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Experience of living with type 1 diabetes in a low-income country: a qualitative study from Liberia

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Abstract

Introduction

While epidemiological data for type 1 diabetes (T1D) in low and middle-income countries (LMICs), and particularly low-income countries (LICs) including Liberia is lacking, prevalence in LICs is thought to be increasing. T1D care in LICs is often impacted by challenges in diagnosis and management. These challenges, including misdiagnosis and access to insulin, can affect T1D outcomes and frequency of severe complications. Despite the severe nature of T1D and growing burden in sub-Saharan Africa, little is currently known about the impact of T1D on patients and caregivers in the region.

Methods

We conducted a qualitative study consisting of interviews with T1D patients, caregivers, providers, civil society members, and a policymaker in Liberia to better understand the psychosocial and economic impact of living with T1D, knowledge of T1D and self-management, and barriers and facilitators for accessing T1D care.

Results

This study found T1D to have a major psychosocial and economic impact on patients and caregivers, who reported stigma, diabetes distress, and food insecurity. Patients, caregivers and providers possessed the knowledge necessary to effectively manage T1D but insufficient community awareness leads to delayed diagnosis, often in an emergency department. Most patients reported receiving free services and materials, though the cost of transportation to clinic visits and recommended foods is a barrier to disease management. Many providers noted the lack of national T1D-specific guidelines and registries. Policymakers reported a lack of prioritization of and resources for T1D. These barriers, combined with scarcity and expense of appropriate foods, pose severe barriers for self-management of T1D.

Conclusion

T1D was found to have a significant impact on patients and caregivers, and informants identified several key individual and systems-level barriers to effective T1D care in Liberia. Addressing these concerns is vital for designing sustainable and effective programs for treating patients living with T1D.

Keywords: diabetes, qualitative study

Strengths and Limitations

- First qualitative study of type one diabetes in a low-income country
- One of the first studies in Sub-Saharan Africa to comprehensively interview people living with type one diabetes, their caregivers, health care providers, pharmacists, civil society, and policy makers
- This study includes patients from five different health centers in three regions of Liberia representing diverse models of healthcare and funding
- The majority of patients interviewed received subsidized insulin, whereas the majority of patients in Liberia do not receive subsidized insulin.

INTRODUCTION

"If you meet today a person that just got diabetes, and the person is feeling bad, what would you tell them?

I will tell them sorry."

- *A conversation between a clinician and person living with type 1 diabetes in rural Liberia*

Type 1 diabetes (T1D) is a severe chronic autoimmune disease in which the pancreas produces little or no insulin. It typically presents in young people and necessitates artificial insulin replacement therapy.[1] Epidemiological data for T1D in low and middle-income countries (LMICs) is lacking,[2] but prevalence is estimated at 0.012% in Sub-Saharan Africa (SSA) and thought to be increasing. Average life expectancy is estimated at five years after diagnosis and T1D patients without access to proper care generally do not survive one year.[3] There is limited data on life expectancy following initial diagnosis of T1D in high-income countries but this is estimated at over 40 years.[4-6]

People living with T1D (PLWT1D) require daily insulin injections to maintain appropriate blood glucose (BG) levels. A recent study suggested that in LMICs, the price of insulin is a major barrier, and is available in about 50% of public facilities and less than 40% of private facilities.[2, 7] While the median buyer price for one vial of insulin was $4.31 globally from 1996 to 2013, in LMICs it was higher, at $6.90.[8] The main cause of mortality for PLWT1D globally is lack of access to insulin, reflecting shortcomings in availability and affordability.[3]

T1D care in LMICs is affected by numerous challenges in diagnosis and management. Late diagnosis and misdiagnosis remain common, influenced by lack of awareness and familiarity with T1D and access to diagnostic resources; there is often a greater focus on endemic infectious diseases at the expense of chronic ones. Inadequate management impacts patient outcomes and frequency of severe complications, including challenges in adjusting insulin doses given limited home glucose monitoring and food insecurity, high levels of infectious disease, and complications such as diabetic ketoacidosis (DKA) and hypoglycemia.[9]

In an assessment of pediatric diabetes care in 64 countries, Liberia was one of six countries receiving the lowest Life for a Child (LFAC) index score, a measure which captures availability of essential components of care, including insulin, BG monitoring, diabetes education, and complications screening.[10] While access to care remains limited, organizations like Partners in Health (PIH) and the International Diabetes Federation's LFAC program support provision of T1D care at several facilities in Maryland County, Monrovia, and Ganta.

Despite the severity and increasing burden of T1D in SSA, there is little research on the impact of T1D on patients and caregivers, especially in low-income countries (LIC). This study is the first to examine the impact of T1D on patients, caregivers, and health systems across Liberia, and the first qualitative study in this area in a LIC in SSA. In this study, we examine the psychosocial and economic impact of living with T1D, knowledge of T1D and self-management, and barriers and facilitators for accessing T1D care.

METHODS

Framework

To identify PLWT1D and healthcare provider experience relating to diabetes management, we used a framework utilizing theories from implementation research[11] and behavior change.[12] The framework encapsulates barriers to diabetes management and facilitates exploration of mediating pathways and moderators.[13]

Data collection

Interviews were conducted in October to December 2019 by a trained nurse practitioner (CT) and physician assistant (CR) in English or Liberian English. Both researchers were currently practicing in Harper. All participants gave signed informed consent prior to being interviewed. Standardized interview

scripts were used and sessions were audio recorded. Study informants included one from the MOH, two from diabetes civil society organizations (LFAC and Diabetes and Endocrine Society of Liberia (DESOL)), and informants recruited from five health facilities across Liberia (Table 1): 1) JJ Dossen (JJD) in Maryland County 2) Pleebo in Maryland County, 3) John F Kennedy Medical Center (JFK) in Monrovia, 4) James Davis Junior (JDJ) Memorial Hospital in Monrovia, and 5) Ganta United Methodist Hospital in Ganta. T1D clinics in Ganta and JDJ are funded through LFAC and provide free insulin and materials to all PLWT1D 26 years and younger. PIH provides assistance to clinics in Maryland Country, including provision of free insulin and materials for PLWT1D. Interview topics varied by informant (Table 2). Interviews were conducted until thematic saturation was achieved.

Table 1: Informant characteristics

Characteristic	Frequency (n = 28)	Percentage
Stakeholder type		
Patient	10	35.7
Caregiver	5	17.9
Provider	10	35.7
Endocrinologist	1	10.0
Pediatrician	2	20.0
Internist	2	20.0
Physician Assistant	1	10.0
Nurse	3	30.0
Pharmacist	1	10.0
Civil society member	2	7.1
Policymaker	1	3.6
Site		
Ministry of Health, Monrovia	1	3.6
JFK Medical Center	4	14.3
JDJ Hospital	4	14.8
Ganta United Methodist Hospital	7	25.0
J.J. Dossen Hospital	9	32.1
Pleebo Health Center	3	10.7
Sex		
Female	17	60.7
Male	11	39.3
	Mean (SD)	Range
Patient age (years)	18.9 (6.8)	10-30

Table 2: Interview question topics

	Informant type				
Topics	Patient	Caregiver	Provider	Civil society member	Policymaker
	Knowledge of diabetes and diagnosis	Burden of illness on family	Experience and tasks	Role of civil society	Health system

Management	Management	Care provision and coordination	Services provided and recipients	Barriers in program implementation
Healthcare experiences and recommendations	Facilitators and barriers to care	Facilitators and barriers	Facilitators and barriers to providing services	Key systems-level facilitators
Facilitators and barriers to care	Everyday life changes due to T1D	Relationship with patients	Challenges in access	Areas for improvement
Adherence	Costs	Provision of social support	Availability of social support for patients and families	Commitment to T1D care
Self-management		Screening for mental health		
Effect on daily and community life		Health systems level areas for improvement		
Catastrophic costs		Training		
Lifestyle choices				

Data analysis

Interviews were transcribed and, when necessary, translated directly from Liberian English to English during transcription. All coding was conducted in Dedoose.[14] The subsequent analysis was comprised of two iterative steps. We began with a-priori thematic analysis and, after initial coding based upon these themes, expanded our coding structure to encompass additional themes that emerged through the first step of analysis. Three of the four researchers involved in analysis have no relation to the community where study participants were recruited. The fourth resided in Maryland County for three months and participated in medical care for some participants. We held a virtual meeting between individuals involved in analysis to discuss major themes and issues that arose from the analysis. To ensure quality of results, all researchers independently coded a representative sample of interviews and met to ensure consistency across the coding structure. The revised coding structure was used to recode the initial interview sample and all subsequent interviews. Results were reported using Standards for Reporting Qualitative Research.

Ethical considerations

This work received ethical approvals from the Harvard Longwood Campus and University of Liberia Institutional Review Boards. It conformed to all principles embodied in the Declaration of Helsinki.

Patient and public involvement

The aim of this study was to understand the experience of PLWT1D, particularly their priorities, experiences, and preferences. Research questions and measures were designed with the help of an author (CN) who lives with T1D. This author was involved in protocol development and interview guide design.

PLWT1D in Liberia were actively recruited and interviewed in this study. As part of informed consent, they were informed of the time required to participate.

RESULTS

Psychosocial/economic impact of T1D

> *Patient#7:* "...*my life changed because since I was diagnosed in 2014, I stopped going out with my friends...not clubbing or nothing, normally we used to go play football, sometimes we [hung out]. But .. its always 'My man, that stuff I can't eat, I don't do that.' or 'My man let's do JBC [communal contributions to food]' and everybody is putting money together... Someone else, 'Oh my man you're selfish.' But I really didn't want to tell him why the reason I was doing it. So I would say I was close with them but all of a sudden I became selfish and other things. And it hurt me a lot."*

Informants identified alienation from peers at school as an important contributor to psychosocial stress. They reported feeling worried that people felt sorry for them and feelings alienated from inability to consume the same foods as their peers. Indeed, some reported not eating in front of others. Others reported worrying about injecting insulin in front of their peers. Overall, PLWT1D shared a significant desire to hide their T1D diagnosis from peers.

Diabetes distress refers to the accumulation of everyday stresses among individuals with diabetes over time as they struggle with managing their T1D.[15] This concept was reflected in responses from PLWT1D and providers, especially surrounding daily insulin injections and fingersticks. One provider discussed how children will run from their caregivers when they try to inject insulin, while another caregiver commented on the extreme distress her daughter experienced around fingersticks:

> *Caregiver#2:* "*Sometimes she feels so bad. You know, when she's at play and I call her to come and do the test, she say, 'hey man, I'm tired with this sickness, I just want to die now. Every day, all my fingers hurting, I'm tired.'"*

Many caregivers discussed feeling overwhelmed by the difficulty of caring for their loved ones with T1D. They noted the burden of financial stress, amount of time spent actively helping loved ones manage T1D, and fear of leaving them alone.

One aspect of T1D's broader economic impact in Liberia is its effect on the ability of PLWT1D and their caregivers to attend school and work. While some younger PLWT1D and their caregivers discussed attending school, one PLWT1D reported leaving school due to T1D. PLWT1D and providers explained that patients may also be unable to work, especially when feeling poorly due to complications of T1D.

Knowledge

PLWT1D and caregivers described the signs and symptoms leading to their T1D diagnosis including the "3 Ps" of hyperglycemia (polydipsia (excessive thirst), polyphagia (constant hunger), and polyuria ("going pee-pee fast-fast")), glycosuria (ants attracted to their urine), gastrointestinal issues (vomiting and abdominal pain), weight loss (their body "reducing" or "getting dry" or "being to dry dry"), weakness and

fatigue, malaise (feeling "not myself", "feeling different", or "getting/being sick"), mood swings, a sense of dread, altered mental status, and frequent fungal infections. Only providers and civil society mentioned symptoms suggesting potentially life-threatening situations, including confusion and loss of consciousness.

Self-management

Most PLWT1D reported checking their own BG levels at home, typically two to three times per day. Several patients mentioned recording their readings in logbooks for providers to use for adjusting insulin dosages. Many identified readings constituting high or low BG and explained how they would respond to them. Others reported not checking BG levels at home and relying upon readings from clinic visits. Importantly, PLWT1D correctly identified signs of hypoglycemia and its causes, including skipping meals and taking too much insulin. The foods informants mentioned as treatment for hypoglycemia included sugar, rice, and juice. Despite knowing they were at risk for hypoglycemia and how treat it, only two informants reported keeping something in their room overnight or carrying something with them at all times for treating potential hypoglycemic episodes.

PLWT1D and caregivers identified foods including bulgur wheat and green plantain as diabetic-friendly or discussed diet as a way of controlling diabetes. Some discussed modifying meal sizes rather than avoiding foods with a high carbohydrate content. Two caregivers reported preparing food for their children to take to school to help them avoid eating the "wrong" foods.

> *Interviewer: Have you ever missed a time you were supposed to take your insulin?*
> *Patient#9 (Ganta): Yes. Sometimes if I feel normal in my body, I feel reluctant to take my insulin and check my sugar.*

All PLWT1D correctly identified the two types of insulin and reported being on a standard regimen of two daily injections, with adjustments for high or low BG. Almost half reported missing insulin doses occasionally for reasons including forgetfulness, being in a rush to go to school/work, running out, insufficient funds, or feeling reluctant to take insulin or check their BG that day. Although providers and civil society members reported patients reducing insulin dose to make their insulin last longer, no PLWT1D and only one caregiver whose sister aged out of the LFAC program reported decreasing insulin doses due to a lack of money.

(Mis)diagnosis

Providers reported that patients tend to receive the initial diagnosis of T1D at the emergency department (ED) in a state of crisis (often due to DKA) rather than an outpatient clinic, likely due to a lack of awareness and knowledge of T1D in the community and possibly amongst frontline providers. Most PLWT1D and caregivers reported no knowledge of T1D prior to diagnosis and were not previously acquainted with anyone with T1D; those who had a family member or close contact living with T1D were more likely to recognize early symptoms of the disease. While providers were aware of T1D symptoms, patients were sometimes misdiagnosed with malaria as it is endemic to the region and better known to providers. Some patients with new onset T1D were treated for other conditions and providers only considered T1D after their status did not improve. Providers and caregivers discussed how achieving a correct diagnosis required persistence and advocacy by families.

Providers reported T1D is generally diagnosed clinically with basic labs including point-of-care glucose testing and urinary ketones due to unavailability of traditional laboratory tests including C-peptide and

antibodies. Clinicians have developed effective ability to diagnose and manage T1D with available resources. Providers reported utilizing hemoglobin A1c, random blood glucose, urinalysis, chemistries, and glucose tolerance tests for diagnosis. Several providers mentioned the use of urinary ketones in the absence of serum ketones and arterial blood gases. Due to lack of laboratory studies, providers use patient's age, basic labs, and urine ketones to differentiate between T1D and T2D.

Barriers and facilitators

> *Provider#9: It's challenging for younger children to adhere to treatment. Because their food insecurity is high, there is peer pressure, the patient goes to school, their family is not there and they are used to … eating along with their friends, they are a peer group.*

Individual-level barriers and facilitators

Providers identified numerous barriers faced by PLWT1D, including low health literacy, poor adherence to diet recommendations, high costs, and limited access to insulin. For some PLWT1D and caregivers, low literacy and numeracy affect comprehension of diabetes education and self-management activities, and patients with low literacy typically require ongoing counselling to improve adherence.

All informants mentioned the challenges of adhering to diet recommendations, related to peer pressure, cost of food, and food availability. One provider suggested that patients eat less frequently than they report. A common concern was inability to afford foods including vegetables and bulgur wheat, which are more expensive than rice. One interpreter poignantly summarized this sentiment:

> *Interpreter: People telling her that the condition she has, the diabetes, is a rich people sickness. That you have to buy all kinds of vegetables, all kinds of stuff, and they tell you not to eat rice. But for her, she's from a poor family. Her family cannot afford all those vegetables, those extra things to balance her diet. So sometimes she keeps herself hungry because she doesn't want to eat rice for her sugar to raise up. Sometimes it's a worry for her. Sometimes she just has to manage and eat rice and her sugar goes up. All those things are a worry for her. It's a problem.*

Food insecurity also impacts patients' BG levels and insulin use. They may skip insulin doses or take insulin without food, increasing their risk for severe hypoglycemia. Families often face the difficult choice of paying for food instead of insulin, supplies, and transport to the clinic. A physician in Monrovia described dealing with this difficult situation:

> *Provider#6: Once the relatives of a patient know they have to spend this amount of money for a medication to control this, they make a choice very quickly. They look at daily bread for everybody and choose that first. Whenever they get extra money to buy insulin they do that, and it's very painful. That's the major challenge. And now, they also have to check their glucose levels, to buy the machine and the strips, that's costly too. Everything around care, especially at home, becomes difficult. I see the stress from patients and relatives,… you try to negotiate the amount of times they can do testing, and where you can get this medication, that's when we're calling LFAC or sending them to places where they can get free insulin and what have you. And that's a great difficulty, especially if they can't even afford to pay their way to where the free insulin is, or to get food for their family members on a daily basis. So that's the major challenge.*

One provider in Maryland County discussed the unique approach of providing food assistance to ease the burden of food insecurity among their patients. Specifically, the clinic has started providing rice, vegetables, and fruits.

PWT1D and their families incur significant expenses related to management of the disease. For those not receiving subsidized care, inability to afford insulin and other supplies was a major challenge identified by patients, caregivers, providers, and civil society members. Though PLWT1D identified consistent availability of insulin at clinics as a facilitator, in some settings it was not always accessible due to cost. Informants noted this potentially led to lower adherence, particularly in reducing or skipping doses, and distress for patients.

For patients not receiving subsidized care, purchasing insulin and related supplies including test strips, syringes, and ice for storage is costly. Informants explained that patients typically spend $20 to $30 USD per vial of insulin, up to $60 a month for two vials, an unaffordable amount for many patients. PLWT1D worry about insufficient finances for insulin and having to skip or reduce doses. Providers reiterated that patients did not always take recommended doses of insulin due to cost.

> **Provider#9:** *If you have patients buying their own insulin, especially with the economy we are faced with in this country it's going to be difficult telling most patients there is nothing we can do but just to allow you to die.*

For PLWT1D receiving free insulin and supplies, burdensome expenses still exist. Across facilities, informants identified transportation costs contributing to significant out-of-pocket expenses and missed appointments. At Ganta and JJD, patients come from as far as Ivory Coast and Monrovia to receive subsidized care.

In addition to these routine expenses, PLWT1D admitted at some hospitals without free care for complications like DKA may face steep bills upon discharge as some hospitals have admission fees, daily bed fees and medications or lab charges. In other hospitals, most services are free, but there are expenses including lost income of patient and caregiver attending them in the hospital, expenses for items not provided or available at the hospital. Providers explained that these bills are often unaffordable for patients, who must raise funds or seek help from the hospital.

> **Provider#8:** *Sometimes they will need fluid, in crisis sometimes, they spend up to fifteen, twenty, thirty thousand [Liberian dollars]. Sometimes to even raise that money after they have been discharged…we have to go beg the hospital, please help them. right now, the hospital is in crisis, so the hospital doesn't even have enough supply before money.*

PLWT1D receiving free services and medications at facilities subsidizing care reported it enabled them to manage their T1D. PLWT1D living far from the clinic were given large supplies of insulin, sometimes lasting multiple months between clinic visits, and reported that this gave them more flexibility and less pressure when it was difficult to attend clinic appointments. Some patients acknowledged that this helped them to stay healthy.

PLWT1D receiving care at LFAC-supported facilities face the challenge of aging out of the program at age 27. A provider explained that after aging out, patients must purchase their own insulin and supplies. The pathway for transition of patients out of this program is unclear. It is unclear if patients receiving care at these facilities are aware of the forthcoming transition, as this was not mentioned by any patients.

Insulin starts to degrade at room temperature and spoils if stored above 32^0C. Due to temperatures in Liberia, insulin storage was identified as a substantial barrier to effective T1D management. Only three informants reported being able to store their insulin in a refrigerator and reported problems with electricity availability. Informants reported storing their insulin in banana trees by cutting small openings into the tree trunk and in coolers, with or without ice.

Systems-level barriers and facilitators

A policymaker explained that few resources are directed towards T1D care in Liberia, reflected in a lack of trained staff, supply chain issues, and lack of funds at the facility level.

> *Policymaker: Often people will die very young without being diagnosed. As a result, people don't see those cases and when you want to do advocacy they will tell you we don't see those cases. But we know those cases occur, but before they are diagnosed they pass off and they are buried and then no one knows them… The figures are not there, the people don't see it, so it's difficult to raise awareness, and because we are not responding, people are not aware, so it's a kind of circle… Then the other side to it, because there has not been a lot of focus on the area the resources for care have been scarce. So how do you go out to even say you are creating awareness when the people come and you don't have anything to give them?*

This informant expressed that in addition to the longstanding prioritization of and resource allocation towards communicable diseases such as malaria, tuberculosis, and HIV, there remains a lack of data demonstrating T1D burden in Liberia, making it difficult to advocate for greater allocation of resources for T1D. Much of this could be due to the lack of T1D registries, and the fact that T1D and T2D are generally grouped together when data are collected.

Providers and policymakers recognize the need for national guidelines - while there are guidelines for the management of all diabetes emergencies developed by DESOL, there are no national T1D guidelines. Some providers reported using LFAC guidelines, while others reported using WHO guidelines, or T2D guidelines. Some providers at PIH-supported sites also reported using protocols developed by PIH. Notably, providers from the same facilities reported using different guidelines and many said that the only visible guidelines were for T2D.

Nearly all PLWT1D and caregivers reported receiving T1D education at the clinic. Providers explained that in addition to orienting patients upon diagnosis, they typically provide education and counselling on a regular basis. During clinic visits, PLWT1D received education on self-management activities including checking blood glucose levels and use of insulin, insulin storage, diet, potential complications, and recognizing symptoms of hyper- and hypo-glycemia. Supportive companions are also involved in education since they play a key role in supporting disease management, particularly for younger patients. One provider expressed that most patients respond well to education and utilize the knowledge in adhering to self-management activities.

Many providers and the policymaker reported underdiagnosis was a significant problem related to low community awareness of the disease and lack of adequate provider knowledge to recognize and correctly diagnose the disease.

> *Provider#7: There could be a lot of people out there with the condition that they don't know about. And even providers that are not trained will not recognize it. But I think there needs to be more awareness and more publicity regarding this.*

Informants explained that, as previously discussed, this lack of awareness can lead to later diagnosis in an acute state or even lack of diagnosis prior to T1D-related death.

DISCUSSION

This study found T1D to have major psychosocial and economic impacts on PLWT1D and their families. Patients and caregivers reported high levels of stigma, diabetes distress and food insecurity. Many patients reported challenges with correctly storing insulin. Reassuringly, both PLWT1D and caregivers possessed the knowledge necessary to effectively manage T1D, though a lack of community knowledge and awareness leads to delayed diagnosis and many PLWT1D presenting in the ED. Many patients reported receiving free services and materials. However, while PIH and LFAC-assisted sites provide these services and materials for free, other sites across the country do not, and LFAC sites only provide materials through the age of 26. Even patients who receive free services and materials, the cost of transportation to clinic visits and recommended foods are barriers to effective disease management. Many providers noted the lack of T1D specific guidelines and registries. Policymakers reported a lack of prioritization of and resources for T1D. These barriers, combined with scarcity and expense of appropriate foods, pose severe barriers for self-management of T1D. Addressing these concerns is vital for designing sustainable and effective programs for treating PLWT1D.

Comparison with other studies

There is a notable lack of qualitative research on T1D in LMICs, particularly in rural areas. A recent review of publications yielded only five qualitative studies of T1D in SSA, all from middle-income countries, including two conducted in South Africa, one in Accra, Ghana, and one in Ghana including patients with T1D and T2D.[16-19] The remaining study, conducted in Zambia, included patients, caregivers, and health practitioners, and investigated stress and quality of life in PLWT1D.[20] These authors similarly found high levels of stress, disclosure avoidance, and caregiver burnout.[20] The study conducted in Accra identified barriers faced by families of PLWT1D reflecting those identified by informants in this study, including misdiagnosis, the impact of school on self-management, and the financial burden of the disease. To our knowledge, however, this study is the largest, most comprehensive qualitative study of T1D in SSA, and the first from a LIC.

As noted, very little has been written on T1D in LICs, but studies of T2D have highlighted depression, stigma, and diabetes distress or burnout.[20-24] Despite the implications for T1D management, very little has been written on techniques for insulin storage in hot countries with low levels of refrigeration. Ogle and colleagues did a thorough analysis of 12 traditional techniques of refrigeration from seven countries, including goat skins and clay pots, with varying levels of effectiveness, although none were included that were reported in this study.[25] A review of the literature did not find any studies reporting on banana trees for insulin storage. Other authors have found food insecurity to be a factor in management in all types of diabetes, although less has been written solely in the context of T1D.[19 26 27]

Our study identified challenges with diabetes management related to literacy levels in the population. There are few studies in LMICs that have addressed this issue. A recent study in Ahmedabad Gujarat, India showed that an estimated 70% of rural PLWT1D were insufficiently educated to manage their own conditions.[30] On the other hand, two studies from one hospital in Tanzania found that caregiver and patient educational levels were not significantly associated with glycemic control or frequency of complications.[31 32]

This study had several limitations. Despite interviewer's best efforts, it was often challenging to find quiet places to conduct interviews, which caused several interruptions. Patients and caregivers with

higher education levels tended to be more likely to speak, and some PLWT1D were interviewed by people they may have seen as providers and therefore been less likely to speak negatively of the program. Finally, most of the patients and caregivers interviewed received care at PIH or LFAC centers, and therefore received subsided services and are not representative of the broader population.

Future implications

Efforts are underway to expand T1D in sub-Saharan Africa and elsewhere both through focused T1D initiatives and integrated PEN-Plus strategies. [33-36] These strategies aim for at least intermediate levels of glycemic control that will require diabetes self-management education. Ultimately, greater allocation of resources toward T1D care and services in Liberia is needed to address systems- and individual-level barriers.[2]

This study identified areas of both health system improvement and social protection that are needed to improve the quality of T1D care in LICs. Providers interviewed highlighted the importance of standardized record keeping and guidelines, while patients emphasized the need to address food insecurity, stigma, and insulin storage.

Advocacy efforts for additional T1D resources must be supported by data highlighting the burden of this disease. Thus, including regional or national systems of electronic medical records (EMR) or other methods of monitoring patient care and outcomes are needed. EMR are not only needed to assess the magnitude of the problem, but also as part of quality improvement efforts, and have been shown to lead to better patient care and clinical outcomes, and subsequently significantly reduce morbidity and mortality associated with T1D complications.[37]

T1D guidelines will also raise awareness of T1D among governments, providers, public health practitioners and advocates, caregivers and patients and point toward useful resources [38]. Additionally, they can assist providers, PLWT1D, and caregivers in managing diabetes in a standardized, evidence-based way to ensure safe care in a timely manner, taking into account the local context and resource availability.[38-41] Morbidity and mortality will be improved through the use of T1D-specific guidelines, as they will enable clinicians to effectively prioritize objectives as they relate to diabetes management and care, provide guidance on how to support PLWT1D and their caregivers, and enable standard screening for T1D complications [39-42].

The findings from this study have important implications for ongoing T1D program design. More research is needed to better quantify the impact of these issues on PLWT1D in more diverse settings. However, it is already clear from this report that interventions such as food packages or cash transfers may be necessary for high-quality T1D care in high-poverty settings. Additionally, educational initiatives and opportunities for T1D patients and families to build and become engaged in T1D communities, such as patient advocacy and support groups may be necessary to address societal stigma for this disease. Finally, additional research on local solutions and providing improved insulin storage containers and the development of heat-stable insulins may be a priority. Indeed, while comprehensive recommendations to revise T1D programs as described above are beyond the scope of this paper, our findings serve as a strong starting point for using a behavior change framework to implement such changes, which is the goal of future work.[11]

CONCLUSION

This study fills an important gap in the existing literature as the first study conducted in a LIC in SSA to examine the impact of T1D on patients, caregivers, and health systems. We found T1D has a major

psychosocial impact on PLWT1D and caregivers. While patients and caregivers possessed adequate knowledge to effectively manage T1D, informants identified important individual and systems-level barriers to T1D care in Liberia. These findings demonstrate the need for additional research to quantify the impact of these issues and initiatives to address barriers to care in high-poverty settings such as Liberia.

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COMPETING INTERESTS

The authors report no competing interests.

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CONTRIBUTORSHIP STATEMENT

Design of project and tools: AJA, CT, CN, LS, CR, GB
Data acquisition and management: CT, JP, TA, RC, CR
Data analysis: AJA, CT, LD, LS
Manuscript drafting: AJA, CT, LD, LS, GB
All authors contributed to final manuscript

DATA SHARING

Deidentified quotes of informants taken from qualitative interviews are available upon request from the corresponding author, AJA. The codebook utilized for analysis is also available.
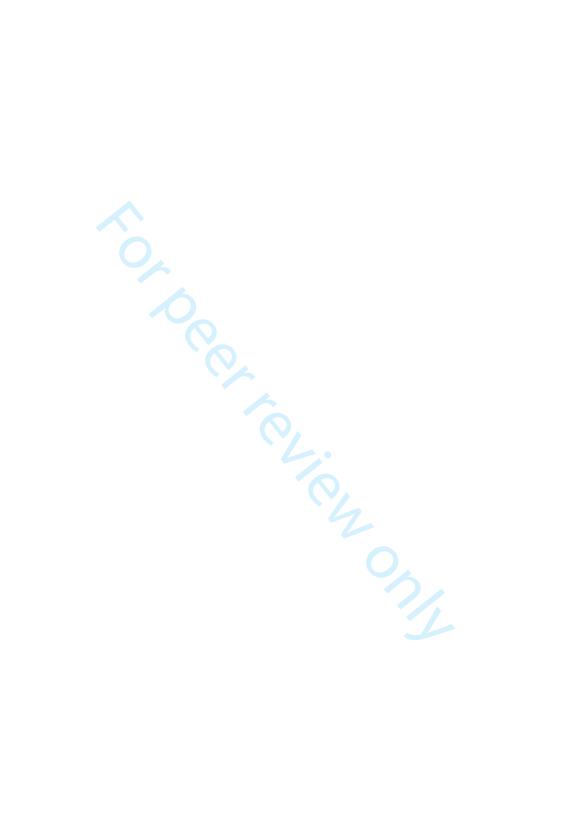
REFERENCES

1. Definition and diagnosis of diabetes mellitus and intermediate hyperglycemia: report of a WHO/IDF consultation: World Health Organization, 2006.

2. Atun R, Davies J, Gale EAM, et al. Diabetes in sub-Saharan Africa: from clinical care to health policy. *The Lancet Diabetes & Endocrinology* 2017;5(8):622-67. doi: https://doi.org/10.1016/S2213-8587(17)30181-X

3. Beran D, Yudkin JS. Diabetes care in sub-Saharan Africa. *Lancet (London, England)* 2006;368(9548):1689-95. doi: 10.1016/s0140-6736(06)69704-3 [published Online First: 2006/11/14]

4. Huo L, Harding JL, Peeters A, et al. Life expectancy of type 1 diabetic patients during 1997–2010: a national Australian registry-based cohort study. *Diabetologia* 2016;59(6):1177-85. doi: 10.1007/s00125-015-3857-4

5. Livingstone SJ, Levin D, Looker HC, et al. Estimated Life Expectancy in a Scottish Cohort With Type 1 Diabetes, 2008-2010. *JAMA* 2015;313(1):37. doi: 10.1001/jama.2014.16425

6. Petrie D, Lung TWC, Rawshani A, et al. Recent trends in life expectancy for people with type 1 diabetes in Sweden. *Diabetologia* 2016;59(6):1167-76. doi: 10.1007/s00125-016-3914-7

7. Beran D, Hirsch IB, Yudkin JS. Why Are We Failing to Address the Issue of Access to Insulin? A National and Global Perspective. *Diabetes care* 2018;41(6):1125-31. doi: 10.2337/dc17-2123 [published Online First: 2018/05/23]

8. Ewen M, Beran D, Joosse H-J, et al. Insulin prices profile. Amsterdam: Health Action International, 2016.

9. Bahendeka SK. Diabetes in sub-Saharan Africa: let us not forget type 1. *The lancet Diabetes & endocrinology* 2017;5(8):575-77. doi: 10.1016/s2213-8587(17)30223-1 [published Online First: 2017/07/10]

10. Ogle GD MA, Silink M. The IDF Life for a Child Program Index of diabetes care for children and youth. *Pediatric Diabetes* 2016;17(5):374-84. doi: https://doi.org/10.1111/pedi.12296

11. Michie S, Johnston M, Abraham C, et al. Making psychological theory useful for implementing evidence based practice: A consensus approach. . *Qual Saf Health Care* 2005;14(1):26-33.

12. Michie S, Atkins L, West R. The Behaviour change Wheel: A guide to designing intervention. London: Silverback Publishing 2014.

13. Davies P WA, Grimshaw JM. A systematic review of the use of theory in the design of guideline dissemination and implementation strategies and interpretation of the results of rigorous evaluations *Implement Sci* 2010;5 doi: https://doi.org/10.1186/1748-5908-5-14

14. Dedoose Version 8.3.35, web application for managing, analyzing, and presenting qualitative and mixed metho research data [program], 2020.

15. Diabetes Distress Assessment & Resource Center 2017 [Available from: https://diabetesdistress.org/ accessed September 25 2020.

16. Brown O, Fouche P, Coetzee M. Bouncing forward: families living with a type 1 diabetic child. *SA Fam Pract* 2010;52(6):536-41.

17. Jonker D, Deacon E, van Rensburg E, et al. Illness perception of adolescents with well-controlled type 1 diabetes mellitus. *Health Psychology Open* 2018;July-December 2019:1-9.

18. Kratzer J. Structural barriers to coping with type 1 diabetes mellitus in Ghana: experiences of diabetic youth and their families. *Ghana Medical Journal* 2012;46:39-45.

19. de-Graft Aikins A. Healer shopping in Africa: new evidence from rural-urban qualitative study of Ghanaian diabetes experiences. *BMJ* 2005;331(7519):737. doi: 10.1136/bmj.331.7519.737

20. Hapunda G, Abubakar A, van de Vijver F, et al. Living with type 1 diabetes is challenging for Zambian adolescents: qualitative data on stress, coping with stress and quality of care and life. *BMC endocrine disorders* 2015;15:20. doi: 10.1186/s12902-015-0013-6

21. Edah JO, Goar SG, Odoh G, et al. Undiagnosed depression among adults with diabetes mellitus in Jos. *Niger J Clin Pract* 2020;23:1431-36. doi: 10.4103/njcp.njcp_155_20.

22. Wolde AK, Wondim MG. Diabetic distress among diabetic patients in the referral hospital of Amhara Regional State, Ethiopia. *International Quarterly of Community Health Education* 2020;40(2) doi: 10.1177/0272684X19857580 [published Online First: June 27, 2019]

23. Mendenhall E, Musau A, Bosire E, et al. What drives distress? Rethinking the roles of emotion and diagnosis among people with diabetes in Nairobi, Kenya. *Anthropol Med* 2020;27(3):252-67. doi: 10.1080/13648470.2019.1650243 [published Online First: December 6, 2019]

24. Mogre V, Johnson NA, Tzelepis F, et al. Barriers to diabetic self-care: A qualitative study of patients' and healthcare providers' perspectives. *J Clin Nurs* 2019;28(11-12):2296-308. doi: 10.1111/jocn.14835 [published Online First: March 6, 2019]

25. Ogle GD, Abudllah M, Mason D, et al. Insulin storage in hot climates without refrigeracy: temperature reduction efficacy of clay pots and other techniques. *Diabetic medicine : a journal of the British Diabetic Association* 2016;33(11):1544-53. doi: 10.1111/dme.13194 [published Online First: 2016 Aug 28]

26. Cheng S, Kamano J, Kirui NK, et al. Prevalence of food insecurity in patients with diabetes in western Kenya. *Diabetic medicine : a journal of the British Diabetic Association* 2013;30(6):215-22. doi: 10.1111/dme.12174 [published Online First: 2013 Apr 12]

27. Ogunrinu T, Gamboa-Maldonado T, Ndinda Ngewa R, et al. A qualitative study of health education experiences and self-management practices among patients with type 2 diabetes at Malamulo Adventist Hospital in Thyolo District, Malawi. *Malawi medical journal : the journal of Medical Association of Malawi* 2017;29(2)

28. Bank TW. Literacy rate, adult total (% of people ages 15 and above) - Liberia, 2017.

29. Boren SA. A review of health literacy and diabetes: opportunities for technology. *Journal of diabetes science and technology* 2009;3(1):202-9. doi: 10.1177/193229680900300124 [published Online First: 2010/01/05]

30. Pacaud D, Lemay J-F, Richmond E, et al. Contribution of SWEET to improve paediatric diabetes care in developing countries. *Pediatr Diabetes* 2016:46-52. doi: 10.1111/pedi.12427

31. Noorani M, Ramaiya K, Manji K. Glycaemic control in type 1 diabetes mellitus among children and adolescents in a resource limited setting in Dar es Salaam - Tanzania. *BMC endocrine disorders* 2016;16(1):29. doi: 10.1186/s12902-016-0113-y [published Online First: 2016/06/02]

32. Majaliwa ES, Munubhi E, Ramaiya K, et al. Survey on acute and chronic complications in children and adolescents with type 1 diabetes at Muhimbili National Hospital in Dar es Salaam, Tanzania. *Diabetes care* 2007;30(9):2187-92.

33. Tapela N, Bukhman G, Ngoga G, et al. Treatment of non-communicable disease in rural resource-constrained settings: a comprehensive, integrated, nurse-led care model at public facilities in Rwanda *The Lancet Global Health* 2015;3 doi: https://doi.org/10.1016/S2214-109X(15)70155-5

34. Eberly LA, Rusangwa C, Ng'ang'a L, et al. Cost of integrated chronic care for severe non-communicable diseases at district hospitals in rural Rwanda. *BMJ Global Health* 2019;4 doi: 10.1136/bmjgh-2019-001449

35. Jasem D, Majaliwa ES, Ramaiya K, et al. Incidence, prevalence and clinical manifestations at onset of juvenile diabetes in Tanzania. *Diabetes Research and Clinical Practice* 2019;156:10787. doi: 10.1016/j.diabres.2019.107817 [published Online First: August 16, 2019]

36. Marshall SL, Edidin D, Arena VC, et al. Prevalence and incidence of clinically recognized cases of Type 1 diabetes in children and adolescents in Rwanda, Africa. *Diabetic medicine : a journal of the British Diabetic Association* 2015;32(9):1186-92. doi: 10.1111/dme.12701 [published Online First: February 12, 2015]

37. Pastakia SD, Karwa R, Kahn CB, et al. The evolution of diabetes care in the rural, resource-constrained setting of western Kenya. *Ann Pharmacother* 2011;45(6):721-6. doi: 10.1345/aph.1P779 [published Online First: 2011 May 10]

38. Codner E, Acerini CL, Craig ME, et al. ISPAD Clinical Practice Consensus Guidelines 2018: What is new in diabetes care? *Pediatr Diabetes* 2018;19 Suppl 27:5-6. doi: 10.1111/pedi.12759 [published Online First: 2018/10/03]

39. Association AD. Standards of Medical Care in Diabets - 2020. *Diabetes Care* 2020;43:S1-S212.

40. Codner E, Acerini C, Craig ME, et al. ISPAD Clinical Practice Consensus Guidelines 2018: Introduction to the Limited Care guidance appendix. *Pediatr Diabetes* 2018;19 Suppl 27:326-27. doi: 10.1111/pedi.12765 [published Online First: 2018/09/04]

41. Codner E, Acerini CL, Craig ME, et al. ISPAD Clinical Practice Consensus Guidelines 2018: Limited Care Guidance Appendix. *Pediatr Diabetes* 2018;19 Suppl 27:328-38. doi: 10.1111/pedi.12767 [published Online First: 2018/10/03]

42. Zargar AH. Type 1 diabetes guidelines: Are they enough? *Indian Journal of Endocrinology and Metabolism* 2015;19:S18-S21. doi: 10.4103/2230-8210.155355

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4
Purpose or research question - Purpose of the study and specific objectives or questions	4

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	5
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4,6
Context - Setting/site and salient contextual factors; rationale**	4-5
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4-5
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4-5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4-6

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	4-6
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	7-11
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	7-11

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	12-13
Limitations - Trustworthiness and limitations of findings	12-13

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	14

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

2

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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Experience of living with type 1 diabetes in a low-income country: a qualitative study from Liberia

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Experience of living with type 1 diabetes in a low-income country: a qualitative study from Liberia

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Abstract

Introduction

While epidemiological data for type 1 diabetes (T1D) in low and middle-income countries (LMICs), and particularly low-income countries (LICs) including Liberia is lacking, prevalence in LICs is thought to be increasing. T1D care in LICs is often impacted by challenges in diagnosis and management. These challenges, including misdiagnosis and access to insulin, can affect T1D outcomes and frequency of severe complications. Despite the severe nature of T1D and growing burden in sub-Saharan Africa, little is currently known about the impact of T1D on patients and caregivers in the region.

Methods

We conducted a qualitative study consisting of interviews with T1D patients, caregivers, providers, civil society members, and a policymaker in Liberia to better understand the psychosocial and economic impact of living with T1D, knowledge of T1D and self-management, and barriers and facilitators for accessing T1D care.

Results

This study found T1D to have a major psychosocial and economic impact on patients and caregivers, who reported stigma, diabetes distress, and food insecurity. Patients, caregivers and providers possessed the knowledge necessary to effectively manage T1D but insufficient community awareness leads to delayed diagnosis, often in an emergency department. Most patients reported receiving free services and materials, though the cost of transportation to clinic visits and recommended foods is a barrier to disease management. Many providers noted the lack of national T1D-specific guidelines and registries. Policymakers reported a lack of prioritization of and resources for T1D. These barriers, combined with scarcity and expense of appropriate foods, pose severe barriers for self-management of T1D.

Conclusion

T1D was found to have a significant impact on patients and caregivers, and informants identified several key individual and systems-level barriers to effective T1D care in Liberia. Addressing these concerns is vital for designing sustainable and effective programs for treating patients living with T1D.

Keywords: diabetes, qualitative study

Strengths and Limitations

- First qualitative study of type one diabetes in a low-income country
- One of the first studies in Sub-Saharan Africa to comprehensively interview people living with type one diabetes, their caregivers, health care providers, pharmacists, civil society, and policy makers
- This study includes patients from five different health centers in three regions of Liberia representing diverse models of healthcare and funding

INTRODUCTION

"If you meet today a person that just got diabetes, and the person is feeling bad, what would you tell them?

I will tell them sorry."

- *A conversation between a clinician and person living with type 1 diabetes in rural Liberia*

Type 1 diabetes (T1D) is a severe chronic autoimmune disease in which the pancreas produces little or no insulin. It typically presents in young people and necessitates artificial insulin replacement therapy.[1] Epidemiological data for T1D in low and middle-income countries (LMICs) is lacking,[2] but prevalence is estimated at 0.012% in Sub-Saharan Africa (SSA) and thought to be increasing. Average life expectancy is estimated at five years after diagnosis and T1D patients without access to proper care generally do not survive one year.[3] There is limited data on life expectancy following initial diagnosis of T1D in high-income countries but this is estimated at over 40 years.[4-6]

People living with T1D (PLWT1D) require daily insulin injections to maintain appropriate blood glucose (BG) levels. A recent study suggested that in LMICs, the price of insulin is a major barrier, and is available in about 50% of public facilities and less than 40% of private facilities.[2, 7] While the median buyer price for one vial of insulin was $4.31 globally from 1996 to 2013, in LMICs it was higher, at $6.90.[8] The main cause of mortality for PLWT1D globally is lack of access to insulin, reflecting shortcomings in availability and affordability.[3]

T1D care in LMICs is affected by numerous challenges in diagnosis and management. Late diagnosis and misdiagnosis remain common, influenced by lack of awareness and familiarity with T1D and access to diagnostic resources; there is often a greater focus on endemic infectious diseases at the expense of chronic ones. Inadequate management impacts patient outcomes and frequency of severe complications, including challenges in adjusting insulin doses given limited home glucose monitoring and food insecurity, high levels of infectious disease, and complications such as diabetic ketoacidosis (DKA) and hypoglycemia.[9]

In an assessment of pediatric diabetes care in 64 countries, Liberia was one of six countries receiving the lowest Life for a Child (LFAC) index score, a measure which captures availability of essential components of care, including insulin, BG monitoring, diabetes education, and complications screening.[10] Access to care for PLWT1D in Liberia is very limited and only provided in a few centers by organizations including Partners in Health (PIH) in facilities in Pleebo and Harper (Maryland County) and the International Diabetes Federation's LFAC program at facilities in Monrovia (Montserrado County), and Ganta (Nimba County).

Despite the severity and increasing burden of T1D in SSA, there is little research on the impact of T1D on patients and caregivers, especially in low-income countries (LIC). This study is the first to examine the impact of T1D on patients, caregivers, and health systems across Liberia, and the first qualitative study in this area in a LIC in SSA. In this study, we examine the psychosocial and economic impact of living with T1D, knowledge of T1D and self-management, and barriers and facilitators for accessing T1D care.
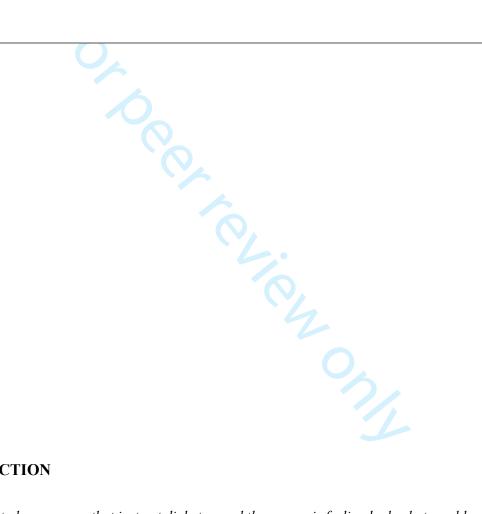
METHODS

Framework

To identify PLWT1D and healthcare provider experience relating to diabetes management, we used a framework utilizing theories from implementation research[11] and behavior change.[12] The framework encapsulates barriers to diabetes management and facilitates exploration of mediating pathways and moderators.[13]

Data collection

Interviews were conducted in October to December 2019 by a trained nurse practitioner (CT) and physician assistant (CR) in English or Liberian English. Both researchers were currently practicing in Harper. All participants gave signed informed consent prior to being interviewed. Standardized semi-

structured interview scripts (supplementary file 1) were used and sessions were audio recorded. Study informants included one from the MOH, two from diabetes civil society organizations (LFAC and Diabetes and Endocrine Society of Liberia (DESOL)), and informants recruited from the five health facilities in the capital and two rural regions of Liberia known to provide care for PLWT1D (Table 1): 1) JJ Dossen (JJD) Hospital in Maryland County 2) Pleebo Health Center in Maryland County, 3) John F Kennedy Medical Center (JFK) in Monrovia, 4) James Davis Junior (JDJ) Memorial Hospital in Monrovia, and 5) Ganta United Methodist Hospital in Ganta. T1D clinics in Ganta and JDJ are funded through LFAC and provide free insulin and materials to all PLWT1D 26 years and younger. PIH provides assistance to clinics in Maryland Country, including provision of free insulin and materials for PLWT1D. Interview topics varied by informant (Table 2). Interviews were conducted until thematic saturation was achieved. Patients to be interviewed were selected based on age, availability, and willingness to participate. We interviewed five patients with a secondary school education, two with less than a secondary school education, and three with a college education. We interviewed three patients between ten and 18, and seven over the age of 18. We interviewed families of younger patients.

Table 1: Informant characteristics

Characteristic	Number (*n* = 28)	Percentage
Stakeholder type		
Patient	10	35.7
Caregiver	5	17.9
Provider	10	35.7
Endocrinologist	1	10.0
Pediatrician	2	20.0
Internist	2	20.0
Physician Assistant	1	10.0
Nurse	3	30.0
Pharmacist	1	10.0
Civil society member	2	7.1
Policymaker	1	3.6
Site		
Ministry of Health, Monrovia	1	3.6
JFK Medical Center	4	14.3
JDJ Hospital	4	14.8
Ganta United Methodist Hospital	7	25.0
J.J. Dossen Hospital	9	32.1
Pleebo Health Center	3	10.7
Sex		
Female	17	60.7
Male	11	39.3
	Mean (SD)	**Range**
Patient age (years)	18.9 (6.8)	10-30

Table 2: Interview question topics

Topics	**Informant type**

	Patient	*Caregiver*	*Provider*	*Civil society member*	*Policymaker*
	Knowledge of diabetes and diagnosis	Burden of illness on family	Knowledge of diabetes and diagnosis	Role of civil society	Health system
	Management	Management	Experience and tasks	Services provided and recipients	Barriers in program implementation
	Healthcare experiences and recommendations	Facilitators and barriers to care	Care provision and coordination	Facilitators and barriers to providing services	Key systems-level facilitators
	Facilitators and barriers to care	Everyday life changes due to T1D	Facilitators and barriers	Challenges in access	Areas for improvement
	Adherence	Costs	Relationship with patients	Availability of social support for patients and families	Commitment to T1D care
	Self-management		Provision of social support		
	Effect on daily and community life		Screening for mental health		
	Catastrophic costs		Health systems level areas for improvement		
	Lifestyle choices		Training		

Data analysis

Interviews were transcribed and, when necessary, translated directly from Liberian English to English during transcription. All coding was conducted in Dedoose.[14] The subsequent analysis was comprised of two iterative steps. We began with a-priori thematic analysis and, after initial coding based upon these themes, expanded our coding structure to encompass additional themes that emerged through the first step of analysis. Three of the four researchers involved in analysis have no relation to the community where study participants were recruited. The fourth resided in Maryland County for three months and participated in medical care for some participants. We held a virtual meeting between individuals involved in analysis to discuss major themes and issues that arose from the analysis. To ensure quality of results, all researchers independently coded a representative sample of interviews and met to ensure consistency across the coding structure. The revised coding structure was used to recode the initial interview sample and all subsequent interviews. Results were reported using Standards for Reporting Qualitative Research.

Ethical considerations

This work received ethical approvals from the Harvard Longwood Campus and University of Liberia Institutional Review Boards. It conformed to all principles embodied in the Declaration of Helsinki.

Patient and public involvement

The aim of this study was to understand the experience of PLWT1D, particularly their priorities, experiences, and preferences. Research questions and measures were designed with the help of an author (CN) who lives with T1D. This author was involved in protocol development and interview guide design.

PLWT1D in Liberia were actively recruited and interviewed in this study. As part of informed consent, they were informed of the time required to participate.

RESULTS

Psychosocial/economic impact of T1D

> *Patient#7: "...my life changed because since I was diagnosed in 2014, I stopped going out with my friends…not clubbing or nothing, normally we used to go play football, sometimes we [hung out]. But .. its always 'My man, that stuff I can't eat, I don't do that.' or 'My man let's do JBC [communal contributions to food]' and everybody is putting money together… Someone else, 'Oh my man you're selfish.' But I really didn't want to tell him why the reason I was doing it. So I would say I was close with them but all of a sudden I became selfish and other things. And it hurt me a lot."*

Informants identified alienation from peers at school as an important contributor to psychosocial stress. They reported feeling worried that people felt sorry for them and feelings alienated from inability to consume the same foods as their peers. Indeed, some reported not eating in front of others. Others reported worrying about injecting insulin in front of their peers. Overall, PLWT1D shared a significant desire to hide their T1D diagnosis from peers. PLWT1D reported skipping insulin doses when participating in sports or physical labor due to a fear of hypoglycemia, especially in the context of food insecurity.

Diabetes distress refers to the accumulation of everyday stresses among individuals with diabetes over time as they struggle with managing their T1D.[15] This concept was reflected in responses from PLWT1D and providers, especially surrounding daily insulin injections and fingersticks. One provider discussed how children will run from their caregivers when they try to inject insulin, while another caregiver commented on the extreme distress her daughter experienced around fingersticks:

> *Caregiver#2: "Sometimes she feels so bad. You know, when she's at play and I call her to come and do the test, she say, 'hey man, I'm tired with this sickness, I just want to die now. Every day, all my fingers hurting, I'm tired.'"*

Many caregivers discussed feeling overwhelmed by the difficulty of caring for their loved ones with T1D. They noted the burden of financial stress, amount of time spent actively helping loved ones manage T1D, and fear of leaving them alone.

One aspect of T1D's broader economic impact in Liberia is its effect on the ability of PLWT1D and their caregivers to attend school and work. While some younger PLWT1D and their caregivers discussed attending school, one PLWT1D reported leaving school due to T1D. PLWT1D and providers explained that patients may also be unable to work, especially when feeling poorly due to complications of T1D.

Knowledge and self-management

PLWT1D and caregivers described the signs and symptoms leading to their T1D diagnosis including the "3 Ps" of hyperglycemia (polydipsia (excessive thirst), polyphagia (constant hunger), and polyuria ("going pee-pee fast-fast")), glycosuria (ants attracted to their urine), gastrointestinal issues (vomiting and abdominal pain), weight loss (their body "reducing" or "getting dry" or "being to dry dry"), weakness and fatigue, malaise (feeling "not myself", "feeling different", or "getting/being sick"), mood swings, a sense of dread, altered mental status, and frequent fungal infections. Only providers and civil society mentioned symptoms suggesting potentially life-threatening situations, including confusion and loss of consciousness. Most PLWT1D reported checking their own BG levels at home, typically two to three times per day. Several patients mentioned recording their readings in logbooks for providers to use for adjusting insulin dosages. Many identified readings constituting high or low BG and explained how they would respond to them. Others reported not checking BG levels at home and relying upon readings from clinic visits. Importantly, PLWT1D correctly identified signs of hypoglycemia and its causes, including skipping meals and taking too much insulin. The foods informants mentioned as treatment for hypoglycemia included sugar, rice, and juice. Despite knowing they were at risk for hypoglycemia and how treat it, only two informants reported keeping something in their room overnight or carrying something with them at all times for treating potential hypoglycemic episodes.

PLWT1D and caregivers identified foods including bulgur wheat and green plantain as diabetic-friendly or discussed diet as a way of controlling diabetes. Some discussed modifying meal sizes rather than avoiding foods with a high carbohydrate content. Two caregivers reported preparing food for their children to take to school to help them avoid eating the "wrong" foods.

> **Interviewer:** *Have you ever missed a time you were supposed to take your insulin?*
> **Patient#9 (Ganta):** *Yes. Sometimes if I feel normal in my body, I feel reluctant to take my insulin and check my sugar.*

All PLWT1D correctly identified the two types of insulin and reported being on a standard regimen of two daily injections, with adjustments for high or low BG. Almost half reported missing insulin doses occasionally for reasons including forgetfulness, being in a rush to go to school/work, running out, insufficient funds, or feeling reluctant to take insulin or check their BG that day. Although providers and civil society members reported patients reducing insulin dose to make their insulin last longer, no PLWT1D and only one caregiver whose sister aged out of the LFAC program reported decreasing insulin doses due to a lack of money.

Mis- or late diagnosis

Providers reported that patients tend to receive the initial diagnosis of T1D at the emergency department (ED) in a state of crisis (often due to DKA) rather than an outpatient clinic, likely due to a lack of awareness and knowledge of T1D in the community and possibly amongst frontline providers. Most PLWT1D and caregivers reported no knowledge of T1D prior to diagnosis and were not previously acquainted with anyone with T1D; those who had a family member or close contact living with T1D were more likely to recognize early symptoms of the disease. While providers were aware of T1D symptoms,

patients were sometimes misdiagnosed with malaria as it is endemic to the region and better known to providers. Some patients with new onset T1D were treated for other conditions and providers only considered T1D after their status did not improve. Providers and caregivers discussed how achieving a correct diagnosis required persistence and advocacy by families.

Providers reported T1D is generally diagnosed clinically with basic labs including point-of-care glucose testing and urinary ketones due to unavailability of traditional laboratory tests including C-peptide and antibodies. Clinicians have developed effective ability to diagnose and manage T1D with available resources. Providers reported utilizing hemoglobin A1c, random blood glucose, urinalysis, chemistries, and glucose tolerance tests for diagnosis. Several providers mentioned the use of urinary ketones in the absence of serum ketones and arterial blood gases. Providers use patient's age, basic labs, and urine ketones to differentiate between T1D and T2D.

Barriers and facilitators

> **Provider#9:** *It's challenging for younger children to adhere to treatment. Because their food insecurity is high, there is peer pressure, the patient goes to school, their family is not there and they are used to … eating along with their friends, they are a peer group.*

Individual-level barriers and facilitators

Providers identified numerous barriers faced by PLWT1D, including low numeracy, literacy, and health literacy, poor adherence to diet recommendations, high costs, and limited access to insulin. For some PLWT1D and caregivers, low literacy and numeracy affect comprehension of diabetes education and self-management activities, and patients with low literacy typically require ongoing counselling to improve adherence.

Unlike other regions of the world, diabetes education in Liberia does not primarily focus on the importance of regular exercise as most Liberians have a lifestyle that requires them to be more active based on work and walking for basic needs. Education is more focused on diet. All informants mentioned the challenges of adhering to diet recommendations, related to peer pressure, cost of food, and food availability. One provider suggested that patients eat less frequently than they report. A common concern was inability to afford foods including vegetables and bulgur wheat, which are more expensive than rice. One interpreter poignantly summarized this sentiment:

> **Interpreter:** *People telling her that the condition she has, the diabetes, is a rich people sickness. That you have to buy all kinds of vegetables, all kinds of stuff, and they tell you not to eat rice. But for her, she's from a poor family. Her family cannot afford all those vegetables, those extra things to balance her diet. So sometimes she keeps herself hungry because she doesn't want to eat rice for her sugar to raise up. Sometimes it's a worry for her. Sometimes she just has to manage and eat rice and her sugar goes up. All those things are a worry for her. It's a problem.*

Food insecurity also impacts patients' BG levels and insulin use. They may skip insulin doses or take insulin without food, increasing their risk for severe hypoglycemia. Families often face the difficult choice of paying for food instead of insulin, supplies, and transport to the clinic. A physician in Monrovia described dealing with this difficult situation:

> **Provider#6:** *Once the relatives of a patient know they have to spend this amount of money for a medication to control this, they make a choice very quickly. They look at daily bread for everybody and choose that first. Whenever they get extra money to buy insulin they do that, and it's very*

painful. That's the major challenge. And now, they also have to check their glucose levels, to buy the machine and the strips, that's costly too. Everything around care, especially at home, becomes difficult. I see the stress from patients and relatives,… you try to negotiate the amount of times they can do testing, and where you can get this medication, that's when we're calling LFAC or sending them to places where they can get free insulin and what have you. And that's a great difficulty, especially if they can't even afford to pay their way to where the free insulin is, or to get food for their family members on a daily basis. So that's the major challenge.

One provider in Maryland County discussed the unique approach of providing food assistance to ease the burden of food insecurity among their patients. Specifically, the clinic has started providing rice, vegetables, and fruits.

PWT1D and their families incur significant expenses related to management of the disease. For those not receiving subsidized care, inability to afford insulin and other supplies was a major challenge identified by patients, caregivers, providers, and civil society members. Though PLWT1D identified consistent availability of insulin at clinics as a facilitator, in some settings it was not always accessible due to cost. Informants noted this potentially led to lower adherence, particularly in reducing or skipping doses, and distress for patients.

For patients not receiving subsidized care, purchasing insulin and related supplies including test strips, syringes, and ice for storage is costly. Informants explained that patients typically spend $20 to $30 USD per vial of insulin, up to $60 a month for two vials, an unaffordable amount for many patients, most of whom make between $100 and $200 dollars per month. PLWT1D worry about insufficient finances for insulin and having to skip or reduce doses. Providers reiterated that patients did not always take recommended doses of insulin due to cost.

> **Provider#9:** *If you have patients buying their own insulin, especially with the economy we are faced with in this country it's going to be difficult telling most patients there is nothing we can do but just to allow you to die.*

For PLWT1D receiving free insulin and supplies, burdensome expenses still exist. Across facilities, informants identified transportation costs contributing to significant out-of-pocket expenses and missed appointments. At Ganta and JJD, patients come from as far as Ivory Coast and Monrovia to receive subsidized care.

In addition to these routine expenses, PLWT1D admitted at some hospitals without free care for complications like DKA may face steep bills upon discharge as some hospitals have admission fees, daily bed fees and medications or lab charges. In other hospitals, most services are free, but there are expenses including lost income of patient and caregiver attending them in the hospital, expenses for items not provided or available at the hospital. Providers explained that these bills are often unaffordable for patients, who must raise funds or seek help from the hospital.

> **Provider#8:** *Sometimes they will need fluid, in crisis sometimes, they spend up to fifteen, twenty, thirty thousand [Liberian dollars]. Sometimes to even raise that money after they have been discharged…we have to go beg the hospital, please help them. right now, the hospital is in crisis, so the hospital doesn't even have enough supply before money.*

PLWT1D receiving free services and medications at facilities subsidizing care reported it enabled them to manage their T1D. PLWT1D living far from the clinic were given large supplies of insulin, sometimes

lasting multiple months between clinic visits, and reported that this gave them more flexibility and less pressure when it was difficult to attend clinic appointments. Some patients acknowledged that this helped them to stay healthy.

PLWT1D receiving care at LFAC-supported facilities face the challenge of aging out of the program at age 27. A provider explained that after aging out, patients must purchase their own insulin and supplies. The pathway for transition of patients out of this program is unclear. It is unclear if patients receiving care at these facilities are aware of the forthcoming transition, as this was not mentioned by any patients.

Insulin starts to degrade at room temperature and spoils if stored above 32^0C. Due to the warm climate in Liberia, insulin storage was identified as a substantial barrier to effective T1D management. Only three informants reported being able to store their insulin in a refrigerator and reported problems with electricity availability. Informants reported storing their insulin in banana trees by cutting small openings into the tree trunk and in coolers, with or without ice.

Systems-level barriers and facilitators

A policymaker explained that few resources are directed towards T1D care in Liberia, reflected in a lack of trained staff, supply chain issues, and lack of funds at the facility level.

> *Policymaker: Often people will die very young without being diagnosed. As a result, people don't see those cases and when you want to do advocacy they will tell you we don't see those cases. But we know those cases occur, but before they are diagnosed they pass off and they are buried and then no one knows them… The figures are not there, the people don't see it, so it's difficult to raise awareness, and because we are not responding, people are not aware, so it's a kind of circle… Then the other side to it, because there has not been a lot of focus on the area the resources for care have been scarce. So how do you go out to even say you are creating awareness when the people come and you don't have anything to give them?*

This informant expressed that in addition to the longstanding prioritization of and resource allocation towards communicable diseases such as malaria, tuberculosis, and HIV, there remains a lack of data demonstrating T1D burden in Liberia, making it difficult to advocate for greater allocation of resources for T1D. Much of this could be due to the lack of T1D registries, and the fact that T1D and T2D are generally grouped together when data are collected.

Providers and policymakers recognize the need for national guidelines - while there are guidelines for the management of all diabetes emergencies developed by DESOL, there are no national T1D guidelines. Some providers reported using LFAC guidelines, while others reported using WHO guidelines, or T2D guidelines. Some providers at PIH-supported sites also reported using protocols developed by PIH. Notably, providers from the same facilities reported using different guidelines and many said that the only visible guidelines were for T2D.

Nearly all PLWT1D and caregivers reported receiving T1D education at the clinic. Providers explained that in addition to orienting patients upon diagnosis, they typically provide education and counselling on a regular basis. During clinic visits, PLWT1D received education on self-management activities including checking blood glucose levels and use of insulin, insulin storage, diet, potential complications, and recognizing symptoms of hyper- and hypo-glycemia. Supportive companions are also involved in education since they play a key role in supporting disease management, particularly for younger patients. One provider expressed that most patients respond well to education and utilize the knowledge in adhering to self-management activities.

Many providers and the policymaker reported underdiagnosis was a significant problem related to low community awareness of the disease and lack of adequate provider knowledge to recognize and correctly diagnose the disease.

> ***Provider#7:*** *There could be a lot of people out there with the condition that they don't know about. And even providers that are not trained will not recognize it. But I think there needs to be more awareness and more publicity regarding this.*

Informants explained that, as previously discussed, this lack of awareness can lead to later diagnosis in an acute state or even lack of diagnosis prior to T1D-related death.

DISCUSSION

This study found T1D to have major psychosocial and economic impacts on PLWT1D and their families. Patients and caregivers reported high levels of stigma, diabetes distress and food insecurity. Many patients reported challenges with correctly storing insulin. Reassuringly, both PLWT1D and caregivers possessed the knowledge necessary to effectively manage T1D, though a lack of community knowledge and awareness leads to delayed diagnosis and many PLWT1D presenting in the ED. Many patients reported receiving free services and materials. However, while PIH and LFAC-assisted sites provide these services and materials for free, other sites across the country do not, and LFAC sites only provide materials through the age of 26. Even patients who receive free services and materials, the cost of transportation to clinic visits and recommended foods are barriers to effective disease management. Many providers noted the lack of T1D specific guidelines and registries. Policymakers reported a lack of prioritization of and resources for T1D. These barriers, combined with scarcity and expense of appropriate foods, pose severe barriers for self-management of T1D. Addressing these concerns is vital for designing sustainable and effective programs for treating PLWT1D.

Comparison with other studies

There is a notable lack of qualitative research on T1D in LMICs, particularly in rural areas. A recent review of publications yielded only five qualitative studies of T1D in SSA, all from middle-income countries, including two conducted in South Africa, one in Accra, Ghana, and one in Ghana including patients with T1D and T2D.[16-19] The remaining study, conducted in Zambia, included patients, caregivers, and health practitioners, and investigated stress and quality of life in PLWT1D.[20] These authors similarly found high levels of stress, disclosure avoidance, and caregiver burnout.[20] The study conducted in Accra identified barriers faced by families of PLWT1D reflecting those identified by informants in this study, including misdiagnosis, the impact of school on self-management, and the financial burden of the disease. To our knowledge, however, this study is the largest, most comprehensive qualitative study of T1D in SSA, and the first from a LIC.

As noted, very little has been written on T1D in LICs, but studies of T2D have highlighted depression, stigma, and diabetes distress or burnout.[20-24] Despite the implications for T1D management, very little has been written on techniques for insulin storage in hot countries with low levels of refrigeration. Ogle and colleagues did a thorough analysis of 12 traditional techniques of refrigeration from seven countries, including goat skins and clay pots, with varying levels of effectiveness, although none were included that were reported in this study.[25] A review of the literature did not find any studies reporting on banana trees for insulin storage. Other authors have found food insecurity to be a factor in management in all types of diabetes, although less has been written solely in the context of T1D.[19 26 27]

Our study identified challenges with diabetes management related to numeracy and literacy levels in the population. There are few studies in LMICs that have addressed this issue. A recent study in Ahmedabad Gujarat, India showed that an estimated 70% of rural PLWT1D were insufficiently educated to manage their own conditions.[28] On the other hand, two studies from one hospital in Tanzania found that caregiver and patient educational levels were not significantly associated with glycemic control or frequency of complications.[29-30]

This study had several limitations. Despite interviewer's best efforts, it was often challenging to find quiet places to conduct interviews, which caused several interruptions. Patients and caregivers with higher education levels tended to be more likely to speak, and some PLWT1D were interviewed by people they may have seen as providers and therefore been less likely to speak negatively of the program. Finally, most of the patients and caregivers interviewed received care at PIH or LFAC centers, and therefore received subsided services and are not representative of the broader population.

Future implications

Efforts are underway to expand T1D in sub-Saharan Africa and elsewhere both through focused T1D initiatives and integrated PEN-Plus strategies.[31-35] These strategies aim for at least intermediate levels of glycemic control that will require diabetes self-management education. Ultimately, greater allocation of resources toward T1D care and services in Liberia is needed to address systems- and individual-level barriers.[2]

This study identified areas of both health system improvement and social protection that are needed to improve the quality of T1D care in LICs. Providers interviewed highlighted the importance of standardized record keeping and guidelines, while patients emphasized the need to address food insecurity, stigma, and insulin storage.

Advocacy efforts for additional T1D resources must be supported by data highlighting the burden of this disease. Thus, including regional or national systems of electronic medical records (EMR) or other methods of monitoring patient care and outcomes are needed. EMR are not only needed to assess the magnitude of the problem, but also as part of quality improvement efforts, and have been shown to lead to better patient care and clinical outcomes, and subsequently significantly reduce morbidity and mortality associated with T1D complications.[36]

T1D guidelines will also raise awareness of T1D among governments, providers, public health practitioners and advocates, caregivers and patients and point toward useful resources.[37] Additionally, they can assist providers, PLWT1D, and caregivers in managing diabetes in a standardized, evidence-based way to ensure safe care in a timely manner, taking into account the local context and resource availability.[37-40] Morbidity and mortality will be improved through the use of T1D-specific guidelines, as they will enable clinicians to effectively prioritize objectives as they relate to diabetes management and care, provide guidance on how to support PLWT1D and their caregivers, and enable standard screening for T1D complications.[38-41]

The findings from this study have important implications for ongoing T1D program design. More research is needed to better quantify the impact of these issues on PLWT1D in more diverse settings. However, it is already clear from this report that interventions such as food packages or cash transfers may be necessary for high-quality T1D care in high-poverty settings. Additionally, educational initiatives and opportunities for T1D patients and families to build and become engaged in T1D communities, such as patient advocacy and support groups may be necessary to address societal stigma for this disease. Finally, additional research on local solutions and providing improved insulin storage containers and the

development of heat-stable insulins may be a priority. Indeed, while comprehensive recommendations to revise T1D programs as described above are beyond the scope of this paper, our findings serve as a strong starting point for using a behavior change framework to implement such changes, which is the goal of future work.[11]

CONCLUSION

This study fills an important gap in the existing literature as the first study conducted in a LIC in SSA to examine the impact of T1D on patients, caregivers, and health systems. We found T1D has a major psychosocial impact on PLWT1D and caregivers. While patients and caregivers possessed adequate knowledge to effectively manage T1D, informants identified important individual and systems-level barriers to T1D care in Liberia. These findings demonstrate the need for additional research to quantify the impact of these issues and initiatives to address barriers to care in high-poverty settings such as Liberia.

COMPETING INTERESTS

The authors report no competing interests.

CONTRIBUTORSHIP STATEMENT

Design of project and tools: AJA, CT, CN, LS, CR, GB
Data acquisition and management: CT, JP, TA, RC, CR
Data analysis: AJA, CT, LD, LS
Manuscript drafting: AJA, CT, LD, LS, GB
All authors contributed to final manuscript

DATA SHARING

Deidentified quotes of informants taken from qualitative interviews are available upon request from the corresponding author, AJA. The codebook utilized for analysis is also available.

ETHICS STATEMENT

This study obtained ethics from both the Harvard Longwood Campus review board and University of Liberia Institutional Review Board #FWA00004982.

REFERENCES

1. Definition and diagnosis of diabetes mellitus and intermediate hyperglycemia: report of a WHO/IDF consultation: World Health Organization, 2006.

2. Atun R, Davies J, Gale EAM, et al. Diabetes in sub-Saharan Africa: from clinical care to health policy. *The Lancet Diabetes & Endocrinology* 2017;5(8):622-67. doi: https://doi.org/10.1016/S2213-8587(17)30181-X

3. Beran D, Yudkin JS. Diabetes care in sub-Saharan Africa. *Lancet (London, England)* 2006;368(9548):1689-95. doi: 10.1016/s0140-6736(06)69704-3 [published Online First: 2006/11/14]

4. Huo L, Harding JL, Peeters A, et al. Life expectancy of type 1 diabetic patients during 1997–2010: a national Australian registry-based cohort study. *Diabetologia* 2016;59(6):1177-85. doi: 10.1007/s00125-015-3857-4

5. Livingstone SJ, Levin D, Looker HC, et al. Estimated Life Expectancy in a Scottish Cohort With Type 1 Diabetes, 2008-2010. *JAMA* 2015;313(1):37. doi: 10.1001/jama.2014.16425

6. Petrie D, Lung TWC, Rawshani A, et al. Recent trends in life expectancy for people with type 1 diabetes in Sweden. *Diabetologia* 2016;59(6):1167-76. doi: 10.1007/s00125-016-3914-7

7. Beran D, Hirsch IB, Yudkin JS. Why Are We Failing to Address the Issue of Access to Insulin? A National and Global Perspective. *Diabetes care* 2018;41(6):1125-31. doi: 10.2337/dc17-2123 [published Online First: 2018/05/23]

8. Ewen M, Beran D, Joosse H-J, et al. Insulin prices profile. Amsterdam: Health Action International, 2016.

9. Bahendeka SK. Diabetes in sub-Saharan Africa: let us not forget type 1. *The lancet Diabetes & endocrinology* 2017;5(8):575-77. doi: 10.1016/s2213-8587(17)30223-1 [published Online First: 2017/07/10]

10. Ogle GD MA, Silink M. The IDF Life for a Child Program Index of diabetes care for children and youth. *Pediatric Diabetes* 2016;17(5):374-84. doi: https://doi.org/10.1111/pedi.12296

11. Michie S, Johnston M, Abraham C, et al. Making psychological theory useful for implementing evidence based practice: A consensus approach. . *Qual Saf Health Care* 2005;14(1):26-33.

12. Michie S, Atkins L, West R. The Behaviour change Wheel: A guide to designing intervention. London: Silverback Publishing 2014.

13. Davies P WA, Grimshaw JM. A systematic review of the use of theory in the design of guideline dissemination and implementation strategies and interpretation of the results of rigorous evaluations *Implement Sci* 2010;5 doi: https://doi.org/10.1186/1748-5908-5-14

14. Dedoose Version 8.3.35, web application for managing, analyzing, and presenting qualitative and mixed metho research data [program], 2020.

15. Diabetes Distress Assessment & Resource Center 2017 [Available from: https://diabetesdistress.org/ accessed September 25 2020.

16. Brown O, Fouche P, Coetzee M. Bouncing forward: families living with a type 1 diabetic child. *SA Fam Pract* 2010;52(6):536-41.

17. Jonker D, Deacon E, van Rensburg E, et al. Illness perception of adolescents with well-controlled type 1 diabetes mellitus. *Health Psychology Open* 2018;July-December 2019:1-9.

18. Kratzer J. Structural barriers to coping with type 1 diabetes mellitus in Ghana: experiences of diabetic youth and their families. *Ghana Medical Journal* 2012;46:39-45.

19. de-Graft Aikins A. Healer shopping in Africa: new evidence from rural-urban qualitative study of Ghanaian diabetes experiences. *BMJ* 2005;331(7519):737. doi: 10.1136/bmj.331.7519.737

20. Hapunda G, Abubakar A, van de Vijver F, et al. Living with type 1 diabetes is challenging for Zambian adolescents: qualitative data on stress, coping with stress and quality of care and life. *BMC endocrine disorders* 2015;15:20. doi: 10.1186/s12902-015-0013-6

21. Edah JO, Goar SG, Odoh G, et al. Undiagnosed depression among adults with diabetes mellitus in Jos. *Niger J Clin Pract* 2020;23:1431-36. doi: 10.4103/njcp.njcp_155_20.

22. Wolde AK, Wondim MG. Diabetic distress among diabetic patients in the referral hospital of Amhara Regional State, Ethiopia. *International Quarterly of Community Health Education* 2020;40(2) doi: 10.1177/0272684X19857580 [published Online First: June 27, 2019]

23. Mendenhall E, Musau A, Bosire E, et al. What drives distress? Rethinking the roles of emotion and diagnosis among people with diabetes in Nairobi, Kenya. *Anthropol Med* 2020;27(3):252-67. doi: 10.1080/13648470.2019.1650243 [published Online First: December 6, 2019]

24. Mogre V, Johnson NA, Tzelepis F, et al. Barriers to diabetic self-care: A qualitative study of patients' and healthcare providers' perspectives. *J Clin Nurs* 2019;28(11-12):2296-308. doi: 10.1111/jocn.14835 [published Online First: March 6, 2019]

25. Ogle GD, Abudllah M, Mason D, et al. Insulin storage in hot climates without refrigeracy: temperature reduction efficacy of clay pots and other techniques. *Diabetic medicine : a journal of the British Diabetic Association* 2016;33(11):1544-53. doi: 10.1111/dme.13194 [published Online First: 2016 Aug 28]

26. Cheng S, Kamano J, Kirui NK, et al. Prevalence of food insecurity in patients with diabetes in western Kenya. *Diabetic medicine : a journal of the British Diabetic Association* 2013;30(6):215-22. doi: 10.1111/dme.12174 [published Online First: 2013 Apr 12]

27. Ogunrinu T, Gamboa-Maldonado T, Ndinda Ngewa R, et al. A qualitative study of health education experiences and self-management practices among patients with type 2 diabetes at Malamulo Adventist Hospital in Thyolo District, Malawi. *Malawi medical journal : the journal of Medical Association of Malawi* 2017;29(2)

28. Pacaud D, Lemay J-F, Richmond E, et al. Contribution of SWEET to improve paediatric diabetes care in developing countries. *Pediatr Diabetes* 2016:46-52. doi: 10.1111/pedi.12427

29. Noorani M, Ramaiya K, Manji K. Glycaemic control in type 1 diabetes mellitus among children and adolescents in a resource limited setting in Dar es Salaam - Tanzania. *BMC endocrine disorders* 2016;16(1):29. doi: 10.1186/s12902-016-0113-y [published Online First: 2016/06/02]

30. Majaliwa ES, Munubhi E, Ramaiya K, et al. Survey on acute and chronic complications in children and adolescents with type 1 diabetes at Muhimbili National Hospital in Dar es Salaam, Tanzania. *Diabetes care* 2007;30(9):2187-92.

31. WHO PEN and integrated outpatient care for severe, chronic NCDs at first referral hospitals in the African Region (PEN-Plus): report on regional consultation. World Health Organization Regional Office for Africa, 2019

32. Tapela N, Bukhman G, Ngoga G, et al. Treatment of non-communicable disease in rural resource-constrained settings: a comprehensive, integrated, nurse-led care model at public facilities in Rwanda *The Lancet Global Health* 2015;3 doi: https://doi.org/10.1016/S2214-109X(15)70155-5

33. Eberly LA, Rusangwa C, Ng'ang'a L, et al. Cost of integrated chronic care for severe non-communicable diseases at district hospitals in rural Rwanda. *BMJ Global Health* 2019;4 doi: 10.1136/bmjgh-2019-001449

34. Jasem D, Majaliwa ES, Ramaiya K, et al. Incidence, prevalence and clinical manifestations at onset of juvenile diabetes in Tanzania. *Diabetes Research and Clinical Practice* 2019;156:10787. doi: 10.1016/j.diabres.2019.107817 [published Online First: August 16, 2019]

35. Marshall SL, Edidin D, Arena VC, et al. Prevalence and incidence of clinically recognized cases of Type 1 diabetes in children and adolescents in Rwanda, Africa. *Diabetic medicine : a journal of the British Diabetic Association* 2015;32(9):1186-92. doi: 10.1111/dme.12701 [published Online First: February 12, 2015]

36. Pastakia SD, Karwa R, Kahn CB, et al. The evolution of diabetes care in the rural, resource-constrained setting of western Kenya. *Ann Pharmacother* 2011;45(6):721-6. doi: 10.1345/aph.1P779 [published Online First: 2011 May 10]

37. Codner E, Acerini CL, Craig ME, et al. ISPAD Clinical Practice Consensus Guidelines 2018: What is new in diabetes care? *Pediatr Diabetes* 2018;19 Suppl 27:5-6. doi: 10.1111/pedi.12759 [published Online First: 2018/10/03]

38. Association AD. Standards of Medical Care in Diabets - 2020. *Diabetes Care* 2020;43:S1-S212.

39. Codner E, Acerini C, Craig ME, et al. ISPAD Clinical Practice Consensus Guidelines 2018: Introduction to the Limited Care guidance appendix. *Pediatr Diabetes* 2018;19 Suppl 27:326-27. doi: 10.1111/pedi.12765 [published Online First: 2018/09/04]

40. Codner E, Acerini CL, Craig ME, et al. ISPAD Clinical Practice Consensus Guidelines 2018: Limited Care Guidance Appendix. *Pediatr Diabetes* 2018;19 Suppl 27:328-38. doi: 10.1111/pedi.12767 [published Online First: 2018/10/03]

41. Zargar AH. Type 1 diabetes guidelines: Are they enough? *Indian Journal of Endocrinology and Metabolism* 2015;19:S18-S21. doi: 10.4103/2230-8210.155355

Supplementary file 1. Interview guides

Please remember these are guides only - please conduct these interviews following the topic guide but allow for flexibility

Table 1. Patient interview guide.

Question
1. How often do you attend school? Do you enjoy it?
2. Can you tell me about who you live with?
3. How long have you had T1D?
4. Pre-diagnosis, had you heard of diabetes? What did you know about it?
5. Does anyone else in your family have a history of diabetes? Do any of your friends?
6. When you first became ill, what prompted you to seek care?
7. How you were diagnosed? (probe for symptoms, length of time before diagnosis)
8. Do you use any alternative treatments other than the ones that your provider has given you?
9. Can you walk me through a typical clinic visit?
10. How often do you attend?
11. How often do you miss appointments? Why do you miss appointments? How long did you wait to reschedule or attend a new appointment?
12. When you go to clinic who do you normally see? (probe for type of HCP, etc, do they normally see same person, or different every time)
13. Does your HCP ask about your feelings about care?
14. What is your treatment schedule (probe to see if it is clear and if they have knowledge?)
15. How long do you usually wait to see your HCP at the clinic?
16. Do you ever leave the clinic without seeing a health care provider? Can you give me an example? Were you given a reason for it? (probe for wait time, unavailable HCP etc)
17. How often do you see your pharmacist? (probe for interaction? Do they just see pharmacist to pick up drugs, or have any counselling) (if do not see pharmacist skip to number 24)
18. Have you received good information (counseling) from the pharmacist?
19. Where is the pharmacist located (in hospital, do they have to travel)? Do you see the same pharmacist, or different ones?
20. How long do you have to wait to see the pharmacist?
21. How regularly do you leave without your needed medications? When this happens, what do they tell you? What do you do? Where do you get your needed medications?
22. Have you ever taken a reduced dose of your medication to make it last longer? How often? Why did you do this? (probe for cost, stock-out, etc)
23. Do you regularly see a community health worker? If so, do you speak with them about your T1D? Can you tell me about an interaction with them? How have they helped you? How have they influenced your care?
24. How would you rate the quality of care that you receive?
25. What is one thing that would improve the quality of your health care experience?
26. Could you walk me through a typical day regarding your illness? (probe for if they check their blood glucose, if so how often, do they have a log book)
27. How often do you check your blood glucose?
28. When do you check your blood glucose? (Probe for different times of the day, different days etc).
29. Do you check your blood glucose yourself or does someone help you? Who?

30.	Do you ever not buy strips because of costs or lack of availability?
31.	How do you use your blood glucose reading to inform your self-management (probe for insulin, diet, exercise, water)
32.	How do you know when your blood glucose is out of its range?
33.	How often do you experience hypoglycemic events?
34.	How often do you experience hyperglycemic events?
35.	How do you manage your hyper/hypoglycemic events?
36.	How often do you need help to manage your hyper/hypoglycemic event? (probe for severe)
37.	What proportion of your day do you spend worrying about your diabetes?
38.	What proportion of your day do you spend managing your diabetes?
39.	Do you feel like you have your condition under control?
40.	How often do you take insulin? Do you ever skip doses? Why?
41.	Who gives you injections?
42.	How do you store your insulin? (probe for knowledge on cold chain)
43.	Have you engaged with any support groups, camps, or diabetes associations? What have you gained from these interactions? (probe for financial, access to HCP, psychological support, knowledge)
44.	Discuss how your life has changed since your diagnosis? How does it affect what you eat? What you drink? What you do on a day to day basis? What activities you participate in?
45.	Has your perception of your future changed since your diagnosis?
46.	Do you check your blood glucose in public? Do you have injections in public? Why or why not?
47.	Can you tell me about a time you tried to hide your condition?
48.	Do you have insurance?
49.	How often do you miss work/school because of your condition? Include clinic visits, illness, hospitalization. How often does a family member or carer miss work because of your condition?
50.	What are your typical out of pocket costs for transport? Insulin? Strips? Days off of work?
51.	Activity: Show cards with different readings on them. What would they do?

Table 2. Family member interview guide

Question
1. Would you tell me about what work you do?
2. Can you tell me about your family structure? Who lives in your house?
3. What is your house made of?
4. Can you tell me about your family member who has T1D?
5. How long has your family member had T1D?
6. Pre-diagnosis, had you heard of diabetes? What did you know about it?
7. Does anyone else in your family have a history of diabetes? Do any of your friends?
8. When your family member first became ill, what prompted them to seek care? How you they diagnosed? (probe for symptoms, length of time before diagnosis)
9. Do you think alternative treatments other than the ones that the provider you know has prescribed are effective?
10. How often do you attend your family member's clinic visits?
11. Can you walk me through a typical clinic visit that you attend?
12. How far do you have to travel to see the health care provider?
13. How often does your family member miss appointments? Why do you miss appointments? How long did you wait to reschedule or attend a new appointment?
14. When you go to clinic who do you normally see? (probe for type of HCP, etc, do they normally see same person, or different every time)
15. Does your HCP ask about your feelings about care?
16. What is your family members' treatment schedule (probe to see if it is clear and if they have knowledge?)
17. How long do you usually wait to see their HCP at the clinic ?
18. Do you ever leave the clinic without seeing a health care provider? Can you give me an example? Were you given a reason for it? (probe for wait time, unavailable HCP, etc)
19. When attending a T1D appointment, how often do you see a pharmacist? (probe for interaction? Ie do they just pick up drugs, or have any counselling) (if do not see pharmacist skip to number 24)
20. Have you received good information (counseling) from the pharmacist?
21. Where is the pharmacist located (in hospital, do they have to travel)? Do you see the same pharmacist, or different ones?
22. How long do you have to wait to see the pharmacist?
23. How regularly do you leave without the needed medications? When this happens, what do they tell you? What do you do? Where do you get the needed medications?
24. Has your family member ever taken a reduced dose of your medication to make it last longer? How often? Why (probe for cost, stock-out, etc)?
25. Do you regularly see a community health worker? If so, do you speak with them about your T1D? Can you tell me about an interaction with them? How have they helped you? How have they influenced your care?
Treatment and self-management:
26. How do you know when your family member's blood glucose is out of its range?
27. How do you help your family member manage their hyper/hypoglycemic events?
28. What proportion of your day do you spend thinking about your family member's diabetes?
29. What proportion of your day do you spend helping manage diabetes?

30.	Do you feel like your family member has their condition under control?
31.	Do you help give injections?
32.	How is insulin stored in your household? (probe for knowledge on cold chain)
33.	Are you aware of any peer support groups?
34.	Discuss how your life has changed since your family member's diagnosis? How does it affect what you eat? What you drink? What you do on a day to day basis? What activities you participate in?
35.	Has your perception of your future changed since your diagnosis?
36.	How often do **you** miss work/school because of your family member's condition? Include clinic visits, illness, hospitalization.
37.	What are your typical out of pocket costs for transport? Insulin? Strips? Days off of work?
38.	Activity: Show cards with different readings on them. What would they do?

Table 3. Healthcare professionals interview guide

	HEALTHCARE PROFESSIONALS' EXPERIENCE AND TASKS
1.	Can you tell me about your role as a clinician/nurse/specialist?
2.	How is service organized at your facility?
3.	What is your level of training?
4.	Can you describe the other health care professionals you work with?
5.	How is T1D diagnosed? What are the key steps?
6.	What are the key symptoms?
7.	Can you tell me about the training that you have had specifically for T1D? Who provided the training? When did you receive your training?
8.	How often do you have continuing medical education? How much of it is specific to T1D?
9.	How often do you see patients with T1D?
10.	Do you feel that your training is adequate for treating patients with T1D?
11.	What other training do you think you would benefit from?
	TREATMENT
12.	Could you please explain to me the steps that a patient follows when they come to you and you suspect T1D? (probe for diagnosis/symptoms, comorbidities, severity, family history, etc)
13.	What services do you provide to patients with T1D at your facility? (probe for medications, education, schedule of care)
14.	How is this care coordinated with the rest of the team you work with, and with other services (secondary care, primary care)?
15.	How is T1D care organized at your facility? (probe for if they have clinics, individual appointments, etc)
16.	When a patient is first diagnosed, what education initially is provided?
17.	How often does the patient receive follow up education? How is this education structured?
18.	What are the things that you think work well?
19.	How do you think you could coordinate care better? What are the biggest challenges?
20.	How many patients do you typically see a day? How many have T1D?
	CLINICAL GUIDELINES
21.	What clinical guidelines on T1D exist in Liberia? How are these developed?
22.	What are your views on clinical guidelines? Do you think these are useful?
23.	What are some of the barriers/facilitators of implementing clinical guidelines?
24.	Are clinical guidelines visible/available in your facility?
25.	How often do you reference clinical guidelines?
	RELATIONSHIPS WITH PATIENTS
26.	Can you tell me about your interactions with patients? What are challenges to effective communication?
27.	Overall how would you rate the literacy/numeracy in your treatment population? Do you feel it is sufficient for effective self-management?
28.	What do you think are the key challenges to adherence to treatment in your own experience?
29.	What are the areas where more could be done to inform the patient? How could this be implemented?
30.	Do you feel that you have sufficient time with each patient? Why or why not?

31.	To what extent do your patients apply the knowledge that you give them? (Prompt: do they feel their patients listen to them)
32.	To what degree are parents/carers/family members (when relevant) included in the consultation?
	HEALTH SYSTEM ISSUES
33.	What areas do you think work well in your system regarding T1D?
34.	Do you think all patients have the same access to care? Why or why not? (Probe for distance, SES, literacy/numeracy)
35.	What areas could be improved to make your work easier and more enjoyable? (Probe for: Is funding a key concern for you? Lack of physical resources? Or the lack of human resources, or the information systems, or poor facilities, or access to care?)
36.	What could be done to improve the patient journey?
37.	What questions do you ask about patient's current health and self-management? (treatment)
38.	What else do you screen for? (Probe for mental health questions, wellbeing, co-morbidities)
39.	Who else do you recommend the patients speak with? (probe for social workers, peers support, civil society groups, pharmacists, etc)
40.	What social support mechanisms are available to your patients? (probe for counselling, travel expenses, community health worker assignments anything else)
41.	How do your patients get access to them?
42.	Under what circumstances do patients get referred to you?
43.	Under what circumstances do you refer patients to other providers?
44.	Are there age restrictions to care? What happens when patients age out of philanthropy programmes? (for example, after they are 18 no longer pediatric)
45.	Does the level of care change as a patient ages?
46.	What does insurance cover for your patients?
	Closing Questions
47.	Before we wrap up, do you have any final thoughts that you'd like to share?
48.	This brings us to the end of our interview for today. Do you have any final questions?

Table 4. Civil society interview guide

	HEALTHCARE PROFESSIONALS' EXPERIENCE AND TASKS
1.	Can you tell me about your role as a clinician/nurse/specialist?
2.	How is service organized at your facility?
3.	What is your level of training?
4.	Can you describe the other health care professionals you work with?
5.	How is T1D diagnosed? What are the key steps?
6.	What are the key symptoms?
7.	Can you tell me about the training that you have had specifically for T1D? Who provided the training? When did you receive your training?
8.	How often do you have continuing medical education? How much of it is specific to T1D?
9.	How often do you see patients with T1D?
10.	Do you feel that your training is adequate for treating patients with T1D?
11.	What other training do you think you would benefit from?
	TREATMENT
12.	Could you please explain to me the steps that a patient follows when they come to you and you suspect T1D? (probe for diagnosis/symptoms, comorbidities, severity, family history, etc)
13.	What services do you provide to patients with T1D at your facility? (probe for medications, education, schedule of care)
14.	How is this care coordinated with the rest of the team you work with, and with other services (secondary care, primary care)?
15.	How is T1D care organized at your facility? (probe for if they have clinics, individual appointments, etc)
16.	When a patient is first diagnosed, what education initially is provided?
17.	How often does the patient receive follow up education? How is this education structured?
18.	What are the things that you think work well?
19.	How do you think you could coordinate care better? What are the biggest challenges?
20.	How many patients do you typically see a day? How many have T1D?
	CLINICAL GUIDELINES
21.	What clinical guidelines on T1D exist in Liberia? How are these developed?
22.	What are your views on clinical guidelines? Do you think these are useful?
23.	What are some of the barriers/facilitators of implementing clinical guidelines?
24.	Are clinical guidelines visible/available in your facility?
25.	How often do you reference clinical guidelines?
	RELATIONSHIPS WITH PATIENTS
26.	Can you tell me about your interactions with patients? What are challenges to effective communication?
27.	Overall how would you rate the literacy/numeracy in your treatment population? Do you feel it is sufficient for effective self-management?
28.	What do you think are the key challenges to adherence to treatment in your own experience?
29.	What are the areas where more could be done to inform the patient? How could this be implemented?
30.	Do you feel that you have sufficient time with each patient? Why or why not?

31.	To what extent do your patients apply the knowledge that you give them? (Prompt: do they feel their patients listen to them)
32.	To what degree are parents/carers/family members (when relevant) included in the consultation?
	HEALTH SYSTEM ISSUES
33.	What areas do you think work well in your system regarding T1D?
34.	Do you think all patients have the same access to care? Why or why not? (Probe for distance, SES, literacy/numeracy)
35.	What areas could be improved to make your work easier and more enjoyable? (Probe for: Is funding a key concern for you? Lack of physical resources? Or the lack of human resources, or the information systems, or poor facilities, or access to care?)
36.	What could be done to improve the patient journey?
37.	What questions do you ask about patient's current health and self-management? (treatment)
38.	What else do you screen for? (Probe for mental health questions, wellbeing, co-morbidities)
39.	Who else do you recommend the patients speak with? (probe for social workers, peers support, civil society groups, pharmacists, etc)
40.	What social support mechanisms are available to your patients? (probe for counselling, travel expenses, community health worker assignments anything else)
41.	How do your patients get access to them?
42.	Under what circumstances do patients get referred to you?
43.	Under what circumstances do you refer patients to other providers?
44.	Are there age restrictions to care? What happens when patients age out of philanthropy programmes? (for example, after they are 18 no longer pediatric)
45.	Does the level of care change as a patient ages?
46.	What does insurance cover for your patients?
	Closing Questions
47.	Before we wrap up, do you have any final thoughts that you'd like to share?
48.	This brings us to the end of our interview for today. Do you have any final questions?

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4
Purpose or research question - Purpose of the study and specific objectives or questions	4

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	5
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4,6
Context - Setting/site and salient contextual factors; rationale**	4-5
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4-5
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4-5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4-6

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	4-6
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	7-11
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	7-11

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	12-13
Limitations - Trustworthiness and limitations of findings	12-13

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	14

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

2

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388