Reviewer’s report

Title: “I just keep thinking that I don’t want to rely on people.” A qualitative study of how people living with dementia achieve and maintain independence at home: Stakeholder perspectives.

Version: 0 Date: 10 Oct 2019

Reviewer: Carmelle Peisah

Reviewer's report:

This is a lovely paper that addresses an important gap in the literature by exploring the nuanced perspectives of people with dementia, family carers and professionals, on living independently in the community. I have "study jealousy," it is such a great study. My comments are few but I agree with the authors that the study has elaborated a rich and important qualitative data set, but perhaps the findings could be highlighted better, given its great potential value and significance.

Method
Were the people with dementia and carers matched or were they completely different samples? If they were matched why was the ethnic mix so different for the two groups, was it because you had several carers for the same person? My apologies if I have missed this.

Results
It is unusual for all three groups to be examined together, but I understand you were looking for commonalities (the usual goal of a qualitative thematic approach) AND differences, although the rationale of and presentation of this slightly unusual approach wasn't clear. You present the commonalities and pepper it with differences but in an adhoc way. I like the idea of this but want it presented to me, as a reader, more meaningfully, to show the dissonance between the person experiencing the illness, the role of the carer as protector, advocate etc and then the professional perspective: what we think people need or "should get". We all love using quotes in qual work, but this currently reads as statement, quote, statement quote statement quote etc. Perhaps it might be useful to look at each theme and subtheme and how it manifests in each group, but in a table eg for "changing roles" : carer being a jailer/parenting; person with dementia "no longer the boss" and the professionals' understanding which takes into account the past relationship, attachment etc. This will help us understand how and why "we" (carers and professionals") get things wrong and how this dissonance might provide barriers to true patient-centred care.

Discussion
I love that this has informed the NIDUS intervention and look forward to reading that - perhaps you could explain a bit more specifically how it did inform that - beyond the "goals of the person" and "the needs of the caregiver", which we always purport to target, all a bit generic, which your study is not. How have these findings made you (and by implication us) do things differently? We promote positive risk taking but how do we do that while acknowledging the different and opposing fears of the person with dementia and their carers, especially when ultimately, it is the person with dementia's will and preferences (ideally competent choices) that must be honoured first and foremost?

With regards to limitations, of course you have to use volunteers but perhaps acknowledge that this might have skewed the data somewhat - perhaps there is less dissonance amongst this group - one would imagine that those embroiled in family conflict etc may not volunteer. Presumably this was a motivated group of carers trying to do their best (and possibly better) for the person with dementia.
Also there is abundant literature about the cultural differences in the understanding and interpretation of autonomy, and you do have a nice mix here, especially amongst your carers- perhaps you could comment on this, was there any data about this?

**Are the methods appropriate and well described?**
If not, please specify what is required in your comments to the authors.

Yes

**Does the work include the necessary controls?**
If not, please specify which controls are required in your comments to the authors.

Unable to assess

**Are the conclusions drawn adequately supported by the data shown?**
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Yes

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Not relevant to this manuscript

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