Reviewer’s report

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

Version: 4 Date: 29 March 2013

Reviewer: Jane Speight

Reviewer’s report:

I thank the authors for responding to the feedback and making substantial revisions. The manuscript is considerably improved. However, concern remains regarding the manuscript write up, in particular the lack of succinctness within the introduction and limited in depth discussion of the emerging themes. Please see below major concerns to be addressed, followed by a list of minor edits.

Major Compulsory Revisions:

1. Introduction:
   a. The manuscript has been improved through the inclusion of a review of diabetes-related distress and a rationale for the aim of the study and chosen sample. However, the new content is extensive and could be reduced to about half the size while still covering all important areas and allowing for more space in the discussion section. For example paragraph three could be cut into a few short sentences. No description of the measures of distress are required other than to say that distress has typically been measured quantitatively using the PAID and DDS, provide references and then move on to results of those studies which are relevant to the paper.

   b. A discussion of the relationship between depression and diabetes-related distress is found in the introduction. This is a useful inclusion; in particular it provides a rationale for drawing on research into depression in this age group. However authors start discussing depression and distress as “depression/distress” not indicating which one they are specifically referring to. Please change all Depression/Distress to refer to either “Both depression and distress” or specify which you actually mean. While there is overlap in results of studies exploring depression and distress, and how they have been measured, they are indeed separate concepts.

2. Discussion: The discussion is relatively brief compared to the introduction and results section and focusing mainly on potential interventions and implications rather than a discussion of the results at hand. In fact, it appears there are only a couple of sentences dedicated to the interview themes. Consideration of the following may improve the discussion.

   a. A thorough discussion of the emerging themes and relationship to prior research should be included. For example 2 of the 8 themes refer to the stigma associated with type 1 diabetes, However there is no discussion of these findings, despite this being a relatively novel area of research in diabetes.
Schabert et al (2013) have recently published a review article exploring this issue in ‘The Patient’. This is an important finding from the study which deserves thorough discussion as do other emerging themes.

b. The discussion of the occurrence of distress amongst participants despite the generally optimal HbA1c is very interesting and an important implication of results however it could be reduced substantially and should come after further discussion of the themes.

c. Discussion about the lack of health care professional attention to distress and reasons for this: Authors make broad generalisations throughout this section about the lack of support from health care professions and reasons for this. This is outside the scope of the study. For example: “Participants’ distress appeared to often go unnoticed by health care professionals”. We know that participants felt unnoticed, but we cannot confirm from this study whether it was indeed unnoticed by health professionals. Authors need to pay careful attention to the implications of their language.

d. In the introduction there is a lengthy discussion of the relationship between depression and distress, but no reference to depression occurs in the discussion – in particular, the authors could consider whether the emerging themes constitute distress or depression to further the debate about the emotional impact of diabetes. If depression is not a key component of the research then perhaps it is also not necessary to discuss it within the introduction?

e. I appreciate that another reviewer requested inclusion of a discussion around the potential impact of the Irish health care system on the study findings. However, the discussion included goes beyond necessary and offers little contribution to the discussion. Authors might instead highlight in one of two sentences (at most) that current issues surrounding limited access to diabetes specialist staff (and so on) is an important concern within the Irish health care system followed by a statement about the universality of distress among people with type 1 diabetes suggesting that the findings are not limited to the group at hand.

Minor Essential Revisions (Minor issues not for publication):

1. Careful attention to grammatical and typographical errors is required.

2. Better word smithing is required to reduce the word count without losing important information, to take this from a first draft to a polished paper.

Methods:

1. Sample size…1st paragraph: Could be shortened to two sentences. Include reference 40 after the first sentence and remove everything up until the introduction of Table 2 showing that data saturation had been reached.

2. Sample size…2nd paragraph: great to see a detailed discussion of the impact of the interviewer on the interviewee’s discussion and results. However this should really occur in the discussion not the methods. In the methods all that is needed is who interviewed the participants and the setting of interview (e.g. phone, in person).
3. Sample size...2nd paragraph: Please specify how many phone interviews and how many interviews were undertaken in person. Also, please provide a range of the time interviews took (e.g. “interviews lasted between xx and xx minutes).

4. Sample size...2nd paragraph “the interviewer probed around particular issues that were raised” : was this systematically done? Perhaps ‘struggle with health care systems’ was only raised in certain interviews because it was only ‘probed' for in those interviews?

Tables:
1. Table 2: Four participants (15, 23, 26, 35) have no crosses in any of the themes. What did these participants discuss? Are there reasons why these participants didn’t discuss the theme topics? This needs to be discussed within the results.

Results:
1. Title “Young adults Interview” should be removed.
2. Stigma and Type 2 diabetes subsections: are the 12 people who mentioned stigma and the 13 people who discussed the type 2 theme different or the same people? Doesn’t the type 2 specific stigma fall under the overall perceived stigma? As such all who perceived stigma surrounding being misidentified as have type 2, should also be included as discussing worry about how others view them.
3. Day to day management, 1st paragraph: Grammatical and typographical errors in the final sentence.
4. Day to day management, “I felt guilty because I knew I should have been stricter than I was....”: Typo.
5. Complications and the future, 3rd paragraph beginning “the unfairness of diabetes-related risk...”: This paragraph is a good example of how the authors have included their own interpretations on the data within the results rather than reporting the facts. For example “for these interviewees, diabetes was a universe where good deeds often went unrewarded...”. Is this a quote from an interview? If so include the quote, if not then perhaps rephrase to something less definitive and make it clear that this is the authors interpretation. E.g. “It seemed that for these interviewees diabetes was a universe...”
6. Negative media reps, quotes: speech marks should be put around “holy crap”.
7. Psychological tactics: This section also includes discussion of management strategies. As such the title should be changed to reflect this.
8. Psychological tactics: Typos “avoid r thinking” and “appeared to became so annoyed”
9. Psychological tactics, 3rd paragraph: The first sentence implies that improving diabetes medication outcomes is a choice rather than a complex behavioural and medical process “another strategy was to develop increased control over diabetes”.
10. Support from family members, 1st paragraph, 2nd sentence: do you really
mean that families monitor participants blood glucose and eating? In diabetes, “monitor” is a term which is generally synonymous with blood glucose measuring/checking/testing. I assume families aren’t monitoring participants’ blood glucose levels. Perhaps you mean having conversation with participants about blood glucose and food choices? Regardless, the quote included doesn’t properly reflect this statement.

11. Support from family members, 2nd paragraph, 3rd sentence: perhaps a better wording for “regulating” would be “attending to”?

12. Support from peers, 2nd paragraph: typo: “emotionality”

Discussion:

1. See Major revision regarding shortening discussion of implications, Irish health care system and instead include discussion of the study results.

2. Second paragraph, last sentence, “professional’s refusal to address the topic of distress”: this is a strong term which generalises the care of health care professionals. This term and other sentences throughout this paragraph should be made more subtle and it should be made clear that you are talking about some health care professionals or health professionals from the perspective or participants – not all health professionals.

3. 3rd paragraph, “forthcoming article”: If the article you are referring to is in press please provide reference. Otherwise, please remove.

4. 4th paragraph: Please define DAFNE and say why it would be useful. Or remove and just state that structured education courses are required and why.

5. 5th paragraph, limitations, final sentence: Final sentence implies that those people for whom peer support interventions would not be effective care less about their diabetes. This needs rewording.

6. 5th paragraph, limitations: Include a small section on the influence of the interviewer on the interview results. This information could be moved from the methods section. This should include discussion of the gender of the interviewer given the primary female participant group and the fact that sensitive issues may have not been discussed.

Level of interest: An article of importance in its field

Quality of written English: Needs some language corrections before being published

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