To the Editor,

BMC Endocrine Disorder

Dear Editor,

Re: MS 5331777761450528 Living with type 1 diabetes is challenging for Zambian adolescents: qualitative data on stress, coping with stress and quality of care and life

We are very thankful for the thoughtful comments on the previous version of our manuscript and the opportunity to re-submit our manuscript to your esteemed journal.

Below are revisions made to the manuscript as per reviewers’ comments.

Referee 1: Katherine Barnard

How many people were approached to get the full number of 22 i.e. how many people refused to participate

Authors’ response. In total 25 people were approached to participate in the study. Out of the 25 targeted, three declined to participate i.e. 2 women (1 adolescent
and 1 guardian) and 1 male guardian declined. We added this missing information to the text in line 141-143.

Were the semi-structured interviews piloted on potential participants prior to use?

Author’s response: Semi-structured interviews were not piloted but they were discussed with health practitioners under the diabetes association for content-related validity (expert validity) before data was collected. We added this to the text in line 151-161.

Were people with diabetes involved in designing the semi structured interviews?

Authors’ response: patients with diabetes were not involved in designing the interview questions. We have been involved in more studies involving T1D patients in the area, which informed our choice of questions. No text changed.

Data analysis – repletion about transcription with paragraphs above. Could delete this sentence.

Authors’ response: We are not sure to which sentence this comment refers.

Results: it would be helpful to report how many adolescents reported data relevant to themes e.g. stressors – how many participants experienced discrimination etc? How many felt they lacked family support? I appreciate this is a qualitative study however it would be helpful to know a bit more detail.

Authors’ response: we have added the number and percentage of participants that mentioned each main theme.

Reviewer 2: R.A.C. Ruiter

Just a few lines that I believe the paper discusses an important large parts of the introduction, methods and discussion section are well written. However, the abstract and results section need to be rewritten to provide structure to the reader. A focus on the abstract only.

Author’s response: the results in the abstract have been made more coherent by deleting the last sentence and add it just after the sentence in line 44.

Does the paper intend to find out the sources of stress and also coping strategies, stigma and QoL; or are the three considered source of stress? I guess the sources of all four are investigated.

Authors’ response: the study intended to find sources of stress, stress coping
strategies that adolescents employed to cope with stress, stigma they experienced as a result of having diabetes and their perceived quality of life and care. The study objectives are specified at the end of the introduction.

How is stressed defined; what are indices of stress in diabetes and the target population?

Authors’ response: in line 72 we now defined the concept “Stress is a physiological or a psychological response to external stimuli or stressful events themselves which can be negative or positive or both.” We also added indices of stress in line 73 which we feel may also apply to the target population “Common signs of stress in patients include changes in sleep patterns, changes in appetites, anxious thoughts, and irritability”

Does poor nutrition affect quality of health care?

Author’s response: What affects quality of health care is diet and not poor nutrition, although poor nutrition is also common due to high poverty levels. Diet intake of calories or carbohydrates for example can affect glucose levels and lead to dangerous hypoglycaemia or hyperglycemia. We have since changed and reflected this change in lines 45 and 314.

Findings discussed in the discussion are not in the results section

Authors’ response: Thank you for the comment. We were not sure which results were meant here. In any case, we checked for such results to ensure that the new version does not present new findings in the Discussion.

Overall, more structure is need. Figure 1 is helpful in this respect but does it list many more factors than explored? Still the results section can be more structured, maybe more in line with the figure.

Authors’ response: Referral problems and lack of skilled manpower were some of the factors that were in the results and did not appear in the figure. To bring more structure which are in line with the figure, we have made sure results were discussed in line with the main themes and under headings which reflect the main theme under discussion. The figure also reflects main themes and their sub-themes presented in the results section. See lines 182-186, 224, 290-291, 312-326 and on page 28 two sub-themes have been added to the changes we have implemented

Reviewer 3: Cephas Sialubanje

Introduction section
Line 74. The authors state correctly that the date in Africa is still scarce on the subject. However, I guess they still need to provide a brief “global” description of the problem from the available literature (from WHO?) on the prevalence of stress among the diabetic patients (preferably among the adolescents) so as to give the reader an idea of the magnitude of the problem, justifying the need for research.

Author’s response: Point well taken, we have added literature that may help show the magnitude of the problem and justify the need for research in lines 77-88 and 91-95 “Stressful experiences influence diabetes control not only because of the devastating effect on poor blood glucose control but also the association between high blood glucose levels and the development of diabetes related complications [5, 8]. For example, in prospective studies involving individuals with type 1 diabetes, patients who reported negative stress showed deteriorating glycemic control over time [9]. In addition to the physiological influence that stress has on glycemia, stress interferes with the ability to self-manage diabetes such as monitoring glucose frequently, following a meal plan and correctly preparing or remembering to take insulin or oral medication at the right time [5]. In adolescents with Type 1 diabetes specifically, research shows that stress stems from the need to manage a complex medical condition that requires daily completion of multiple self-care behaviors, the impact of diabetes on social interactions with family members, peers and teachers as well as the interference of symptoms such as hypoglycemia with daily activities [10].

Lines 91-95 “The few African studies that have been conducted suggest that there is link between stress and development of diabetes. In Kenya for example, patients linked diabetes to stress caused by disharmony, and conflicts within the family and strong emotions due to shock [12]. In South Africa, children with diabetes were found to have experienced more frequent stressful events compared to control children [13].

Objectives

Line 85 before the authors ask on the sources of stress, they need to include a question on the perspectives/lived experiences regarding diabetes. This will be in line with their research question which explores experiences, challenges…

Authors' response: we used the statement “lived experiences” refer to the experiences adolescents go through because of stress, challenges with diabetes care and poor quality of live. We have corrected this statement in line 107-108 and it now read “Given the above background, in the present study we explored sources of stress, ways of coping with stress, perceived quality of care and life as experienced by Zambian adolescents living with type 1 diabetes (T1D)…” if we added a theme “lived experiences”, we would be fishing for themes which may need to be analysed using a phenomenological approach and our study did not
employ this approach.

Results

Line 160 the theme “stressors” describe both the lived experience regarding diabetes, types of stress and its causes, as perceived by adolescents, caregivers and the service providers. So far, the authors are salient on the lived experiences of the adolescents. They could consider splitting the theme into two so that it highlights both aspects; it will be easier to read and will be in line with the research question. For example, one part may be on lived experiences while another on stressors and their causes. Most of the information is there in the text, but it will need to be edited accordingly.

Authors’ response: consistent with the response above, the term “lived experiences” was used as an umbrella term to cover stress, in patients, challenges with diabetes care and quality of life. It was therefore, not meant to be a theme. We have edited it in line 107-108.

Line 236 the authors only reported on what health workers and peer educators said about the quality of care; they are silent on how the adolescents and caregivers perceive these services. They need to be consistent with their research question (introduction line 87) which focuses on perceived quality of health care which should be reported both from users and providers’ point of view

Authors’ response: in lines 312—326 we have added the views of the adolescents and caregiver. “Specifically, adolescents and caregivers reported lack of nearby health facilities, expensive and sometimes inaccessible insulin, challenges handling medicine and following a recommended diet as some of the factors that were affecting quality of care. Others included poverty. Many patients bemoaned lack of money to buy food when they had an appointment at the hospital and they had to wait for a while before they could be attended;

The biggest is distance and transport- you see we all have to come here (UTH) because in clinics they don’t do reviews. So we all have to come here for reviews and some come very far and transport is very expensive. But also transport money and money for food. Especially if I am here and I am hungry I need money to buy the food I was told to be eating but I cannot get money here. Grade 8 male

The medicine that we receive requires that we keep it in the fridge but when I am at the farm I don’t know how I can handle this medication. Female aged 36

Line 341 to 343. The authors state an important point that “only the patients in the urban bigger hospitals are given free syringes whenever available, whereas
patients in rural areas still need to buy syringes. There is a seeming contradiction because in the results section they only state that lack of commodities... make some patients stay for days without insulin (line 249-250). Secondly, this is a qualitative study conducted at an urban tertiary hospital; it did not collect data from the rural areas. Let the authors clarify this point.

Author’s response: we indeed mentioned that “only patients in urban bigger hospitals are given free syringes whenever available”, this statement was meant to say it’s not always that syringes are available. Because it does not come out very clearly we have added to that sentence in line 414 the following sentence “because sometimes the hospitals do run out of these commodities”. For the second part of the reviewer’s comments, we have added “city” to the sentence in line 124 to make it clear that the main referral hospital data was collected from in Lusaka was in a city and not rural area.

Limitations of the study

The major weakness of the study is that the study limitations are not acknowledged. For example, the first author collected the data, wrote field notes, and analysed the data, and probably wrote the manuscript. Let the authors explain how the first author managed to carry out all the task; the potential bias introduced in the study need to be discussed. Secondly, in line 209 to 212, the authors state that adolescents experienced stigmatisation from peers and society… and that social stigmatisation was common during play with peers. Much as this finding is important, the authors need to admit that this “story” is not balanced as they did not get the views from the peers accused of perpetuating the stigma, this should be discussed as a limitation.

Authors’ responses: first this study was part of a PhD project, and as with many PhD studies, the first author collected data, conducted initial data analysis and developed the first draft. However, there was discussion and quality control through member check to insure content validity. In line 177 we have added that emergent themes were discussed and refined by G.H and A.A. As such, we do not think that this is sufficient to make it a study limitation. We have added study limitations on line 478-83 “This study had some limitations. To begin with, although the qualitative design enabled us to examine detailed experiences of the subjects in the study and to discover themes as well as their subjective views of the experience living with diabetes, we cannot provide quantitative figures to underscore our findings, nor can we claim representativeness of our findings. Secondly we were unable to collect information from healthy peers to confirm social stigmatization reported by our adolescents.

Minor essential revisions

Abstract.

Under the results section, the ideas are a bit missed up not following smoothly.
Consider editing so that the last sentence on line 41... poor nutrition, low SES... quality of care” come at the end of the sentence on line 44 before conclusion.

Authors’ response: we have edited the section accordingly from line 40-46 which now reads “Stress was commonly reported by adolescents mainly stemming from social, psychological and physical sources. To deal with stress, adolescents often employed different coping strategies such as adapting, accepting and avoiding among others. Both internal factors (those relating to the patients themselves) and external factors (those related to the context of the patients’) influenced the patients’ quality of life. In addition to stress, low quality of life was an issue among adolescents and their families. Poor diet, low socioeconomic status and lack of medicine were factors affecting quality of health care”.

Introduction

Line 65… the sentence....” Frequent monitoring glucose” should be edited to read “frequent glucose monitoring”...

Authors’ response: We have changed that as reflected in line 69.

Line 70… the word “show” should read “shows”

Author response: we have changed that in line 89

Line 79… you can use the word glucometer instead of “glucose meter”

Authors’ response: we have changed to the suggested word in line 105

Research questions and objectives.

The research question is very clear, but there is need to bring the objectives in line with the objectives. For example on line 85, before the question on source of stress, the authors need to include a question on lived experience and perceptions on stress. This will be in line with the research question which explores experiences, challenges...

Authors’ response: the research question has been revised and the word “experiences” just after the word “life” and now reads “the present study we explored sources of stress, ways of coping with stress, perceived quality of care and life as experienced by Zambian adolescents…” as reflected in line 107 -109.

Line 113. Delete the words “the study benefited from including…”instead, the sentence should read “the health care practitioners were included because they…”
Authors’ response: in line 140 we have changed the text accordingly.

Line 130: should read… “Guiding questions focused on experiences, challenges, perceived quality of care and life…” so that it is in line with the research question in the introduction section (line 81-84).

Authors’ response: like we have mentioned above, because we do not have data to substantiate “experiences” we have deleted this statement.

Line 133. Include a subheading…” ethical approval/consideration.

Authors’ response: we have added the heading in line 164.

Line 146 should read “emergent themes were discussed and refined by”.

Authors’ response: we have added G.H and A.A in line 177

Line 150. The sentence… “The study explored…. Should be consistent with the research question in introduction line 81-84 which focuses on experiences and challenges.

Authors’ response: in accordance with the earlier argument we have edited the terms “experiences and challenges”. And now reads “The study explored, stressors, stress coping strategies, diabetes care, stigma and quality of life as experienced by adolescents…”

Line 175… should read “wondered why they had to do…” the word “they” is missing.

Authors’ response: we have added the word “they” in line 210.

Line 183… the sentence “especially among the boys”. The word “the” is missing. Also line 184 the word “the” is missing before female.

Authors’ response: line 217 and 218 we have added the word “the”

Line 199 the word “hypos” should be written in full or better still should be deleted and a more appropriate word such as “severely low blood sugar levels” should be used

Authors’ response: line 236 we have deleted hypo and added severely low blood
sugar levels”

Line 202 delete the word diabetes. The sentence should read “managing their diabetes sugar levels...”

Authors; response. Line 239 we have deleted the word ‘diabetes”

Line 203 you could use a more socially acceptable word, probably “probably having infections in their private parts” rather than sexual organs.

Authors’ response: line 240 we have decided to maintain the word sexual organs and not replaced with “private parts” as suggested by the reviewer because the term private part is ambiguous and what is private varies from culture to culture and may include exposing the following hair, legs, lips etc. were as the term sexual organs is more specific and qualifies for what we are discussing in the manuscripts.

Line 269 the sentence “diabetes was regarded as being associated with a shorter life expectancy due to poor health care system…” may need to be edited to read due to various factors including poor health care systems, socio economic circumstances, cultural factors…” this will present a more comprehensive picture of the factors affecting the adolescent’s quality of life.

Authors’ response: in this sentence we were arguing for factors associated with short life expectancy and not necessarily QoL as such, we have amended the sentence to include socioeconomic circumstances but not cultural factors because we did not have data to support this claim but also we are not aware of cultural factors that may affect quality of life in diabetes patients. This is reflected in line 329-330.

Line 299 probably repeat the research question as presented in the introduction line 81 to 85 i.e. “explore experiences, challenges, perceived quality of care and life of Zambian adolescents living with type diabetes.

Authors’ response: as alluded to above, we have no data on experiences and as such we have deleted the words “experiences and challenges which were used to mean “stress, and challenges with diabetes care experiences of adolescents.

Line 301 to convey a better meaning, this sentence could read “this is the first qualitative study in Zambia to explore this subject, providing views from all three stakeholders.

Authors’ response: we have corrected this in line 366-367.
Line 304 to 305. There is repetition, delete the word “sources” at the end of the sentences.

Authors’ response: we have deleted source in line 373.

Line 307. Should read “advice” and not “advise”

Authors’ response: we have changed to “advice” line 375.

Line 314: delete the word “adequate”

Authors’ response: we have deleted “adequate” in line 379

Line 315: add the word “also” so that the sentence reads “…in the process of not only adapting to the situation but also help…”

Authors’ response: we have added the word “also” line 384

Line 334. The authors state that adolescents must be taught skills that are more adaptive. Let them briefly explain the adaptive strategies.

Authors’ response: we have added examples of adaptive strategies in line 404-406 “such as improving self-care skills and healthy lifestyles coupled with positively interpreting their situations, doing something about the source of stress and accepting their health circumstances”

Line 336. Briefly describe the main findings or recommendations of this study to help the reader

Authors’ response: A summary of findings and recommendation were added in the conclusion section.

Line 358 “diabetes health care” is quite broad. Let the authors clarify to the reader what they mean. Do they mean effect of the strategic plan on the quality of care for diabetes patients? Or is it the commodity availability for diabetic patients? Or indeed skills levels for diabetes healthcare providers?

Authors’ response: we have clarified this concern in line 432-33 by adding the sentence “especially commodity availability for patients, and needed health care providers and skills”.

Line 363 include the word “among”… so that the sentence should read “especially among the girls”.
Authors’ response: we have added the word “among” in line 438.

Line 400 to 401. The sentence is not correctly constructed; needs to be corrected. Probably, it should read…”stress and stigmatization, poor health care, and advice by family and friends”.

Authors’ response: we have corrected this sentence in line 485-86 to read “stress and stigmatization, poor health care and wrong advice by family and friend…”

Line 409 to 410 should read… “Face the challenges of improving health care delivery to patients with TID who also face high poverty levels”.

Authors’ response: we have added “of improving” line 494 and “who also face” line 495 to make it read as above.

Line 410. The abbreviation CSII is appearing here for the first time. Write it in full before using abbreviations.

Authors’ response: we have written it in full in line 496 “Continuous Subcutaneous Insulin Infusion”

Thank you very much,

Given Hapunda