PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	“I’m not a druggie, I’m just a diabetic”: a qualitative study of stigma from the perspective of adults with type 1 diabetes
AUTHORS	Browne, Jessica; Ventura, Adriana; Mosely, Kylie; Speight, Jane

VERSION 1 - REVIEW

REVIEWER	Rise, Marit By Norwegian University of Science and Technology, Department of public health.
REVIEW RETURNED	20-May-2014

GENERAL COMMENTS	This manuscript is systematic, well written and describes robust work using qualitative research methodology. The subject is interesting, as are the results. As part of the strengths and limitations section in the discussion I would like to see added a short discussion about the authors’ backgrounds and starting points for this research and how this might have influenced the results. This is an important part of the reflexivity which is a general recommendation when reporting qualitative studies. I will leave it to the editor to decide whether this addition should be mandatory or merely a suggestion.

REVIEWER	Kirsty Winkley King's College London, UK
REVIEW RETURNED	09-Jun-2014

GENERAL COMMENTS	This is a strong qualitative study exploring the experience of stigma in people with type 1 diabetes. It is important because the literature is sparse in this area and this work will inform future interventions to improve health and quality of life in this group. The manuscript is well-written and appropriate methodology has been used. However, I would suggest the following may improve clarity: In the abstract and discussion the authors summarise the findings into 2 distinct themes, T1DM specific stigma and stigma-by-association with T2DM. However, this simple and clear summary is not evident in the results section nor in the table and figure provided. I would therefore suggest that either the structure of the results etc is changed or the summary in the abstract and discussion or perhaps more effort is made to include both approaches? Results: 2 of the participants did not indicate they were stigmatised, can the authors provide more detail on this? It would be interesting to have more detail on the outliers. A sentence here explaining the main themes would also be helpful.

	It would also be helpful to have the number of people who contribute data to each theme throughout, I know it is in the table but it makes it easier to understand the importance of each theme when reading. Blame, the second quotation reported in this section seems very similar to those in stigma by association. Should these 2 themes be merged? If the authors provide the number of participants it would make it clearer how distinct these themes are. Key messages: need to include impact on employment? Is developing a questionnaire a key message of this study? I would suggest removing as it is in future directions Limitations: I would only report those under-represented

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

1. As part of the strengths and limitations section in the discussion I would like to see added a short discussion about the authors' backgrounds and starting points for this research and how this might have influenced the results. This is an important part of the reflexivity which is a general recommendation when reporting qualitative studies.

We have added a paragraph in the 'Strengths and Limitations' section that briefly outlines the possible role of the researchers in knowledge generation, and the efforts made to become aware of these influences and processes.

Reviewer: 2

1. In the abstract and discussion the authors summarise the findings into 2 distinct themes, T1DM specific stigma and stigma-by-association with T2DM. However, this simple and clear summary is not evident in the results section nor in the table and figure provided. I would therefore suggest that either the structure of the results etc is changed or the summary in the abstract and discussion or perhaps more effort is made to include both approaches?

Thank you for this comment. We have not made any edits to the paper on the basis of this reflection. We have not indicated in either the abstract or the discussion/conclusion that "T1DM specific stigma and stigma-by-association with T2DM" are the only "two distinct themes", as suggested by the reviewer. Table 2 and the structure of the results section reflect what we believe are the themes of the data, of which this distinction is only one aspect. Our summary sentences in the abstract and conclusion that the reviewer refers to here are not intended to summarise all the data, but rather these sentences are designed to be read within the context of the paragraphs in which they appear, so that a summary of all the data is evident. In the abstract, the sentence appears in the following context:
"Australian adults with T1DM perceive and experience T1DM-specific stigma as well as stigma-by-association with type 2 diabetes. Such stigma is characterised by blame, negative social judgement, stereotyping, exclusion, rejection and discrimination. Participants identified the media, family and friends, healthcare professionals and school teachers as sources of stigma. The negative consequences of this stigma span numerous life domains, including impact on relationships and social identity, emotional well-being and behavioural management of T1DM. Adults with T1DM can be both the target and the source of diabetes-related stigma."

In the conclusion the sentence appears in the following context:
"Australian adults with T1DM perceive and experience T1DM-specific stigma as well as stigma-by-association with T2DM. The negative consequences of this stigma span numerous life domains,

including relationships and social identity, emotional well-being and behavioural management of T1DM. Adults with T1DM can be both the target and the source of diabetes-related stigma."

We believe that these paragraphs, when taken as a whole, offer an reasonable summary of the data. No single sentence in either of these paragraphs is designed to be the complete summary of the results.

2. Results: 2 of the participants did not indicate they were stigmatised, can the authors provide more detail on this? It would be interesting to have more detail on the outliers.

We have added some detail to the 'Perceptions of Social Stigma' section to provide readers with a greater understanding of the perspectives of the two participants who did not perceive T1DM to be stigmatised.

3. A sentence 'here' explaining the main themes would also be helpful.

Assuming the reviewer is referring to the beginning of the results section, we have added a brief summary of the themes outlined in Table 2 and subsequent results sections to the 'Perceptions of Social Stigma' section.

4. It would also be helpful to have the number of people who contribute data to each theme throughout, I know it is in the table but it makes it easier to understand the importance of each theme when reading.

This information was accessible in Table 2 but we have now made it more explicit by providing totals at the base of each column, so that a reader can easily glean this information at a glance. We decided against including this detail in-text throughout the results section. We take the view that the numbers of participants are not necessary for exploring the experiences of the participants. As the reviewer will be aware, the purpose of qualitative research is to discover meaning and understanding, and in doing so we seek sound findings but do not seek certainty. Indeed, it is better to be abstract. A theme endorsed by 5 participants is no less valid than one endorsed by 15 participants. Thus, we do not believe it will be helpful (and may be misleading) to continually draw the reader's attention throughout the paper to the numbers of participants raising each theme.

5. Blame, the second quotation reported in this section seems very similar to those in stigma by association. Should these 2 themes be merged? If the authors provide the number of participants it would make it clearer how distinct these themes are.

Our view is that stigma-by-association and blame are distinct themes. Table 2 indicates that while 14 people identified blame as a key part of their experience of stigmatisation, 23 people reported stigma by association; some participants perceiving/experiencing one without the other. The 'blame' theme incorporates both blame for sub-optimal management of diabetes, and misplaced blame due to misunderstandings of the causes. We have attempted to reflect these different types of blame through our selection of participant quotes, which appear in the results section.

6. Key messages: need to include impact on employment?
Employment opportunities did not emerge as a key theme of the data, as evident from the structure of the results section and Table 2. Discrimination or restrictions in the employment context were examples given by some participants in relation to the broader themes of exclusion / rejection / discrimination. Our key messages reflect the major themes that emerged from the data, and we are concerned that adding a point about employment would misrepresent the data by potentially over-stating this issue. We have, however, added a point about non-disclosure in various environments,

which also links to the workplace issue and thus provides a better summary of the data.

7. Is developing a questionnaire a key message of this study? I would suggest removing as it is in future directions
We agree. We have removed it from the ‘Key Messages’ section.

8. Limitations: I would only report those under-represented

We have amended the ‘Strengths and Limitations’ section under ‘Article Summary’ to focus only on those under-represented in the sample. This improves both clarity and brevity. A full discussion of the limitations can still be found in the discussion section.