Author’s response to reviews

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.

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Dear Dr Cassady-Cain,

Re: “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. BGTC-D-19-00383

Thank you for the opportunity to revise this paper. We describe below how we have responded to the reviewers’ and editorial comments.

Reviewer 1: Donovan T. Maust (Reviewer 1): This is an informative, clearly-written paper. I have a few relatively minor suggestions for changes that future readers might find helpful.

Thank you for your positive response.

Introduction:
- p.3, lines 16-18: I'm not quite sure the point of this sentence? Is "time they are able to stay at home" the interest there, and then you are saying there are just 3 studies that have considered that as an outcome? Given the focus on independent living I suspect this may be the case, but it is awkward wording.
Apologies, we have amended and simplified the sentence to highlight that only two interventions have demonstrated an increase in the time people living with dementia have been able to stay at home. We have also updated the references. We now say: “However to date, only two psychosocial interventions have resulted in an increase in the time people with dementia remain living in their own homes.”

Results:
- I don't know if journal format will allow, but I would number the text headings as they are in the table (so 1.1 Adapting the environment, 1.2 Balancing autonomy and minimizing harm, etc.). It was a bit hard to keep the organization/themes in my head reading through the results.
- might be nice to also have one final table that highlights notable differences between the stakeholder groups on each of the themes or sub-themes. Again, a bit hard to keep track of through the text.

We have added in numbered text headings (assuming the journal format allows) to help structure the results section. I have also added two columns to table 4, one to show which stakeholder groups are covered by each sub-theme and one to summarise the notable differences and tensions between stakeholder groups.

Discussion:
- p.22, lines 11-13—from ref, these appear to be concepts specific to older adults but not dementia? Would just be explicit here who these concepts were previously applied to—described based on what type of a population?
We have clarified that these concept were previously applied to older people living in a range of residential settings and how they may be particularly relevant to people living with dementia: “Concepts such as relative interdependence, delegated autonomy and social and spatial independence have previously been applied to understanding independence in older people living in a range of residential settings (1). These concepts feel especially relevant to the nuanced and complex experiences of people living with dementia and those caring from them and to the dynamic nature of interactions and negotiations around independence discussed in this paper.”

Carmelle Peisah (Reviewer 2): 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.

Thank you we are glad you share our view on the importance of the study and we have attempted below to respond to your suggestions to increase the potential value and significance of the findings.

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.

The samples were not matched, so we did not exclusively interview family carer and people living with dementia dyads. This was partially due to recruiting from a range of different services but also because we wanted a diverse sample, for example including people living with dementia without a close family member and family carers who were caring for people with more severe dementia (and therefore were
not eligible to be interviewed themselves). We have added a point of clarification to our methods: “Where possible we interviewed dyads of people living with dementia and their relative either together or separately (depending on their preferences), but overall, because we were recruiting from a range of services, not everyone had a family carer available and others declined to take part, only a proportion of our sample were matched.”.

We have also simplified our description in the results section: “Of the people living with dementia that were interviewed, five were interviewed alone and not matched (i.e. their carer did not take part in an interview), three had a carer present in their interview but the carer did not take part in an separate interview, two had a carer present in their interview and their carer also took part in a separate interview, and one did not have their carer present but the carer took part in a separate interview.”

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.

We have revised the results section to highlight the dissonance between the person living with dementia, the family carer and the professional experiences and we believe that this now better represents the complexity and interrelatedness of the stakeholder experiences. We have done this by amending the text, removing certain quotes and adding in more explanatory analysis. We have also amended the table of themes to highlight key differences and tensions amongst the different stakeholders and to more methodically outline which stakeholder experiences contributed to each sub-theme.

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?

We hope to publish our initial feasibility study later in the year and will soon begin our full RCT testing the intervention. In addition to informing the content of the intervention, this study made clear to us that we needed an intervention that was flexible enough to account for the different perspectives held by family carers and people living with dementia and to train our facilitators (who are non-clinically trained graduates) to manage the complexity and negotiate around these challenges within the sessions.
As a direct result of these interviews we have included a focus, within the facilitator training on the facilitators supporting people living with dementia to access appropriate support, and on how to communicate and negotiate effectively when there are different views held. We have added the following text into the manuscript: “The findings from this qualitative study have directly informed the NIDUS intervention content, including modules on managing risk, communication with services, a local resource directory and getting out and about. They have also informed the training for facilitators on managing multiple and differing perspective and regular discussion on who attends session and how to meaningfully include the person living with dementia. We included vignettes and direct quotations from these interviews in the manuals to inform discussion and highlight the tensions and dilemmas that people may be experiencing, as well as potential solutions. The qualitative work reported in this paper also informed our overall approach in designing the NIDUS intervention: building on existing skills and resources and connecting with wider support networks.”

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.

We agree and have added the following text to our limitations: “Additionally, ultimately we interviewed those who were keen and willing (and had the capacity to consent) to participate, therefore there is an inherent bias in our sample. It may be that those family carers and people living with dementia who chose to participate were less likely to be experiencing challenges or disagreements in relation to independence at home and it is likely that the health and social care professionals were particularly motivated or engaged in the topic.”

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?

We agree that we had a particularly culturally diverse population, especially among the family carers that participated and we felt that the richness of this data and the unique and original perspective that this represented warranted a separate paper which has recently been published in the Gerontologist. The paper is entitled “In the Bengali Vocabulary, There Is No Such Word as Care Home”: Caring Experiences of UK Bangladeshi and Indian Family Carers of People Living with Dementia at Home. We have now added a reference and the following text to this manuscript: “Notably, nearly half of the family carers we interviewed came from South Asian backgrounds and we have explored how their cultural identities and values influenced their experiences, negotiation of the caring role and relationship with services elsewhere (35).”

In addition to the specific comments detailed above we have also checked the declarations are in order and have updated the references and amended any errors.

We hope that our responses address the concerns raised by the reviewers and look forward to hearing from you.

Dr Penny Rapaport
(On behalf of all authors)

1. Hillcoat-Nallétamby S. The meaning of “independence” for older people in different residential