Owusu *et al. Health Economics Review* (2024) 14:74
https://doi.org/10.1186/s13561-024-00531-5

Health Economics Review

RESEARCH Open Access

'The national health insurance policy provides little to no benefit to young persons living with type 1 diabetes (T1D)': a qualitative study of T1D management cost-burden in Southern Ghana

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Abstract

Background Type 1 diabetes (T1D) management exerts a considerable financial burden on patients, caregivers, and developing nations at large. In Ghana, a key governments effort to attenuate the financial burden of T1D on patients was to fashion safety-net mechanisms through financial risk pooling/sharing known as the National Health Insurance Scheme (NHIS). However, there is limited research on patients and caregivers' experiences with the cost of managing T1D within the NHIS in Ghana.

Objective This study explored the cost of T1D management, and the impact of the NHIS policy on mitigating costs of care.

Methods A semi-structured interview guide was developed to collect qualitative data from 28 young people living with T1D (PLWD), 12 caregivers, 6 healthcare providers, and other stakeholders in Western, Central and the Greater Accra regions. Multiple data collection techniques including mystery client and in-depth interviews were used to collect data. Thematic content analysis was performed with QSR NVivo 14.

Results Five key domains/themes which are: cost of T1D management supplies; cost of clinical care; cost of transportation; cost of diet; and NHIS were identified. The daily cost of blood glucose testing and insulin injection per day was between GHC 5–7 (US$ 0.6 to 1.0). The NHIS did not cover supplies such as strips, glucometers, HbA1c tests, and periodic medical tests. Even for those cost which were covered by the NHIS (mainly pre-mixed insulin), marked government delays in funds reimbursement to accredited NHIS facilities compelled providers to push the financial obligation onto patients and caregivers. Such cost obligations were fulfilled through out-of-pocket top-up or full payment of insulin of about GHC 15–25 (US$ 2–4), and GHC 25–50 (US$4–8) depending on the region and place of residence.

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Conclusion The cost of managing T1D was a burden for patients and their caregivers. There was a commodification of life-saving insulin on the Ghanaian market, and the NHIS did not function well to ease the cost-burden of T1D management on patients and caregivers. The findings call for the need to scale up NHIS services to include simple supplies, particularly test strips, and always ensure the availability of life-saving insulin in healthcare facilities.

Keywords Diabetes, Healthcare financing, Health insurance, Universal health coverage (UHC), SARS-COV-2, Mystery client.

Introduction

Over the past two decades, there has been an epidemiological transition from a pandemic of infectious diseases to chronic diseases. Chronic disease such as diabetes mellitus (DM) has become a major global public health condition affecting over 537 million people across the world [1]. Although the major type of DM (type 2) is "caused" by lifestyle and is found mostly in adults, the peak age of type 1 diabetes (T1D) onset is childhood and young adulthood [2, 3]. Globally, T1D is prevalent in over 1.2 million young people aged 0–19 years, and 19,700 cases are diagnosed annually [4]. Similarly, an estimated 2,551 young persons are living with T1D in Ghana [4].

Type 1 diabetes is a chronic health condition with no day-off management. It is caused by an autoimmune destruction of the pancreas resulting in insulin deficiency. Unlike T2D, T1D persists for a longer duration due to its early development in childhood. It presents among young people who are more likely to be economically dependent, and is associated with disruptive complications. Consequently, the management of T1D places a heavy financial burden on patients and their caregivers in Ghana [5]. Governments efforts to attenuate the financial burden of managing diseases was to fashion safety-net mechanisms through financial risk pooling/sharing. In Ghana, this is done through the National Health Insurance Scheme (NHIS) [6]. The NHIS serves as a major policy towards meeting the health-related component of Ghana's SDGs, Poverty Reduction Strategy, and Universal Health Coverage (UHC) which seeks to deliver affordable and accessible healthcare, particularly to the poor and vulnerable in society [7]. For instance, health financing is in line with the 2030 UHC target of an 80 per cent reduction of healthcare costs for patients and making healthcare accessible to 80 per cent of the population [8].

Healthcare financing in Ghana evolved to its current state through a series of social interventions which solved a problem, but in turn, created problems requiring further solutions. For instance, healthcare was free in public health facilities immediately after independence [9]. However, economic recessions and political instability in the early 1960s and 1970s respectively, resulted in the payment of user fees for all medical conditions except for certain specified communicable diseases in the 1980s, and consequently, the popular "Cash and Carry" method [10]. The Cash and Carry led to a drop in out-patient attendance in the early 1990's from about 1.2 to 0.35 per person per year [10]. The NHIS was therefore established in 2003 (under Act 650 of parliament) to replace the Cash and Carry system thereby extending blanket accreditation to all public health facilities and provisional private health care facilities.

Enrolment onto the NHIS requires the payment of GHC 7.2 (US$ 1) to GHC 48 (about US$ 8) based on one's ability to pay [11], and renewable on an annual basis except for vulnerable categories of people including those below age 18 years, the aged above 70 years, Social Security and National Insurance Trust (SSNIT) contributors, pregnant women, and the disabled [6]. Thus, funds for the scheme are sourced mainly from the national health insurance levy (70%), social security contributions, and investment income (7%). Currently, having an active NHIS card guarantees free access to public health centres including teaching hospitals, regional hospitals, district hospitals, quasi-health facilities, accredited pharmacy shops, and private hospitals/clinics to enjoy a minimum package of health care including free consultation, admission, and insulin (pre-mixed) when available. According to the Ghana Adolescent Health Service Policy and Strategy (2016), nearly six out of ten young people aged 15–19 and five out of 10 young people aged 20–24 are covered by the NHIS. However, supplies such as strips and glucometers are not covered by the NHIS.

Undoubtedly, pooling risks/benefits together has the potential to improve access to T1D care and improve quality of life via access to professional care and essential drugs which are critical for T1D management. However, there is currently no published research focused on the costs of T1D management among young people within a highly referenced social protection health insurance scheme in Ghana.

Materials and methods

Study design and participants selection

Data were drawn from a qualitative study on the lived experiences of young persons living with T1D in southern Ghana. Specifically, data were collected in selected healthcare facilities, Diabetes Youth Care [DYC] support group centres and in the homes of patients in the Western, Central and the Greater Accra regions. The study interviewed 47 participants made up of 28 PLWD, 12 primary caregivers (PCGs), 6 healthcare providers (HCPs), and an access to insulin care manager in an insulin distribution company in Ghana. The study employed maximum variation and snowball sampling techniques which enabled participants with different socio-demographic characteristics such as age, sex, and place of residence to be drawn into the study. For caregivers with more than an eligible child living with T1D (n=3), all the children were interviewed, in some instances, only a child was interviewed due to their availability. Key inclusion criteria entailed a diagnosis of T1D according to the Ghana Health Service guidelines (a range of random venous plasma glucose above 11.1 mmol/L or fasting A1C>6.0% (6.9 mmol/L) as retrieved from hospital/camp registers; persons aged 14 to 24 years and resident in Western, Central and Greater Accra regions. PCGs who lived with, and HCPs who provided care for a PLWD aged 14–24 years for not less than 24 months were interviewed. Participants' selection and data analysis were ongoing to help gauge saturation – a point where no new information relating to the study criteria and objectives were identified. After interviewing the 25th PLWD, and the 10th PCG, we had gathered robust information to answer the objectives. However, two additional interviews were conducted among each participant category to help gauge saturation.

Data collection procedure

Ethical clearance [ID: UCCIRB/CHLS/2021/19] was sought from the University of Cape Coast IRB. At the healthcare facility and DYC support group (a support network for young people living with T1D in Ghana) meetings, interviews were granted in small conference rooms. Healthcare providers and caregivers who accompanied their children to seek health care consented to T1D patients below age 18 after seeking their assent. Interviews were conducted at locations agreed upon with participants. The study employed unique approaches to data collection in the peak of the SARS-COV-2 pandemic. Data collection methods were both traditional (face-to-face interviews, mystery clients) and digital (telephone interviews, videoconferencing, asynchronous interviews, and returned emails [12–14]). These inclusive methodologies were tailored to the unique situations of participants as well as in unison with contemporary research methods during global pandemic of infectious diseases.

A maximum of one interview was conducted in a day using English, Fanti, and Twi languages as best spoken and understood by participants. Interviews lasted between 40 and 120 min and were audio-recorded. The instrument used for data collection was a semi-structured interview guide. The interviews in Twi and Fante were transcribed verbatim into the English language the same day and password protected.

Data processing, analysis, themes, and presentation

The transcripts were coded independently by the field assistants in QSR NVivo 14. The Codebook was shared [among BAO and DD], discussed, and themes were generated from the codes. Data collection and analysis were done simultaneously. A thematic content analysis was employed as the analytical technique for this study [15]. In all, five (5) themes/domains were identified from the transcripts, with four themes on costs, and a theme on NHIS. QSR NVivo facilitated the comparison of different codes via Matrix coding including participant's ages, sex, and place of residents with their insulin sources, and prices. The findings are presented in themes.

Rigour

Quality assurance mechanisms were embedded in the study design. These measures cut across the design of the study, data collection, and analysis phases. Efforts at ensuring the *confirmability* of the findings entailed a chain of evidence including participant confirmation. Others included appropriate research design, as well as methods that have been employed in related studies [5, 16, 17]. Transcripts were emailed to participants with active email addresses and all healthcare providers to confirm their information. *Credibility* measures included participant observation whereby field assistants assumed a mystery client approach [12]. This was done to ascertain the prices of insulin on the market and pharmacy acceptance/non-acceptance of NHIS. Others included a prolonged engagement with participants, triangulation of data sources, participants re-checking through returned transcripts, and independent coding of transcripts. To further ensure that the results were *reliable*, the self-developed semi-structured interview guides were informed by gaps in literature, and the lead authors regular interactions with PLWD and their caregivers. The open-ended questions allowed participants to express their deep-seated concerns on costs of care and NHIS. The study made use of acceptable standards and practices of data analysis and reporting that followed the consolidated criteria for reporting qualitative research (COREQ) [18].

Results

Background characteristics of participants

Forty-seven (47) participants representing different target groups were interviewed (See Table 1). 28 of them were PLWD. Within this group, there was an equal representation of males and females. Ten of the PLWD were aged below 19 years, and they had lived with T1D for about 8 years. Twelve of them reported that a nuclear family member has diabetes, and most (n=19) PLWD were students who stayed with their caregivers - mostly their mothers. All the PLWD were actively covered by the

Table 1 Basic socio-demographic characteristics of participants

Participant Characteristics	Participant Categories				Total (47)
	PLWD (28)	PCG's (12)	HCPs (6)	ACM (1)	
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					
<5 years	5	4	1	1	11
5-10 years	17	6	3	-	26
>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
Don?t know	3	-	-	-	3
Primary caregiver (PCG)					
None	6	-	-	-	6
Both Parents	3	-	-	-	3
Mother/Grandmother	11	-	-	-	11
Father	3	-	-	-	3
Other relatives	3	-	-	-	3
Non-relative	2	-	-	-	2
PCG Occupation					
Salary earner	-	2	-	-	2
Petty trader	-	8	-	-	8
Unemployed	-	2	-	-	2
Religious affiliation					
Christian	25	11	5	1	42
Muslim	3	1	1	0	5
Position					
Physician	-	-	2	-	2
Pharmacist	-	-	2	-	2
Nurse	-	-	2	-	2
ACM	-	-	-	1	1

NHIS. A PLWD was married, and two others were cohabiting. Three of them had recently joined the DYC, and 7 were irregular meeting attendants. The average age of the PCGs was 45 years, mostly with Junior High School (JHS) and Senior High School (SHS) levels of education. Nine of the 12 caregivers were biological mothers of a PLWD, among which three (3) had diabetes including T1D. Eight of the PCGs were married and mostly engaged in petty trading in their local markets. The primary caregivers (PCGs) had been engaged in T1D caregiving for about 6 years. The healthcare providers (HCPs) were physicians ($n=2$), nurses ($n=2$), and pharmacists ($n=2$) who had been directly engaged in TID care for the past 7 years. An Access to Care Manager (ACM) for an insulin-distributing company participated in the study as well.

Themes

The findings from the 47 key informant interviews are reported on five main domains which were identified, namely: cost of T1D management supplies; cost of clinical care; cost of transportation; cost of diet; and NHIS. Domains of T1D management that were reported to be expensive were management supplies such as test strips and glucometers, clinical supplies such as insulin and laboratory costs, and cost of transportation.

Cost-burden of T1D management supplies and clinical care

The study participants including HCPs reported that glucose testing devices, strips, and insulin were expensive for most PLWD and their caregivers. Some participants provided insights into the clinical and logistics costs of T1D management. In their revelations, this was what was said:

> *"Test strips are the most extravagant part of her condition. I buy the bottle at GHC 120 [about US$ 17] and it comes in 50 pieces, and she uses it within a month" [a 41-year-old mother with 5 years of lived experience].*
> *"Glucometer is sold here at GHC200 [about US$ 28], and the test strip is GHC 5 [about 0.6 Cents] per unit" [Nurse in-Charge of Diabetes Unit].*
> *"I use Lantus and Act Rapid combination. Lantus is GHC 100 [about US$ 14] per pen which I use per week, and a vial of act rapid insulin is GHC 40 [about US$ 6] a month i.e., GHC 440/month [about US$ 62] for just my insulin" [a 24-year-old female PLWD with 13 years of lived experience].*

Other participants revealed that the prices of insulin on the Ghanaian market, particularly in the out-of-hospital pharmacies are poorly regulated. In his revelation, an Access to Insulin Care Manager had this to say "*We don't have very good control of the prices at the pharmacies* ".

Laboratory costs took the form of periodic eye, kidney, liver, and blood tests which were not covered by the NHIS. On laboratory costs for instance, participants had this to say:

> *"Sometimes, when she goes into crisis [diabetic coma] and we go for admission, by the time we*

> *return, about GHC 4,000 – GHC 5000 [about US$ 570 – US$ 714] will be gone" [a 55-year-old mother with 5 years of lived experience].*
> *"Most of their diagnostic investigations are not covered by health insurance" [Nurse in Charge of diabetes Unit].*

Cost-burden of transportation and diet

Transportation costs manifested in the form of travelling across regions to get insulin, caregivers absenting themselves from social support meetings, and quarrelling with commercial vehicle drivers over transportation fees. In explaining the cost-burden of transportation, this was what was said:

> *"I quarrel with car mates a lot about lorry fares. They always say she [T1D child] is no more a child and has developed breasts so she is not supposed to sit on my lap in the car" [a 53-year-old guardian with 3 years of lived experience].*
> *"Whenever there is a shortage of insulin at the hospital, we had to travel across regions to get some" [a 21-year-old male PLWD with 7 years of lived experience].*
> *"At first, I used to go [support group meetings] with them [children living with T1D] but now, I just allow them to go because of the costs of transportation" [a 60-year-old mother with 6 years of lived experience].*

An emergent issue was the geographical inaccessibility to insulin in some parts of the country. Some PLWD whose condition were diagnosed in the Northern parts of Ghana did not have access to insulin as a first-line medication to treating T1D. For instance, a female PLWD with 5 years of lived experience shared her diagnosis experience whilst in the Upper East region "*I collapsed, so they checked my BG* [blood glucose] *and it was above 33.3mmol/L that was when they started treating diabetes by giving me metformin tablets*.

Also common was the cost-burden of preparing adequate meal for PLWD. Most PLWD from deprived backgrounds justified their inability to purchase a well-balanced diet with their poor socio-economic status. For instance, assertions such as *the cost of foodstuffs are high, especially vegetables and those rich in protein; the "gari"* [a local food made from cassava] *is not good for me, but that is not expensive. If I get 50 pesewas* [about 0.07 Cents], *I can buy it. I don't have money to buy wheat rice* [a 20-year-old male PLWD with 4 years of lived experience] and *They are not able to comply because of the financial burden that comes with diet modification* [Nurse in Charge of a diabetic Unit] were reported by participants.

T1D management within the NHIS policy framework in Ghana

The final theme identified concerned T1D management within the NHIS. Two major sub-themes were identified and these are: limited NHIS coverage; and out-of-pocket top-ups/payment of insulin.

Limited NHIS Coverage

The NHIS covered pre-mixed insulin and syringes when available at healthcare facilities. There were spatial variations in accessing life-saving insulin under the NHIS due to the distance to NHIS-accredited facilities. It was reported that T1D management supplies such as test strips, glucometers, eyeglasses, and periodic medical reviews including foot, kidney, and HbA1c tests were not covered under the NHIS. Some of the PLWD described the NHIS coverage of insulin as inadequate. In explaining the issue of limited NHIS coverage, this was what was said:

> *"The insurance provides less or equal to no help at all in the management and treatment of diabetes. It covers just a vial or two of Mixtard© insulin for each diabetic and that's all. I use Novo rapid© and Lantus©, and I don't get them at public hospitals because insurance doesn't cover them. All other treatment costs are incurred by my parents and it's disheartening because the drugs and labs are not cheap" [an 18-year-old female PLWD with 17 years of lived experience].*
> *"Insulin aside, there are other equally important things that the insurance doesn't cover. For instance, strips are not covered under NHIS, and strips are expensive" [a 24-year-old male PLWD with 11 years of lived experience].*

In situations where healthcare facilities run out of insulin, PLWD who are covered by the NHIS were given prescription forms to go for insulin in NHIS-accredited pharmacies outside the hospital setting. However, PLWD and their caregivers are usually asked to top-up/pay for the cost of insulin. In explaining this issue, this was what was said:

> *"The pharmacist told me that insulin that is covered under NHIS is not available, especially ** pharmacy and ** pharmacy" [a 53-year-old guardian with 3 years of lived experience].*
> *"...a major challenge has been inadequate NHIS coverage" [a female family physician specialist with 6 years of working with PLWD].*

Top-ups at NHIS-accredited pharmacies

The erratic supply of insulin in public healthcare facilities compelled PLWD and their PCGs to purchase insulin from outside pharmacies. The price of pre-mixed insulin vials ranges between GHC 45-GHC 50 per vial [US$ $5–6]. When available, the price of insulin in the healthcare facilities compared to the market prices were lower irrespective of their NHIS accreditation status. Most participants shared their experiences with purchasing insulin from outside pharmacies and described the cost of insulin in most pharmacies as exorbitant.

> *"... insulin is covered under the NHIS, when I go there [hospital] and they don't have it, they give me a prescription form to receive insulin at the pharmacies nearby, but when I go, they [pharmacy attendant] make me add money to it, and that is the problem most of us are facing" [a 24-year-old female PLWD with 13 years of lived experience].*
> *"When I went to the pharmacy, they asked me to top up before giving me the insulin" [a 21-year-old male PLWD with 7 years of lived experience].*

These issues were explored further by assuming a participant-observer role, and the reality of top-ups were evident. Two pharmacies were visited by field assistants and a young person living with T1D to inquire about the cost of insulin when served with an NHIS form from a public healthcare facility. We found that, in most instances, pharmacy attendants asked the researcher to *go prepare and come back* [suggesting the need to go home and bring some money]. The amount of money PLWD or their PCGs top-up at NHIS-accredited pharmacies were reported as follows.

> *"I top up with GHC 20 [about US$2.5] when I go to the pharmacy" [a 15-year-old male PLWD with 7 years of lived experience].*
> *"When I went, they said I should add money to it. I added GHC 50.00 [about US$ 6], and they gave me two vials" [a 20-year-old female PLWD with 6 years of lived experience].*

Discussion

In this study, we sought to understand the cost of T1D management, and the impact of the NHIS policy in mitigating the financial burden of care incurred by patients and their caregivers in Ghana. The results/findings were presented across five domains which were: cost of management supplies, cost of clinical care, cost of transportation, cost of diet, and NHIS-related concerns. The results show that the management of T1D poses a considerable financial burden on PLWD and their caregivers, yet, the NHIS is failing to mitigate such cost burden. In situations where more than a household member had T1D, and/or people suffered from comorbidities, there was a catastrophic health expenditure which exerts further financial burden on individuals and their households as confirmed in other studies [19].

As found in this study, the average cost of a glucometer was GHC 220 (about US$ 37.00), a test strip costs GHC5 (about US$1.0), and a syringe costs GHC 1.20 (about 18 Cents). Thus, in the advent of no other T1D management costs, testing and insulin injection per day was between GHC 5 – GHC7 (about US$1). In other reports, the cost of a glucometer, test strip, and syringe were $15–$121, $1.20, and $0.15 respectively [20]. An earlier study in Ghana found that insulin injection can cost between GHC2 and GHC5 [less than US$ 1] per day [5]. Considering the socio-economic background of the caregivers, and that 8.4% of Ghanaians live in extreme poverty of less than US$ 1.25 a day [21], adequate management of T1D is a challenge. Again, the average household income in urban and rural areas in Ghana per day is GHC 44.86 (about US$ 8) and GHC 16.11 (about US$ 2.5) respectively [22]. Meanwhile, the average household size in Ghana is about four (4) [22, 23]. Thus, when evenly shared across household members, every Ghanaian living in urban and rural areas has a daily household per capita income of GHC 11.2 (about US$ 2) and GHC 4.0 (less than US$1) respectively [22]. This implies that, for the average Ghanaian PLWD in urban areas, more than half of their daily household per capita income is spent on daily T1D care. Among PLWD in remote areas, the daily costs of T1D testing and insulin injection per day outweigh their daily household per capita income. It is therefore not surprising that some caregivers in Ghana borrowed money, took loans, and/or sold household items to provide care for their children living with T1D [16]. Also, due to strip "insecurity", most PLWD could not reach the recommendation of testing glucose levels at least 6 times a day [24]. Thus, without adequate social protection schemes such as an efficient health insurance for T1D care in Ghana, the cost of T1D management can drift several households into a vicious cycle of poverty.

Geography matters in the discussion of health and illness. The difficulty in accessing healthcare was a concern for PLWD who had to travel long distances to get insulin and attend healthcare and support group meetings. Young persons living with T1D either reported to health facilities every two to three months for periodic reviews or attended the DYC monthly support group meetings in urban areas. For most PLWD and their PCGs from remote areas, the cost of transportation to access bi-monthly periodic hospital check-ups, and monthly psychosocial support services were challenging. In a related study, Owusu et al. [17] found that PLWD and had limited access to healthcare or social support services possessed limited scope of knowledge on T1D management and employed trial-and-error approaches to manage their T1D. For T1D patients who were diagnosed in some hospitals particularly in the Northern parts of Ghana, insulin was not the first-line medication prescribed for the treatment of high blood glucose as it was lacking. Clinicians, therefore, prescribed other medications including metformin and other oral medications which are inappropriate for managing T1D [17].

Contrary to our findings, an earlier research found that most PLWD in Ghana were not covered under the NHIS [5]. Generally, this could be due to the limited subscription rates across the country, - less than half (40%) of Ghanaians have subscribed to the NHIS [6], or unwillingness to renew membership status due to the limited scope of the benefit package. In our study, all PLWD were actively covered under the NHIS, and this presents an opportunity to improve their health. However, the NHIS was described as providing "little to no benefit" to young persons living with T1D, and this leaves much to be desired. Undoubtedly, fixing the NHIS-related challenges identified, and scaling-up services to cover T1D management supplies will cater for most of the financial burden and worries that T1D patients faced. Again, not all PLWD inject pre-mixed insulin - the only medication covered by the NHIS. That is, patients on other insulin kinds which are not covered by the NHIS (e.g., long, and rapid-acting insulin) incurred a higher cost of care. Evidence supports that pre-mixed insulin does not allow for a separate correction to be made for high blood glucose, and therefore not ideal for managing T1D [25, 26].

It has been two (2) decades since the implementation of the NHIS policy in Ghana, and therefore imperative to improve the services covered under the NHIS policy for PLWD. In the United Kingdom for instance, test strips are free on the National Health Service, and in Australia, small amounts of money are paid for strips [27]. In Ghana, when premixed insulin is available in public healthcare facilities and NHIS-accredited pharmacies, PLWD and are covered by the NHIS obtain two vials of 10 ml insulin free of charge for 2 months. However, a major source of worry and anxiety is the erratic supply of insulin in public healthcare facilities, leading to the purchase of insulin from private outlets. Due to the marked government delays in funds reimbursement to NHIS-accredited facilities, costs are shifted onto PLWD and their caregivers which they fulfilled via out-of-pocket top-ups, or full payment of insulin of about GHC 30 (US$5). The cost of care has implications for T1D management. For instance, Daneman found that parents in resource-limited areas choose between starvation for the other children without diabetes, or the death of the child with diabetes as a means of family survival [28]. There is a need to reduce premature deaths from NCDs including T1D by 1/3rd (SDG 3.4) and improve the health and general well-being of young people living with T1D in Ghana by addressing the NHIS-related barriers identified.

Implications for policy and practice

Due to their low socioeconomic status [22], most Ghanaian teenagers and young adults have very little purchasing power, which affects their capacity to acquire healthcare. This may be more so for young people who lack parental or other forms of support. Given the costs and limited NHIS coverage constraints identified, one may question whether what governments do about health financing via health insurance policies makes a difference in the life of PLWD. The NHIS policy does make a difference because it is always available and provides premixed insulin free of charge. However, the NHIS is failing to meet the increasing cost of T1D care. Further, insulin is not the most expensive component of T1D management, and for some young people, pre-mixed insulin is not the optimal insulin for T1D management [29]. As such, scaling up the range of services provided under the NHIS, particularly test strips and certain kinds of insulin, and the extent of financial protection or liability to subscribers will offer the most hope of resolving or managing the dilemmas of PLWD and their caregivers. There is a need for the various healthcare facilities to ensure regular stocking of life-saving insulin, and addressing the constraints of the NHIS will offer improved benefits beyond patients, to enhance the socio-economic well-being of caregivers. These are key concerns to achieve Universal Health Coverage (UHC), and consequently, the country's health-related SDG targets.

Strengths and limitations of the study

The strength of this study is the methodology employed to investigate the phenomenon particularly the mystery client approach, and the triangulation of data sources across different participant categories. For instance, the mystery client approach was helpful to collect reliable data by avoiding the Hawthorne effect. However, the study design has its limitations. The results are non-generalisable to contexts (largely geographical and differential access to care e.g., other private health insurance holders) not studied in this research. All cedis-to-dollar conversions were based on the last quarter of 2021 when the data was collected. Due to the volatility in market prices particularly for insulin, caution should be taken when interpreting the results on cost of care.

Conclusion

The cost of managing T1D was a burden for patients and their caregivers, particularly for those in remote areas. The cost-burden incurred from T1D management concerned costs of management supplies, costs of clinical care, cost of transportation, and dietary costs. The NHIS is steadily failing to meet the cost-reduction expectations of patients and their caregivers. These results call for the need to alleviate the financial obligations of patients and their caregivers by scaling-up NHIS services to include simple non-insulin T1D supplies, particularly test strips, and always ensure the availability of life-saving insulin in healthcare facilities.

Abbreviations

T1D	Type 1 diabetes
NHIS	National Health Insurance Scheme
PLWD	Persons living with T1D
GHC	Ghana Cedis
HbA1c	Glycosylated Hemoglobin
UHC	Universal Health Coverage
DM	Diabetes Mellitus
T2D	Type 2 diabetes
SDGs	Sustainable Development Goals
SSNIT	Social Security and National Insurance trust
PCG	Primary Caregiver
HCPs	Healthcare Provider
MmoL/L	millimoles per litre
DYC	Diabetes Youth Care
DKA	Diabetes Ketoacidosis
BG	Blood Glucose

Acknowledgements

We are grateful to all the young persons living with T1D and their caregivers who participated in this study, including those who have since passed on. We are also thankful to the healthcare providers and the Diabetes Youth Care for facilitating access to the network of young persons living with T1D in southern Ghana. We also acknowledge the support of the data collection team, especially Prince Ofori-Boateng, Castro Ayebeng and Wonder Agbemavie.

Author contributions

BAO: Conceptualisation, methodology, fieldwork, analysis, writing, review, editing, submission. NAB: Writing, review, editing. DTD: Conceptualisation, methodology, interpretation, review, editing, and over all supervision.

Funding

None.

Data availability

The transcribed data and/or analysed during the current study is available upon request from the Department of Population and Health, UCC at pop.health@ucc.edu.gh.

Declarations

Ethics approval and consent to participate

Ethical clearance was sought from the University of Cape Coast Ethical Review Board and the Department of Population and Health. Informed consent was sought from participants before data collection. All data collection methods were in accordance with relevant guidelines and regulations.

Consent for publication

Not Applicable.

Competing interests

The authors declare no competing interests as defined by BMC, BMC Health Economics Review journal or other interests that might be perceived to influence the results and/or discussion reported in this paper.

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Received: 22 August 2023 / Accepted: 1 July 2024

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