Author’s response to reviews

Title: What works for whom in the management of diabetes in people living with dementia: a realist review

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Author’s response to reviews:

Dear Dr Marinelli

Thank you for the comments on our manuscript. Our response to the comments are detailed below and revisions to the manuscript have been highlighted using the track changes facility. We hope that we have now addressed the comments satisfactorily.

Yours sincerely

Frances Bunn
We would ask you to add a 'Data availability' statement to the Declarations section of the manuscript.

Authors’ response: The following statement has been added:

- The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Reviewer reports:

Reviewer #1 Diana Sherifali:

Congratulations to the authors on this substantial and timely manuscript. My review of this manuscript comes from two lenses: a) systematic review methods (realist review); and b) research interests in diabetes in older adults. I have not major concerns with this manuscript, however I will make some minor queries related to points a and b above.

With respect to methods, can the authors explain:

1) what is meant by "decisions made at different points in time were recorded in an excel spreadsheet" - is this referring to 2 reviewers screening independently? if so, what happened in the case of discrepancies?

The text on p 5 of the manuscript has been revised to the following:

Records and full text papers were screened for inclusion by two of four reviewers (FB, PJ, BR, DT). The reviewers then met to discuss decisions and resolve any disagreements. Decisions on inclusion made at different points in time were recorded in an Excel spreadsheet.

2) what is meant by 'good enough and relevant enough' (page 5 - line 52). Does this imply data saturation?

Authors response: The text on p5/6 has been amended to add additional information on what is meant by good enough and relevant. The text now reads:

Good enough’ was based on the quality of evidence, for example was it of a sufficient standard for the type of research, and whether the claims made were considered to be trustworthy. ‘Relevance’ related to whether the authors provided sufficient descriptive detail and/or theoretical discussion to contribute to the theories generated in Phase 1
3) On page 6 Line 51, the authors note the countries for which the studies were completed. Canada is missing...reference #93. And in true Canadian fashion, I will apologize (sorry) for pointing this out.

Authors response: this has been changed to UK, North America or mainland Europe (p6)

With respect to the research interests/content...I would like the authors to consider:

1) rewording some of the language in the last paragraph before strengths and limitations (Page 13, line 27). There are some long, awkward sentences and terms that are a bit outdated (i.e. Disciplines)

Authors response: This paragraph has been edited (see p 13/14)

2) Recognizing that the main and fundamental limitation is the limited evidence related to management of diabetes in PLWD and that the authors note (page 14 - line 20) that the evidence does not consider BOTH conditions, I would suggest the authors address the issue of limited evidence from the context of multimorbidity and the colinearity of the conditions (diabetes + dementia + many more) and what ‘further work’ needs to be done. This could be added in the conclusions section (Page 14, line 42).

Authors response: This point has now been picked up in the first paragraph of the section on strengths and limitations. We have added the following sentence

‘This lack of evidence is compounded by few insights into how when the person develops dementia or diabetes affects treatment’.

In addition the discussion now includes a paragraph considering issues around multimorbidity and frailty (see P14)

Otherwise, there are a few typos or extra words. A thorough review for syntax and grammar should be completed.

Authors response: the paper has been reviewed and any errors identified corrected
Reviewer #2 Sean Dinneen:

Summary: the authors describe a "realist review" of the literature on the management of diabetes in people living with dementia (PWLD). The aim of the review was to identify "programme mechanisms" to improve the management of diabetes in PLWD and identify areas needing further research. The project was delivered in 4 phases including a phase in which the scope of the review was defined, a phase involving retrieval and synthesis of evidence and 2 phases in which the theories and hypotheses generated from the literature were tested and refined. The latter involved qualitative work. Eighty nine papers were identified including studies involving PLWD and diabetes and people living with one or other condition. Six potential mechanisms whereby interventions might work (or not) were identified. These included attitudes towards PLWD, person-centred care planning, providing tailored and flexible care, continuity of care, family engagement and use of technology.

Major comments: this is an excellent paper which I enjoyed reading. The methodology is thorough and backed up by a published protocol describing the planned methods. In addition the reporting of the work is framed around a CONSORT-type set of standards for realist reviews called RAMESES. The following comments reflect the perspective of a "jobbing diabetologist" interested in and working in this area (clinically) but not overly familiar with the (research) methodology.

Authors response: thank you for your positive comments on the paper

(1) the authors comment that very few RCTs have been published in this area. It would be useful to reflect on why this is the case and on the quality of the RCTs that were included in the review. I assume that the work presented in this paper is going to inform the development of a (complex) intervention. If this is the case it would be helpful to clarify how the authors see that work developing based on the findings of the review.

Authors response: Some additional statements about future research have been added to the discussion p14/15

(2) a lot of the terminology used in the description of the results is not familiar terminology. In particular the term CMO is hard to decipher. It would be helpful if this term could be explained more clearly or (preferably) if an alternative term could be used.

Authors response: definitions of the key realist terms and how they have been applied in the review are not outlined in Box 1.
Definitions of key Realist terminology used in the review can be seen in Box 1. These context-mechanism-outcome (CMO) configurations are developed iteratively through data collection, theorising and stakeholder engagement.

(3) a lot of the conclusions of this realist review could be applied more broadly to diabetes care in any age setting. We are being encouraged (for example by ADA/EASD guideline writers) to deliver a more personalised approach to medication choice in diabetes care; continuity of care and incremental change is always sought after in chronic disease; an emphasis on holistic approaches and quality of life as an important patient outcome is true for young adults just as it is for older adults. The authors may want to reflect on this and consider mentioning it in their discussion.

Authors response: the reviewer makes a good point. We have added a paragraph (p14 discussion) to reflect this.

Many of the conclusions in this review about diabetes care are not specific to people with dementia. For example, personalised approaches to medication choice, continuity of care and a focus on individual patient preferences are relevant to all age groups [128][129]. The review shows, however, how a diagnosis of dementia creates extra and different needs from those experienced by people with diabetes but without dementia. People with dementia and diabetes are more likely to be dependent on support from unpaid carers, may have more trouble accessing diabetes related healthcare [11], and are at greater risk of complications such as hypoglycaemic episodes. Future research should consider the impact of involving family-carers in self-management interventions for people with diabetes and dementia, look at ways to improve medication management and explore how professionals can recognise when a person is no longer able to self-manage and provide appropriate support.

(4) the term "frailty" is hardly mentioned in the review and yet in the gerontology literature it seems to be increasingly used to try to understand and frame approaches to care delivery in older people with diabetes. I would be interested in the authors' thoughts on how their work and their findings relate to the evolving literature on frailty.

Authors response: Whilst frailty is not the focus of this paper we agree it is an important issue. A sentence to reflect this has been added to the first paragraph of the background

‘Furthermore there appears to be a reciprocal relationship between hypoglycaemia, dementia and frailty’ (p3)
And the issue has been included in the discussion

A UK study found that PLWD had an average of 4.6 chronic diseases in addition to their dementia [126], meaning that diabetes may be only one of several health-care concerns for older people with dementia. In addition, diabetes and frailty are closely interrelated [127], and the relationship between hypoglycaemia, frailty and dementia appear to be reciprocal, with each potentially exacerbating the others [8]. Guidelines on diabetes care in older people and those with dementia emphasise the need to consider the significance of frailty and the need to avoid hypoglycaemia [12][114]. Despite this there is evidence that a substantial proportion of older adults are potentially overtreated [128]. Performance measures should incentivise appropriate de-intensification as well as intensification of medication regimens [8], and research is needed to consider whether care pathways for this group need to be specific to diabetes and dementia or whether a pathway for older adults with complex needs, such as frailty or multimorbidity, is more appropriate.