

Involving people living with dementia in the validation of analysis of qualitative interviews – the Journeying through Dementia Trial

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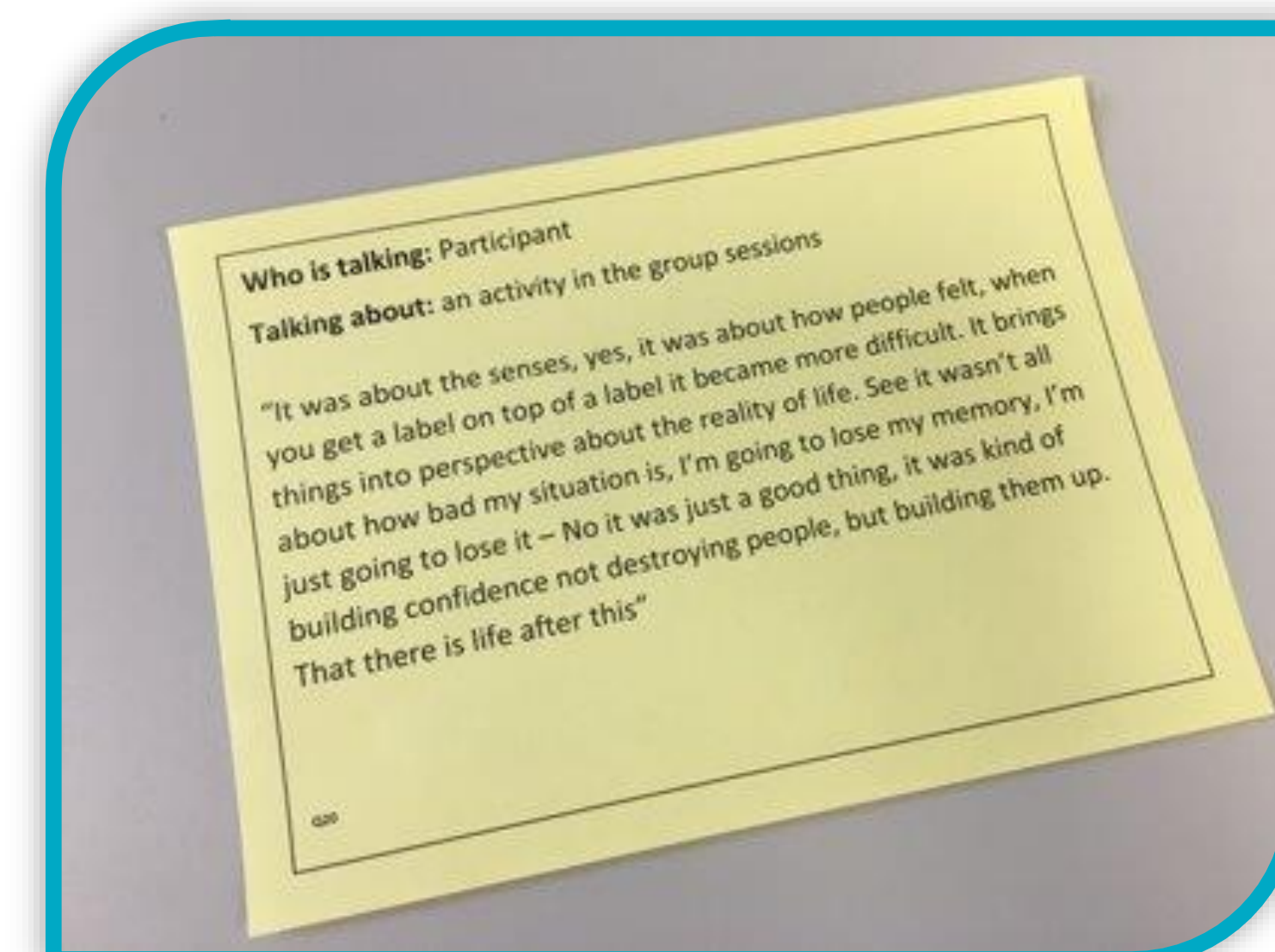
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Background

The value of patient and public involvement in research is well documented. However, the involvement of people living with dementia is relatively new. Whilst PPI engagement empowers and values the voice of lived experience, there is also a need to understand how best to create meaningful opportunities in situations where engagement can be challenging. We reflect on our experience of conducting co-researcher workshops with people living with mild dementia and their carers as part of the Journeying through Dementia (JtD) trial.

Methods

- Two half day workshops were conducted with people living with dementia and their carers.
- 16 people attended either one or both workshops.
- Recruitment was through the JtD trial Advisory Group of people living with dementia and volunteers from the Bradford Experts by Experience cohort.
- Workshops involved discussions of interpretations of anonymised qualitative interview data.
- Twenty quotations (9 in workshop one, and 11 in workshop two) were reviewed and interpreted.
- Guidance was provided on the activity.



Findings

Factor	Approach	Reflection
Type of activity chosen	<ul style="list-style-type: none"> • We proposed a 'card sort' activity in which quotation would be presented and then organised into themes. • Planned for mixed and split group sessions to enable the different voices (those living with dementia and their carers) to be heard creating more equality and different perspectives. • A working pace was set reflecting the abilities of the participants. 	<ul style="list-style-type: none"> • Card sort activity rejected at the first workshop due to cognitive capacity of the people living with dementia. Instead employed a simpler approach looking at one quote at a time. • We only ran mixed groups, split groups were not appropriate based on level of cognition and participant preference. • Future workshops could use paired activity (person with dementia with a researcher), although this would be more resource intensive.
How guidance was provided	<ul style="list-style-type: none"> • Informal style to create a comfortable environment. • Presented a summary of the study and the purpose of the workshops with time for questions. • Worked through examples of the task all together using a step-by-step approach with guidance and prompting to practice the exercise and establish a baseline of engagement. • The workshop lead used paraphrasing and summary reflection as a tool to elicit understanding. 	<ul style="list-style-type: none"> • Using ongoing evaluation and participant feedback was essential. • Allowing some time and space for open discussion helped the group bond and gave confidence to members to speak within the group environment. This needs to be balanced against fatigue and completion of the task. • Although the researchers considered use of language and terminology before the workshop, it was more difficult to do this during the discussion. Facilitator checking could identify issues during delivery.
Presentation and engagement	<ul style="list-style-type: none"> • Quotation printed in a format to support those with visual impairments. • Provided factual contextual information for each quote. • Individual copies provided to prevent confusion and help focus. • Decided on the day which quotation to include based on the ability of those present. • Started with simpler quotes moving to more complex quotes to allow learning and to build confidence. • We managed the quotation one at a time. 	<ul style="list-style-type: none"> • Providing context for quotation could have influenced interpretations. However without the wider context co-researchers sometimes misunderstood a quotation. Information given should make the task accessible for co-researchers with dementia. • Discussion was generally led by the carers, people with dementia needed more prompting to engage them in the activity. • Variability within the group meant it was complex to ensure the task was engaging to everyone but not patronising.

Discussion



Beresford-Dent J, Sprange K, Mountain G, Mason C, Wright J, Craig C, Birt L. Embedding patient and public involvement in dementia research: Reflections from experiences during the 'Journeying through Dementia' randomised controlled trial. *Dementia* (London). 2022 Aug;21(6):1987-2003. doi: 10.1177/14713012221106816.

- The workshops were delivered with a degree success.
- Overall carers were better able to engage than people living with dementia due to cognitive challenges.
- Practical considerations included venue choice, format of session and style and content of communication
- Other considerations included the type of activity chosen, how guidance is provided and expectation of engagement.
- The activity was complicated by individuals' symptoms of dementia and ultimately their ability to maintain engagement in the workshop.
- A range of approaches were needed to support and maintain engagement.
- Although our co-researchers were able to engage to a degree with the activity offering valuable insight and observations to our analysis, those contemplating co-research with people living with dementia need to consider the planning and preparation of any activity, as well as the need to be adaptable to individual needs.

