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A qualitative study of type 1 diabetes complications, mental health, and structural pathways of complications occurrence among young people (14–24 years) and caregivers in southern Ghana

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ABSTRACT

Background: Young people (aged 14–24 years) living with Type 1 Diabetes (T1D), especially, those in low-resource settings experiencing having T1D complications, and poor mental health. Yet, little is known about T1D complications, mental health, and their lived experiences among young people and their caregivers in Ghana**.**

Objective: This article sought to understand a) the dynamics of T1D complications, mental health, and lived experiences, and b) drawing on this evidence, develop structural and behavioural pathways of T1D complication occurrence among young people in Ghana.

Methods: The study design was interpretivist phenomenology (qualitative). Twenty-eight young people living with T1D (YPLWD), 12 caregivers, and six healthcare providers across three regions in southern Ghana were purposively recruited and interviewed using interview guides. The methods included a photovoice where the YPLWD took photographs to highlight visible complications. Themes were formed from the quotes and photovoice. The analytical technique was thematic - performed with the aid of QSR NVivo 14.

Results: Four main themes which were: physical complications, mental health, other adverse health outcomes, and structural pathways of complication occurrence were identified from the analyses. Physical complications discussed included visual impairment, diabetic coma, reproductive ill-health, and kidney disease. We found on the average, eight (8) years of living with T1D (with minimum and maximum years of 2 and 4 respectively). Mental health issues including anxiety and suicidal ideation transcended YPLWD to caregivers. Multiple structural and behavioural risk factors of T1D complications were also found.

Conclusion: The YPLWD and caregivers in Ghana experienced multiple T1D complications and poor mental health. Unfortunately, these manifested early in their natural history of T1D, and were influenced by inadequate structural resources, and the adoption of sub-optimal self-care practices. This article underscores the need to improve structural T1D resources, promote optimal blood glucose control, alongside mental/psychosocial support for patients and their caregivers in Ghana.

1. Introduction

Type 1 diabetes (T1D) is a common metabolic disorder and the most common endocrine disease among young people globally (Ziegler, 2018). It is caused by insulin deficiency following destruction of the insulin-producing pancreatic beta cells (Roep et al., 2021). Current estimates show that about 9 million people, representing 10% of the global diabetes prevalence are living with T1D (Ogle et al., 2022). In Ghana, about 2,761 young people aged less than 20 years are estimated to be living with T1D (Ogle et al., 2022).

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The incredibly unique multi-centre and randomised Diabetes Control and Complications Trial (DCCT, 1993) in USA and Canada showed that good glycaemic control is central to the prevention of T1D complications (Nathan and DCCT/Edic Research Group, 2014). The DCCT demonstrated the effectiveness of glucose therapy in reducing long-term complications of T1D. Glycaemic control seeks to a) reduce glucose levels in the blood b) maintain normal growth and development c) prevent or delay the onset of diabetes complications including ketoacidosis, and d) improve patients' quality of life and their psychosocial well-being (Chiang et al., 2014), thereby improving the prospects of a healthy lifespan. In the quest to achieving these goals, young people living with T1D (YPLWD) in developing countries including Ghana face several barriers to adequate care (Owusu and Doku, 2024; Owusu et al., 2023; Owusu et al., 2023). Barriers such as financial, socio-cultural, poor health systems, and poor self-care are known determinants of T1D complications, and further hamper the achievement of desired glycaemic goals including social and psychological well-being (Owusu et al., 2024; Owusu et al., 2023; Owusu et al., 2023).

Due to hyperglycaemia (higher blood glucose than normal) and glycaemic variability, T1D progressively affects small blood vessels and result in irreversible microvascular complications such as retinopathy (impaired vision), neuropathy (nerve damage), and nephropathy (kidney damage) (Najem et al., 2021; Agochukwu-Mmonu et al., 2021; Missambou et al., 2020; Ahmed et al., 2020). Retinopathy is the major cause of blindness among people living with diabetes (Kropp et al., 2023). Again, due to atherosclerosis, T1D progressively affects large blood vessels and lead to macrovascular complications such as coronary artery disease, cerebrovascular diseases, and peripheral artery diseases, leading to chronic lower limb pain and amputation (Zakir et al., 2023). T1D is a risk factor for diabetic ketoacidosis (DKA), (Jensen et al., 2021; DiMeglio et al., 2018).

As a chronic condition, T1D management is ongoing, complex, and can be very daunting for the YPLWD and their caregivers especially those in resource-limited areas. Adherence to treatment and self-care are important behaviours, critical for T1D management. T1D, therefore, has a profound impact on mental health. Psychosocial disorders including stress, anxiety, and depression are notable among persons living with T1D (Owusu et al., 2023; Lawes et al., 2014). In a related study, YPLWD in Ghana adopted poor coping mechanisms including avoidance and disengagement from T1D self-management (Owusu et al., 2023), and attributed their poor academic performance to the demands of T1D management (Owusu and Doku, 2024). Mental health comorbidities of diabetes compromise adherence to treatment, and thus, increase the risk of micro and macrovascular complications notably blindness, amputations, cognitive decline, poor quality of life, and premature death (Ducat et al., 2014; Siersma et al., 2014).

It is known that sub-optimal/inadequate blood glucose control predisposes patients to complications, disability, poor quality of life, poor mental health, and increased mortality. However, there is dearth of knowledge on T1D complications and mental health among YPLWD and their caregivers in Ghana. A clinical case report by Ameyaw et al. (2020) showed a 17-year-old girl with T1D who suffered amputation on account of poor blood glucose control and poverty (Ameyaw et al., 2020). Beyond this research, much less is known. The nature of youth culture call for a deeper exploration of their behavioural (usually latent) and structural concerns, especially, operant conditioning that contributes to poor blood glucose control amongst them. This article, therefore, seeks to explore T1D complications, mental health, as well as conceptualise key behavioural and structural pathways of complications occurence to provide evidence that can inform the development of T1D interventions to prevent/delay the onset of complications, improve care, as well as the mental health of YPLWD and their caregivers in low-middle-income countries (LMICs).

2. Materials and methods

2.1. Study design and participants selection

This study was a qualitative inquiry driven by a phenomenological study design. Phenomenology is concerned with the study of experiences from individuals' perspective, and bracketing taken for granted assumptions and usual ways of perceiving (Lester, 1999). The study used data from YPLWD, their caregivers, and healthcare providers (See Table 1). This latter group (secondary group) were recruited to provide corroborative information to understand complication occurrence. Participants came from the Greater Accra Region (National capital), Central, and Western Regions where major healthcare facilities in Ghana such as the Korle-Bu Teaching Hospital, Greater Accra Regional Hospital, Cape Coast Teaching Hospital, and Effia-Nkwanta Regional Hospital are located. At each site, a minimum of 8 interviews were conducted. The sites involve a high number of YPLWD who participate in psychosocial support services. The YPLWD were identified at support group centres (n = 13), their home (n = 9), and hospital centres (n = 6). Participants with different socio-demographic, geographic, and clinical characteristics were purposively recruited into the study using maximum variation and convenience sampling techniques. The study employed the inclusion criteria below:

a. A diagnosis of T1D as retrieved from patients' diabetes registers.
b. Continuously reside and receive/provide T1D care (in the case of caregivers) within the past 24 months in the study area. The 24 months continuous were deemed sufficient time to greatly experience the daily life of patients, reduce recall bias, and to provide recent and robust description of events.
c. YPLWD must be aged between 14 and 24 years as younger people were considered to lack the capacity to provide in-depth information about their lived experiences.

2.2. Data collection instruments

Three in-depth interview guides were developed, pre-tested among 2 YPLWD and 2 caregivers in nearby healthcare facilities and used for the data collection. Some key questions on the interview guide were: How has T1D affected your health and general well-being? How has T1D affected your child, and why so? What common complications are diagnosed among YPLWD, and why do such complications occur? Further, the psychosocial component of the interview guide reflected key domains of the Home, Education, Activities, Drugs, Sexuality, Suicide/Depression and Safety (HEADSSS) screening tool (Goldenring and Rosen, 2004). HEADSSS is a validated screening tool to identify psychosocial risks and stressors among adolescents (Goldenring and Rosen, 2004).

2.3. Ethics and data collection procedure

Ethical approval was given by the University of Cape Coast Institutional Review Board (IRB) [Clearance ID: UCCIRB/CHLS/2021/19]. Data collection was conducted from 1st August - 9th September 2021.

Table 1
Participant categories and their medium of interview.

Medium	YPLWD	Caregiver	HCP[a]	ACM[b]	Total
Face-to-face interview and Photovoice	17	12	1	×	30
Telephone interviews	11	×	2	×	13
Videoconferencing	×	×	1	1	2
Asynchronous email	×	×	2	×	2
Total	28	12	6	1	47

[a] HCP – Healthcare Provider.
[b] ACM – Access to Insulin Care Manager.

Participants were recruited from healthcare facilities, Diabetes Youth Care Centres (DYC, a non-governmental organisation that provides psychosocial support to YPLWD and their caregivers in Ghana), and their homes. Caregiver informed consent (both written and oral) and patients' assent were sought for YPLWD below age 18. Interviews were conducted at appropriate locations agreed upon with participants. The data collection was assisted by three postgraduate research assistants (RAs) who have in-depth experience in qualitative research. Interviews were conducted in English, Fanti or Twi languages as best spoken and understood by participants and were audio-recorded. An interview was conducted in a day and transcribed verbatim into English language and password protected. The interviews lasted between 40 and 120 min. Following Wang and Burries photovoice methodology, participants were asked to take pictures depicting health outcomes and/or their T1D lived experiences with their personal mobile phones (Wang and Burris, 1997). During interview sessions, these photos were discussed within four dimensions which were: precursors to events; ascribed meaning; lived experiences; and aftermath concerns. Several photos were taken to address the broader study on T1D lived experiences. Seven (7) participants provided photos on complications (3 on foot issues, 2 on lipodystrophy/abscess, and 2 on insulin injection). Photos on complications that were selected and agreed upon with YPLWD and their caregivers for reporting and publication purposes were retrieved from the data and presented to support the issues and themes that were identified. Table 1 summarises the data collection methods and participant categories.

2.4. *Data analysis and presentation of results*

The field notes, transcripts, and photos were imported into QSR NVivo 14 for a computer-assisted qualitative data analysis (CAQDAS). Using thematic analysis method, which is linked with phenomenological study design, we took a combined approach to analyses, enabling themes to be developed both inductively from the accounts of participant experiences, and deductively from the research team and literature. The inductive coding assisted in exploring pathways of complication occurrence and lived experiences. Three individuals including the lead author assigned *in-vivo* codes to the data files and reviewed the codes. The team met regularly to critically explore participant responses, discussed divergent findings, and identified themes. The analysis revealed four major themes (Table 3) which are physical complications, mental health, other adverse health outcomes, and structural and behavioural pathways of complication occurrence. We summarized the codes and case classifications for each theme to explore patterns using Matrix coding.

The findings were presented in an in-line quote (*sandwich*) format where participants' data were placed within authors' sentences for thought coherence (Gopaldas, 2016). Such an approach further helps to contextualise findings thereby enhancing meaning for readers (Cristancho et al., 2021). Where appropriate, block quotes were employed to long interview excerpts. Participants' information were presented using an *in-vivo* pseudonym [*warrior*] to wit "T1D fighters" which is a term the YPLWD in DYC choose to call themselves. Quote "Tidying-up" (i.e., minor edits) was done in some instances to maintain grammatical integrity and contextualise evidence despite maintaining participants meaning [this we signalled by using square brackets *[]* and ellipsis *(…)*]. Further, power quotes (i.e., more compelling quotes) were presented in a thematic framework (Table 3), and proof quotes were presented in the text. The different sources of quotes employed reflect strong patterns in the data. Due to the triangulation of data sources, we used composite narratives from multiple participants – patients, caregivers, or healthcare professionals in different constructions to offer readers rhetorical control. In discussing the findings, we employed the *Claim, Data*, and *Elaboration*, also known as *Telling, Showing*, and *Telling* sequence (Cristancho et al., 2021; Golden-Biddle and Locke, 2006). The study made use of acceptable standards and practices of data analysis and reporting that followed the Consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

Table 2
Socio-demographic characteristics of study participants.

Participant Characteristics	Participant Categories				Total (47)
	YPLWD (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

3. Results

3.1. *Background characteristics of study participants*

Forty-seven participants representing different groups (YPLWD, caregivers, and healthcare providers), regions and sex were interviewed (Table 2). Out of this number, 28 were YPLWD. Within this group, there was equal representation of males and females. Their average age was 20 years, ranging between 14 and 24 years. The average age of living with T1D was about 8 years (minimum duration = 2 years; maximum duration = 19 years). Majority of the YPLWD wore a medically prescribed eyeglasses due to T1D (n = 21). Fifteen participants reported an immediate family history of diabetes [undifferentiated]. In terms of education, most YPLWD were students (n = 19) with Senior High School level of education (n = 11). In the home setting, primary caregivers were mostly their mothers (n = 11). All YPLWD were actively covered under the National Health Insurance Scheme. One participant was married, and two others were cohabiting. Three participants had recently joined DYC, and 7 were irregular meeting attendees. Among the 12 caregivers, the average age was 45 years (minimum = 30 years, maximum = 60

Table 3
Thematic framework.

Themes & sub-themes	Source	In-vivo [*Excerpts from transcripts*]
Physical Complications		
Visual impairment	14	When I started work, I went to do medicals and failed eye test *[Male, 24 years, 11 years of LE]*
Diabetic coma	5	*I collapsed … this was like the third time since my diagnosis* [Female, 20 years, 5 years of LE]
Foot ulcer	4	It’s difficult getting it *[wound]* to heal *[Female,19 years,7 years of LE]*
Neuropathy	3	*If I put cold water on it* [leg], *I can’t even feel anything* [Female, 24 years, 13 years of LE]
Reproductive health	3	I am unable to maintain an erection. It *[penis]* starts to erect and stops moments after *[Male, 20 years, 10 years of LE]*
Tooth loss	3	*It has affected my teeth, the front ones have fallen* [Female, 18 years, 5 years of LE].
Kidney problems	2	… *my kidney is not in a good shape* [Female, 20 years, 5 years of LE]
Mental/Psychosocial distress		
Stress	13	*That’s a whole lot of testing and injection in a day* [Female, 20 years, 5 years of LE]
Anxiety	8	*When she calls me from the boarding house and I see her call, then I start to panic* [Mother, 60 years, 6 years of LE]
Burnout/Depression	7	*He gets furious and avoids treatment. Yelling, “Why should I get this disease* [Mother, 56 years, 6 years of LE, all 2 kids have T1D].
Social Isolation	5	*I developed the habit of not going out to avoid the constant question of why I inject myself* [Female, 24 years, 13 years of LE]
Poor sleep	5	*I have to be waking up frequently to urinate at night* [Female, 20 years, 5 years of LE]
Suicidal ideation	4	*I thought of killing my child and then kill myself* [Female, 24 years, 9 years of LE].
Other adverse health outcomes		
Weight loss/stunted growth	11	*He can’t grow well, all his younger siblings have grown well unlike him* [starts to cry] [Mother, 39 years*]*
Abscess and lipodystrophy	8	*The place has swollen so I have changed it. Now I do it on my thighs, but that has started to swell. My thighs are tired, so they do it on my buttocks. My mother said I should do it on my stomach. I didn’t even want to do it on my thighs how much more my stomach* [Male, 17 years, 4 years of LE]
Structural and behavioural factors		
Structural and behavioural	–	*When there is a shortage of insulin, I reduce the unit of insulin shots I take in a day”.* [a 20-year-old male warrior with 6 years of LE]

years). One had a tertiary education. Nine of the 12 primary caregivers were biological mothers of a YPLWD. Family history of diabetes (undifferentiated) was also reported by some caregivers, amongst whom four had diabetes (both types). Most (n = 7) of the caregivers were engaged in petty trading and had been engaged in T1D care for an average of 6 years (minimum = 3 years; maximum = 15 years). The HCPs had been directly engaged with T1D patients for the past 7 years in their respective healthcare facilities.

3.2. Themes

Four broad themes which are *physical complications, mental health, other adverse health outcomes*, and *structural and behavioural determinants of complications* were identified from the interviews and photovoice. Theme 1 [*physical complications*] concerned all T1D-related health conditions which had perceptible manifestations. This included retinopathy, diabetic coma, foot ulcer, neuropathy, reproductive health, and nephropathy. The second theme [*mental/psychosocial distress*] was developed from findings on poor mental health including anxiety, suicidal ideation, and poor social well-being. The third theme [*Other adverse health outcomes*] was formed from T1D-aggravated conditions and sequalae including injection abscess, and pregnancy apprehensions/congenital anomalies. The final theme [*structural and behavioural pathways*] was developed from structural and behavioural factors which contributed to T1D complications. Table 3 summarises these theme inventories.

3.3. Physical complications of type 1 diabetes

3.3.1. Retinopathy/visual impairment

Multiple microvascular complications were found among the YPLWD. The most common complication was visual impairment/retinopathy. Most of the YPLWD had problems with their eyesight and/or wore glasses. This common complication was a major source of worry for patients and caregivers, especially for students living with T1D. In their assertions, this was what was said:

> They *[optometrist]* asked me to read some letters and I wasn’t seeing them well, even after trying several times, it was still difficult to read the letters *[a 24-year-old male warrior with 10 years of lived experience].*

Some YPLWD avoided the wearing of eyeglasses. In explaining this issue, this was what was said by a 21-year-old female warrior with 7 years of lived experience “*I stopped wearing the lens because it was too heavy, and the medications were hurting my eyes”*. In corroborating this issue about non-use of eyeglasses, this was what a 50-year-old mother with 7 years of lived experience had to say, “*she has stopped wearing her specs* [spectacles] *because her friends laugh at her”*.

*3.3.2. **Diabetic Coma/Ketoacidosis/Seizure***

For most participants, their condition was diagnosed at healthcare facilities during coma incidence or after their body produced excess blood acids, also known as ketones or diabetes ketoacidosis (DKA)”. Assertions such as “*I collapsed and was rushed to the hospital* [a 20-year-old female warrior with 5 years of lived experience]”, and others by a 21-year-old female warrior with 7 years of lived experience such as “*I had a crisis* [collapsed] *and was rushed again to the hospital and they found it* [diabetes]” substantiates the finding on coma incidence. Coma events were confirmed by caregivers amongst whom a 56-year-old mother shared that *“when he goes off, he collapses.*

3.3.3. Neuropathy and foot ulcer

For neuropathy and foot ulcer, participants shared their ordeals of the numbness of their feet. For instance, a 24-year-old female warrior with 13 years of lived experience revealed that: *If I put cold water on it* [leg], *I can’t even feel anything. It has become numb. Concerning foot ulcer, some YPLWD suffered impaired wound healing as shown in* Fig. 1.

A female participant who was also living with disabilities had her toe amputated (see Fig. 2). During photo discussions, her caregiver (mother)

Fig. 1. A 15-year-old female warrior’s photograph meant to show impaired wound healing for 3 months.

Fig. 2. A 16-year-old female warrior showing a photograph of her amputated toe.

shared her experience about how her daughter developed the wound leading to her toe amputation "*She had a sore on her foot and it affected her toes. It took some time for the toes to heal, but the big toe was not healing so they* [healthcare providers] *cut the toe out*" [a mother of a 16-year-old female warrior with 7 years of lived experience].

3.3.4. Reproductive health

The females living with T1D who had experienced pregnancy revealed congenital anomalies, or neonatal death due to diabetes. Also, the females reported about reduced sexual drive, and undesirable urinary tract infections. In explaining the issue of congenital anomalies, this was what was said *"I got pregnant and gave birth to a baby boy, but the baby had no ears, and his spinal cord was not normal, so he died later* [a 24-year-old female warrior with 9 years of lived experiences]. To buttress this issue, a 56-year-old mother living with diabetes and 6 years of lived experience whose two children are living with T1D had a similar experience. In her revelations, she stated how she lost her unborn babies due to T1D "*Imagine if my two boys were to be alive. I remember the days I felt the foetus kicking, those were the times they were dying, and I didn't know.*

Concerning reduced sexual drive and itchiness around their sexual organs, this was what some participants had to say:

> *Personally, sometimes my condition reduces my desire* [libido] *for sexual intercourse. That is how I see it. It is on and off occasionally. So, if you are staying with a man who does not understand your condition, he might say that you are denying him sexual intercourse.* [a 24-year-old female warrior with 8 years of lived experience]

> *Sometimes I experience itches around my vagina. But by the grace of God, it is gone. I was given a medicine and anytime I take it, the itches stop and so I am okay.* [a 21-year-old female warrior with 6 years of lived experience]

Among the males living with T1D, erectile dysfunction (ED) was reported. According to these young males, the effect of T1D on their erection was a reason for shying away from romantic relationships. In explaining this issue, this was what a 20-year-old male warrior with 4 years of lived experience had to say about ED:

> *"The last time I had an erection was about two months ago. It's part of the reasons why I am not too interested in romantic relationships because I am afraid I will embarrass myself"*.

3.3.5. Nephropathy/kidney diseases

The participants revealed that they have lost some peers living with T1D to kidney issues. For some YPLWD, kidney function tests were rarely done. Others revealed swollen feet and faces and attributed this to their kidneys. In a discussion with a 20-year-old female warrior with 5 years of lived experience, this was what she had to say:

> *"The Doctor read my kidney function results and said my kidney is not in a good shape"*.

In corroborating this evidence, this was what a 56-year-old mother with 6 years of lived experience revealed when she went to the hospital:

> "*Yesterday when we* [with her children living with T1D] *went to the hospital, I met a very sick young girl and her mother said they* [Doctor] *said her kidney is not responding well. I felt so bad and cried throughout"*.

3.4. Type 1 diabetes and poor mental health/psycho-social well-being

Open discussions using the HEADSSS assessment tool revealed that YPLWD experienced poor mental health due to their chronic condition and its management. The major issues that were saturated in the data were distress, anxiety, burnout leading to depression, suicidal ideation, social isolation, and poor sleep patterns. These psychosocial experiences, particularly anxiety, suicidal ideation, and poor sleep patterns transcended YPLWD to their caregivers.

3.4.1. Type 1 diabetes distress

The YPLWD reported distress from the struggles to achieving target range glucose levels, and continuous self-monitoring of blood glucose (SMBG). Assertions such as "… *that's a whole lot of testing and injection in a day"* [a 20-year-old female warrior with 5 years of lived experience] were commonly reported by participants. *Distress episodes were compounded during typical events where controlling blood glucose (BG) was a hurdle.* In explaining this issue, this is what was said:

> *I remember well last year we went to Bolgatanga (up North) for men's camp. I was going to bed, and I thought my sugar was low, so I tested my sugar, and it was low, so I called my mom to help me deal with it. So, I took some cake, 15 minutes later it was lower, I took sugar tab and 15 minutes later it hadn't gone up at all, and I took it again. So, for like an hour and 10 minutes we were trying to get it to go up. After that it finally went up, and another hour later it went down again. I guess she extra dosed me on sugar so it wouldn't go low, and, in the morning, it [blood glucose level] was in the 20s, and sometimes I find it very stressful. There are times I felt like giving up because I was so tired* [a 15-year-old male warrior with 5 years of lived experience].

Beyond the difficulty in glucose control, caregiver stress was further due to their participation in the care of their children living with T1D. This manifested in the form of traveling with their children who otherwise would have been left behind, diet, and insulin injection reminders. In explaining the stress from traveling with their children, this was what was said:

> "*She has younger siblings but anytime I travel, I must take her rather along because of her condition, and it get stressful at times* [a 41-year-old mother with 5 years of lived experience].

3.4.2. Type 1 diabetes burnout, depression, and suicidal ideation

Participants expressed burnout/extremely diminished physical and emotional energy from the continuous management of T1D and described it as depressing. They expressed such burnout sentiments in the form of despair, suicidal ideations, chronic fatigue, and grief. Among YPLWD, these assertions were overwhelming. In explaining this issue, a 20-year-old female warrior with 5 years of lived experiences shared this experience.

> *"I gave up injecting my insulin, I said I wouldn't do it again, what will come should come, I am tired! I felt so depressed, and it lasted for a long time, so I began to break down. I had a few friends and professional counsellors who spoke to me and advised me to get back on treatment"*.

Concerning suicidal ideation, a 21-year-old male warrior with 10 years of lived experience had this to say *"there are a lot of things that go through my head. I wonder whether I should kill myself because this condition is very bad"*. Also, a 24-year-old female warrior with 9 years of lived experience revealed a situation where she thought of suicide after her newly born child was diagnosed with diabetes. "*I thought of killing my child and then kill myself*".

3.4.3. Type 1 diabetes worries, anxiety, and problems with emotions

Anxiety episodes among YPLWD stemmed from finger pricking, insulin injection, and complications. Among caregivers, T1D complications, daily insulin injection, death of other children living with T1D, and worries about the future of their children living with T1D particularly, on their education and career progression, employment, social relations, and untimely death were major sources of anxiety. For instance, on education, this was what a 41-year-old mother with 5 years of lived experience said:

> "*It's about her school. I am afraid she will want to go to boarding school. I can't allow her to go to boarding school … she may sleep and something* [near-death/death] *may occur because no one will be watchful of her*".

Among some caregivers whose children living with T1D had travelled, receiving a phone call from their children sparked mixed feelings. For instance, a caregiver reported on how receiving a phone call from her child living with T1D in school makes her live in perpetual state of anxiety by revealing that "*when I see her call, then I start to panic thinking that something bad might have happened to her*".

As mentioned, complications, death of other warriors, and continuous insulin therapy were major sources of worry for caregivers. For instance, caregivers were worried about the continuous insulin injection by their children. In explaining this issue, this was what a caregiver who is also diabetic had to say:

> *They* [both of her children] *are too young to be injecting themselves every day … I have been living with diabetes for the past 25–26 years and all our drugs were fine. We injected once a day, and now we inject more than once a day. These days the drug* [insulin] *is not that good … So, we plead, they* [hospital] *should give us the good drugs. Last year, we lost* [talking about death] A and B [pseudonyms of warriors] *who were amongst the healthy boys we all know. To give birth to a child only to suffer this condition is very worrying* [starts to cry]*, who will take care of us when we are older …* [crying]*, my children are too young to be going through this condition* [a 56-year-old mother with 6 years of lived experience, all 2 kids have T1D].

Participants showed emotions from the pain of pricking and insulin injection to the untimely demise of their friends living with T1D. They demonstrated that T1D is a very sad chronic condition. During interviews, some of the participants especially the caregivers shed tears as they recounted their lived experiences. Assertions such as "for people like us, we don't live longer *[starts to cry]" by a 14-year-old female warrior with 2 years of lived experience were common. In buttressing the issue of untimely death, a 24-year-old warrior with 10 years of lived experience revealed this "Last year, I was calling him* [best friend living with T1D] *on phone … but it wasn't going through. So, I went to his house, and was told that he has passed on* [starts to cry].

3.4.4. Type 1 diabetes and social isolation

T1D was a major reason for social isolation. Isolation was either due to schoolteachers excluding warriors from engaging in social activities enjoyed by their peers without diabetes, and fear of stigma, which manifested in the form of hiding their self-monitoring of blood glucose (SMBG) and insulin injections from their peers. Concerning the exclusion from engaging in sports activities, a 21-year-old male warrior with 7 years of lived experience had this to say *"Lots of my friends started staying away from me. They would not allow me to play football with them because I was fragile to them"*. In corroborating this assertion, a 21-year-old male warrior with 10 years of lived experience had this to say *"They* [teachers] *don't include us during games. I remember one teacher told him* [a diabetic friend] *that I will not include you for you to collapse on me. I don't want any police case"*.

When explaining the issue of social isolation from their colleagues without diabetes, this was what a 24-year-old female warrior with 13 years of lived experience reported *"I developed the habit of not going out to avoid the constant questions of why I inject myself"*. Isolation was also confirmed by caregivers who shared that *"Other kids in the house are not like that, she isolates herself whilst others are playing"* [a 53-year-old guardian with 3 years of lived experience].

3.4.5. Type 1 diabetes and poor sleep quality

Sleep time was a major issue of concern for the YPLWD and caregivers. The YPLWD reported difficulty in sleeping due to elevated blood glucose and consequently, frequent urination at night. Some *in-vivo* evidence was shared "I have been experiencing hyperglycaemia for two days now due to my brittle T1D. I remain up all night because I keep on peeing *[an 18-*year-old *female warrior with 17 years of lived experience]. This sentiment was also confirmed by a* 20-year-old female warrior with 5 years of lived experience *who revealed this "sleep becomes difficult because then I must be urinating frequently"*. Among caregivers, poor sleep quality was due to caregivers being watchful of their children with T1D to prevent diabetic coma at night. Concerning this, a *41-year-old mother with 5 years of lived experience had this to say "*I don't sleep deep. I occasionally wake her up at night and asks her whether she's checked her sugar or she's hungry. At times, waking her up takes some time, and I get to know that she may be going hypo".

3.5. Other adverse outcomes of type 1 diabetes

3.5.1. Type 1 diabetes and weight loss

Weight loss *amongst YPLWD was a major observation made by caregivers. For instance, a 50-year-old mother with 7 years of lived experience had this to say "*As you see him now *[seated about 5 m from the interview spot]*, he doesn't look like his age, he can't grow fat, and always slim. *These concerns were affirmed by a* 39-year-old mother *who expressed her emotions as she recounted the physical stature of his son in relation to her other children "… all his younger siblings have grown so nice and looking fine, but as for him* [takes deep breath, starts to cry].

3.5.2. Type 1 diabetes lipodystrophy and injection abscess

Insulin injection led to abscesses and/or lipodystrophy at the injection sites (See Fig. 3). This was common among participants who failed to change/rotate their injection sites, and among those who failed to change their needles frequently. Using verbal accounts of their deep-seated concerns and photo-evidence, the participants had this to say "*One of my thighs swelled due to the injection. It looked like a boil. I reported it to the hospital, and I was transferred to a surgeon, and they cut that part of the skin. The cut was very big and deep* [a 24-year-old female warrior with 13 years of lived experience].

To buttress this experience, a patient revealed that she is anxious about going through such an experience. In her revelation, this is what was said:

Fig. 3. A 20-year-old female warrior showing a photograph of a scar from an abscess.

> *"I have black spots and sometimes the place gets swollen, so I stopped injecting my insulin. I remember we went for a camp in Accra and saw the sore from an injection on one of my friend's arms, they had put cotton in the sore and it was so bad, I was frightened so I don't want to get to that stage.* [a 21-year-old female warrior with 3 years of lived experience]

A participant shared a photo-evidence depicting a healed abscess on her thigh due to continuous insulin injection.

3.6. Structural and behavioural pathways of T1D complications occurrences

The analyses revealed multiple structural and behavioural factors that contributed to the emergence of T1D complications. The key structural concerns were erratic supply of insulin, poor access to professional healthcare, remote place of residence, financial constraints, and classroom practices that hinder students from eating in class/or using the washroom regularly, leading to hypoglycaemia or hyperglycaemia respectively. Concerning these structural factors, assertions such as "*I was not having the money to go to the hospital", "they* [healthcare providers] *did not know about my condition that much so I later consulted with a specialist in Accra" "… when I went, they* [hospital] *were not having insulin and asked that I go and buy"* were common experiences of the YPLWD. Concerning the issue of classroom practices, this was what a 20-year-old female warrior with 6 years of lived experience had to say, *"I usually went out to urinate or sought permission to go and take care of other stuffs, but some teachers were hesitant, and for most of them, they wouldn't allow me to take toffees while in class"*.

Sub-optimal behavioural practices which contributed to T1D complications were insulin rationing and/or avoidance, poor storage of insulin, caregiver (grandparent) beliefs about diabetes, spirituality, re-use of strips, avoidance of self-monitoring of blood glucose, excessive use of insulin, and absent-mindedness due to competing academic/work demands. When explaining the issue of caregiver beliefs, a 21-year-old female warrior with 7 years of lived experience revealed this:

> "*When I completed JHS* [Junior High School]*, I went to stay with my grandmother at …, and with her, it was all about prayers. She stopped me from injecting for about four months. Upon return* [back to her usual place of residence], *my mother burst in tears when she saw me because I had grown very lean. I never told my mom while I was away that I wasn't taking my medications."*

Insulin was excessively used by some YPLWD after consuming high glucose foods at parties to significantly reduce their glucose level and escape parental chastisement. In their revelations, this was what was said "*I was served with food and drinks at the party, I took a lot of the drinks, and my sugar levels went high so I took a lot of insulin to lower it so that my parents wouldn't know*". To reduce regular SMBG and pain from pricks and injections, some young persons avoided food. In explaining this issue, this was what a 17-year-old female warrior with two years of lived experience had to say, "*anytime I'm about to eat, I must take my insulin, so when I don't eat, there is no need to inject myself and go through this pain. I will rather starve myself instead of injecting myself all the time*".

These structural and behavioural risk factors are important predisposing factors for T1D complications and consequently poor mental health. The mechanisms of these findings have been conceptualised in Fig. 4. In conceptual terms, T1D complications among YPLWD in Ghana is highly influenced by limited structural resources towards optimal T1D management. These structural constraints compromise self-care, and results in poor blood glucose control, hyperglycaemia, and complications. Particularly for the YPLWD who were economically dependent on their caregivers, structural factors such as shortage of insulin, limited access to professional healthcare, caregiver beliefs, and financial constraints were important pre-disposing factors for their adoption of poor self-care practices. Similarly, the economic activities performed by some YPLWD such as engagement in strenuous agricultural production, mining, and hawking exposes YPLWD to foot ulcer/and or impaired wound healing, which also affects adequate self-care, and later result in micro and macrovascular complications including foot ulcer. Undoubtedly, YPLWD-related factors such as age and sex may play a role in the development of T1D complications. However, this study posits that such individual level factors are necessary, yet needless to advance our discourse on structural and behavioural determinants of complications, and also that the data did not highlight strong evidence to support this. There is a bidirectional relationship between complications and poor mental health, implying that optimal blood glucose control could enhance better mental health outcomes, just like improved mental health could positively impact adherence, self-care, and reduced T1D complications.

4. Discussion

As young people living with T1D (YPLWD) strive to adequately manage their chronic condition, they encounter management complexities and structural constraints which leads to their experiences of several undesirable T1D health outcomes. This study explored the role/impact of T1D on health-related outcomes of YPLWD and their caregivers, and reported the results under four thematic areas which were: physical complications, mental/psychosocial outcomes, other adverse health outcomes, and structural and behavioural pathways of complication occurrence. The common complications found were visual impairment, foot ulcer, neuropathy, and reproductive ill-health. Several other health outcomes including weight loss, injection site abscess, lipodystrophy, and congenital anomalies were reported as well. Beyond these physical health outcomes, T1D was a major reason for patients' experiences of multiple mental/psychosocial distress particularly distress, anxiety, suicidal ideation, and poor sleep quality. These disorders transcended YPLWD to affect their caregivers in major ways. The results indicate that structural factors (usually distal and beyond the control of the YPLWD), and behavioural factors (more proximal) are important predisposing factors for the development of T1D complications.

These findings offer novel insights particularly on the forms/nature of T1D complications, psychosocial distress, T1D lived experiences, and pathways of complication occurrence in low-resource settings. In some studies, across Africa, YPLWD experience microvascular complications such as retinopathy, neuropathy, nephropathy, sexual dysfunctions, and DKA (Najem et al., 2021; Agochukwu-Mmonu et al., 2021; Missambou

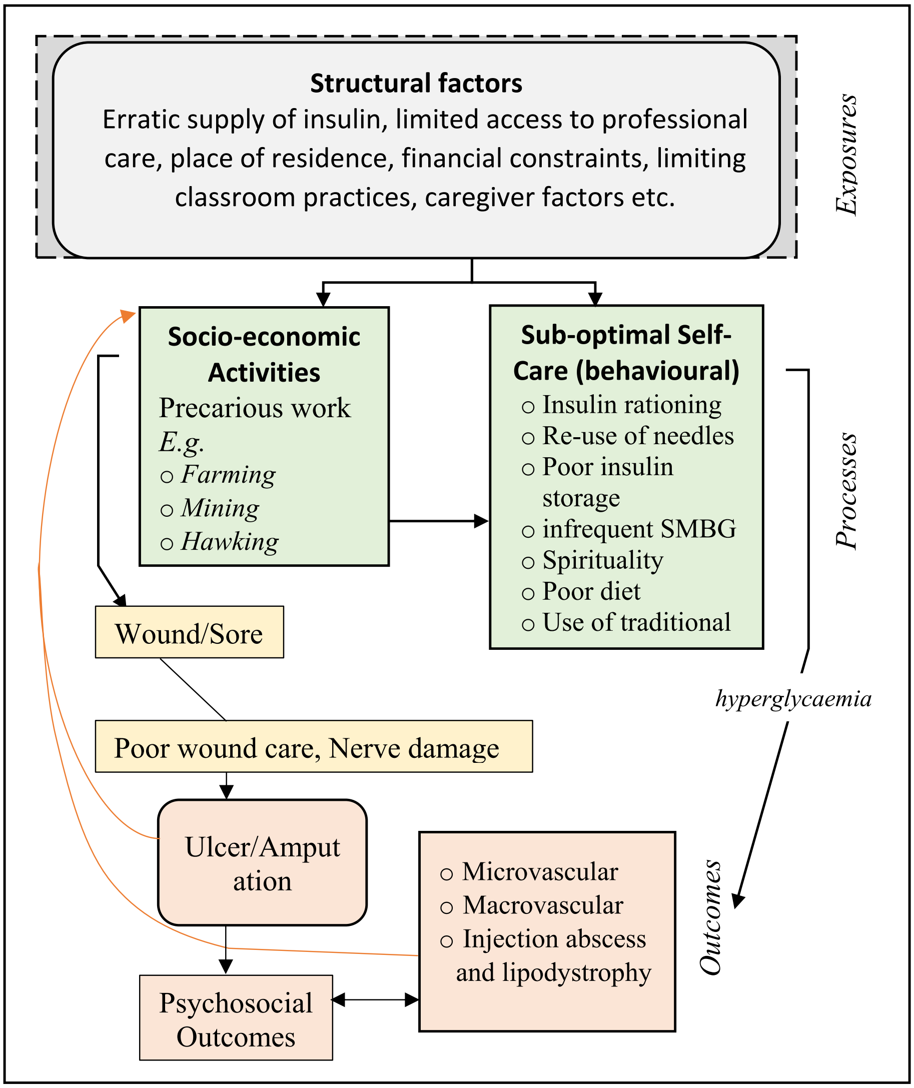

Fig. 4. Structural and behavioural pathways of complications occurrence among young people living with T1D in low resource settings.
Source: Owusu B.A et al., 2024.

et al., 2020; Ahmed et al., 2020). Impaired vision as found in this study was a great source of worry particularly for the YPLWD without ophthalmic lens who had to squint and read from chalk/marker boards in school. For the males living with diabetes, sexual problems, most commonly arousal difficulties are noted (Maiorino et al., 2014, 2017; Enzlin et al., 2003). The reproductive health concerns identified were major source of worry for the YPLWD. Tooth loss, and poor tooth hygiene among YPLWD have been confirmed in other studies (Orbak et al., 2008; Moore et al., 2001).

Diabetic neuropathy (nerve damage) and peripheral artery disease (reduction of blood flow and supply to the foot) respectively increase the risk of foot injury and cause slow recovery from injuries respectively (Burgess et al., 2021). This situation is found to be common among the socio-economically disadvantaged. In a clinical case study report in Ghana, amputation among YPLWD has been linked to poor socio-economic background, and difficulty in accessing supervised care as confirmed by our findings on structural determinants (Ameyaw et al., 2020). Weight loss serves as a major reason for diabetes-related stigma and decreased efforts to initiate or sustain friendships or intimacy as confirmed in other studies (Cheung et al., 2006). The YPLWD experienced diabetes ketoacidosis (DKA) resulting from an absolute or relative deficiency of insulin and associated with structural brain abnormalities, impaired cognitive function, and a common cause of death among YPLWD (Lovshin et al., 2018; Persson et al., 2013).

In other studies, cardiovascular disease risk factors including high blood pressure, and early signs of kidney disease are elevated among YPLWD (Knerr et al., 2008; Rodriguez et al., 2006). High blood glucose is responsible for the destruction of multiple organs in the body (Gordin and Groop, 2016; Melendez-Ramirez et al., 2010). It has also been associated with psycho-social distress such as poor sleep quality due to glucose fluctuations and nocturia (Patel et al., 2018; Turner et al., 2016; Estrada et al., 2012). These complications are key reasons for the poor quality of life among YPLWD (Siersma et al., 2014; Iversen et al., 2009; Debono and Cachia, 2007).

Clinically significant T1D complications take decades to appear (Cooke and Plotnick, 2008), and with about 8 years' average duration of living with T1D as found in this study, one would expect minimal chronic T1D complications. For instance, in developed countries such as the UK, common complications such as eye damage occur within 20 years of diagnosis (UK Prospective Diabetes Study). In other studies, erectile dysfunction (ED) increases with age (Thorve et al., 2011; Bacon et al., 2002), and cardiovascular events occur in the third decade of life (Constantino et al., 2013). These findings and our results seem to indicate that YPLWD in Ghana are facing microvascular complications rather early, and/or their diagnosis was preceded by a complicated incident as confirmed. In exploring the plausible reasons for the early development of T1D complications and poor mental health among YPLWD in Ghana, we have come to understand the immense influence of structural and behavioural factors as key pre-disposing risk factors. Limited access to optimal T1D management resources including appropriate insulin, professional care, healthcare affordability, caregiver factors, and poor socio-economic status, as well as sub-optimal behavioural/self-care factors such as insulin rationing, poor insulin storage, poor diet, spirituality, and use of traditional medicine by YPLWD are important factors contributing towards T1D complications and resulting in poor mental health among young persons in Ghana.

It is well known that contemporary outcome measures of T1D transcends biomedical results or physical complications which are traditionally assessed during clinical encounters, to include a holistic emphasis on patients' psychosocial well-being and their quality of life. In exploring the psychosocial concerns faced by YPLWD and their caregivers, multiple mental health disorders such as disstress, burnout, and anxiety were found. These results are confirmed in several studies elsewhere (Hapunda et al., 2015; Hanna et al., 2014; Spencer et al., 2013; Perfect and Jaramillo, 2012). For instance, parenting a child with diabetes is an emotionally laden role (Nardi et al., 2008; Mellin et al., 2004). Parents are therefore not exempt from anxiety as they worry about the potential side effects of continuous insulin therapy on their children, lower life expectancy observed among YPLWD, and constantly comparing their child with diabetes to their siblings or peers without diabetes and observing major physical and behavioural differences. Among females living with T1D, there were apprehensions of being unable to get pregnant, have children, or risk having babies with congenital malformations. These psychosocial disorders impede treatment adherence and result in major life dissatisfaction (Palladino et al., 2013; Perfect and Jaramillo, 2012).

A bidirectional relationship seems to exist between T1D complications and poor mental health – T1D complications such as impaired wound healing, retinopathy, and reproductive ill-health may lead to poor mental health and problems with emotions notably distress, anxiety, sadness, as well as stigma, just as poor mental health could lead to the development of debilitating complications via poor self-care. T1D management requires a balance set of complex clinical, social, and behavioural tasks by the YPLWD and their caregivers including regularly checking blood glucose levels to adjust multiple doses of insulin needed day and night, and balanced with food and physical activity, and this can be very daunting for the YPLWD and their caregivers.

4.1. *Implication for policy, practice, and research*

Efforts should be made to ensure that current healthcare resources for T1D management including insulin (preferably multiple dose injections using short and long-acting insulin), test strips, glucometers, lancets, syringes among others, as well as the human resources involved in T1D care are adequately available and equitably shared to help patients achieve the desired HbA1C of $<$7.5%. The YPLWD should be encouraged and supported to adopt optimal self-care practices. Given there are resource barriers and/or constraints leading to patients experiencing complications early-on in their disease state, clinicians and other stakeholders working in the T1D care space need to do better with health education, complication screening and management. There is the urgent need to screen for complications among YPLWD and be aware of its underlying determinants to tailor integrated and person-centred interventions to reverse any adverse outcomes or delay its progression. T1D screening should be done regularly, and preventive measures advised accordingly. Patients must be screened for diabetic retinopathy as this is more likely than refractive error in patients with T1D. The American Diabetes Association (ADA) recommends eye and nerve screening from age 11 years and done every 2 years or lesser depending on individual clinical situations (Targets, 2019; Donaghue et al., 2018).

Complications in diabetes are linked with lower socioeconomic status and structural barriers. As such, socio-economic disadvantage (SED) should be topical in clinical discussions and stakeholder interventions on T1D management. There is the need to ensure access to a more enabling T1D treatment plan, which implies making technologies such as continuous glucose monitors (CGM), and hybrid closed loop technologies available and accessible under the NHIS. Due to the chronic nature of T1D, technological innovations that enhances treatment modalities (e.g., from pricking to automatic glucose monitors) are important for patients/caregivers to have improved treatment alternatives, and consequently, sense a change/progress in their management lifecourse.

In Ghana, and many other resource-limited countries where mental health support systems are poorly developed, YPLWD risks falling through the cracks, and this is more likely for their caregivers. As such, there is the need to provide regular psychosocial support for YPLWD and their caregivers as part of their routine healthcare. Due to the possible bi-directional relationship between complications and poor mental health, we highly recommend the integration of clinical care and mental health care for YPLWD and their caregivers. This will imply the provision of regular psychosocial support to YPLWD and their caregivers by experts who are also knowledgeable about mental healthcare. This could be done during their periodic T1D check-up in healthcare facilities, or through community health services. Acknowledging resource constraints in LMICs including Ghana, training a critical mass of healthcare professionals involved in the T1D management space on mental health could offer some clinical and psychological benefits to YPLWD and their caregivers in Ghana.

As a chronic condition, other scholars' question whether complications can be prevented (Viswanathan, 2015). However, it is known that keeping HbA1c levels below 7.5% is ideal (Chiang et al., 2014). As such, there is the need for caregivers including healthcare providers to promote ideal glucose control among YPLWD and track the progress or otherwise being made to offer targeted support. In terms of research, there is the need to conduct surveys to explore the prevalence of common T1D complications, and social determinants of T1D health outcomes including mental health among YPLWD and their caregivers in LMICs. Such studies should include structural, behavioural (self-care), and adherence to management factors.

4.2. *Strengths and limitations of this study*

The strength of this study lies in the methodology and its contribution to T1D research in LMICs including Ghana. The study relied on existing connection with the YPLWD and employed methodologies that made it possible to get close to the participants, enabling them to trust and freely reveal their lived experiences. This approach, and consequently, the structural and behavioural pathways of complication occurrence are critical to understanding T1D complications among YPLWD. Again, the results provide important considerations for researchers when predicting complications among young people, particularly on structural, behavioural, and bio-social factors which are usually missed. Nonetheless, there are some limitations of this study; the results are non-generalisable to populations outside our established inclusion criteria.

5. Conclusion

Young people living with type 1 diabetes in southern Ghana experience multiple burdens of T1D complications, poor mental health, and other undesirable health outcomes which adversely affect their overall health and general well-being. The psychosocial conditions transcended the young persons to affect their caregivers in adverse ways. These health consequences occur early-on in disease duration, and were due to several structural and behavioural factors which needs to be addressed. Without timely, situation-specific, and age-appropriate interventions, the health burden of T1D on young persons and their caregivers will worsen.

CRediT authorship contribution statement

Bernard Afriyie Owusu: Writing – review & editing, Writing – original draft, Visualization, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Prince Ofori-Boateng:** Resources, Project administration, Methodology, Data curation, Conceptualization. **Elizabeth Bankah:** Writing – review & editing, Project administration. **Nana Ama Barnes:** Writing – review & editing, Resources. **Yacoba Atiase:** Writing – review & editing. **Ernest Yorke:** Writing – review & editing. **Marc Kwame Dzradosi:** Writing – review & editing. **David Teye Doku:** Writing – review & editing, Supervision, Conceptualization.

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.

Availability of data and materials

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.

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Declaration of competing interest

The authors declare no competing interests as defined by Elsevier, Social Science and Medicine journal or other interests that might be perceived to influence the results and/or discussion reported in this paper.

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