EMPIRICAL RESEARCH QUALITATIVE



Knowledge of young people living with type 1 diabetes and their caregivers about its management

Bernard Afriyie Owusu¹ | Prince Ofori-Boateng^{1,2} | Angus Forbes³ | David Teye Doku¹

Correspondence

Bernard Afriyie Owusu, Department of Population and Health, University of Cape Coast, Cape Coast, Ghana,

Email: bernard.owusu@stu.ucc.edu.gh

Funding information

Samuel and Emelia Brew-Butler Research

Abstract

Aims and Objective: We sought to investigate knowledge and skills of type 1 diabetes (T1D) management among young people living with the disease and their caregivers. Our aim is to provide baseline evidence to inform T1D self-management education for young people living with the disease and their caregivers.

Background: Both local and international guidelines recommend ongoing T1D selfmanagement education for people living with the disease. This is because T1D often develops among young people who rarely have the competencies to adequately manage their condition. However, the extent to which young people living with T1D and their caregivers can self-manage this chronic disease in a low-resource country like Ghana is unknown.

Methods: Using a phenomenological study design, semi-structured interviews were conducted with 28 young people living with type 1 diabetes, 12 caregivers and 6 healthcare providers in southern Ghana. Data were collected at homes, hospitals and support group centres of participants via face-to-face interviews, photovoice and video-conferencing. The data were analysed thematically using QSR NVivo 11.

Results: The young people living with T1D and their caregivers demonstrated knowledge and skills in the self-monitoring of blood glucose, and the treatment of hyperglycaemia. Areas of more marginal or lack of knowledge were concerning carbohydrate counting, severe hypoglycaemia and the management of intercurrent illnesses. Young persons living with T1D and their caregivers received their management information from healthcare and non-healthcare providers. Access to diabetes self-management education influenced T1D management knowledge and practices.

Conclusion: Young people living with type 1 diabetes and their caregivers possessed limited scope of knowledge on type 1 diabetes self-management. Multiple sources of T1D knowledge were found, some of which may not be helpful to patients. The knowledge gaps identified compromises transitional independence and self-management capacity.

Relevance to Clinical Practice: It is important for clinicians and organizations that provide T1D education to provide diabetes self-management education also on managing

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2022 The Authors. Nursing Open published by John Wiley & Sons Ltd.

¹Department of Population and Health, University of Cape Coast, Cape Coast,

²Cape Coast Teaching Hospital, Central Region, Cape Coast, Ghana

³Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, Kings College London, London, UK

hypoglycaemia, carbohydrate counting and managing T1D during intercurrent life events among young people living with T1D.

No Patient or Public Contribution: Patients and their caregivers were interviewed as research participants. They did not conceptualize, analyse, interpret or prepare the manuscript.

KEYWORDS

Covid-19, diabetes mellitus, diabetes self-management education, health literacy, juvenile diabetes, knowledge, nutrition, self-care, vignette

1 | INTRODUCTION

Diabetes mellitus is a major global public health condition affecting over 537 million people across the world. Type 1 diabetes (T1D) is the most common endocrine disease among children and adolescents (Los & Wilt, 2022). It has been estimated that there are over 1.2 million young people aged 0–19 years living with T1D, and around 20,000 cases are diagnosed annually (IDF, 2021). In Ghana which is a low-middle-income country, over 2,551 young people are living with T1D (IDF, 2021) and this prevalence is increasing by around 3% per year (Sarfo-Kantanka et al., 2020).

Type 1 diabetes often develops among young people who rarely have the skills, knowledge and self-efficacy to properly manage their condition (Nafradi et al., 2017; Sherifali et al., 2018). As such, the American Diabetes Association recommends ongoing diabetes self-management education (DSME) for people living with diabetes (Powers et al., 2020). Diabetes self-management education is also in line with the WHO's best practices for chronic disease management which is to "educate and support people to manage their chronic condition" (Epping-Jordan et al., 2001). It entails facilitating the knowledge, skills and ability of young people to manage their T1D (Powers et al., 2015). In developed countries such as Germany and the United Kingdom, DSME is usually structured and continuous (Carmienke et al., 2022; Hermanns et al., 2020), and it has been found to improve self-care, coping abilities and lifestyle modifications (Carmienke et al., 2020; Norris et al., 2001). Consequently, effective self-management reduces the risk of both micro and macro-vascular complications that cause damage to the eyes, kidneys, feet and cardiovascular system (Berkman et al., 2011; Chatterjee et al., 2017; Mayberry & Osborn, 2012). Diabetes selfmanagement education transcends beyond young people; it presents opportunities to improve the health and general well-being of caregivers (Felix et al., 2020), and the quality of care by healthcare providers (ADA, 2017).

In resource-poor regions of the world including Ghana, access to DSME is challenging (Patterson, Harjutsalo, et al., 2019). Despite its inclusion in current public health protocols, access to DSME is lacking in Ghana, thereby limiting the opportunities for young people in learning how best to manage their diabetes. While some young people may compensate for the lack of DSME by using internet sources or friends abroad to learn about their condition (Kratzer, 2012), many currently do not access the education they

What does this paper contribute to the wider global clinical community?

- Type 1 diabetes (T1D) management among young people requires continuous diabetes self-management education which is limited in both home and clinical settings in developing countries.
- Young people living with T1D and their caregivers in southern Ghana possess limited scope of knowledge on carbohydrate counting, hypoglycaemia management and the management of T1D during intercurrent events such as pregnancy.
- Young people living with T1D and their caregivers at home in southern Ghana rely on multiple sources of T1D management information, some of which may not be helpful to them.

need. Existing studies in Ghana (Ameyaw et al., 2020; Kratzer, 2012; Sarfo-Kantanka et al., 2020) have failed to explore the T1D management knowledge of young people and their caregivers. To the best of our knowledge, the study presented in this paper is the first to address this research question in Ghana. Understanding the T1D management knowledge of young people living with T1D will provide the basis to gauge transitional independence, autonomy and self-management competencies at home, school and beyond. It will also provide baseline evidence to inform DSME for patients and clinical practice.

2 | MATERIALS AND METHODS

A qualitative study was undertaken to explore the understanding and experiences of young people concerning diabetes self-management in selected regions (Western, Central and Greater Accra) in Ghana using a phenomenological (descriptive and interpretative) study design. Phenomenology entails a description of participants lived experiences and practices based on the meaning they ascribe to the phenomenon (descriptive), to a deeper exploration of underlying reasons and meanings (interpretative; Creswell et al., 2007). Scholars inductively explore participants' meanings of their experiences and

organize them into meaningful themes (Sanders et al., 2019). This approach has been used to understand lived experiences among young people living with T1D and their caregivers (Spencer et al., 2013), and the attitudes of young people living with T1D towards exercise (Ryninks et al., 2015).

2.1 | Sampling and inclusion criteria

Data were drawn from 47 participants. In all, 28 young people aged 14-24 years living with T1D who self-managed their condition, 12 primary caregivers and 6 healthcare providers were interviewed spanning 1st August 2021-9th September 2021. Participants living with T1D were identified at the Diabetes Youth Care (DYC, a non-governmental organization that provides psychosocial support to diverse categories of young people living with T1D and their caregivers in Ghana) support group meetings (N = 13), their homes (N = 9) and healthcare facilities (N = 6), and recruited into the study using maximum variation, convenience and snow-ball sampling techniques (Sharma, 2017). This selection approach enabled participants with different socio-demographic characteristics such as place of residence, duration of living with T1D and expert and non-expert (newly joined the DYC) young people to be included as participants. Inclusion criteria entailed a diagnosis of T1D according to the MoH guidelines (a range of random venous plasma glucose above 11.1 mmol/L or fasting A1C >6.0% (6.9 mmol/L; MoH, 2017) as retrieved from their hospital and DYC diabetes registers; aged between 14-24 years as we considered younger people to lack the capability to provide in-depth information, and residing in southern Ghana. Among the primary caregivers and healthcare providers, living with and providing care for a diabetic child aged 14-24 years for a minimum of 24 months (deemed sufficient time to reduce recall bias) respectively, were selected to provide contextual evidence about T1D management knowledge at home and healthcare settings. Data collection and analyses were re-iterative, and this helped to gauge saturation as shown in Figure 1.

2.2 | Study context

Ghana is broadly divided into three ecological zones – southern, middle and northern zones. Healthcare facilities, such as the Korle-Bu Teaching Hospital, Accra Regional Hospital and Cape Coast Teaching Hospitals in southern Ghana are major referral points for T1D care (Essuman et al., 2021). The zone also benefits from improved socio-economic infrastructure including major health infrastructure, professional care and pharmacies. Most young people including those from remote areas receive their regular hospital check-ups from these health facilities in southern Ghana. Also operational in this zone is the DYC which provides monthly diabetes self-management education for young people and their caregivers.

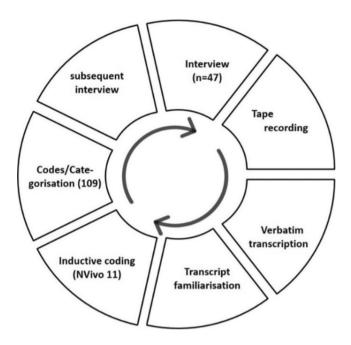


FIGURE 1 Re-iterative process of data collection and analysis

2.3 | Data collection procedure

Ethical clearance [Clearance ID: UCCIRB/CHLS/2021/19] was sought from the University of Cape Coast Institutional Review Board. The principal investigator is a volunteer with the DYC, and this established relationship served to encourage young persons and their primary caregivers to participate and feel comfortable sharing their in-depth experiences with field assistants. Interviews were conducted at the healthcare facilities and in the home of participants where healthcare providers and primary caregivers consented on behalf of T1D patients below age 18 after seeking their assent. A range of data was collected from various sources using face-to-face interviews, observation, telephone interviews, video-conferencing, asynchronous interviews, photovoice, vignettes and returned emails. These inclusive methodologies were to suit the unique situations of participants and accommodate their health and safety during the global Covid-19 pandemic. Interviews were conducted at a location chosen by participants and at a mutually agreeable time. Interviews were conducted in English, Fanti and Twi languages as best spoken and understood by participants. Interviews lasted between 40-120 min and were audio-recorded. A semi-structured interview guide was developed, pre-tested and used for the data collection. Using vignette approaches, participants were asked questions such as "how do you respond to, and manage low blood sugar or high blood sugar" [Supplementary 1]. Responses were probed to elucidate participants understanding. After each day of data collection, interviews were transcribed verbatim into the English language on a personal computer and secured with a password. Young persons living with T1D were anonymised using an in-vivo pseudonym [warriors] to wit fighters of T1D, a name they have chosen to call themselves.

2429

2.4 | Quality assurance

Quality assurance mechanisms were embedded in the study design to ensure the collection of valid results during the planning, data collection and analysis phases (Erlandson et al., 1993; Green et al., 2007; Noble & Smith, 2015). To enhance the transferability of the findings, we used maximum variation sampling techniques to ensure the participants represent different socio-economic groups of people in society. Credibility measures employed methods such as observation, prolonged engagement with participants, triangulation of data sources, participants re-checking through returned transcripts and independent coding by BAO and POB. Confirmability approaches included studying the same issues using a chain of evidence - interviews, observations and photo evidence. Others included appropriate research design, and methods that have been employed in related studies (Green et al., 2007). Transcripts were emailed to participants with active email addresses and all healthcare providers to reflect on the data and make changes where appropriate. The use of thick descriptions and presentation of discrepant information will allow readers to vicariously reflect on the data themselves. To ensure that the results are reliable, the semi-structured interview guide was informed by a systematic review of the literature, gaps in the literature and our regular interaction with T1D patients and their caregivers. Unlike closed-ended questions, the open-ended questions allowed participants to express themselves to cover the depths of the issues discussed. Interviews were also conducted at the homes of most participants, allowing several observations to be made which were probed during the interviews. The study made use of acceptable standards and practices of data analysis and reporting that followed the Consolidated criteria for reporting qualitative research.

2.5 | Data processing, analysis and presentation

The data collected were transcribed and password protected. The transcripts were imported into QSR NVivo 11 for analysis. Data collection and analysis were done simultaneously (Figure 1). The analytical technique chosen for this study was thematic analysis (Moustakas, 2004). This entailed the analysis of significant statements, the generation of meaningful units, and the development of what Moustakas (2004) called an "essence description." The software assisted in the incorporation of text, photograph, audio and video data, and classified according to participants' socio-demographic characteristics. Beyond these, QSR NVivo facilitated the comparison of different codes. For instance, comparing participants' age, sex, region and so on with their knowledge and sources of information. Two field assistants [BAO and POB] independently assigned codes to portions of the transcripts that relate to the study objectives, discussed the codes and generated themes from the codes with DTD. We used a combination of an in-line quote (sandwich) and block quotes to present participants' revelations. Using the sandwich approach, the informants' revelations were placed within the authors' sentence for thought coherence as employed in other studies (Gopaldas, 2016; Owusu, 2022).

3 | FINDINGS

3.1 | Background characteristics of study participants

Forty-seven participants representing different target groups (young people living with T1D, primary caregivers and healthcare providers), out of which 28 were young people living with T1D were interviewed. In this group, there was equal representation of males and females. The mean age was 20 years, ranging between 14-24 years, and their mean age of living with T1D was 8 years. Fifteen participants reported an immediate family history of diabetes, and most participants (N = 19) were students who lived with their primary caregivers - mostly their mothers and guardians. All young people living with T1D had active national health insurance cards. One participant was married and two others were cohabiting. Among the females living with T1D (N = 14), three of them had experienced unsuccessful pregnancies. Three participants had newly joined the DYC and 7 were irregular attendees. The average age of the primary caregivers was 45 years, mostly with a basic level of education (N = 8). Nine of the 12 caregivers were biological mothers of diabetic children, and a family history of diabetes including T1D was also reported by some primary caregivers. Four of the primary caregivers were living with diabetes (undifferentiated). Eight of the primary caregivers were married and were mostly engaged in petty trading (N = 7) or unemployed (N = 2). Primary caregivers have been engaged in T1D caregiving for about 6 years. Out of the six healthcare providers, two were physicians, two were nurses and two were pharmacists who had been directly engaged with TID patients for the past 7 years in their respective healthcare facilities. This is summarized in Table 1.

3.2 | Themes

Three main themes were identified from the data. These themes were Management Knowledge, Knowledge Sources and Gaps in Knowledge. The first theme [Management knowledge] was drawn from knowledge on: self-monitoring of blood glucose (SMBG), hypoglycaemia, hyperglycaemia, diet, exercise and managing T1D during intercurrent ill health. The second theme [Knowledge sources] was informed by the findings on the sources of T1D management knowledge (see Table 2). The final theme [Knowledge gaps] was informed by findings on limited T1D management knowledge areas which require health education and promotion interventions (see Table 2).

3.3 | T1D management knowledge

The T1D management knowledge concerned the exploration of self-monitoring of blood glucose (SMBG), low or high BG, diet, exercise and the management of T1D during intercurrent ill health.

TABLE 1 Basic socio-demographic characteristics of participants

	Participant categories Warriors				
Participant characteristics	(28)	PCG's (12)	HCP's (6)	ACM (1)	Total (47)
Sex					
Female	14	11	3	-	28
Male	14	1	3	1	19
Age group (in years)					
14-19	10	-	-	-	10
20-24	18	-	-	-	18
30-39	-	4	3	-	7
40-49	-	3	2	1	6
50 and above	-	5	1	-	6
Duration of living with/providing T1D care					
Less than 5 years	5	4	1	1	11
5-10 Years	17	6	3	-	26
Above 10 years	6	2	2	-	10
Highest educational level					
Never attended	-	1	-	-	1
Primary	2	4	-	-	6
JHS	7	3	-	1	17
SSS/SHS	11	3	-	-	14
Tertiary	8	1	6	-	9
Family history of DM					
Yes	12	7	-	-	19
No	13	5	-	-	18
Do not know	3	-	-	-	3
Primary caregiver (PCG)					
None	6	-	-	-	6
Both parents	3	-	-	-	3
Mother/grandmother	11	-	-	-	11
Father	3	-	-	-	3
Other relatives	3	-	-	-	3
None relative	2	-	-	-	2
PCG occupation					
Salary earner	-	2	-	-	2
Petty trading	-	8	-	-	8
Unemployed	-	2	-	-	2
Religious affiliation					
Christian	25	11	6	1	43
Muslim	3	1	1	0	5
Position					
Physician	-	-	2	-	2
Pharmacist	-	-	2	-	2
Nurse	-	-	2	-	2
ACM	-	-	-	1	1

3.4 | Knowledge about SMBG levels

Self-monitoring of BG (SMBG) was identified by participants as a fundamental component of their T1D care. Young people living

with T1D possessed substantial knowledge of SMBG. They shared insightful approaches about how they monitored their BG; from hygienic practices to the glucose testing procedure. In explaining this issue, this was what was said:

Healthcare providers

Actually, my daughter is so friendly so all her doctors and nurses really admire her. She likes asking her own questions, and seeks details of it [a-*55-year-old mother with 5* years of lived experience].



Family members

She stopped me from injecting for like threefour months. I grew so lean that when my mother saw me, she started crying" [a 21female-warrior with 7 years of lived experience]



I read fliers and books to educate myself and educate her also [a 53-year-old quardian with 3 years of lived experience1

Diabetes Youth Care

They teach us at DYC. *In fact, had it not been* DYC, things would have been difficult for me. [a 20-year-old female warrior with 6 years of lived experience]



Experiential learning

When I eat and it's good for me, then I stick with it. I know it's good when my sugars shoot up fast [treating hypo] after eating it [a 20 year old male warrior with 4 years lived experience].



University program.

My University program has positively impacted my management, be it diet. medication support [a 21-year-old female warrior with 7 vears of lived experience1



Online sources

I google for insulin calculation, basics of diahetes and complications. I also use Centre health App [an-18-year-old female warrior with 17 years of lived experience]



Diabetes friends

My paddy (close friend) is also diabetic and sometimes educate me *[a 24-vear-old male]* warrior with 11 years of lived experiencel



Knowledge Gaps

- o Carb. Counting
- o Meal planning
- o Cure for T1D
- o SMBG

I take cotton, dip it into a spirit and clean the injection spot, then I take my needle, prick my finger, and then check with the test strips. After, then I take the strip off and put it in a dustbin

[a 19-year-old female warrior with 7 years of lived experiencel

Young people reported that they kept glucometers and checked their BG levels regularly. For instance, a 20-year-old female warrior with 10 years of lived experience said "My glucometer is always with me. I make sure I check my sugar when I feel my sugars are high."

low BG were toffees/candies, sugary drinks (minerals) and biscuits. In explaining this issue, this was what was said:

> I always keep a packet of candy in my school bag. I eat them whenever I feel like I am having hypo.

> > [a 21-year-old male warrior with 6 years of lived experience]

Further, monitoring of BG to re-check the normalization of

sugar levels was reported by some expert patients and those who

had higher incomes and resided in urban areas. Excerpts from participants support this finding. For instance, in their revelation, this was what an 18-year-old female warrior with 17 years of lived experience said:

...quick intake of simple carbohydrates to raise my sugar level... I'll also check again in about 15 minutes and titrate my insulin doses during the day to prevent other hypos.

3.5 | Knowledge about treating hypoglycaemia and hyperglycaemia

The general approach young people adopted for treating hypoglycaemia (low blood sugar) was the consumption of simple carbohydrates. The common sweetened products taken after pre-empting

The fear of hypoglycaemia, particularly nocturnal hypoglycaemia made primary caregivers vigilant in reminding young people to check their BG levels, particularly at night. This was based on the knowledge that BG levels can drop very low when not treated well during the day. For instance, a 50-year-old mother with 7 years of lived experience had this to say:

He will be pressing his phone and fall asleep, then I will go and wake him up and remind him to check his sugar.

Concerning hyperglycaemia, young people and their primary caregivers were particular about insulin injection, and others such as exercise, drinking lots of water and decreasing carbohydrate intake to treat high blood sugar. Evidence to support this theme were narrations from participants and photo evidence. In their narrations, this was what was said:

I take in a calculated shot of short-acting insulin, decrease carbohydrate intake, increase water intake and check my blood glucose. If it's still high after several checks within 12 hours I check in with the doctor.

[a 24-year-old -female warrior with 19 years of lived experience]

In Figure 2 [taken on 14th August 2021], a 21-year-old male warrior injects his insulin shots around his abdomen and a few centimetres from his naval – a recommended spot for insulin injection.

3.6 | Diabetes management knowledge on diet and exercise

Young people possessed some marginal knowledge on the use of diet and the nature of exercises that are beneficial for T1D management. Concerning diet, although most of them were knowledgeable about the food to avoid, the dynamics of diet modification and carbohydrate counting were an issue of concern. On foods to avoid, for instance, some participants had this to say:

I am to avoid sugar and starchy food. For instance, sugar or tea bread in place of wheat bread. Even with that, I am to take just a slide, and my teacup compared to the usual ones is smaller.

[a 17-year-old male warrior with 4 years of lived experience]

Similarly, concerning exercise, it were identified that, although exercise was a key behavioural approach to managing T1D, few of them knew about T1D management using exercise, and the nature of exercises to be undertaken. As such, only a participant indicated the use of exercise to manage his T1D. However, the fear of cuts/wounds [due to

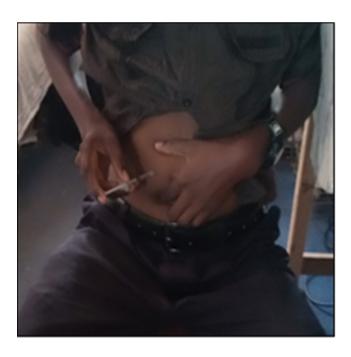


FIGURE 2 Insulin injection demonstration

impaired wound healing] deterred his engagement in exercise. In his revelation, this was what he said:

I do engage in certain activities, but I am careful so as to prevent cuts.

[a 17-year-old male warrior with 4 years of lived experienc]

3.7 | Knowledge about managing T1D during intercurrent ill health

When ill or pregnant, young people living with T1D frequently checked their BG, took their insulin shots, and increased their insulin dosage when needed. Among those with higher levels of education, and who had direct contact with medical staff, seeking medical attention before taking other medications was found. For instance, some participants said this:

I continuously take my insulin shots when I am sick, I don't stop managing.

[a 24-year-old male warrior with 10 years of lived experience]

Some medications have syrups in the form of sugars so I seek a prescription from my healthcare providers about the best medication to use.

[a 21-year-old female warrior with 7 years of lived experience]

Young people, particularly expert patients and some primary caregivers shared their concerns about the inability of healthcare

providers to understand their needs. For instance, during pregnancy, some young people reported that healthcare providers did not understand their condition and therefore had to change their doctors. To some parents, healthcare providers were fixated on their child's T1D even when presented with other health conditions and felt they were being *experimented with*. They revealed this:

Anytime I get sick and I come to the hospital they [healthcare providers] say it's because of my T1D. Even when I have a headache, they say it is my condition. So, when I get sick, I don't come to the hospital any longer.

[a 24-year-old female warrior with 9 years of lived experience]

During my pregnancy, I had to change a few doctors because I felt they didn't understand my type of insulin [a 24-year-old female warrior with 19 years of lived experience, and a Nurse]

3.8 | Sources of T1D management knowledge

The second theme concerned the sources of T1D management knowledge. Participants relied on several sources of T1D management information. These sources were healthcare providers, the DYC, internet sources, family members living with diabetes, experiential learning, peers living with diabetes, books/fliers and choosing academic programmes related to health. These information sources, in order of commonality, are summarized in Table 2.

3.9 | Major sources of T1D management knowledge

Healthcare providers including physicians, nurses, pharmacists, counsellors and nutritionists at the various healthcare facilities, and other non-medical volunteers at the DYC were the major providers of diabetes self-management education. They provided T1D management information mostly on diet, insulin and foot care through one-on-one contact with patients either at the hospital, or through informal relationships with young people living with T1D or their primary caregivers, and also in groups. Some young people, primary caregivers and healthcare providers shared their experiences.

At this hospital, they put us in a hall and educate us on how to prepare our food. They said we should blend the tomatoes, pepper and all vegetables and put it on fire before adding small oil to avoid oil concentration.

[a 48-year-old mother with 11 years of lived experience]

They are provided with education with regards to diet and medication on each clinic day on a one-on-one basis as well as how to store and inject insulin.

[Nurse in charge of a diabetic unit]

For instance, the DYC provides monthly psycho-social support to young people and their caregivers, and through international collaborations, some *warriors* can attend international programmes and learn about T1D with other young people living with T1D across the world.

My uncle and sister [primary caregivers] do not know about diabetes. Had it not been for DYC, managing my condition would have been very difficult.

[a 20-year-old female warrior with 6 years of lived experience]

I have had diabetes education organised by DYC at support group sessions, online, at annual camps as well as workshops abroad. All of these events have one way or the other made me very knowledgeable about my condition.

[a 21-year-old warrior with 7 years of lived experience]

3.10 | Other sources of T1D management knowledge

Young people living with T1D learn about their condition through other sources. For instance, although young people and their primary caregivers rarely had specific web pages they accessed for T1D management information, those with smartphones and educated primary caregivers searched the internet to learn about T1D management. They mostly searched for information related to diet and cures for T1D. In explaining this issue, this was what was said:

I google for insulin calculation, basics of diabetes and complications. I also use Centre health App (for recommendations and latest info on diabetes treatment) Blood Glucose Passport App (for logging of my data and calculating my estimated HbA1c levels).

[an 18-year-old female warrior with 17 years of lived experience]

When I was first diagnosed, my dad made me read some pages of the web, and there I learned that T1D is a condition which occurs when the pancreas stops producing insulin and so I need to take insulin for the rest of my life. Recently, he's letting me to read more about finding cure for diabetes and the way they kind of do it.

[a 15-year-old male warrior with 5 years of lived experience]

Older relatives living with T2D sometimes held views that were divergent from the needs of young people living with T1D. Some encouraged the use of T2D treatments including metformin (oral antidiabetic) whenever they could not afford insulin or when insulin was not available. Others were opposed to insulin injections. In explaining this issue, some participants made this revelation:

When we can't afford insulin, I give her metformin, it is also very good.

[a 53-year-old guardian of a young person with 3 years of T1D lived experience]

When I completed JHS, I went to stay with my grandmum, and with her, it was all about prayers. She stopped me from injecting for like three-four months. I grew so lean that when my mother saw me, she started crying. [a 21-female-warrior with 7 years of lived experience]

Young people living with T1D also learn about their condition through trials with diet and experiences from watching their parents manage their diabetes. For instance, *I learn from watching my mother take care of her condition* [a 15-year-old male warrior with 5 years of T1D lived experience]. Similarly, some primary caregivers learn about T1D from their children living with T1D through participation in T1D care. For instance, a guardian shared:

Knowing he is diabetic, I asked him why he still keeps toffees and he taught me about low sugar. He said toffees are taken during emergencies to increase sugar levels. [a 30-year-old guardian with 7 years of lived experience]

Young people living with T1D also learned about diabetes from their peers living with T1D via WhatsApp platforms, home visitations, borrowing insulin from each other, attending diabetes-related programmes, reading books, choosing specific university programmes and also from T1D-related fliers. For instance, a 21-year-old female warrior with 7 years of lived experience had this to say:

I chose this programme [mentions programme name] and it has positively impacted my management approaches be it diet, medication, and support to others. Having diabetes and learning about it makes it quite easier for me

3.11 | Gaps in T1D management knowledge: what do young people and their primary caregivers want to know about T1D management?

An important theme that was identified concerned T1D management gaps. We found that knowledge about diet, particularly on meal planning and carbohydrate counting, management of complications including foot care, and taking care of younger children living with

T1D were major issues of concern to participants. Most participants expressed concerns about the difficulty in carbohydrate counting and meal planning. In their assertions, this was what was said:

Usually, meal planning is explained to us by healthcare providers in a general manner and we end up going home without the necessary food items to practice good meal planning.

[a 21-year-old male warrior with 7 years of lived experience]

My main challenge is knowing the carbohydrate content in the food I eat. Carbohydrate determines the amount of insulin I should inject, yet there isn't any information on how to accurately calculate the amount of carbs in a food.

[a 24-year-old female nurse, and a warrior with 19 years of lived experience]

Others expressed their quest to learn about and treat complications such as diabetes ketoacidosis (DKA), foot care and retinopathy. For instance, a 21-year-old male warrior with 10 years of lived experience shared this:

> I want to know about DKA and to others...I think it is the foot care, and I want to know the reason why I am facing this eye problem.

[a 19-year-old female warrior with 7 years of lived experience]

Knowledge about the organs involved in the mechanisms of T1D was also lacking. For instance, excerpts from a 20-year-old male warrior with 6 years of lived experience were:

...that will be about the Beta-cells of the pancreas, because damage to the Beta cells precisely is what causes diabetes. I will like to know how to revive, heal, or cure the damaged Beta cell

We found it was particularly challenging for primary caregivers to encourage their children living with T1D to adopt healthy practices when they were outside their direct care. For instance, a 37-year-old mother with 5 years of lived experience revealed this:

Taking care of a diabetic child is difficult. It [diabetes self-management education] should be about caring for a diabetic child generally

4 | DISCUSSION

This study sought to explore diabetes self-management knowledge of young people living with T1D and their caregivers in southern Ghana. The findings indicate that young people living with T1D and their caregivers possessed substantial knowledge and skills in their self-monitoring of BG, and the treatment of hyperglycaemia. However, there were knowledge gaps on carbohydrate counting, management of hypoglycaemia and management of T1D during major adverse life events such as pregnancy.

Diabetes self-management education for young people living with T1D and their caregivers is essential if they are going to develop the competencies required to manage T1D effectively. For young people living with T1D who are left to manage their condition within existing structural barriers in Ghana (Kratzer, 2012), having substantial knowledge of diabetes self-management can be rewarding. T1D education reduces the risk of both micro and macro vascular T1D complications and improves health outcomes (Chatterjee et al., 2017).

Low T1D management knowledge as was evident in many of the participants in this study is a risk factor for both acute and chronic diabetes and mortality (Borschuk & Everhart, 2015). Our findings are similar to other studies but contradicts their finding in Ireland and the United Kingdom that no knowledge deficit was found concerning hypoglycaemia and exercise (Khamis et al., 2004; Ryninks et al., 2015). Young people and their caregivers who have limited knowledge of T1D management are less likely to reach management goals (van den Boom et al., 2019), and consequently experience higher T1D mortality (Ameyaw et al., 2020; Patterson, Harjutsalo, et al., 2019; Patterson, Karuranga, et al., 2019). Generally, the awareness that T1D is a genetic condition related to the inability of the pancreas to produce insulin is encouraging. For instance, a study by Kratzer (2012) in Accra which suggested that eating too much sugar was the cause of T1D, led to self-blame among young people living with T1D. At the time of her study (Kratzer, 2012), the DYC was not operational, and young people had limited avenues to learn about their condition. The diabetes self-management education provided by DYC seems to be having a positive impact on most young people living with T1D and their caregivers. However, there is always the risk that in a poorer country like Ghana, such resources may be vulnerable as they depend on NGO funding, rather than sustainable government healthcare provisions.

The sources of T1D management knowledge are myriad, and this has been confirmed in other studies (Herrman, 2006; Karlsson et al., 2008; Ligita et al., 2019; Roper et al., 2009; Sparapani et al., 2012). Young people living with T1D, particularly those with no primary caregivers and who come from remote areas learned about their condition through a trial-and-error approach as confirmed in their studies (Seo et al., 2020). As a chronic condition, management knowledge accumulates with time and should be topical in clinical settings. This finding contradicts earlier findings in Accra that youths and primary caregivers learn from internet sources and friends abroad (Kratzer, 2012). It is worth noting that Kratzer (2012) studied relatively higher socio-economic status participants, urban residents, and those who consulted with highly trained physicians.

T1D management knowledge gaps have been reported in other studies (Niba, 2016) and found among families (Klatman et al., 2019;

Lindberg & Söderberg, 2015). The difficulty in calculating the carbohydrate content of most foodstuffs consumed in Ghana, and the failure of dieticians to provide contextual diet plans that can easily be adopted by young people and their primary caregivers is critical. For instance, healthcare providers asking young people to cut down or quit consuming carbohydrate foods albeit the grim socioeconomic circumstances of most families providing T1D care in Ghana may prove difficult and unattainable. We recommend carbohydrate counting or experience-based estimation to achieve optimal glycaemic control as put forward elsewhere (American Diabetes Association, 2017; Kratzer, 2012). Diet plays an important role in BG control. The limited knowledge of diet among young people living with T1D has also been confirmed in Ghana and elsewhere (Kratzer, 2012; Moawad et al., 2014). It is therefore not surprising that young people relied on their parents to calculate the carbohydrate quantity to consume (Rankin et al., 2018). Experienced-based estimation and keeping track of carbohydrates consumed (carb counting), particularly on sugars and starchy foods helps to match physical activity and insulin dosage to the food consumed thereby reducing hyperglycaemia associated with the consumption of high carbohydrate foods. Other than this, the prescriptive approach used by healthcare systems, particularly on diet is failing to meet the holistic expectation of care by young people living with T1D due to other operating contextual factors which were usually missed. Other scholars, therefore, recommend the need to recognize the social circumstances such as social relationships and living conditions of young people (Roper et al., 2009; Sanders et al., 2019). In other studies, health systems knowledge gaps such as those found in this study, including limited knowledge of T1D management during pregnancy, insulin types and fear of insulin prescription have been confirmed (Klatman et al., 2019; Lindberg & Söderberg, 2015). For instance, healthcare providers' inability to detect or adequately treat T1D among pregnant mothers living with T1D led to several foetal demise and anomalies which has long-term adverse health and socioeconomic impact on young mothers living with T1D. Knowledge gaps have also been identified among healthcare professionals in other countries (Klatman et al., 2019; Lindberg & Söderberg, 2015; Majaliwa et al., 2007).

4.1 | Strengths and limitations of the study

A major strength of this research methodology was the use of both traditional and contemporary methods of data collection to explore the knowledge of young people living with T1D, their caregivers and healthcare providers in dyad relationships. This study employed methods that were brought together based on thorough consideration of local contexts, and the feasibility of such approaches in soliciting reliable data during the Covid-19 pandemic. The major limitation is that this study cannot be generalized to other populations and sub-groups outside our inclusion criteria. Although the study used maximum variation, convenience and snow-ball sampling techniques, most participants interviewed were members of the DYC.

As such, generally, their knowledge about T1D management may be better, compared to the general population from which the sample was drawn.

4.2 | Implications for policy, practice and future research

The finding that young people living with T1D and their primary caregivers have marginal knowledge of the management of hypoglycaemia, carbohydrate counting, physical activity and managing T1D during adverse life events has implications for policy and practice. Clinicians and the DYC need to provide diabetes self-management education focusing on these areas if significant efforts to reduce T1D complications and improve quality of life are to be made. The multiple sources of knowledge of which some may not be helpful to people living with T1D must be coordinated to promote access to reliable information, and the codification of a T1D management guideline for young people living with T1D and their primary caregivers. Young people's experiential understanding of their T1D should be topical in clinical setting discussions to prevent caregiver imposition, and ensure that young people living with T1D and their primary caregivers benefit from diabetes self-management education. Future research needs to explore the human resource capacity of healthcare systems in providing diabetes self-management education for young people and their primary caregivers.

5 | CONCLUSION

Young persons living with T1D and their caregivers possess limited scope of knowledge on T1D management. Although, they were knowledgeable and skilled about the SMBG, and treatment of hyperglycaemia, there was marginal knowledge on carbohydrate counting, management of severe hypoglycaemia and the management of T1D during intercurrent ill health such as during pregnancy. Also, young persons living with T1D relied on various sources of information to learn about their T1D, some of which may not be useful to them.

AUTHOR CONTRIBUTIONS

BAO: Conceptualisation, methodology, fieldwork, analysis and interpretation, writing, review, editing and submission. POB: Conceptualisation, fieldwork, review and editing. AF: Writing and review. DTD: Conceptualisation, methodology, analysis and interpretation, review, editing and overall supervision.

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/recommendations/)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data.
- drafting the article or revising it critically for important intellectual content.

ACKNOWLEDGEMENTS

The authors are thankful to the Diabetes Youth Care (DYC) for their immense support in facilitating access to young people living with type 1 diabetes in southern Ghana. We are also grateful to all caregivers including healthcare providers from the various healthcare facilities who participated in this research. The authors are grateful to Samuel and Emelia Brew-Butler/SGS/GRASAG-UCC for the financial support towards the conduct of this research.

FUNDING INFORMATION

Financial support from Samuel and Emelia Brew-Butler/SGS/GRASAG-UCC Research Grant was received for the conduct of this research

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICAL APPROVAL

Ethical clearance [ID: UCCIRB/CHLS/2021/19] was sought from the University of Cape Coast IRB. The study adhered to the Covid-19 social distancing protocols of 2 meters interviewing distance between field assistants and participants. At the support group centres, some participants retained signed copies of the inform consent/assent forms whereas others gave verbal consent. Participants' information were coded using a shared in-vivo term they had chosen to call themselves [warriors] such that their information cannot be traced back to them. Participants were compensated for their transportation and airtime costs incurred.

ORCID

Bernard Afriyie Owusu https://orcid.org/0000-0002-6216-4006

REFERENCES

- American Diabetes Association. (2017). 1. Promoting health and reducing disparities in populations. *Diabetes Care*, 40(Supplement 1), S6–S10.
- Ameyaw, E., Asafo-Agyei, S. B., Boakye-Yiadom, A. P., Baffoe-Sarpong, K., & Duku, F. A. (2020). Amputation in a 17 year old Ghanaian with type 1 diabetes: A case report. *Endocrine and Metabolic Science*, 1(3-4), 100070.
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*. 155(2), 97–107.
- Borschuk, A. P., & Everhart, R. S. (2015). Health disparities among youth with type 1 diabetes: A systematic review of the current literature. Families, Systems & Health, 33(3), 297–313.
- Carmienke, S., Baumert, J., Gabrys, L., Heise, M., Frese, T., Heidemann, C., & Fink, A. (2020). Participation in structured diabetes mellitus self-management education program and association with lifestyle behavior: Results from a population-based study. *BMJ Open Diabetes Research and Care*, 8(1), e001066.

- Carmienke, S., Fink, A., Baumert, J., Heidemann, C., Du, Y., Frese, T., & Heise, M. (2022). Participation in structured diabetes selfmanagement education programs and its associations with selfmanagement behaviour-a nationwide population-based study. Patient Education and Counseling, 105(4), 843-850.
- Chatteriee, S., Khunti, K., & Davies, M. J. (2017), Type 2 diabetes, The Lancet, 389(10085), 2239-2251.
- Creswell, J. W., Hanson, W. E., Clark Plano, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. The Counseling Psychologist, 35(2), 236-264.
- Epping-Jordan, J., Bengoa, R., Kawar, R., & Sabaté, E. (2001). The challenge of chronic conditions: WHO responds: The sooner governments act, the better. BMJ, 323(7319), 947-948.
- Erlandson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). Doing naturalistic inquiry: A guide to methods. Sage.
- Essuman, V. A., Tagoe, N. N., Akpalu, J., Essuman, A., Sackey, A. H., Hayfron-Benjamin, C. F., Asare, G., Abaidoo, B., Amoah, A., Ndanu, T., Ofori-Adjei, I., Barnes, N. A., Appiah-Thompson, B. L., & Amoaku, W. M. (2021). Morbidity and complications of diabetes mellitus in children and adolescents in Ghana: Protocol for a longitudinal study. JMIR Research Protocols, 10(1), e21440.
- Felix, H. C., Narcisse, M. R., Long, C. R., & McElfish, P. A. (2020). Effects of a family diabetes self-management education intervention on the patients' supporters. Families, Systems, & Health, 38(2), 121.
- Gopaldas, A. (2016). A front-to-back guide to writing a qualitative research article. Qualitative Market Research: An International Journal, 19(1), 115-121.
- Green, J., Willis, K., Hughes, E., Small, R., Welch, N., Gibbs, L., & Daly, J. (2007). Generating best evidence from qualitative research: The role of data analysis. Australian and New Zealand Journal of Public Health, 31(6), 545-550.
- Hermanns, N., Ehrmann, D., Finke-Groene, K., & Kulzer, B. (2020). Trends in diabetes self-management education: Where are we coming from and where are we going? A narrative review. Diabetic Medicine, 37(3), 436-447.
- Herrman, J. W. (2006). Children's and young adolescents' voices: Perceptions of the costs and rewards of diabetes and its treatment. Journal of Pediatric Nursing, 21(3), 211–221.
- IDF Diabetes Atlas. (2021). IDF Diabetes Atlas (10th ed.). International Diabetes Federation.
- Karlsson, A., Arman, M., & Wikblad, K. (2008). Teenagers with type 1 diabetes—A phenomenological study of the transition towards autonomy in self-management. International Journal of Nursing Studies, 45(4), 562-570.
- Khamis, A., Hoashi, S., Duffy, G., Forde, R., Vizzard, N., Keenan, P., Cregan, D., RGR Firth, & Kinsley, B. (2004). Diabetes knowledge deficits in adolescents and young adults with type 1 diabetes mellitus. In Endocrine Abstracts (Vol. 7). Bioscientifica.
- Klatman, E. L., Jenkins, A. J., Ahmedani, M. Y., & Ogle, G. D. (2019). Blood glucose meters and test strips: Global market and challenges to access in low-resource settings. The Lancet Diabetes & Endocrinology, 7(2), 150-160.
- Kratzer, J. (2012). Structural barriers to coping with type 1 diabetes mellitus in Ghana: Experiences of diabetic youth and their families. Ghana Medical Journal, 46(2), 39-45.
- Ligita, T., Wicking, K., Francis, K., Harvey, N., & Nurjannah, I. (2019). How people living with diabetes in Indonesia learn about their disease: A grounded theory study. PLoS One, 14(2), e0212019.
- Lindberg, B., & Söderberg, S. (2015). Standing on their own feet: Experiences of young people living with type 1 diabetes when entering adulthood-A qualitative study. International Diabetes Nursing, 12(3), 79-85.
- Los, E., & Wilt, A. S. (2022). Diabetes mellitus type 1 in children. In StatPearls [Internet]. StatPearls Publishing.
- Majaliwa, E. S., Munubhi, E., Ramaiya, K., Mpembeni, R., Sanyiwa, A., Mohn, A., & Chiarelli, F. (2007). Survey on acute and chronic

- complications in children and adolescents with type 1 diabetes at Muhimbili National Hospital in Dar es Salaam, Tanzania. Diabetes Care, 30(9), 2187-2192.
- Mayberry, L. S., & Osborn, C. Y. (2012). Family support, medication adherence, and glycemic control among adults with type 2 diabetes. Diabetes Care, 35(6), 1239-1245.
- Ministry of Health Republic of Ghana. (2017). Standard treatment guidelines (7th ed.). Ghana National Drugs Programme (GNDP), Ministry of Health.
- Moawad, S., Badawy, A. S., Al-saffar, Z. A., Al-Hamdan, N., & Awadien, A. M. (2014). Assessment of knowledge among Saudi diabetic children/adolescent at Riyadh city. American Journal of Nursing Science, 3(1), 5-12.
- Moustakas, C. (2004). Phenomenological research methods. Sage.
- Nafradi, L., Nakamoto, K., & Schulz, P. J. (2017). Is patient empowerment the key to promote adherence? A systematic review of the relationship between self-efficacy, health locus of control and medication adherence. PLoS One, 12(10), e0186458.
- Niba, L. L. (2016). Determinants of outcome of children with type 1 diabetes in the North West Region of Cameroon (Doctoral dissertation, Imu).
- Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. Evidence-Based Nursing, 18(2), 34-35.
- Norris, S. L., Engelgau, M. M., & Venkat Narayan, K. M. (2001). Effectiveness of self-management training in type 2 diabetes: A systematic review of randomized controlled trials. Diabetes Care, 24(3), 561-587.
- Owusu, B. A. (2022). Perceived causes and diagnosis of febrile convulsion in selected rural contexts in Cape Coast Metropolis, Ghana. BMC Pediatrics, 22(1), 1-9.
- Patterson, C. C., Harjutsalo, V., Rosenbauer, J., Neu, A., Cinek, O., Skrivarhaug, T., Rami-Merhar, B., Soltesz, G., Svensson, J., Parslow, R. C., Castell, C., Schoenle, E. J., Bingley, P. J., Dahlquist, G., Jarosz-Chobot, P. K., Marčiulionytė, D., Roche, E. F., Rothe, U., Bratina, N., ... Green, A. (2019). Trends and cyclical variation in the incidence of childhood type 1 diabetes in 26 European centres in the 25 year period 1989-2013: A multicentre prospective registration study. Diabetologia, 62(3), 408-417.
- Patterson, C. C., Karuranga, S., Salpea, P., Saeedi, P., Dahlquist, G., Soltesz, G., & Ogle, G. D. (2019). Worldwide estimates of incidence, prevalence and mortality of type 1 diabetes in children and adolescents: Results from the international diabetes federation diabetes atlas. Diabetes Research and Clinical Practice, 157, 107842.
- Powers, M. A., Bardsley, J., Cypress, M., Duker, P., Funnell, M. M., Hess Fischl, A., Maryniuk, M. D., Siminerio, L., & Vivian, E. (2015). Diabetes self-management education and support in type 2 diabetes: A joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the academy of nutrition and dietetics. Diabetes Care, 38(7), 1372-1382.
- Powers, M. A., Bardsley, J. K., Cypress, M., Funnell, M. M., Harms, D., Hess-Fischl, A., Hooks, B., Isaacs, D., Mandel, E. D., Maryniuk, M. D., Norton, A., Rinker, J., Siminerio, L. M., & Uelmen, S. (2020). Diabetes self-management education and support in adults with type 2 diabetes: A consensus report of the American Diabetes Association, the Association of Diabetes Care & education specialists, the academy of nutrition and dietetics, the American Academy of family physicians, the American Academy of PAs, the American Association of Nurse Practitioners, and the American Pharmacists Association. Diabetes Care, 43(7), 1636-1649.
- Rankin, D., Harden, J., Barnard, K., Bath, L., Noyes, K., Stephen, J., & Lawton, J. (2018). Barriers and facilitators to taking on diabetes self-management tasks in pre-adolescent children with type 1 diabetes: A qualitative study. BMC Endocrine Disorders, 18(1), 1-9.
- Roper, S. O., Call, A., Leishman, J., Cole Ratcliffe, G., Mandleco, B. L., Dyches, T. T., & Marshall, E. S. (2009). Type 1 diabetes: Children and adolescents' knowledge and questions. Journal of Advanced Nursing, 65(8), 1705-1714.
- Ryninks, K., Sutton, E., Thomas, E., Jago, R., Shield, J. P., & Burren, C. P. (2015). Attitudes to exercise and diabetes in young people with



- type 1 diabetes mellitus: A qualitative analysis. PLoS One, 10(10), e0137562.
- Sanders, T., Elliott, J., Norman, P., Johnson, B., & Heller, S. (2019). Disruptive illness contexts and liminality in the accounts of young people with type 1 diabetes. *Sociology of Health & Illness*, 41(7), 1289–1304.
- Sarfo-Kantanka, O., Asamoah-Boaheng, M., Arthur, J., Agyei, M., Barnes, N. A., Tenkorang, E. Y., & Midodzi, W. (2020). Trends in type 1 diabetes diagnosis in Ghana. *International Health*, 14, 442–446.
- Seo, H. E., Kim, M., Doo, E. Y., & Choi, J. (2020). Process of diabetes management in young adults with type 1 diabetes. Western Journal of Nursing Research, 42(4), 278–285.
- Sharma, G. (2017). Pros and cons of different sampling techniques. International Journal of Applied Research, 3(7), 749–752.
- Sherifali, D., Berard, L. D., Gucciardi, E., MacDonald, B., & MacNeill, G. (2018). Self-management education and support. Canadian Journal of Diabetes, 42, S36–S41.
- Sparapani, V. D. C., Borges, A. L. V., Dantas, I. R. D. O., Pan, R., & Nascimento, L. C. (2012). Children with Type 1 diabetes mellitus and their friends: The influence of this interaction in the management of the disease. Revista Latino-Americana de Enfermagem, 20(1), 117–125.
- Spencer, J. E., Cooper, H. C., & Milton, B. (2013). The lived experiences of young people (13–16 years) with Type 1 diabetes mellitus and their parents–a qualitative phenomenological study. *Diabetic Medicine*, 30(1), e17–e24.

van den Boom, L., Karges, B., Auzanneau, M., Rami-Merhar, B., Lilienthal, E., von Sengbusch, S., Datz, N., Schröder, C., Kapellen, T., Laimer, M., Schmid, S. M., Müller, H., Wolf, J., & Holl, R. W. (2019). Temporal trends and contemporary use of insulin pump therapy and glucose monitoring among children, adolescents, and adults with type 1 diabetes between 1995 and 2017. *Diabetes Care*, 42(11), 2050–2056.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Owusu, B. A., Ofori-Boateng, P., Forbes, A., & Doku, D. T. (2023). Knowledge of young people living with type 1 diabetes and their caregivers about its management. *Nursing Open*, 10, 2426–2438. https://doi.org/10.1002/nop2.1498