PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	Understanding the needs and experiences of people with young onset dementia: a qualitative study
AUTHORS	Rabanal, Luisa; Chatwin, John; Walker, Andy; O'Sullivan, Maria O'Sullivan; Williamson, Tracey

VERSION 1 – REVIEW

REVIEWER	Aud Johannessen Norwegian National Advisory Unit on Ageing and Health
REVIEW RETURNED	12-Jan-2018

GENERAL COMMENTS	First, thank you for reviewing this paper Keywords: I would have left out carers, added early-onset dementia, and also remove IPA. Strength and limitations You should add that the some of the interviews were together with carers, because I suppose that affect the interviews and the voice of people with dementia. Bacground: Page 3 line 41. In their forties and fifties. YOD is earlier than 65 years. Perhaps you change should change the sentence. Sample: First p. 19. The first sentence. Use the abbreviation YOD, and also throughout the paper. Secondly, do the table give a meaning. I think that you should write it directly into the paper, and delete the table. The next sentence Of these,…. Belongs to the interviews. Interviews: Change it and put in Data collection: The researchers really made a great effort to develop the interview guide, but why did you not ask people with YOD themselves about the guide. Analysis: p 4, line 52 Who is LR co-author?, and also TW co-author or author? Results: p. 5 line 6 and 7. I think that these two sentences belong to the data collection section. I suggest that you start with The analysis revealed four…….. You have presented the result in an understandable and interesting way. It is easy to follow, but I suggest that you rewrite the result section because you have not written about the fourth superordinate theme, and that is a very important theme, because that is hardly expressed in research. So, my suggestion is that you shrink the text, if necessary, and then write about the main theme 4 also. The three first main themes are to be find in other published research papers Johannessen, A., & Möller, A. (2013). Experiences of persons with early-onset dementia in everyday life: A qualitative study. Dementia, 12(4), 410–24. Also Spreadbury & Kipps (2017) writes about this topic. Discussion: When you rewrite the results you may also rewrite the

	discussion. You should also mention that economic demands linked to people with YOD and that one third of them actually have children that still are living at home.

REVIEWER	M.Breza National and Kapodistrian University of Athens, Greece
REVIEW RETURNED	17-Jan-2018

GENERAL COMMENTS	Comment: More information is required about the small sample size (limitation of this study) in the discussion section.

REVIEWER	Claire Goodman Centre for Research in Primary and Community Care University of Hertfordshire, UK
REVIEW RETURNED	08-Feb-2018

GENERAL COMMENTS	The aim of this study was to explore the experiences and needs of younger people living with dementia The statement that there are over 40, 000 people with YOD comes from the Prince et al 2014 report and is an estimate based on expert opinion. It is unknown how many people in the population have YOD. The premise of this paper is that there is limited knowledge of the experience of living with YOD. A recently published review challenges that assumption (1). There is a 15 year history of studies many of which have similar findings and conclusions to this study The methods section should provide more information about • Who the YOD organisations were • How many members they had Five of the interviews were dyads, how was the interview organised and framed to reflect the IPA focus on an individual's experience? Reference is made to a maximum diversity sample. Were participants recruited on the basis that they were from diverse backgrounds with different experiences with some people not being asked to take part in an interview, OR that those who were willing to be interviewed were diverse in background and experience? There was a steering group that included 7 people living with YOD and 5 carers who advised on the interview guide. Was it possible to differentiate between advice given based on personal experience as part of the study design and data collected from people with YOD? How does this development of a semi structured interview guide fit with the assumptions of IPA as described, in particular that it allows the participant to focus on their own (idiosyncratic) experiences? There is a description of the assumptions of IPA that inform analysis but how the analysis of this data was organised is not described The presentation of findings is well structured and the supporting quotes fit with the themes as described. The difficulties experienced during and post diagnosis and how people with YOD differ from older people with dementia are already well documented. The authors need to demonstrate how this work builds on what is already known,

	Iimportant findings, that could have been expanded upon concerned how offers of help were received by people with YOD and the importance of the groups. The point is well made that these findings are despite the extra investment and policy initiatives to improve the overall experience and care of people living with dementia. The authors may like to consider the relevance of the findings for existing dementia initiatives e.g. the Dementia Engagement and Empowerment Project (DEEP), Innovations in Dementia, and Dementia Friendly Communities. All of whom involve and work with people with YOD as well as older people. Reference Mayrhofer A, Mathie E, McKeown J, Bunn F, Goodman C. Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review. Aging & Mental Health. 2017 Jun 1:1-9.

VERSION 1 – AUTHOR RESPONSE

Reviewer(s)' Comments to Author:

Reviewer: 1 (Changes highlighted in yellow on marked copy)
Reviewer Name: Aud Johannessen

Institution and Country: Norwegian National Advisory Unit on Ageing and Health
Please state any competing interests or state ‘None declared’: non

Keywords: I would have left out carers, added early-onset dementia, and also remove IPA.
RESPONSE: keywords are now: Young onset dementia; Dementia; Health Policy

Strength and limitations
You should add that the some of the interviews were together with carers, because I suppose that affect the interviews and the voice of people with dementia.
RESPONSE: This has been added to the strengths and limitations section.

Bacground: Page 3 line 41. In their forties and fifties. YOD is earlier than 65 years. Perhaps you change should change the sentence.
RESPONSE: The sentence has been changed to: ‘For people who receive a diagnosis of dementia at a relatively young age. . .’

Sample: First p. 19. The first sentence. Use the abbreviation YOD, and also throughout the paper.
RESPONSE: ‘Young onset dementia (YOD)’ is now given in full the first time it occurs in the main text (page 2), and ‘YOD’ from then on. This has also been done in the abstract.

Secondly, do the table give a meaning. I think that you should write it directly into the paper, and delete the table.
RESPONSE: Yes, we agree table 1 probably isn’t required. We have removed it and incorporated age at diagnosis information in the Methods (sample) section. Table 2 is now re-labelled table 1 in the main text.

The researchers really made a great effort to develop the interview guide, but why did you not ask people with YOD themselves about the guide.
RESPONSE: People with YOD were consulted over the development of the interview guide through a project advisory group. This has now been clarified in the text (Page 3)

Analysis: p 4, line 52 Who is LR co-author?, and also TW co-author or author?
RESPONSE: Yes, LR and TW refer to first author and a co-author. This may not have been clear on the anonymised version of the article.

Results: p. 5 line 6 and 7. I think that these two sentences belong to the data collection section.
I suggest that you start with The analysis revealed four……..
RESPONSE: Lines 5 and 6 have been moved to the data collection section, and the sub-heading 'emergent themes' has been removed.

You have presented the result in an understandable and interesting way. It is easy to follow, but I suggest that you rewrite the result section because you have not written about the fourth superordinate theme, and that is a very important theme, because that is hardly expressed in research. So, my suggestion is that you shrink the text, if necessary, and then write about the main theme 4 also. Discussion: When you rewrite the results you may also rewrite the discussion.
RESPONSE: Although we agree that the fourth theme is important, because it was not particularly well represented in this corpus we decided to focus the paper on the first three themes. In the light of the comments from the other reviewers we have chosen to concentrate on improving what we have already written and address specific points raised rather than add entirely new sections.

You should also mention that economic demands linked to people with YOD and that one third of them actually have children that still are living at home.
RESPONSE: These points have been included on (page 3).

Reviewer: 2 (Comments highlighted in red on marked copy)
Reviewer Name: M.Breza

Institution and Country: National and Kapodistrian University of Athens, Greece

Please state any competing interests or state 'None declared': None declared.

Please leave your comments for the authors below

Comment: More information is required about the small sample size (limitation of this study) in the discussion section.
RESPONSE: We have clarified that the sample size is appropriate for an in-depth qualitative study of this nature. (In limitations of the study and discussion sections).

Reviewer: 3 (Changes highlighted in green on marked copy)
Reviewer Name: Claire Goodman

Institution and Country: Centre for Research in Primary and Community Care, University of Hertfordshire, UK

Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below
The aim of this study was to explore the experiences and needs of younger people living with dementia
The statement that there are over 40, 000 people with YOD comes from the Prince et al 2014 report and is an estimate based on expert opinion. It is unknown how many people in the population have YOD. The premise of this paper is that there is limited knowledge of the experience of living with YOD. A recently published review challenges that assumption (1). There is a 15 year history of studies many of which have similar findings and conclusions to this study
RESPONSE: These points have been clarified in the text and refs updated (page 2 and conclusion).

The methods section should provide more information about
- Who the YOD organisations were
- How many members they had

RESPONSE: This information is now included in the methods section.

Five of the interviews were dyads, how was the interview organised and framed to reflect the IPA focus on an individual's experience?
RESPONSE: This has been clarified: 'To ensure that the PWD had the dominant voice during interviews that were conducted with carers present, questions were directed primarily at the PWD; the carer would interject if they felt they had extra information to support what the PWD was saying.'

Reference is made to a maximum diversity sample. Were participants recruited on the basis that they were from diverse backgrounds with different experiences with some people not being asked to take part in an interview, OR that those who were willing to be interviewed were diverse in background and experience?

RESPONSE: It is the latter; those who were willing to be interviewed were diverse in background and experience. For clarity, this phrase has been removed (see reviewer 1 comments).

There was a steering group that included 7 people living with YOD and 5 carers who advised on the interview guide. Was it possible to differentiate between advice given based on personal experience as part of the study design and data collected from people with YOD?
RESPONSE: Yes, although the points raised by the steering group were often very similar to those ultimately reported by participants, the open thematic structure of the interviews meant that direct prompting could be avoided.

How does this development of a semi structured interview guide fit with the assumptions of IPA as described, in particular that it allows the participant to focus on their own (idiosyncratic) experiences?
RESPONSE: As with the last point, the researcher approach was sufficiently flexible to allow participants to explore their own experiences, regardless of whether or not these strictly followed the structure of the interview guide.

There is a description of the assumptions of IPA that inform analysis but how the analysis of this data was organised is not described.
RESPONSE: The following text has now been added (page 4/5):
'At a practical level, transcripts were first analysed individually and read several times while simultaneously listening to the audio-recording. The written content was formatted into a table to facilitate the annotation process. First, simple, descriptive comments were made while reading and listening to the transcript in order to reveal the content. The process was repeated a second and third time to note linguistic (use of language, laughter and voice tone) and conceptual (questions and interpretations of the text) comments respectively. The conceptual level of annotation is particularly

important because it adds depth to the analysis. Various techniques were employed to search for connections across themes, on a case by case basis. These included abstraction (grouping similar themes), polarisation (focusing on differences between themes) and numeration (looking at frequencies of themes). The result was a list of superordinate themes and their respective subordinate themes for each participant.'

The presentation of findings is well structured and the supporting quotes fit with the themes as described. The difficulties experienced during and post diagnosis and how people with YOD differ from older people with dementia are already well documented. The authors need to demonstrate how this work builds on what is already known,
RESPONSE: We have re-written the conclusion with this in mind, clarified that the work builds on the findings of other studies and shows that peer support is crucial for people living with YOD, as is the need for them to engage with age appropriate activities.

The point is well made that these findings are despite the extra investment and policy initiatives to improve the overall experience and care of people living with dementia. The authors may like to consider the relevance of the findings for existing dementia initiatives e.g. the Dementia Engagement and Empowerment Project (DEEP), Innovations in Dementia, and Dementia Friendly Communities. All of whom involve and work with people with YOD as well as older people.
RESPONSE: We have now included reference to the need for initiatives such as these to maintain a commitment to people with YOD (page 11 / conclusion).

VERSION 2 – REVIEW

REVIEWER	Claire Goodman University of Hertfordshire, UK
REVIEW RETURNED	04-Apr-2018

GENERAL COMMENTS	The authors have systematically addressed almost all the points made. Thank you. My one (minor) outstanding question concerns the extra detail about the analysis. The revised section presents a text book account of the analytic process as one that was wholly inductive. Does this fit with the study as described? My assumption was that consulting with the advisory group was done to inform data collection, organisation and its interpretation. If not, then why involve them in this way? Be interesting to know for example if the analysis considered if participants'accounts confirmed, augmented or disagreed with the advisory group experiences.

VERSION 2 – AUTHOR RESPONSE

Reviewer(s)' Comments to Author:

Reviewer: 3

My one (minor) outstanding question concerns the extra detail about the analysis.

The revised section presents a text book account of the analytic process as one that was wholly inductive. Does this fit with the study as described?

My assumption was that consulting with the advisory group was done to inform data collection, organisation and its interpretation. If not, then why involve them in this way? Be interesting to know for example if the analysis considered if participants' accounts confirmed, augmented or disagreed with the advisory group experiences.

- We’ve clarified how input from the advisory and steering groups was used to develop the initial interview topic guide (in the revised patient and public involvement section).