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Barriers and facilitators to accessing Non-Communicable Disease services among children, adolescents and young people with Type 1 Diabetes in Mozambique: a quantitative content analysis using the COM-B framework

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Abstract

Background Non-communicable diseases (NCDs), and diabetes in particular, are on the rise even in sub-Saharan African countries. Despite this, access to care is still poor. This study aimed to assess barriers/facilitators to access NCDs services for children, adolescents and young people with Type 1 Diabetes (T1DM) in Mozambique.

Methods A qualitative cross-sectional study using focus groups (FG) and key-informant interviews was conducted between September and October 2023, involving patients (16–30 years), caregivers of child and adolescent patients and health care staff of 5 health facilities. A deductive approach was adopted using the Capability-Opportunity-Motivation-Behaviour (COM-B) framework to classify themes referring to barriers/facilitators to access. Two researchers carried out quantitative content analysis independently, assessing the inter-rater agreement through Cohen's K.

Results Four FGs were conducted with 26 patients (61.5% female, 16–24 years), three with 18 caregivers (83.3% female) and 16 interviews with healthcare workers. A total of 455 themes were identified, with a predominance of barriers (67.3%) compared to facilitators (32.7%) in accessing T1DM services. The area “Capability” was labelled significantly more often as a barrier (89.5%) than “Motivation” and “Opportunities” (60.2% and 62.6%, $p < 0.001$). The most frequent barriers were related to the psychological ability to accept and manage the disease in the absence of professional psychological support, inadequate interactions with healthcare personnel, long waits in the outpatient clinic and stigma towards diabetes in the community. Social support from family and friends appears

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to be an important facilitator. Social opportunities emerge more often as facilitators (76/105, 72.4%) than physical opportunities, which were 79.0% ($n = 139/176$) of the barriers in the 'Opportunities' area ($p < 0.001$).

Conclusions The study highlights the difficulties of patients suffering from T1DM, in particular due to the lack of psychological support and inadequacies of the health services. It also points out the need to improve the training of healthcare personnel and to strengthen the health literacy of patients to improve recognition and management of the disease, respectively. Increased awareness by the community, supported by structured interventions, could also contribute to reducing stigma towards patients and improving the quality of care.

Keywords Diabetes, Non-communicable diseases, Accessibility, Mozambique

Text box 1. Contributions to the literature

- There is limited evidence on factors that facilitate or hinder access to health services for patients with diabetes mellitus type one (T1DM), especially in developing countries and in younger age groups such as adolescents and young adults.
- Limited access to healthcare services has proven to be an obstacle to the diagnosis and treatment of patients with diabetes, thus leading to poorer outcomes.
- Public health policies aimed at improving access to health services for people with T1DM are key to achieving the 2030 sustainable development goals.

Introduction

The World Health Organisation estimates that 74% of all deaths globally are due to 'non-communicable diseases' (NCDs), and that 86% of premature deaths due to NCDs occur in low- and middle-income countries (LMICs) [1, 2].

Diabetes mellitus is a chronic metabolic disease characterised by hyperglycemia secondary to defects in insulin secretion, action, or both. According to the International Diabetes Federation (IDF), the prevalence worldwide of diabetes mellitus type 1 (T1DM) in the age group 0–19 years was 1,211,900 cases in 2021 with an incidence of 149,500 new cases [3]. Europe and North America remain the regions reporting the highest number of prevalent cases, but as of 2019, people under 20 years with T1DM in Africa region increased more than twofold because of the availability of new data [3].

In Mozambique the estimated prevalence of DM increased from 2.9 (95%CI 2.0–4.2) in 2005 to 7.4 (95%CI 5.5–10.0) in 2015 [4]. Similarly, the percentage change from 1990 to 2021 in age-standardised disability-adjusted life year (DALY) rate was equal to 41.2% (95%CI 11.5 to 73.7) [5]. T1DM cases in Mozambique were estimated at 10,346 in 2022, of which 35.4% (3,662) were aged < 20 years [6].

Promoting awareness and widespread screening strategies for NCDs is crucial to address the rising incidence of these diseases and engage patients in the healthcare pathway [7]. Despite the increased access to diabetes consultations reflecting increased sensitivity to NCDs, and specifically to T1DM, in sub-Saharan African countries,

the number of losses at follow-up and diagnoses at hospitalisation remains high [8].

Limited access to health services has been proven to be a pitfall for diagnosis and treatment in LMICs for patients with diabetes [9]. Recognized elements that influence access to healthcare for NCDs are the distance or travel time between healthcare facilities and users (geographic accessibility), public transport availability, presence of essential equipment in health centers, cost of health services and medications, health workers awareness and sensitivity concerning social and cultural customs [10]. These barriers are most likely to be encountered in developing countries. Indeed, although 80% of people with diabetes mellitus live in LMICs, only 1% of global diabetes-related spending occurs in these countries with only 2/13 African countries meeting the WHO Global Plan of Action on Noncommunicable Diseases (NCD) target of 80% availability of essential medicines, including insulin [11, 12]. On the other hand, facilitators include improving outreach services and fostering affordability through insurance or welfare state support [10, 11].

It is important to understand which of these factors influence and how access to T1DM services in each specific setting, especially in a transformative age such as that of children, adolescents and young adults. It can help reach the standard development goals (SDG), especially SDG 3, "Good Health and Well-being." This goal highlights the importance of early diagnosis and effective treatment, guaranteed by proper access to care, of chronic conditions such as T1DM. Thus, this study aims to use focus group discussions (FGD) and key informant interviews (KII) to identify barriers and facilitators in accessing NCDs services for children, adolescent and young people with T1DM in the province of Sofala and Zambezia (Mozambique). The secondary objective was to assess possible differences in these barriers and facilitators based on type of participant (i.e., caregiver, patient or health care worker).

Methods

Ethical approval

The research was performed following the ethical standards of the 1964 Declaration of Helsinki and was

approved by the Institutional Bioethics Committee for Health (CIBS #8) on October 20th 2023 (protocol number reference 222/CIBS/23).

Study design, setting and population

This is a qualitative cross-sectional study using focus group discussions (FGD) and key informant interviews (KII). It was carried out in the provinces of Sofala and Zambezia (Mozambique), which have an estimated population of 2,600,754 and 5,854,843 respectively with 51.8% and 55.5% aged 0–17 years [13, 14].

The study involved the outpatient department (OPD) services for T1DM at the Central Hospitals of Beira (Sofala) and Quelimane (HCQ, Zambezia), the General Hospital of Quelimane and the District Hospitals of Mocuba (Zambézia) and Guara Guara (Búzi, Sofala). Different hospital levels (general, central and district) were involved to have a better representativeness of the setting. The OPD services involved a total of 4 general practitioners, 2 endocrinologists and 4 nurses. Psychologists and nutritionists collaborating with the T1DM OPD services were also involved. The focal points for T1DM services are one per province.

All patients aged between 16 and 30 years who accessed OPD services for T1DM, based on the diagnosis in the medical records, during the study period were considered eligible for the FGD. Parents or caregivers of those children, adolescents and young adults (aged 5–30 years) attending OPD services for T1DM who had not been included in the focus groups for patients in both provinces were also involved. For the KIIs, all healthcare workers (HCW) employed with both clinical and management roles in the OPD services for T1DM of the abovementioned health facilities were included. Those who had been diagnosed with T1DM less than three months prior to the study and those who were unable to provide informed consent were excluded.

Sample size

To achieve a saturation of 90% of the possible topics expressed through content analysis, a sample of six focus groups is considered sufficient based on the available literature [15]. Therefore, seven FGDs were organised and included in the analysis with a minimum of 6 persons per group. People were enrolled at healthcare facility level in a non-probabilistic method, by convenience, asking face-to-face progressively those who met the inclusion/exclusion criteria and accepted to participate. None of the participants who were asked to participate refused.

Data collection

The FGDs and the KIIs were conducted between September 20th and October 15th, 2023, at the healthcare facilities. All participants aged 18 years or older were asked

to sign an informed consent to the study. For those aged 16–17, consent was asked from both they and their parents or their legal guardian during the routine visit to the outpatient clinic for non-communicable diseases prior to the focus groups.

The groups were on the one hand heterogeneous by sex to stimulate discussion by maximising the production of topics; on the other hand, they were homogeneous by type of participant (caregiver or patient) to promote self-expression [16, 17].

All FGDs and KIIs were conducted in the local official language (Portuguese) by two local researchers (TM, medical doctor and AM, psychologist) following a question guide for the topics to be covered (Annex 1, 2 and 3). Both researchers had previous experience in conducting FGDs and received specific training on the topics and objectives of this study. Both, as staff of the NGO CUAMM, were involved in supporting organizational activities at the outpatient clinics for NCDs but were not directly involved in the clinical care of the patients involved in the study. The FGDs and the KIIs were recorded and transcribed. The FGDs lasted between 90 and 105 min, while KIIs between 25 and 40 min. All the text transcriptions were analysed in Portuguese and translated only for data presentation.

Data analysis

Content analysis

A deductive quantitative content analysis was conducted using the COM-B (Capability, Opportunity, Motivation and Behaviour) framework (Fig. 1) [18]. This instrument is widely used in the literature for studies on access to healthcare services where the behaviour of interest is patient access to healthcare services [19, 20]. Moreover, quantitative content analysis allows the use of statistical tests to assess differences in the area and sub-area retrieved between the different groups of participants, according to our secondary objective [21].

In the COM-B framework, capability refers to a person's psychological and physical ability to undertake a behaviour, thereby accessing mental health services. Psychological capacity mainly includes the knowledge required to perform the behaviour, but also attention, memory or decisional skills. Physical capacity refers to body-related aspects.

Opportunity refers to the external factors - physical and social - that make the behaviour possible. Physical opportunity refers to the environment where behaviour takes place, but also to physical resources such as money or time. Social opportunity involves the socio-ecological context and the people who are closest and most significant to us. Motivation involves all the internal processes that either activate or inhibit a behaviour. These processes can be reflexive, involving plans, beliefs, attitudes



Fig. 1 The Capability, Opportunity, Motivation and Behaviour framework (COM-B) framework [18]

or goals, and automatic, involving emotions and habits that may not be conscious [22].

The basic text element chosen to be classified during content analysis was the “theme”. It can be a single word, a phrase, a sentence, or even a full paragraph [22].

Themes referring to factors that hindered, prevented or limited access to services were identified as barriers. On the contrary, facilitators were elements that encouraged, eased or helped people to access healthcare services for T1DM.

Two researchers (RB and EM, both medical doctors specialised in epidemiology and public health) read through all the FGDs and KIIs and labelled the relevant themes according to the COM-B framework categories. Discrepancies in the labelling process were discussed and resolved by involving a third rater (LN, medical doctor specialised in endocrinology).

The following steps were applied to identify and codify the relevant themes in the FGDs and KIIs: (1) read the text repeatedly to obtain a complete overview; (2) highlight elements in the text that appear to capture a theme of interest; (3) reread the transcript of FGDs and KIIs and label the relevant themes as main areas (Capability, Opportunity or Motivation); (4) distinguished the areas in subareas accordingly with the COM-B framework; (5) assign each subarea a value as facilitator or barrier, based on the effect on access MH services.

Statistical analysis

A descriptive analysis was first conducted; frequency rates and percentages were used for categorical variables

and medians with interquartile range for continuous variables.

To identify the issues that were discussed more frequently by the participants, a frequency count of all areas and subareas retrieved in the FGDs and in the KIIs was performed. To explore the participants’ barriers and facilitator to access to MH services, a bivariate frequency distribution of the positive/negative values given by the participants for each subarea was constructed. To test for differences in the frequency distribution of barriers and facilitators between the different sub-areas of the COM-B framework and based on the type of participant, the χ^2 test or Fisher’s exact test was used, as appropriate.

The “Cohen’s k ” was calculated to assess the agreement between the two raters for both the areas and the sub-areas. The “Cohen’s k ” was considered satisfying for values between 0.61 and 1.00 (from moderate to almost perfect level of agreement) [23].

A p -value < 0.05 was considered significant. All analyses were performed using the R software (version 4.1.1).

Results

Four FGDs were conducted with 26 patients with T1DM (female = 16, 61.5%) and most aged 16–20 ($n = 13$, 50.0%) or 21–24 ($n = 7$, 26.9%) years old and with secondary education ($n = 20$, 76.9%). Three FGDs were conducted with 18 caregivers (female = 15, 83.3%) of young patients mainly aged 11–15 ($n = 11$, 61.1%) or 5–10 ($n = 3$, 16.7%) years old. The majority of the caregivers also had secondary education ($n = 13$, 72.2%).

Key informant interviews were conducted with 16 HCWs. Different professionals were involved: general practitioners ($n=4$), nutritionists ($n=3$), nurses ($n=3$), endocrinologists ($n=2$), psychologists ($n=2$), an ophthalmologist ($n=1$) and a local coordinator for DM for the Sofala province ($n=1$). The majority of the HCWs involved had more than 15 years of work experience ($n=9$, 56.3%), followed by three HCWs (18.8%) with 5 to 9 years of experience and two (12.5%) with 10 to 14 years of work experience.

A total of 455 themes were retrieved from FGDs and KIIs and found as relevant being classified according to the COM-B framework (Fig. 1). The Opportunity area accounted for 61.8% ($n=281$) of all themes, Motivation for 19.3% ($n=88$) and Capability for 18.9% ($n=86$). The interrater agreement over the main area and subarea of the COM-B framework was good (kappa=0.75 [0.95CI 0.66–0.85]). Frequencies of the six subareas of the COM-B framework retrieved in the analysis are shown in Table 1.

Table 1 Numbers and percentages of the retrieved themes in the content analysis of the focus group discussions and key informant interviews (September–October 2023, Sofala and Zambezia provinces, Mozambique) according to the capability, opportunity, motivation and behaviour (COM-B) framework areas and subareas and distinguished by type of participant

Barriers				
	Patient ($n=127$)	Caregiver ($n=112$)	HCW ($n=67$)	Overall ($n=306$)
Capability	29 (22,8%)	33 (29,5%)	15 (22,4%)	77 (25,2%)
Physical	7 (5,5%)	9 (8,0%)	3 (4,5%)	19 (6,2%)
Psychological	22 (17,3%)	24 (21,4%)	12 (17,9%)	58 (19,0%)
Motivation	24 (18,9%)	24 (21,4%)	5 (7,5%)	53 (17,3%)
Automatic	11 (8,7%)	6 (5,4%)	1 (1,5%)	18 (5,9%)
Reflective	13 (10,2%)	18 (16,1%)	4 (6,0%)	35 (11,4%)
Opportunity	74 (58,3%)	55 (49,1%)	47 (70,1%)	176 (57,5%)
Physical	59 (46,5%)	38 (33,9%)	42 (62,7%)	139 (45,4%)
Social	15 (11,8%)	17 (15,2%)	5 (7,5%)	37 (12,1%)
Facilitators				
	Patient ($n=94$)	Caregiver ($n=40$)	HCW ($n=15$)	Overall ($n=149$)
Capability	3 (3,2%)	5 (12,5%)	1 (6,7%)	9 (6,0%)
Physical	1 (1,1%)	2 (5,0%)	0 (0,0%)	3 (2,0%)
Psychological	2 (2,1%)	3 (7,5%)	1 (6,7%)	6 (4,0%)
Motivation	27 (28,7%)	8 (20,0%)	0 (0,0%)	35 (23,5%)
Automatic	7 (7,4%)	0 (0,0%)	0 (0,0%)	7 (4,7%)
Reflective	20 (21,3%)	8 (20,0%)	0 (0,0%)	28 (18,8%)
Opportunity	64 (68,1%)	27 (67,5%)	14 (93,3%)	105 (70,5%)
Physical	11 (11,7%)	5 (12,5%)	13 (86,7%)	29 (19,5%)
Social	53 (56,4%)	22 (55,0%)	1 (6,7%)	76 (51,0%)

Overall, 306 (67.3%) themes were labelled as barriers and 149 (32.7%) as facilitators to access to DM services. Capability area was significantly more often labelled as a barrier (89.5%) compared to both Motivation and Opportunity (60.2% and 62.6% respectively, $p<0.001$). No differences were found in the main areas between the two provinces involved in both barriers ($p=0.072$) nor facilitators ($p=0.461$). Considering the subareas, the psychological capability and the physical opportunity were the main barrier retrieved while social opportunity was the main facilitator ($p<0.001$, Fig. 2).

Opportunity

Opportunity was retrieved as a barrier in 176 themes (57.5% of all barriers). Physical opportunities account for 79.0% ($n=139/176$) of the opportunity barriers and was more frequently labelled as barrier compared to social opportunity being more frequently a facilitator (76/105, 72.4%, $p<0.001$).

We describe the physical opportunity first and then the social one, with barriers presented first followed by the facilitators for each of the subtypes (Fig. 3).

Physical opportunities as barriers were mainly related to negative experiences with health care personnel and the system. Patients' groups reported the problem of making the right diagnoses, the difficulty in communicating with the doctor, the fact that sometimes the doctor was not available for the scheduled visit or spent insufficient time on it, and the long waiting times, especially for laboratory analyses. The latter was a particular issue given the need to go on fasting and having to wait up to four or five hours.

"We went to Chingussura [health centre] and they gave me tablets, like paracetamol and other tablets and I went home and started taking them, but I felt very hungry, and I was eating almost every minute, and I was urinating almost every hour and then we went to Nhangau health centre and from there we tried to talk to the doctors. It was my uncle who said we suspected a disease, diabetes, and to go to Nhaconjo health centre to get tested because there was no equipment to do tests there. So, we went to Nhaconjo and then from there they referred us for the Central Hospital." Female patient.

"The doctor wasn't available to visit me, and I'd go home with no results. At that time there were no machines and it was really difficult, but luckily I used to go and have my blood sugar checked at a neighbour's house, an aunt whose sister had diabetes, so I used to go there and she talked to me and gave me tips, but after having these difficulties I stopped for a while and I didn't come here for almost

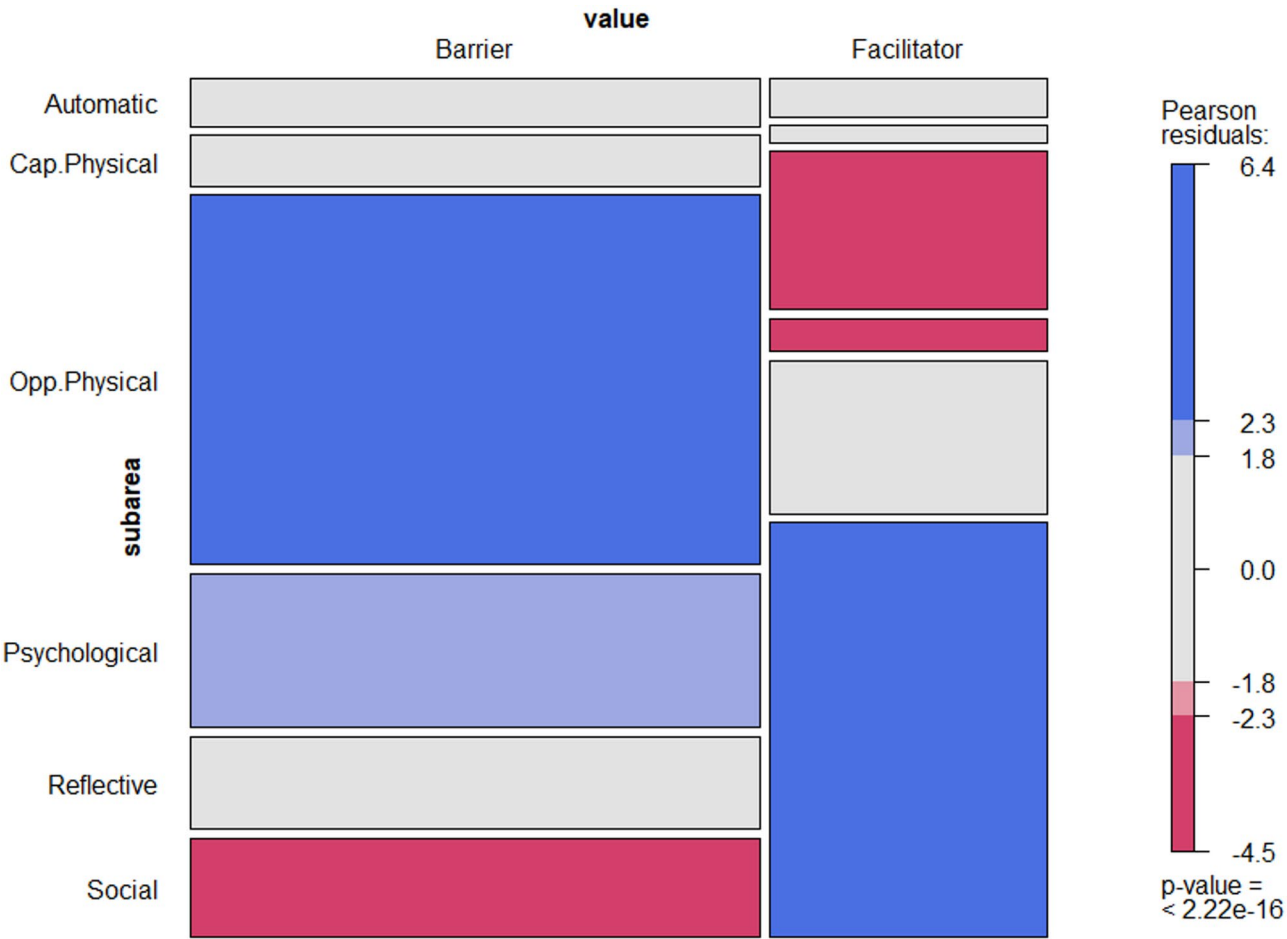


Fig. 2 Mosaic plot representing the proportion of themes retrieved in the focus group discussions and key informant interviews (September–October 2023, Sofala and Zambezia provinces, Mozambique) labelled as facilitator or barrier stratified by the subareas of the Capability, Opportunity, Motivation and Behaviour (COM-B) framework. The blue coloured boxes show a significantly higher frequency compared to the expected values

two months and I ended up losing my patient card.”
Male patient.
“There have been a lot [of problems], especially here in the hospital, just to get an appointment, to be visited is a hard process, to go to the pharmacy is always a mess, it gets on your nerves to be a patient, you arrive here at 8am and leave at 3pm, come on!”
Male patient.

Unavailability of psychologist (or inadequate psychological support) was another physical opportunity barrier revealed through patients’ statements. Patients emphasised that it would be useful to have support from a psychologist during the diabetic visit with the medical doctor.

“[There would be] many things, I don’t know if all of them are possible. Sometimes we could engage with psychologists. That would be a bit better for me. For example for us as diabetics and for me it’s an important point here, I’ve always thought of asking the

doctor sometimes to call a psychologist, to know a little bit more about us, not only about our health, but also about our daily life, in society, in the community, at school, those who work or those who have wives, who are married, also relationships.” *Male patient.*
“As my friend said, a psychologist would be better, because this illness can be explained to us, but it’s difficult to understand, it’s very difficult to understand this disease.” *Female patient.*

Another problem that frequently emerged as a physical opportunity barrier was the cost of insulin and the difficulty in storing it.

“For me, the difficulties I’ve had have been with insulin because the prices of insulin in pharmacies vary, there are other pharmacies that sell 600 meticaïs [~9.5\$], others 500 meticaïs [~8\$], and I think I’ve had these difficulties so far.” *Female patient.*

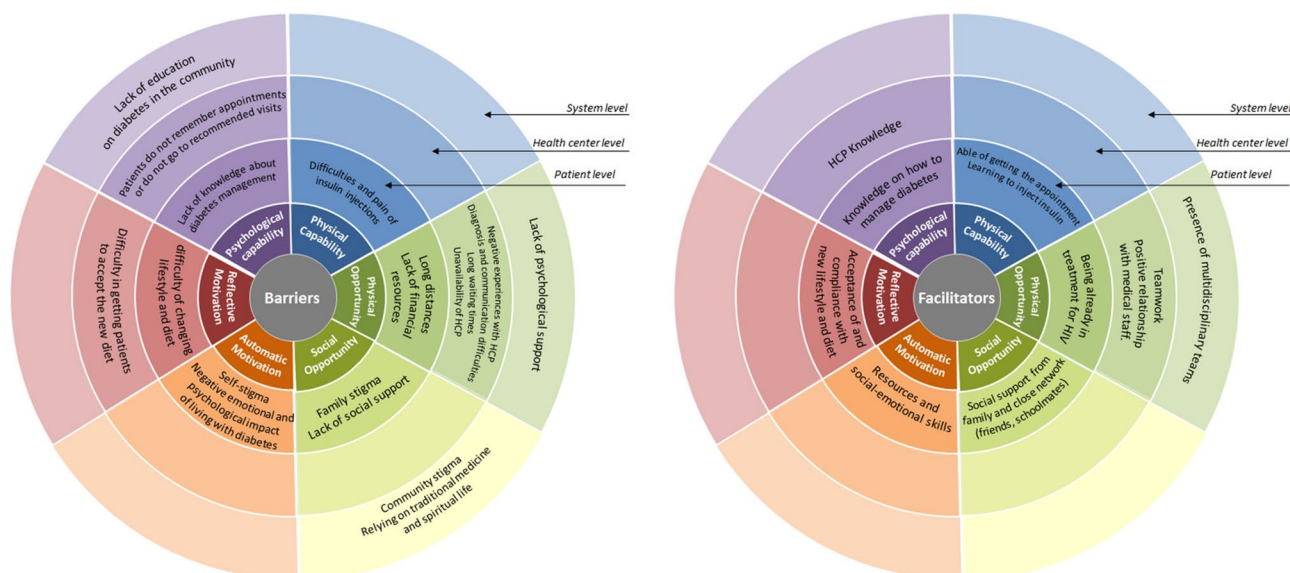


Fig. 3 Diagram of the main topics emerged from the content analysis of the focus group discussions and key informant interviews (September–October 2023, Sofala and Zambezia provinces, Mozambique) stratified according to the six sub-areas of the Capability, Opportunity, Motivation and Behaviour (COM-B) framework and based on the three levels (patient, health centre, system)

"It's the costs, this is an expensive disease, I can tell you, very expensive for food, because [...] now we have to look for a diet according to her situation, and food for a diabetic is very expensive, not to mention the medication itself, so that's what has changed a lot in our lives." Male caregiver.

"The cost of buying insulin and food is difficult, everything related to diabetes is expensive, the device is expensive, the strips are expensive and if you don't give them to us, it's a strain on our budget. I think that everything related to diabetes should be more accessible, I don't blame those who sell it, the private pharmacies, but perhaps the government, the health insurance scheme, should support it in some way because it's difficult. It's a disease that takes a toll on us psychologically, emotionally, and financially too." Female caregiver.

Physical opportunity was also found among the major barriers in the FGDs of HCWs. It was mostly related to the fact that patients lived far away from health care facilities, the lack of staff and the resulting excessive number of patients that a single doctor had to attend to, and the shortage of medication and equipment.

"Because of the difficulties we have in terms of the number of patients with diabetes being followed up here, they often turn up once a month. Patients live far away from the health centre, so weekly is not acceptable to them, they prefer to come once a month and take their medication with them." Medical doctor.

"I have seen how scarce the availability of insulin is in our hospitals [...], we can have it for about six months, then after a while it disappears, we can go three months without insulin, this is hurtful because there are families who cannot afford it, I cannot guarantee good availability, the availability is very scarce." Nutritionist.

Physical opportunity when labelled as a facilitator referred mainly to positive episodes of relationship with medical staff. When it was labelled as a facilitator by the HCWs, it was linked to the fact that a multidisciplinary team was active in taking care of the diabetic patient.

"I used to be one of those people who stayed at home a lot and when I had the slightest symptom I used to run to the emergency room, but lately the doctors became my friends because they knew me, they said 'you're playing with diabetes' and asked me why I didn't take insulin and I didn't know what insulin was or how to take it and one day one of the doctors tried to teach me and the doctor when she came home taught me how to take insulin and how to apply it and now that I apply it so I don't go to the emergency room anymore." Male patient.

"It means that the patient is cared for in a multidisciplinary way because everyone plays their part, we work with the emotional part, others with the medical part and still others with the nutritional part." Psychologist.

Social opportunity accounts for 13.4% of all themes labelled as barriers and is mainly related to the stigma for this disease and the fact that many people in the community still rely on and recommend traditional medicine to treat diabetes. Social opportunity as a barrier was most frequently mentioned in caregivers' FGDs. ($p=0.034$). HCWs also reported stigma and reliance on traditional medicine as a barrier, classified within the social opportunity.

"So, I had those friends who laughed, they said 'diabetes is a very bad disease, if you reach at least 30, then you can die,' so when they said that it scared me, so I decided not to tell them, just to keep it a secret." Male patient.

"She starts to have a stigma problem, starts to think that she is judged and devalued and often does not go to school because of this." Male caregiver.

"They took me to a pastor's house to say a prayer and then they took me to hospital and I remember that I heard an argument between my parents and my grandparents who said that this could be the work of spirit hands and that my grandparents wanted to take me to the traditional healer and my parents didn't want them to and my grandparents claimed that it was the work of evil spirits and that it wasn't normal because we're giving them all kinds of medicines." Female patient.

"But in my husband's family they say that the child isn't diabetic, and when I medicate him in front of them, they don't like it, they say we're harming the child, that medicine isn't good, in my husband's family they started giving him traditional medication, with that traditional measurement the child started to have problems" Female caregiver.

Social opportunity was the main facilitator identified in the content analysis of the FGDs. The principal support in this area was provided by the family, which is seen as the main source of emotional, psychological but also practical support in remembering visits, managing the new nutritional plan and insulin therapy. Another important source of social support came from friends and the school environment, where it was important for patients to share their condition as diabetics, making teachers and classmates better understand this disease and receiving support in their daily management.

"My family always wants to see me well, they tell me 'Now you have to watch what you eat and what you don't eat, this has to decrease a little and this has to increase,' the family is always paying attention, the relationship has changed a lot, now they're more concerned, more focused on me." Male patient.

"In my family my father is very worried about me, sometimes he calls me because at school I have physical education I stay late at school and I don't usually have a snack, I stay late until 4pm, he gets worried and calls me and asks if I have a snack [...], sometimes my friend asks me if you have a snack, I say no, she's going to buy me an apple and come and give it to me." Female patient.

"As for my friends, I have already told them that I have diabetes, and they always advise me and help me not to eat sweets. My teacher also studied diabetes, he shared the information with my classmates because they had many questions about diabetes, the most common were about nutrition, my lifestyle, my biology teacher clarified the doubts, and they were satisfied." Male patient.

Motivation

Reflective was the most frequently retrieved type of motivation (Table 1). It was similarly rated as a facilitator and a barrier. It mainly referred to the difficulty of changing lifestyle and nutrition, as a barrier, and acceptance of and compliance with this change, as a facilitator. In the FGDs of caregivers it resulted more often as a barrier than in patients' ones ($p=0.013$, Fig. 4). In fact, they also highlighted the twofold difficulty of accepting the new lifestyle combined with the challenging moment of adolescence.

"Something has changed in her behaviour, now she is a bit moody and then she is also in her adolescence years, so these things go together, so it is a bit complicated. Sometimes she gets a little aggressive, sometimes she's very sad because she feels offended by something people have done or said and she closes in on herself. It happened last night that she was in her room, lying down, but she was crying, because she had high blood sugar and we talked to her about the fact that she must have hidden food at school, and she had to tell the truth. One thing we noticed in her behaviour is that she has become a liar, she lies about things she shouldn't eat, she insists on denying it, but then later she ends up confessing." Female caregiver.

"I still deny it to this day, I still haven't got used to it, I was born well, when they told me I was diabetic I didn't believe it" Male patient.

"I still haven't got used to it, because I wake up and think it's over and that it was just a one-time case. The medicine part and so on and I felt really bad about it, and I still haven't got 100% used to it, I still think there are a lot of things going on in my head." Female patient.

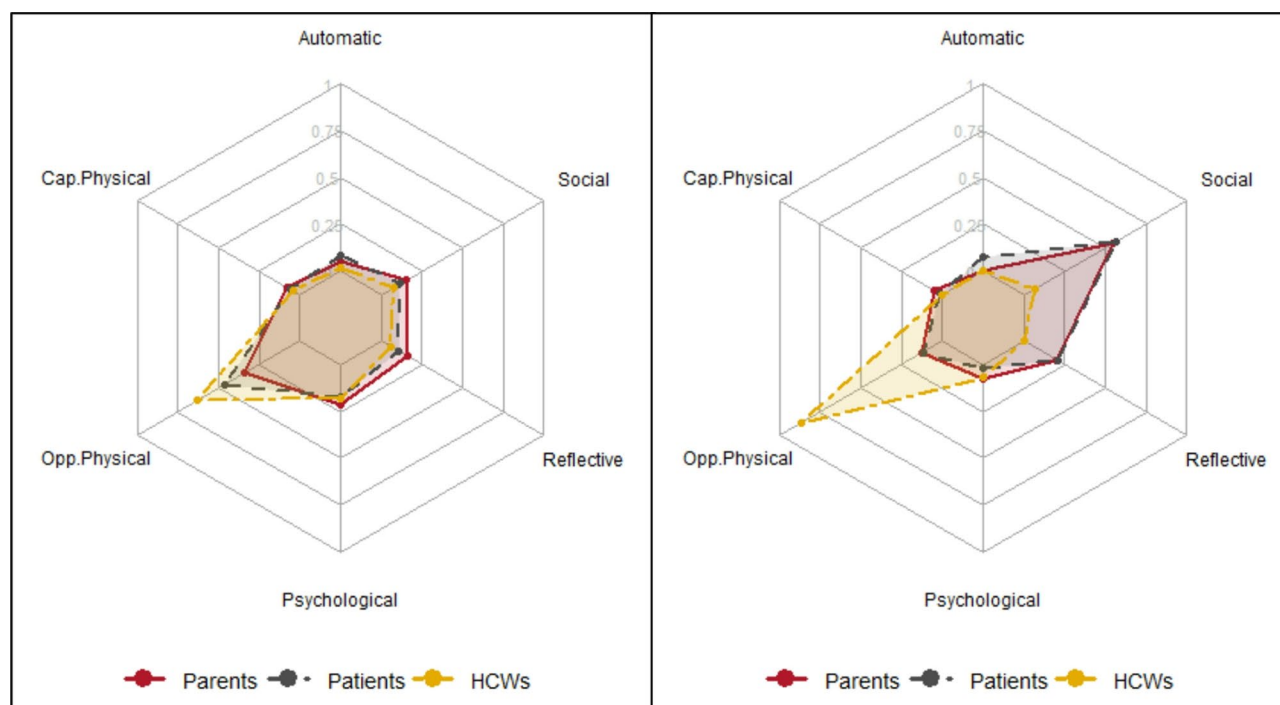


Fig. 4 Barriers (left panel) and Facilitators (right panel) retrieved in the focus group discussions and key informant interviews (September–October 2023, Sofala and Zambezia provinces, Mozambique) classified based on the six subareas of the Capability, Opportunity, Motivation and Behaviour (COM-B) framework and distinguished by type of participant. HCW=health care worker

The HCWs also recognised the difficulty in changing life-style and especially diet, which was classified as a barrier within the Motivation reflective.

“We wonder if the patient has been following the disease at home. The problem isn’t the disease, it’s the person’s awareness that they shouldn’t be eating those things, the nutritional guidelines.” Nurse. Regarding Automatic motivation, it was identified as a barrier related to self-stigma and the negative emotional and psychological impact of living with diabetes on children and young people.

Regarding Automatic motivation, it was identified as a barrier related to self-stigma and the negative emotional and psychological impact of living with diabetes on children and young people.

“I didn’t tell anyone that I was diabetic, I felt ashamed, it was ashaming to say that I can’t eat this.” Female patient.

“I was very sad, and I didn’t talk to anyone, I felt very lonely, my mother sometimes asked me things and I didn’t answer, neither did my father, I isolated myself.” Female patient.

Capability

Psychological capability was the main barrier identified in the FGDs together with physical opportunity. It was related to the lack of knowledge about diabetes in the community and its management by the patient. Participants reported how people do not know what diabetes is and what it means as a chronic disease. They pointed out that for many in the community it could not be a children’s disease, but it is linked to being rich or exclusively to eat too much sugar.

“The reaction is clearly panic because the sentence the world passes on a diabetic is serious. It’s even comparable to a visible death.” Male caregiver.

“At my age, when I tell people that I’m diabetic, some people don’t believe me, they say that at our age you weren’t supposed to have diabetes, apart from age, they also say that it’s a disease of white people and that nowadays things are changing, that’s why people don’t believe me.” Male patient.

“For our community, they think diabetes is a disease of rich people, that’s what they call it, the community marvels when people our age have this disease.” Female patient.

The psychological capability in KIIs with HCWs was mainly seen as a barrier related to the diabetes community’s poor knowledge. It was also linked to the fact that

patients do not remember appointments or do not go to recommended visits with other specialists (e.g. ophthalmologist) because they do not feel sick at the moment. They also showed a distrust towards treatment with the medication given in hospital.

“Follow-up through home visits, telephone communication and awareness-raising in the communities, so that the community knows that this disease exists, because often people discover it after they have had a disease or complication and then treatment gets more difficult.” Medical doctor.

Physical capability was mainly referred to the difficulties and pain of insulin injections.

“When I apply the insulin there are times when I get lazy and end up not calculating the time exactly and that’s been one of the difficulties I often have, maybe also because of my job and the fact that I also sell things on the street, so there are times when I have to apply the insulin on the street, so it’s a bit complicated when I’m there in the shop.” Male patient.

“The pricking part, I never get over it, I always cry when I get pricked, I always cry. I feel a lot of pain in my arms, so mum adopted another system, but my belly started to hurt too, so we told the doctor, the doctor said to change, now we prick my leg, my bum, everywhere but not my belly.” Female patient.

Discussion

This study investigated the main barriers and facilitators to the access to care for children and adolescents suffering from DM type 1 in the Sofala and Zambezia Regions in Mozambique. The FGDs identified more barriers than facilitators, showing how access to healthcare services and medication for young adults and children with T1DM is often complex. The COM-B subarea physical opportunity emerged as the main barrier referring to negative experiences with health care personnel and the system. Community stigma and the difficulties with self-acceptance were also found as factors that can hinder diagnosis and treatment. Interestingly, the caregiver most often found the subarea motivation reflective as a barrier, referring to the double burden of being an adolescent and changing lifestyle due to the diagnosis of diabetes, both factors that can have a negative impact on access to care.

Even though bigger or smaller issues characterised each domain of the framework, the most critical areas were those of psychological capability and physical opportunity. A frequently raised concern, reported by both patients and caregivers, is the difficulty to accept the illness, worsened by the lack of professional mental

health support. Indeed, the aforementioned interviewees often brought up the need for a psychologist to assist children and families during the diagnosis and treatment path. Literature confirms how psychological support with a multicomponent motivational intervention in T1DM vulnerable patients, as children and adolescents are, can contribute to the better management of the disease [24, 25]. People with diabetes that succeed in adopting self-care behaviours, i.e. the belief in one’s capacity to organise and execute the courses of action required to manage a prospective situation [26], showed better glycaemic control and reported higher quality of life [27, 28]. Psychologists, social workers, and other mental health professionals can play a key role in fostering resilience in individuals with diabetes by addressing both psychosocial issues and challenges related to adapting to a chronic condition. Research has shown that people with diabetes are more likely to experience depression, anxiety, and eating disorders, which can hinder their ability to manage diabetes effectively and maintain their blood sugar levels within target ranges. Seeking help from mental health professionals to prevent or address these psychological challenges can enhance both quality of life and engagement in treatment plans. Additionally, mental health professionals can support patients by teaching coping techniques, self-management strategies, fostering positive family dynamics, guiding social skills to seek support, and applying behavioural strategies to help achieve self-management goals [29].

Psychological capability was one of the main barriers retrieved. Interviews or brief motivational counselling with patients could enable them to learn more about the disease and its associated risks [30]. Together with psychological support, education and in particular health literacy can contribute to lifting the stigma and elevating self-control ability to comply with the strict management of meals and daily activities. A higher health literacy is associated with better glycaemic control in adult patients with T1DM [31]. Better health literacy of parents, caregivers and members of the community could also be helpful to adopt evidence-based therapies instead of trusting in traditional healers, and to reduce the stigma of the community against sick children. However, health literacy is influenced, among other factors, by socioeconomic status and education [32, 33], which are usually low in Mozambique, one of the poorest countries in Africa [34].

The other main barrier was the inadequacy of the healthcare service in taking charge of the patients: the diagnosis were often incorrect or delayed, the waiting times for a blood sample or an outpatient visit were too long, especially for fasting patients, and forced the children and their caregivers to long waits, or to have their

visits repeatedly rescheduled for the absence of the healthcare professional.

The incidence of both diabetes type 1 and 2 are increasing in Mozambique, which is experiencing an epidemiological shift from communicable to non-communicable diseases [4]; besides, diabetes in Africa is almost certainly still severely underdiagnosed [35]. Therefore, healthcare staff should be trained to recognise the early signs and symptoms of type 1 diabetes: many patients in the FGDs complained of long delays to come to a correct diagnosis, losing time, energy and money. As reported in the literature, strategies for early recognitions of scarce glycaemic control are feasible in Mozambique [36]. However, the Country suffers from chronic lack of healthcare staff hampering health coverage and the quality and comprehensiveness of the service offered [37]. In addition, for most of the Mozambican population, the nearest health center is often more than an hour's walk away, thus increasing the time, energy and money needed to access healthcare services [38]. However, the Ministry of Health in Mozambique recognizes NCDs as increasingly common conditions in the country and has since developed a strategic plan regarding these illnesses, including diabetes. The NCDs program has embarked on several interventions for the prevention and early detection of NCDs. These include the development of treatment protocols, clinical nutrition and dietary guidelines, training of health workers in the management of NCDs, and raising awareness levels of NCDs among others [39].

The main facilitator was by far social opportunity, especially in the form of the support given by family and friends in accepting the illness, reassuring and taking care of the patient, and managing everyday difficulties. Social support has a recognised role in chronic diseases and in diabetes, especially, on dietary behaviours [40]; families are usually involved in the responsibility for the adoption of regimen requirements, affecting family routines and habits [41]. Many caregivers highlighted the impact of buying insulin and special food on family finances, but also the impact of the diagnosis on the psychological wellbeing of the children, with backlashes on the family harmony and wellbeing. Parents' support is of recognised importance for children with T1DM, also because for many of them the diagnosis came together with the beginning of adolescence, resulting in a sum of personal changes [42]. Parents and caregivers reported often to feel worried and frustrated by the behaviour of their children, which, they felt, changed their personality. Without a support network that helps parents to share the weight of the caregiving, it is very hard for the families to cope with the situation. Pate T and colleagues has shown how a parents group support can help the parents to express their concerns, to give support to one another and, especially, to recognise, accept and regulate their

children's physical and psychological changes and needs [43]. Community-based interventions aiming to build social awareness and cohesion in communities such as those in Mozambique would be a strong asset, not just around the topic of T1DM [44]. Similarly, improving an integrated model for T1DM management would be pivotal [45].

No differences emerge between the two provinces, meaning that the problems are structural rather than context-specific, in terms of both preparedness and organisation of the healthcare services, and cultural beliefs and perceptions. This could be positive, since the strategies to solve the existing problems could be the same and more easily replicable, but also negative, highlighting widespread weaknesses in the healthcare sector and in terms of health literacy.

This study has some limitations. First, the deductive approach may have hidden the arising of new themes that would instead have been captured using an inductive approach. Secondly, qualitative analyses could be affected by a certain subjectivity by the researchers involved, the so-called reflexivity bias. However, the use of the COM-B framework, a widely used tool for analysing access in health care settings, and that codes were simultaneously identified by two researchers mitigates subjectivity and lends robustness to the results. Moreover, focus groups and interviews have inherent limitations, such as the tendency among participants to let certain types of socially acceptable opinions prevail (social desirability bias) and for some to dominate the debate that could bias the results. Lastly, the participants were selected at the outpatient departments, thus leading to a possible selection bias of those who already had a first access to health services.

Despite these limitations, to our knowledge this is one of the few studies investigating the acceptance and access to care of children and adolescents with T1DM in Mozambique. This study could provide a useful insight for NGOs and local healthcare providers to identify the key aspects and the main problems perceived by patients to develop projects and interventions and ultimately to improve the quality of life of young patients living with diabetes. Future interventions should attempt to focus on the identified barriers and should be set in an implementation research framework that can provide evidence of the effectiveness of such interventions. In particular, they should work on training health personnel and increasing resources in terms of staff numbers, drug availability and facilities.

Conclusions

The main barriers to accessing NCD services for T1DM in the present study were related to physical opportunity and psychological capability. The latter includes

the difficulty of accepting the disease and the change in lifestyle, often coupled with the challenging time of adolescence. The other main barriers related to the unpreparedness of health services in terms of personnel, infrastructure and training on T1DM. In contrast, the main facilitators were related to social support from peers and family. Studying context-specific and culturally oriented factors that can promote access to health services are fundamental to achieve the Sustainable Development Goals (SDG) particularly in the context of a disease such as T1DM that is linked with SDG 1 'No Poverty', SDG 10 'Reduced Inequalities', SDG 2 'Zero Hunger' and SDG 3 'Good Health and Well-being' [46].

Supplementary Information

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Supplementary Material 1

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Author contributions

In this work RB, EM, LR and LN conceptualised and designed the study and made substantial contributions to original writing. RB was responsible for the data analysis. RB and EM contributed to qualitative data analysis. CMA, TM, AM, AM, EB and EM contributed to data collection and record transcription. VT and GP supervised the study phases. LC and GP reviewed the study and contributed to data interpretation. All authors reviewed the study critically.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This study was performed following the ethical standards of the 1964 Declaration of Helsinki and was approved by the Institutional Bioethics Committee for Health (CIBS # 8 Zambezia province) on October 20th, 2023 (protocol number Reference 222/CIBS/23). Written informed consent was provided by all the participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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