People with dementia in research: the challenges for participation and collaboration

Linda Birt¹, Georgina Charlesworth², Claudio Di Lorito³, Jacob Waite⁴, Paul Higgs⁴, Phuong Leung⁴, Fiona Poland¹

1 School of Health Sciences, University of East Anglia; 2 Clinical, Education and Health Psychology, UCL; 3 Faculty of Medicine, University of Nottingham; 4 Division of Psychiatry, University College London

The research challenge:
- A dementia diagnosis need not instantly impact on capacity to give informed consent.
- Specialised ethical review committees, although designed to prevent harm, may reduce autonomy and agency for people with dementia.
- Consent can be assessed in different ways throughout the research (Dewing 2007).
- Family, friends or health care workers seem to anticipate risk of harm and distress and so reduce access to research for the person with dementia (Hellström et al. 2007).
- Peer researchers, ‘experts by experience’, bring specific knowledge to the study, but it is unclear how this resonates with the knowledge of academics, ‘experts by education’.
- Peer research involving people with dementia is rarely undertaken.

Table developed from literature review and discussion with European Working Group of People with Dementia (Di Lorito et al, 2017)

<table>
<thead>
<tr>
<th>Population</th>
<th>Potential benefits</th>
<th>Potential challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer-researchers</td>
<td>Feeling they are contributing to change</td>
<td>Emotional overburden</td>
</tr>
<tr>
<td></td>
<td>Relocation within the social sphere</td>
<td>Difficulty in conforming to protocol</td>
</tr>
<tr>
<td></td>
<td>Reduced stigma</td>
<td>Difficulty interpreting what participants say</td>
</tr>
<tr>
<td></td>
<td>Reduced isolation</td>
<td>Difficulty responding appropriately to participants</td>
</tr>
<tr>
<td>Academic researchers</td>
<td>Better understanding experience of living with dementia</td>
<td>Relinquishing power</td>
</tr>
<tr>
<td>Research participants</td>
<td>Feeling more comfortable to open up</td>
<td>Becoming distressed by comparing own skills to the peer-researcher’s</td>
</tr>
<tr>
<td></td>
<td>Helping to accept new dementia identity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reduced stigma</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Feeling more understood given shared lived experience</td>
<td></td>
</tr>
</tbody>
</table>

The realities of developing peer research in a dementia study:
- In the PRIDE study we aimed to work with 8 people with dementia as peer researchers supporting data collection.
- We had two expressions of interest in the role but carer concerns for the potential peer researcher meant undertaking interviews in participants’ homes was not possible.
- People who supported our recruitment were not always confident that this was a role that people with dementia could undertake.
- Expanding the peer researcher role to include data analysis by sharing case studies in group meetings.
- Using the COM-B model (capabilities, opportunities and motivations) to explore attitudes to peer research in dementia studies (Waite, 2017).
- More fully integrating peer researchers in the development of the research may mitigate some of the challenges experienced in this research method.

References:

Further details from Dr Linda Birt
Linda.birt@uea.ac.uk 01603 593298

The work was supported by the Economic and Social Research Council/ National Institute of Health (grant number ES/L001802/1). This paper presents independent research funded by the ESRC/National Institute for Health Research (NIHR). The views expressed are those of the author and not necessarily those of the NHf, the NIHR or the Department of Health.

What is peer-research?
Peer-research is involving the people with experience of the condition in doing research alongside academics.

“So what happens to the research does it just go on the shelf?”
Male, 85, living with dementia

“Mum really would be interested but physically she’s not very steady on her feet. I wouldn’t be happy for her to be getting in a taxi, or travelling in another car”
Daughter of 80 year old lady with dementia

“It’s exciting, it’s incredibly frustrating, but it has the potential to be empowering”
University researcher

“I think the peer researcher with dementia could get harmed. Because you don’t know what’s going to be thrown at them do you? I think it’s a bit dangerous, not physically, but mentally, I think it’s a bit dangerous”
Care worker who is a peer researcher