on the identified codes for in-depth discussion. Though initial coding was conducted by the first, second and last authors, all the authors reviewed and agreed upon the identified themes and subthemes ensuring credibility and rigor of the findings. Following initial analysis, participants were invited to provide feedback on the emerging themes and subthemes to ascertain whether these truly reflected their experiences. To ensure anonymity, adolescents were identified with their corresponding interview orders with the 1st person represented with 'P1' along with their ages.

Results

Characteristics of participants

The adolescents involved in this study were aged 12 to 17 years (Table 1). Ten were females, eleven were Christians and all had been living with T1DM for less than half a decade.

Themes and subthemes

Two themes emerged from this study which were; psychological challenges in living with T1DM and social challenges in living with T1DM, and eight sub-themes (Table 2).

Psychological challenges in living with T1DM

This theme covers adolescents' thoughts, emotions, and perceptions of living with T1DM. From the data analysis, four subthemes emerged related to the psychological challenges faced by adolescents with T1DM: sadness and suicidal thoughts, fear of Diabetes-Related

Complications, behaviour changes, and spiritual causal attribution of the disease.

Sadness and suicidal thoughts

Most participants (11) reported feeling sad after being diagnosed with T1DM. Four participants said they felt unhappy and had thoughts of ending their lives. Among these, one attempted suicide following the diagnosis. This was mainly experienced in the early stages after being diagnosed. Overall, they felt they were very young to have diabetes, being the only person in their family with T1DM, and believed they would no longer need to eat sugary foods.

> *"I was very sad. I ask myself, how can a young person as me be diagnosed with diabetes? I am too young to have such a disease. I feel very sad that have this condition, I am young for this condition". (P 11–13 years)*
> *"Initially, I just wanted to die. Because of this, I will not eat so I can go into hypoglycaemia and die". (P 2–12 years)*
> *"I feel sad that no member of my family has this illness, not my siblings, my father or mother. I am the only in the family with the diagnosis and this make me very sad". (P 8–15 years)*

Fear of diabetes-related complications

Out of the 14 participants, most adolescents (seven females and two males), experienced panic and anxiety about living with T1DM. They were often afraid of developing complications linked to T1DM, such as losing their sight and other parts of their bodies. This is how two of them expressed their fears:

> *"My main fear is that I will develop complications later in life. I am scared my leg will be cut off one day. I have lots of fears, but this is my greatest fear". (P1-15 years)*
> *"I am so afraid one day I may lose my sight totally and not be able to see again. Sometimes the injection sites become hard and I am afraid I will lose that part of my body; part of my body will be cut off". (P 5–13 years)*

Behaviour changes

Some of the adolescents (7) reported experiencing a change in their usual behaviour, particularly in how they respond to emotions. They said they became either more withdrawn or hostile after being diagnosed with T1DM.

> *"I was always used to fighting with my mates but now I don't fight with them as they knew me to be". (P 4–16 years)*
> *"I have become somehow cruel. I have become very aggressive, unnecessarily aggressive. Whatever you do to me, I will also do the same but I was not like this". (P9-12 years)*

Spiritual causal attribution of the disease

Some participants (57%) emphasize the spiritual beliefs they held regarding the cause of their condition. Most of these adolescents stated that their parents seek spiritual alternatives to treatment from churches, witch doctors, and spiritualists, where they are given a range of spiritual instructions to follow.

> *"This condition is spiritual; it has been spiritually bought for me. I believe it is my aunties, from my father's family. I had a dream about it. They bought it for me in a dream". (P 14–15 years)*
> *"I went to church and I was told this is illness spiritual. The behaviour of one of my aunties was evident that the illness is not just an ordinary illness, it is spiritual. These things are evident to make me see that it is spiritual". (P 7–16 years)*
> *"Someone was bewitching me. At times when I visit my grandparents and I listen to their conversations, it makes me believe this is spiritual. My mother has a younger sibling and the way she behaves, if you are not careful you will call her a witch. I have heard it several times that this condition is spiritual from my family". (P 1–12 years)*
> *"At times my mother goes to church and spiritualists. They gave her directions to use oil and some leaves to bathe me at night around 12am for three days or four days". (P 8–15 years)*

Social challenges inliving with T1DM

These were the difficulties adolescents with T1DM face when interacting with others, adapting to social norms, or functioning effectively within society. Four subthemes emerged to describe the social challenges faced by adolescents with T1DM: Stigma, Self-isolation, Secrecy, and Influence on schooling.

Stigma

Some participants (6) experienced various forms of shame from their friends, colleagues, and sometimes family members after they learned of their diagnosis. These individuals withdrew from them, refused to associate with them, called them names, and displayed displeasing expressions when they saw them. These

reactions made the participants feel shameful and dishonourable, as they expressed in their voices:

"My best friend in school was the only person that I told. When I told her that I have diabetes, that very day, she started frowning her face towards me. Nowadays, she doesn't associate with me". (P 6–14 years)
"When she knew I had diabetes, whenever I come close to her, she sees me as something ugly, unpleasant and unkempt. It's as if I look like something detestable". (P 14–15 years)

Self-isolation

This subtheme relates to the insufficient interactive contact between adolescents with T1DM and others. For been stereotyped, some (8) participants did not desire to associate with their peers or take part in social activities. Others separated themselves to prevent developing skin injuries from play activities as directed by their physicians.

"When I noticed she did not want anything to do with me, I also forgot about her. Nowadays I don't want to mingle with anyone". (P 6–14 years)
"The health professionals said I should not engage in vigorous play so I do not get hurt. I therefore, do not even play with anyone. Every day when I come back from school, I don't play with anyone so that I don't get hurt and develop a wound". (P 11–13 years)
"When I had diabetes, the doctor told me I should be very careful because when I get injured and I am not lucky part of my body will be cut off. Since then, I like to be alone and not engage in play to get hurt". (P 5–13 years)

Disease concealment and non-disclosure

Ten (10) out of the fourteen (14) participants kept their diagnoses confidential, especially from their peers; either by word of mouth or in the way they performed their daily self-care activities. They did not disclose their diagnosis due to fear of stigma, social rejection, or having their condition made public.

"If someone knows about the illness, he or she wouldn't feel comfortable to associate with me. I have to hide it so that I can feel free with my boys and class members. I have never thought of telling them". (P 2–12 years)
'I can't take my injection in front of them. Sometimes I go to the lavatory or I will ask them to excuse me. So, when I go and they are there, I will just step back or I rather greet and send the injection to the lavatory". (P 9–12 years)
"No, I don't feel like telling anyone. Maybe if I tell someone, that person will make it public". (P 11–13 years)

Influence on schooling

Most of the participants (10) indicated that the diagnosis of T1DM has negatively affected their studies. Some had to remain day students as their parents wished to supervise their management. Others also reported a decline in their school performance following the diagnosis of T1DM.

"I'm sometimes not smart. There are times I need to be smart but I can't. My father always tells me that nowadays you are not smart you have to think fast. In a way, I will say I am forgetful about things quickly. (P 9–12 years)
"It affected my education at the SHS level. I couldn't complete school because when I go to school sometimes, I go into hypoglycaemia. There were times the least thing I will be admitted and have to miss classes. (P 14–15 years)
"I am a day student. Due to T1DM, I could not go to the boarding house. I want to be a teacher, but because of the condition my family wants me to offer a distance program so I can stay home for the monitoring of my medicines". (P 2–12 years)

Discussion

This study explored the psychosocial experiences of 14 adolescents with T1DM who were receiving healthcare in a tertiary healthcare facility in south-central Ghana. The findings revealed that adolescents with T1DM experienced psychological challenges, including sadness and suicidal ideations, fears of complications of diabetes, behavioural changes and attribution of their conditions to spiritual cause. Their social challenges included self-stigma and stigma from others, self-isolation, disease concealment and non-disclosure, as well as disrupted schooling.

Findings of the present study revealed that participants were sad to be living with T1DM. The majority of the participants were profoundly sad at the initial stage of diagnosis. The fact that participants were sad and had suicidal thoughts, with an attempt in one case, at the initial stage of diagnosis, corroborates similar findings by [20], which indicate that young persons with T1DM tend to display symptoms of depression in the first month after diagnosis, with a greater likelihood of these symptoms worsening within a year. Again, participants feeling of sadness within the first year of diagnosis significantly indicate a problem adjusting early to the diagnosis of T1DM.

Health care providers therefore has a responsibility to promote early adaptation of adolescents with T1DM to reduce psychological challenges in having to living with such chronic illness.

There is a need for psychological assessment early after diagnosis as part of a comprehensive approach allowing for appropriate psychological interventions to help mitigate the psychological impact of having to live with T1DM among this population. Adolescents should be adequately prepared for the challenges they may encounter in adjusting to the diagnosis of T1DM which as a consequence will assist them to be psychologically stable especially at the initial stage of the diagnosis.

Similar to findings from [21, 22], in the present study, some participants expressed profound fear of developing complications associated with their condition, such as losing their eyesight, parts of their limbs, or even dying. This finding indicates that adolescents with T1DM receiving care at the unit are knowledgeable on the complications related to the disease. Such a finding in the present study can be attributed to the fact that all the participants had been living with T1DM for more than six months, giving them ample time to understand disease-related complications. Furthermore, these participants were students, most of whom were in Junior and Senior High School, which may have contributed to their better understanding of disease-related complications.

However, it was identified that health care professionals at the unit provide inappropriate information such as when stated "When I had diabetes, the doctor told me I should be very careful because when I get injured and I am not lucky part of my body will be cut off. Since then, I like to be alone and not engage in play to get hurt". This is discriminating adolescents with T1DM as health care professional make adolescents believe they are different from their peers in terms of engaging in play and other age-related social activities. This finding validates findings from [23] who found discrimination to come from health care provides among adolescents living with chronic diseases.

In the present study, few adolescents reported changes in their emotions compared to before they were diagnosed with T1DM. One became more sober, while another became more aggressive after the diagnosis. These findings seem to differ from those of [24], who indicated that adolescents with T1DM tend to have a higher incidence of affective disorders compared to a healthy control group. In their study, participants exhibited more negative emotions than positive ones, as seen in the controls. These adolescents struggled to find a balance between their emotions and self-control. From this discussion, there may be a need to monitor for affective disorders in adolescents following a T1DM diagnosis and to address them appropriately through psychotherapy.

Additionally, most adolescents in our study attributed spiritual meaning to the cause of their condition. Participants believed their disease was not solely physical but also spiritual. Some thought that certain family members were responsible for their condition. This belief was particularly observed among female participants of the Akan ethnicity, who based their assumptions on circumstances surrounding the diagnosis, which they perceived as mystical. In the African context, especially in Ghana, unexplainable ill health is often thought to be caused by malicious and wicked forces such as witchcraft [25]. Furthermore, outside the normal and natural understanding of the causes of chronic diseases like T1DM, there is a tendency for thoughts of bewitchment by family members or even people within the same geographical area to increase [26]. Similar to the studies by [27] and [28], adolescents suspected some family members, especially their aunties, as the cause of their condition. This finding demonstrates the sociocultural disparity between Western and African cultures. The African traditional religion remains relevant within contemporary health system in Ghana altering participants understanding of the pathology and pathophysiology of T1DM. Adolescents may benefit from an integrated approach where health care providers respect individual culturally beliefs while providing relevant modern day diabetes care. Subsequently, health education and explanations about the disease process of T1DM soon after diagnosis and subsequently whenever they express such beliefs will be useful.

We found that participants were stereotyped, socially withdrawn, struggled to make friends, kept their diagnosis a secret, and had their academic performance affected by living with T1DM. These findings concur with [29], who report that adolescents with T1DM face various forms of stigma in their daily lives. However, in their study, adolescents with T1DM experienced stigma related to following a restricted diet, administering self-injections (suggesting illicit drug use), and transmitting the disease to an unaffected person. In the present study, adolescents may have experienced stigmatization due to inadequate preparation regarding issues of stigma involved in living with T1DM, as most people without diabetes, including nurses, do not consider diabetes a stereotyped diagnosis.

Adolescents in our study concealed their diagnosis from peers both at school and home due to fear of their peers revealing their conditions. This was evident in their self-care activities, especially at school, and in their speech. Additionally, they kept their diagnosis a secret to be accepted and to avoid being labelled as different by their peers and others. This contrasts with findings by [30], who indicated that the majority

of adolescents with T1DM disclose their diagnosis to friends. However, the reasons for secrecy in this study align with findings by [31], who described adolescents as isolating themselves to avoid being perceived as weak, unhealthy, or stigmatized by their peers. For these individuals, maintaining an acceptable social image outweighs managing a normal blood glucose level. Consequently, they hide self-care activities to gain social acceptance. Such behaviour can negatively affect their self-management and overall diabetes outcomes, such as the risk of complications. These findings highlight the need for strategies like identifying trusted persons to whom disclosure can be safely made.

Findings from the qualitative study indicates that the diagnosis of T1DM has negative consequences on the education experience of adolescents with T1DM reported as becoming a non-resident student specifically for parental monitoring of self-care activities and a decline in academic performance adolescents. This finding support findings from [32] who indicate a decline in the academic performance of adolescents with T1DM compared to their peers. This challenge can be attributed to the circumstance that these individuals are more likely to be absent from the classroom due to disease related issues and majority of participants less than a year duration of diagnosis who are still in the period of adjusting to diagnosis. This underscores the need for early school-based interventions including flexible academic accommodation and integration of self-management activities in schools.

In this study, we examine the psychological and social challenges faced by adolescents with T1DM in Ghana. Our findings show that adolescents are more susceptible to experiencing psychological and social difficulties due to living with a chronic illness like T1DM. Furthermore, we found that adolescents with T1DM in Ghana face similar psychological and social challenges as their peers in other settings. These findings align with reports by [31] and [33], who highlight the increased susceptibility of adolescents to psychological difficulties stemming from living with a chronic illness such as T1DM.

Strengths and limitations of the study

The descriptive phenomenological study method employed in this study ensured an in-depth inquiry into the psychosocial experiences of adolescents with T1DM in South-Central Ghana. Again, the study is the first of its kind to be conducted in the country. However, it is not without limitations. Participants were sampled from a single health institution; therefore, adolescents from other health institutions with different psychological and social struggles in living with T1DM, which could have led to different findings in the study, may have been excluded. Again, the majority of the participants (nine out of fourteen) were diagnosed with T1DM for a period of less than a year which constrains transferability as early post-diagnosis experiences differ markedly from longer-term adjustment. Furthermore, using the face-to-face interviews, adolescents could have under reported coupled with potential social desirability bias in their psychological and social challenges in having to live with T1DM.

Conclusion

Adolescents with T1DM face various psychological and social challenges such as stigma, sadness and suicidal thoughts, which not only harm their psychosocial wellbeing but also disrupt their education. However, adolescents' beliefs that T1DM has spiritual causes highlight gaps in their understanding of the condition. Healthcare providers should offer relevant education and support to help adolescents with T1DM gain accurate knowledge, enabling them to better manage their psychosocial issues and improve their wellbeing.

Recommendations for practice

This study points out the need for caregivers, especially nurses, to be trained to skillfully screen adolescents with T1DM periodically for these psychological and social challenges for appropriate attention. Other professionals, such as counsellors and clinical psychologists, will need to be included in general care to handle the psychological and social needs of adolescents with T1DM. Public awareness of T1DM needs to be accelerated through the various communication media to minimize or eliminate stigmatization of adolescents with T1DM. Finally, there is a need for totality of nursing care covering the physical, psychological, social and spiritual needs of adolescents with T1DM.

Recommendation for future research

It is recommended that future research be undertaken at multiple sites to enhance the generalizability of the findings. Furthermore, the study findings provide a foundation for a longitudinal study to examine psychosocial changes in adolescents with T1DM and the development of a targeted culturally specific psychosocial interventions to assist adolescents navigate through the psychological and social challenges experienced in living with T1DM.

Abbreviations

T1DM	Type 1 Diabetes Mellitus
IDF	International Diabetes Federation
JHS	Junior High School
KNUST	Kwame Nkrumah University of Science and Technology
KATH	Komfo Anokye Teaching Hospital
MoH	Ministry of Health

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions
The study was designed by PN, KAK and GPM. Data collection was conducted by PN while data analysis was performed by PN, KAK, and GPM. The writing of the manuscript and reviewing of the final draft was done by PN, KAK, GPM, ET, and EKA. All authors reviewed the content, provided their intellectual input toward study ideas and concepts, and approved the manuscript for submission.

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Data availability
The data that support the findings of this study are included in this manuscript and will also be made available by the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
The study was approved by the Institutional Review Boards of Noguchi Memorial Institute for Medical Research (NMIMR) of the University of Ghana (NMIMR-IRB CPN 011/18–19) and the Committee on Human Research, Publication and Ethics (CHRPE) of the School of Medical Sciences at the Kwame Nkrumah University of Science and Technology (KNUST) Kumasi (CHRPE/RC/192/18). The study also adhered to the Declaration of Helsinki (2024) by protecting the rights of study participants. A written informed parent or legal guardian consent was obtained before the recruitment of any adolescent. Age-appropriate language was used to explain the research to the adolescents and a written assent was obtained.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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References

1. Khdair SI, Al-Naimat OS, Jarrar W, Al-Qerem W, Khudeir FA. The influence of TNF-α, IL-6, TGF-β1, IFN-γ, IL-10 polymorphisms on predisposition to diabetes mellitus among Jordanian patients. Endocr Metab Immune Disord Drug Targets. 2023;23(5):681–91.
2. Mobasseri M, Shirmohammadi M, Amiri T, Vahed N, Fard HH, Ghojazadeh M. Prevalence and incidence of type 1 diabetes in the world: a systematic review and meta-analysis. Health Promot Perspect. 2020;10(2):98.
3. IDF Atlas. 10th ed. Last accessed on 25 June 2025. Available from: https://diabetesatlas.org/atlas/tenth-edition/.
4. Sun H, Saeedi P, Karuranga S, Pinkepank M, Ogurtsova K, Duncan BB, Stein C, Basit A, Chan JC, Mbanya JC, Pavkov ME. IDF Diabetes Atlas: Global, regional and country-level diabetes prevalence estimates for 2021 and projections for 2045. Diabetes Res Clin Pract. 2022;183:109119.
5. Hadad S, Ali MM, Sayed TA. (2021). Psychological and behavioral complications in children and adolescents with type 1 diabetes mellitus in Sohag. Middle East Curr Psychiatry. 2021;28:1–8.
6. Ashraf MN, Cheng AY, Robinson DJ. Emotional, psychological, and social well-being experience of long-term living with type 1 diabetes mellitus: a patient–psychiatrist–endocrinologist perspective. Diabetes Ther. 2024;15(2):317–23.
7. Sawyer SM, Azzopardi PS, Wickremarathne D, Patton GC. The age of adolescence.Lancet Child. Adolesc Health. 2018;2(3):223–8.
8. Alassaf A, Gharaibeh L, Zurikat RO, Farkouh AA, Ibrahim S, Zayed AA, et al. Prevalence of depression in patients with type 1 diabetes between 10 and 17 years of age in Jordan. J Diabetes Res. 2023;2023(1):3542780.
9. Castellano-Guerrero AM, Guerrero R, Relimpio F, Losada F, Mangas MA, Pumar A, Martínez-Brocca MA. Prevalence and predictors of depression and anxiety in adult patients with type 1 diabetes in tertiary care setting. Acta Diabetol. 2018;55:943–53.
10. Owusu BA, Doku DT. Living with type 1 diabetes and schooling among young people in Ghana: a truism of health selection, inadequate support, or artefactual explanation of educational inequalities? BMC Public Health. 2024;24(1):1137.
11. Owusu BA, Ofori-Boateng P, Bankah E, Barnes NA, Atiase Y, Yorke E, et al. A qualitative study of type 1 diabetes complications, mental health, and structural pathways of complications occurrence among young people (14–24 years) and caregivers in southern Ghana. SSM-Mental Health. 2024;6:100368.
12. Ministry of Health. National Guidelines for the Management of Diabetes Mellitus Accra: Ghana. 2023. Available from: https://demsog.com/wp-content/uploads/2024/05/2023-Ghana-Diabetes-Guidelines.pdf.
13. Geneti Y, Wondwossen K, Adimasu M, Deressa D, Aga F, Lami M, et al. Adherence to diabetes self-management and its associated factors among adolescents living with type 1 diabetes at public hospitals in Addis Ababa, Ethiopia: a cross-sectional study. Diabetes Metab Syndr Obes. 2022:659–70.
14. Goble E, Stonick K, Wong A, Britton D. Qualitative research approaches: Descriptive phenomenology in the healthcare field. Student Research Symposium. 2022.
15. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health. 2000;23(4):334–40.
16. Ahmad M, Wilkins S. Purposive sampling in qualitative research: A framework for the entire journey. Qual Quant. 2025;59(2):1461–79.
17. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: Guided by information power. Qual Health Res. 2016;26(13):1753–60.
18. Guba EG, Lincoln YS. Competing paradigms in qualitative research. Handb qualitative Res. 1994;2(163–194):105.
19. Braun V, Clarke V. Toward good practice in thematic analysis: Avoiding common problems and becoming a knowing researcher. Int J transgender health. 2023;24(1):1–6.
20. McGill DE, Volkening LK, Pober DM, Muir AB, Young-Hyman DL, Laffel LM. Depressive symptoms at critical times in youth with type 1 diabetes: following type 1 diabetes diagnosis and insulin pump initiation. J Adolesc Health. 2018;62(2):219–25.
21. Cruz DSM, Silva KL, Souza JTB, Nóbrega MML, Reichert APS, Marqueset DKA, et al. Experiences of adolescents with diabetes mellitus from the perspective of the ethics of alterity. Acta Paul Enferm. 2018;31(2):130e6.
22. Kyngäs H, Barlow J. Diabetes: an adolescent's perspective. J Adv Nurs. 1995;22(5):941e7.
23. Meurillon R, Stheneur C, Le Roux E. Discrimination against adolescents with chronic diseases: A systematic review. Eur J Pediatrics. 2024;184(1):74.
24. Sinnamon GC, Caltabiano M, Baune BT. Differentiating disordered affect in children and adolescents with type 1 diabetes. J Affect Disord. 2013;147(1–3):51–8.
25. White P. The concept of diseases and health care in African traditional religion in Ghana. HTS: Theo Stud. 2015;71(3):1–7.
26. de-Graft Aikins A. The socio-cultural and socio-economic context of Africa" s chronic disease burden. Chronic Non-Communicable Dis Ghana: Multidiscip Perspect. 2013;9:124–36.
27. Abdoli S, Hardy LR, Hall J. The complexities of struggling to live life the experiences of young adults with T1DM living in Appalachia. Diabetes Educ. 2017;43(2):206–15.
28. Schabert J, Browne JL, Mosely K, Speight J. Social stigma in diabetes: a framework to understand a growing problem for an increasing epidemic. Patient Patient Cent Outcomes Res. 2013;6(1):1–0.
29. Chao A, Whittemore R, Minges KE, Murphy KM, Grey M. Self-management in early adolescence and differences by age at diagnosis and duration of type 1 diabetes. Diabetes Educ. 2014;40(2):167–77.

30. Elissa K, Bratt EL, Axelsson ÅB, Khatib S, Sparud-Lundin C. Societal norms and conditions and their influence on daily life in children with type 1 diabetes in the West Bank in Palestine. J Pediatr Nurs. 2017;33:16–22.
31. Butwicka A, Frisén L, Almqvist C, Zethelius B, Lichtenstein P. Risks of psychiatric disorders and suicide attempts in children and adolescents with type 1 diabetes: a population-based cohort study. Diabetes Care. 2015;38(3):453–9.
32. Meo SA, Alkahlan MA, Al-Mubarak MA, Al-Obayli MS, Melaibary BA, Dous AN, Alhassoun AI. Impact of type 1 diabetes mellitus on academic performance. J Int Med Res. 2013;41(3):855–8.
33. Bernstein CM, Stockwell MS, Gallagher MP, Rosenthal SL, Soren K. Mental health issues in adolescents and young adults with type 1 diabetes: prevalence and impact on glycemic control. Clin Pediatr. 2013;52(1):10–5.

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