Reviewer's report

Title: What's distressing about having Type 1 diabetes? A qualitative study of young adults' and healthcare professionals' perspectives

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Reviewer: Jane Speight

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This study quantitatively explores causes of distress amongst young adults with type 1 diabetes (aged 23-30). Themes arising from this study include self-presentation issues, day-to-day diabetes management concerns, struggles in dealing with the healthcare system, and concerns about the future (including pregnancy). Distress was reportedly managed through psychological coping techniques, and reliance on social and familial support networks.

Little research has explored the psychosocial aspects of living with type 1 diabetes specifically within this age group and we know even less about the experience of diabetes-related distress amongst this group. The publication of this qualitative study would add considerably to this field. However, it is suggested that the authors pay careful attention to the write-up of this study in order to adequately and appropriately showcase this important study. Five major concerns to be addressed are below, followed by a list of minor edits.

Major Compulsory Revisions:

1. Introduction: The introduction and rationale of this study could be improved considerably through providing a detailed review of the concept of diabetes-related distress and the research into this area to date, as well as providing a rationale for the aim of the study and the chosen sample. While this would lengthen the introduction, much of what is currently included could be made more concise. Specifically, include details regarding:
   a. How diabetes distress has been measured to date (e.g. PAID and DDS17) and whether diabetes distress has been measured (qualitatively or qualitatively) in this age group.
   b. Findings regarding associations between diabetes-related distress and age in type 1 diabetes.
   c. What components of distress might be applicable to this age group and why further research is needed to explore this qualitatively
   d. Introduce the 'second phase of emerging adulthood' and what is unique about this life stage and its potential impact on living with type 1 diabetes. The information currently provided does not provide a sufficient rationale for the studies focus. E.g. why not explore aged 18-23? Or 18-30?
   e. If the results from the healthcare professionals are to be included in this manuscript than a rationale for this needs to be provided within the introduction.
2. Methods: Further details need to be included here and this section would benefit substantially from the authors use of a qualitative study evaluation checklist as a prompt to ensure all necessary elements of methods are included. The following areas should be addressed:

a. Who facilitated the interviews? E.g. how many facilitators, what is the position of the facilitators? Were they known to participants? Is it expected that the facilitators would have any impact on the information reported by the young adults?

b. What was the setting of the interviews?

c. How were the interview schedules developed? Was it informed by literature, pilot interviews, or expert opinion? Was the schedule altered/improved after initial interviews were undertaken? (if the health professional interviews are to be included, include that schedule as well as the patient schedule)

d. The timing/length of interviews appears to be too precise (1 hour). Is this timing on average? What was the minimum and maximum length of interviews?

e. Currently, there is very little information regarding the sample of healthcare professionals: why was this sample size was chosen, where were they were recruited from, need to provide their sample characteristics/demographics.

f. Further information should be provided on the type of qualitative analysis undertaken. It appears to be thematic analysis, if this is the case then say so.

g. It is stated that two authors coded the interviews, but no information is provide on inter-rater reliability or how discrepancies between the investigators were resolved.

3. Unbalanced sample: The sample used in this study is quite unbalanced and may be improved through removing unrepresentative subgroups. Authors suggest that the small number of men, clinic participants and healthcare professionals actually strengthens the study. This is not convincing, the study would benefit from removing these participants and have a very specific aim and sample relating to young women with type 1 diabetes. Otherwise, further recruitment is needed to target men to balance the sample. Furthermore, the sample of healthcare professionals is also inadequate. It might be better to increase this sample and report on these data in a secondary manuscript. Importantly, the authors should not refer to the overall sample (n=48) as adequate, as these are two different samples serving two different purposes.

4. Presence of author bias: In qualitative research, it is important to recognise the influence the authors/researchers may have on the study, e.g. what the participants were comfortable reporting, interpretation of the interview results. Within the results section, there appears to be a number of statements are made and it is not clear whether these are suggestions made by participants or the interpretations of the authors. The authors consider any bias they may hold in interpreting and writing up the results and consider taking a more neutral approach. For example: within the results section, use of the term “poorly controlled” indicates a bias coming through from the authors; and “These
interviewees were anxious because they knew that even if they did everything ‘right’…. Are we sure that that participants ‘knew’ this? Interpretations of results should be included as suggestions, not facts.

5. Discussion: The limitations of this study were inappropriate and the conclusions invalid. A number of suggestions are made in order to improve the discussion of this paper:

a. Limitation A: The author states earlier that the sample size is reasonable for the method used; as such the assertion that it is in fact small seems contradictory. Should instead specify that the healthcare professional sample is small and justify why it has been included regardless. However it is advised that it be removed.

b. Limitation B: The aim of the study was to quantitatively assess the causes of distress, so it is unclear why it would be a limitation that you have not quantitatively measured distress. This needs further explanation.

c. Limitation C: Asking healthcare professionals about distress experienced by males is not an appropriate attempt at addressing this weakness. Further, the suggestion that the lack of male participants is a finding in itself should be removed. It is suggested that lack of male participants reflects young men’s attitudes towards talking about distress. However, according to the method the study was not advertised as a study investigating distress.

d. Limitation D: The fact that the study sample may be a highly distressed one should not be a limitation of the study, as it set out to purposively sample those individuals who may be most distressed. Further, we cannot be sure that this group is indeed more likely to be highly distressed without any quantitative measure of distress. Is it possible that participants are simply more engaged, hence their use of diabetes social networks. Or their use of diabetes social networks could merely be an extension of more general use of social networks in this age group, with no implication for their level of distress or engagement.

e. It is suggested that a strength of this study is that interviews with health care professionals provide support that the findings within the young adults sample are applicable to wider clinical settings. Given the sample size of healthcare professionals, of which the demographics/characteristics are not provided, and that both healthcare professionals and the young adults reported that distress is rarely discussed in consultations I am unsure how this suggestion could be made.

f. The conclusion focuses on recommendations for alleviating distress rather than the conclusions of the study itself. In addition the 4th sentence reports on the relationship between distress and diabetes outcomes, which is entirely outside of the scope of this study. Conclusions need to be re-written to reflect the findings and implications of this particular study.

Minor Essential Revisions (Minor issues not for publication):

Overall:

1. The paper needs much more careful attention to grammatical and
typographical errors before resubmission.

2. There is frequent and unnecessary repetition throughout the paper, as well as lengthy description of concepts outside of the scope or interest of the study. Attention given to the repetition and unnecessary detail given throughout many paragraph could cut the word count down dramatically which would enable improved discussion of the topic and rationale within the introduction. Some examples include:

a. “Young adults with”, “in their twenties” or similar, sometimes twice in one sentence. It would read better to refer to participants or even ‘they’.

b. Under the Results, “Managing distress” subsection the first two paragraphs begin with almost identical sentences.

c. Detailed description of sampling/recruitment methods and why the study did not employ a sampling method. It is enough to simply discuss how this study recruited participants and why.

Abstract:

1. Background: The first sentence of the background refers to diabetes distress as occurring in “a severe, complex condition like Type 1 diabetes”. This implies that type 1 diabetes is just one of the many conditions in which you may experience diabetes-specific distress. This should be reworded. For example: “Diabetes distress is….. that stem from managing diabetes, a severe, complex condition.”

2. Background, final sentence: It is stated here that the aim of the study is to identify causes of distress in a sample of young adults with type 1 diabetes, but the study also includes sample of health care professionals.

3. Results, 1st sentence: Sentence structure emphasises occurrence of distress in this age group but does not provide comparison. Need to re-word to emphasis findings rather than appear like a comparison.

4. Results, 2nd sentence: What is self-presentational? There is no room to define it so it would be helpful if a different term was used.

5. Conclusion: No need to continually remind the reader about the age of the sample (e.g. “who are in their twenties”).

6. Conclusion: The conclusion might be improved by focusing on the findings and sample of the current study, rather than potential interventions.

Introduction:

1. 1st paragraph: Define psychological morbidity

2. 2nd paragraph, 2nd sentence: Current wording implies that people experience more distress than disorders do. Further, when referring to multiple researchers more than one reference should be provided or at least a reference for a review paper.

3. 2nd paragraph, 3rd sentence: See Comment 1 under abstract.

4. 3rd paragraph: define young adult when it first appears.
5. 3rd paragraph, 1st sentence, “35% experience diabetes distress”: Paper being reference did not measure diabetes distress. It measures general distress (and depression) using the CES-D. Thus the following sentence needs to be re-worded to reflect this, or more appropriate reference need to be provided. Is the focus diabetes-related distress or general distress?

Methods:

1. 1st paragraph: This paragraph includes three sentences, which could be simplified into one sentence, all beginning with “the study”. It would be helpful if you instead referred to “this study”.

2. Recruitment, 1st paragraph: The rationale for focusing on the chosen age group is provided here, but would be better located in the introduction. Further, the American theoretical work should be explained properly or removed.

3. Recruitment, 1st paragraph: Regarding the transferability of this work, I am unsure how interviews with a small number of healthcare professionals provides evidence to indicate that life stages for Irish young adults can be broadly split into two phases.

4. Recruitment, 2nd paragraph: This lengthy paragraph provides detailed definitions or purposeful and random sampling which are unnecessary and distract from the aims of the paper. Simply state what sampling technique was used and why, no need to define it.

5. Recruitment, 2nd paragraph: Suggested that people with T1 diabetes using Facebook diabetes pages would have greater diabetes distress than a clinical sample. There is no evidence to suggest that this would be true, is it potentially more likely that this group is simply more engaged than the average clinic sample rather than more distressed?

6. Recruitment, 3rd paragraph: Remove “unexpectedly”. This and other remarks throughout the method are conversational and should be saved for the discussion.

7. Recruitment, 3rd paragraph: Typo “far more men than women volunteered”.

8. Recruitment, 4th paragraph: The rationale for including healthcare professionals appears much too late. This should be earlier in the methods and justified throughout the introduction.

9. Sample size…1st paragraph: While the sample size of young adults is very reasonable the first sentence of this paragraph attempts to hide the size of the healthcare professional sample which would be improved through further recruitment and interviews.

10. Sample size…1st paragraph: Remove second sentence and add citation to the first sentence.

11. Sample size…1st paragraph: Table 2 refers to the themes which appeared in each of the interviews with young adults, thus it should first appear in the results section rather than the methods.

Tables:
1. Each of 3 tables only refers to the young adult’s participants, not the health care professionals. This lack of detailed information about health care professional responses and characteristics further justifies the removal of this sample of health professionals.

Results:
1. It is preferable that reported theme frequencies (e.g. n=12) are included consistently throughout the results section.
2. Distress is common: This paragraph is listed under sources of distress, but it is not in fact a source of distress.
3. Self-presentational issues, 2nd paragraph: The first sentence of this paragraph reads as if you have undertaken a comparative study. This should be changed to read: “interviewees report that their self-presentational...”.
4. Type 2 diabetes: Appears to be a typo in the last sentence referring to type 2 diabetes when it should be referring to type 1.
5. Day-to-day management, 1st paragraph: The iceberg analogy is an odd inclusion for the results section. Is this something that was raised by participants? If so than a quote should be included. Otherwise, this might be better saved for the discussion if at all.
6. Day-to-day management, 2nd paragraph: Typo “from engaging in fully in”
7. Day-to-day management, 3rd paragraph: Typo “that they there were contravening norms”
8. Healthcare system struggles, 1st paragraph: define CSII and “joined-up” care.
9. Negative media representations: Quotes should include quotation mark when participants indicate what they were saying. E.g. I was like “Jesus Christ”.
11. Managing Distress, 3rd paragraph: Define DAFNE.

Discussion:
1. 1st paragraph, 1st sentence: This could be shortened into two sentences or simply made more concise. Paying closer attention to the write up of this paper will enable readers to focus on the interesting findings rather than being distracted by confusing sentences.
2. 2nd paragraph, 2nd sentence: Lengthy comment about the transition to adult care and the potential for young adults to fall through the gaps of adult medical care. This is an important area of concern which really should be initially raised in the introduction as it actually provides a rationale for this studies focus.
3. 3rd paragraph, 4th sentence: typo.
4. 3rd paragraph: this paragraph includes a number of suggestions as to how distress in young adults with type 1 diabetes might be alleviated. It is important to recognise that this qualitative study provides some useful suggestions, but each
of these suggestions faces major limitations/barriers which are not recognised. This study may in part further inform potential interventions, but further research must be undertaken before proposing these be undertaken.

**Level of interest:** An article of importance in its field

**Quality of written English:** Not suitable for publication unless extensively edited

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I declare that I have no competing interests