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**ARTICLE DETAILS**

<b>TITLE (PROVISIONAL)</b>	How people with dementia and carers understand and react to social functioning changes in mild dementia: a UK-based qualitative study
<b>AUTHORS</b>	Singleton, David; Mukadam, Naaheed; Livingston, Gill; Sommerlad, Andrew

**VERSION 1 - REVIEW**

<b>REVIEWER</b>	Rowan Harwood Nottingham university hospitals UK
<b>REVIEW RETURNED</b>	23-Mar-2017

<b>GENERAL COMMENTS</b>	<p>1. This is an interview study of people with mild dementia and their family carers about 'social change'. People with dementia cited embarrassment, loss of interest, physical illness and fear of falling, and often attributed this to 'dementia'. Carers cited 'choice', death of peers, and personality. Need for additional carer support when out, carer strain and diminishing opportunity were barriers.</p> <p>2. The topic is of considerable importance. Dementia is a major public health problems, the philosophy of person centred dementia care seeks to give proportionate importance to biographical, personality and activity (broadly 'social') factors alongside medical, medication, neuro-psychological, and comorbidity factors. We need to research ways of helping people live better with dementia.</p> <p>3. Only 9 patients and 9 carers were interviewed, but authors state that theoretical saturation was achieved (ie no new themes were emerging from additional interviews). This seems unlikely given the diversity of the population ('range of age, ethnicity and educational background'); authors should justify.</p> <p>4. That said, this is a difficult population to study and interview, and the authors are to be congratulated in recruiting as many participants as they did.</p> <p>5. The authors conclude that 'clinicians should ask about social change'. There may be a role for (increasingly rare) community mental health teams or an expanded role for occupational therapy; otherwise it is unclear what 'clinicians' might do in response, other than explain and sympathise. The most beneficial reported intervention from the data appeared to be the social aspects of CST groups. Or do we need new and more comprehensive types of intervention?</p> <p>6. The introduction is rather carelessly written, with a lack of precision in the use of language nor critical awareness</p>
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	<p>a. p4 line 7 how is social withdrawal, and loss social networks and activities a 'coarsening of social behaviour'?</p> <p>b. p4 line 18 forgetfulness and memory loss are the same thing.</p> <p>c. p4 line 20 is it really true to say that memory loss is attributed to 'the person with dementia wilfully changing their behaviour'?</p> <p>d. p4 ll 26-30. Whilst it may be true that increasing social contact slows cognitive decline, it is equally likely that the relationship is the other way round (less cognitive decline enables more social contact).</p> <p>e. p4 30-33 'dementia characteristics are commonly attributed to normal ageing, or other health problems including physical mental and chronic health conditions and medication rather than the illness itself, leading patients and carers to believe that nothing can be done to help'. This is a vague, poorly specified, and possibly unjustified sentence, ending with a non-sequitur (it is likely that more can be done if problems are due to a co-morbidity or medication than dementia).</p> <p>7. p5 ll 37-47 How was 'social life' defined in the interview schedule? Hobbies and activities may or may not be 'social' (they could be solitary)</p> <p>8. Technical methods and ethical aspects are sound.</p> <p>9. p6 ll32-36 The 'social activities' described are unsurprising: loss of leisure occupation, communication and executive difficulties, and irritability.</p> <p>10. The analysis appears to have been well done, (apart from the query about criteria for theoretical saturation having been reached), and the findings are credible, if unsurprising. But nice to have them documented like this.</p> <p>11. p10 l47 'the dementia team' – explain (including for an international readership)</p> <p>12. A number of new findings appear in the discussion (that those who attributed activity change to dementia had more positive responses). These should be in the results. The discussion is otherwise good</p> <p>13. Kitwood held that people with dementia required additional help to experience wellbeing: an 'enriched' social environment, in which much of the effort in maintaining relationships and occupation had to come from the carer (informal or professional). This study would appear to support this. The findings could equally well fit with a bio- psychosocial of comprehensive geriatric assessment framework. May be worth adding to the discussion</p>
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<b>REVIEWER</b>	Linda McAuliffe Australian Centre for Evidence Based Aged Care (ACEBAC) La Trobe University Melbourne, VIC, AUSTRALIA
<b>REVIEW RETURNED</b>	02-May-2017

<b>GENERAL COMMENTS</b>	<p>Thank you for this most interesting manuscript reporting on the attribution of social changes in dementia (and the consequences) made by people with dementia and their family carers. I recommend that the manuscript be accepted for publication. A few minor amendments are required:</p> <ol style="list-style-type: none"> <li>1. In the Results section - 'were predominantly white' (add the word who immediately before were)</li> <li>2. Page 10 - second last participant quote - 'has started to talk to be people again' (remove 'be')</li> <li>3. Page 11 - add full stop to end of the paragraph that begins with 'We found that...'</li> <li>4. Page 16 - Table 1 'time since diagnosis' section - change less than symbol to less than/equal to symbol for 6 months category (or change middle category to 6-12 months depending on how you have handled the data...)</li> </ol>
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### VERSION 1 – AUTHOR RESPONSE

Reviewer 1: Rowan Harwood

Institution and Country: Nottingham university hospitals UK

1. This is an interview study of people with mild dementia and their family carers about 'social change'. People with dementia cited embarrassment, loss of interest, physical illness and fear of falling, and often attributed this to 'dementia'. Carers cited 'choice', death of peers, and personality. Need for additional carer support when out, carer strain and diminishing opportunity were barriers.
2. The topic is of considerable importance. Dementia is a major public health problems, the philosophy of person centred dementia care seeks to give proportionate importance to biographical, personality and activity (broadly 'social') factors alongside medical, medication, neuro-psychological, and comorbidity factors. We need to research ways of helping people live better with dementia.

Thank you for your comments and review of our paper.

3. Only 9 patients and 9 carers were interviewed, but authors state that theoretical saturation was achieved (ie no new themes were emerging from additional interviews). This seems unlikely given the diversity of the population ('range of age, ethnicity and educational background'); authors should justify.
4. That said, this is a difficult population to study and interview, and the authors are to be congratulated in recruiting as many participants as they did.

We agree that the study sample was relatively small but this is acceptable for qualitative research as we sought detailed information from participants. Regarding our judgement that we reached theoretical saturation during our interviews, we found that, in our later interviews while participants continued to report different specific social activities, we did not obtain new attributions for changes in these domains. Further interviews with a larger sample may, therefore, have yielded other social activities, but were unlikely to result in novel attributions. We have added information on this in the 'limitations' section (see below) and we also acknowledge that our findings may be specific to the particular study population – i.e., other attributions may have been found in more severe dementia or a non-clinical sample.

"Whilst participants continued to describe a range of previously-enjoyed social activities, our latter interviews did not yield new or different attributions for reduced engagement in them, indicating we had reached theoretical saturation regarding our primary objective in our study sample."

5. The authors conclude that 'clinicians should ask about social change'. There may be a role for (increasingly rare) community mental health teams or an expanded role for occupational therapy;

otherwise it is unclear what 'clinicians' might do in response, other than explain and sympathise. The most beneficial reported intervention from the data appeared to be the social aspects of CST groups. Or do we need new and more comprehensive types of intervention?

We agree with this and your later point regarding the clinical implications of this research. CST may act directly to improve social functioning but we think that exploring this will be an objective in future research into CST. Specific targeted interventions for patient and carer could aim to improve social function and subsequent clinical outcomes and we have added this to the 'clinical implications and further research section.

"...the social consequences of CST should be studied in future research. Additionally, there may be a role for new interventions specifically targeting improved social function to improve quality of life and to study how this links with other clinical outcomes."

6. The introduction is rather carelessly written, with a lack of precision in the use of language nor critical awareness

a. p4 line 7 how is social withdrawal, and loss social networks and activities a 'coarsening of social behaviour'?

We have amended the language in this section:

"...decline in everyday activities, such as withdrawal from previously-established social networks, loss of social activities..."

b. p4 line 18 forgetfulness and memory loss are the same thing.

Thank you for pointing this out, we have edited this sentence.

c. p4 line 20 is it really true to say that memory loss is attributed to 'the person with dementia wilfully changing their behaviour'?

The research literature in this area reports that carers frequently believe that a range of behaviours and symptoms are controllable. The Paton et al (2004) reference found that 27% believe memory loss to be 'controllable some or all of the time' and other symptoms such as aggression, apathy, and hallucinations or delusions were even more frequently thought of as controllable. We have however, amended the language used here:

"...frequently misattributed or co-attributed to other causal factors including the person with dementia having some control over their behaviour."

d. p4 ll 26-30. Whilst it may be true that increasing social contact slows cognitive decline, it is equally likely that the relationship is the other way round (less cognitive decline enables more social contact).

We agree that there is likely to be a bidirectional relationship between social and cognitive decline, although for the purposes of this introduction, we have focused on the potential clinical benefits of improving social function. We have simplified this sentence and added a caveat regarding the potential causal direction:

"More social contact has been associated with cognitive improvement in people with early cognitive changes (18, 19), and better quality of life within dementia (20). This suggests, despite social functional decline being characteristic of dementia, that there is a possibility that facilitating increased social contact in people with dementia may improve disease outcomes."

e. p4 30-33 'dementia characteristics are commonly attributed to normal ageing, or other health problems including physical mental and chronic health conditions and medication rather than the illness itself, leading patients and carers to believe that nothing can be done to help'. This is a vague,

poorly specified, and possibly unjustified sentence, ending with a non-sequitur (it is likely that more can be done if problems are due to a co-morbidity or medication than dementia).

Thank you, we have edited this sentence to better convey our intended meaning. Incorrect attribution of early dementia symptoms to other causes may delay diagnosis and treatment of dementia. As you suggest, identification of treatable factors is also important so we have added this to the paragraph: "Social functioning changes can be an early symptom of the condition so timely recognition of such changes may facilitate earlier access to diagnosis and care (21, 22). Dementia characteristics are often attributed to normal aging or other physical, mental and chronic health conditions (7-10), leading to missed or delayed diagnoses (21). Health problems (23, 24) or medication (9, 25) contributing to social decline may also be neglected, resulting in missed opportunity to manage treatable factors."

7. p5 ll 37-47 How was 'social life' defined in the interview schedule? Hobbies and activities may or may not be 'social' (they could be solitary)

We have added to this section. We used case vignettes of characteristic social changes to introduce our areas of interest for interviews. In the interview guide, we used general language in order to obtain a wide range of information from our participants. However, we were most interested in changes to activities with a strong social component, rather than solitary activities, so in our questioning, we pursued these topics.

8. Technical methods and ethical aspects are sound.

9. p6 ll32-36 The 'social activities' described are unsurprising: loss of leisure occupation, communication and executive difficulties, and irritability.

10. The analysis appears to have been well done, (apart from the query about criteria for theoretical saturation having been reached), and the findings are credible, if unsurprising. But nice to have them documented like this.

We agree that, from our clinical experience, these areas are expected, but these findings have not been previously identified in the research literature and we believe that our analysis of patient/carer attribution of these changes and the consequences also adds to the literature.

11. p10 l47 'the dementia team' – explain (including for an international readership)

To clarify this, we have added more information on the setting from which we recruited participants: "The study recruited from Camden and Islington NHS Foundation Trust, which is a UK National Health Service (NHS) mental health provider in a socially diverse population covering inner and suburban London. We recruited participants from the "Memory Services", where patients with suspected dementia are referred for assessment, treatment and ongoing support, including medication and individual and group psychological therapies."

12. A number of new findings appear in the discussion (that those who attributed activity change to dementia had more positive responses). These should be in the results. The discussion is otherwise good

We had introduced this theme in the results section (top of page 11 – quotes from C3, C4, C9B) such as this finding:

"The friend of a person with dementia noted that their recognition of the social consequences of dementia from observing their own mother's experience of the condition, had led to the positive consequence of both the patient and them making efforts to maintain social interaction."

13. Kitwood held that people with dementia required additional help to experience wellbeing: an

'enriched' social environment, in which much of the effort in maintaining relationships and occupation had to come from the carer (informal or professional). This study would appear to support this. The findings could equally well fit with a bio-psychosocial of comprehensive geriatric assessment framework. May be worth adding to the discussion

Thank you – we have added this to the discussion, as below. This is the cornerstone of geriatric (and geriatric psychiatry) assessment, but it may be that further attention should be given to exploring reasons for social functional changes, in addition to provision of social support for activities of daily living etc.

“This approach fits with the ‘biopsychosocial model’ used in older adults’ medicine and psychiatry, in which holistic care is provided by attending to physical, psychological and social needs. As people with dementia frequently lack insight into their condition, and the cognitive and behavioural symptoms impair their ability to manage or change their own behaviour, the input of family carers or healthcare professionals is frequently required to make lasting and meaningful improvements to the social function of a person with dementia (the ‘enriched environment’ advocated by Kitwood.)”

Reviewer 2: Linda McAuliffe

Institution and Country: Australian Centre for Evidence Based Aged Care (ACEBAC), La Trobe University, Melbourne, VIC, AUSTRALIA

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2.

RESPONSE:

Thank you for your comments on our paper – we have made the changes you have suggested.

#### VERSION 2 – REVIEW

<b>REVIEWER</b>	Linda McAuliffe Australian Centre for Evidence Based Aged Care (ACEBAC), La Trobe University, Australia
<b>REVIEW RETURNED</b>	24-May-2017

<b>GENERAL COMMENTS</b>	The authors have satisfactorily revised the manuscript in accordance with the reviewers' comments
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#### VERSION 2 – AUTHOR RESPONSE

Reviewer: 2

Reviewer Name: Linda McAuliffe

The authors have satisfactorily revised the manuscript in accordance with the reviewers' comments

Thank you for your review and comments on our paper.

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# How people with dementia and carers understand and react to social functioning changes in mild dementia: a UK-based qualitative study

David Singleton, Naaheed Mukadam, Gill Livingston and Andrew Sommerlad

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