What motivates patients and carers to participate in dementia studies?

Emma Law and colleagues used the participation chain model to analyse why people took part in research, and why they might not want to co-operate in future

Abstract

Aim The aim of this study was to explore what motivates people to participate in dementia research.

Method Three focus groups, attended by carers and people with dementia who had already volunteered to take part in dementia research, were used to explore motivation. Their thoughts and feelings about brain tissue donation were also explored. An adaptation of the participation chain model was used. A fourth focus group was given a supplementary questionnaire examining use of resources. Focus group content was analysed using a content analysis approach to identify themes.

Findings Individualistic motivations included increased confidence and a chance to have a say. Collectivistic motivations included ‘helping through being part of something bigger’. Mobilisation (catalysing) issues included a desire for change, and ‘being asked’. In response to the questionnaire participants identified that they would have taken part regardless of any tangible benefits, with all saying that they would not have been put off by any of the costs.

Conclusion Participants in these focus groups were keen to be involved in dementia research and discounted any potential costs to themselves. They highlighted that being asked was an important factor in engaging them in dementia research.

Keywords Dementia, motivation, participation, research
undertaken by Involve (Brodie et al 2009) has derived a framework for understanding individuals’ pathways through participation (Figure 2), which is useful to consider in the context of the focus groups discussed in this article.

**Aim**
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**Method**
The researchers sought to analyse the contents of focus group meetings to identify what they had in common with the participation chain model.

A focus group is, in essence, a group interview (Petty et al 2012) on a particular subject – dementia research – involving ideally between five and 13 people (Matthews and Ross 2010).

The focus group methodology was chosen because it can provide an in-depth understanding of people’s views and experiences (Gilbert 2008). Morgan (1993) hypothesises that focus groups should be used when exploring complex behaviours and motivations as well as the degree of consensus on a topic.

In this study three groups were used that had been set up to discuss aspects of the development of the Scottish Dementia Clinical Research Network (SDCRN), including their views on a recently developed dementia brain tissue bank in Scotland to which SDCRN staff ask people to donate post-mortem tissue. Participation in a focus group was used as an example of participation in research. The elements of the participation chain (resources, mobilisation, and individualistic and collectivistic motivation) were adapted iteratively for a fourth focus group. This is a common methodology used in social research where themes are developed incrementally by repeating and then
adjusting the questions depending on the results from each wave (Bryman 2008). Here, the elements of the participation chain were examined more directly, although the recruitment process for the fourth group was no different than that for the preceding three groups.

Participants were chosen from the Scottish Dementia Research Interest Register (SDRIR), which comprises people with dementia and their carers who have consented to be approached about dementia research, and who had previously expressed an interest in being contacted for inclusion in a focus group. Methods of recruitment to the SDRIR are described elsewhere (Law et al 2013). Participants were invited to attend by letter with accompanying information about the rationale for the focus groups and expectations of researchers and participants. Informed consent was sought either from participants or from their power of attorney or nearest relative.

Each focus group took place in separate health board areas of Scotland (Table 1): NHS Greater Glasgow and Clyde (FG1), NHS Dumfries and Galloway (FG2), NHS Grampian (FG3) and NHS Lothian (FG4). All were taped and transcribed. The groups were held on health board premises. Lunch was provided and travel expenses were reimbursed. The focus groups lasted, in total, between 60 and 90 minutes, were facilitated by two SDCRN staff and were taped with everyone’s consent. There was an opportunity to ask the facilitators questions during lunch. These were not taped.

The specific questions about dementia research put to the first three focus groups were:
1. What do you think of the role of the SDCRN in research?
2. Why did you agree to participate in this focus group?
3. What are your expectations of participating in a focus group?
4. What are your thoughts and feelings around brain tissue donation?
5. Would the group be interested in having a further meeting?

Transcripts of the focus groups were analysed using a content analysis approach to identify themes. The text was coded for themes that generated a coding schedule and coding manual.

**Ethical considerations** Ethical approval to contact people on the SDRIR was obtained from Scotland A Research Ethics Committee, which specialises in issues where research participants may lack capacity. Ethical approval to conduct the specific research concerning the participation chain was granted by the research ethics committee of the University of Stirling.

**Findings**

The groups took place between August 2011 and April 2012. Table 1 shows the number of participants by health board area. This article presents results from answers to questions 2 and 3, set out in elements of the participation chain.

**Motivation** Individualistic motivations with positive benefits for participants were expressed in all the focus groups (FGs): increased self-confidence; a sense of achievement; a chance to have a say; feeling more in control; and a valuable learning experience:
- ‘I think that new research is to find out what does help’ (FG1, C).
- ‘I want to grab every bit of information I can’ (FG3, C).

Collectivist motivations were more difficult to separate into discrete codes, as they often overlapped: a sense of community; shared values; and shared goals:
- ‘I’m pro any organisation or any person that will do anything to help us with the problem we have' (FG1, C).

To understand these motivations more fully, the responses were coded in terms of ‘self-interest’, ‘collective self-interest’ and ‘collective interest’:
- ‘Spreading the research that’s being done. I would be very interested to know what is being done and what might be being done’ (FG2, P).
- ‘We have got to open that door and by the SDCRN we can open that door’ (FG2, C).

**Mobilisation** Mobilisation issues varied across the groups but the areas that were coded for included: a negative relationship with services; a desire for change; a sense of deprivation; and being asked:
- ‘We’ve been involved with a pilot scheme of Global Positioning System because my wife went AWOL one night, which caused a bit of uproar one way and another’ (FG4, C).

**Resources** Analysis of the first three focus groups revealed that comments on ‘motivation’ and ‘mobilisation’ dominated the content. To amplify

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<th>Table 1 Focus group composition</th>
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<td>Focus group (FG)</td>
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resources’ a brief supplementary questionnaire was developed for participants of the fourth group, administered on arrival, to determine educational level, benefits and costs of participating. Questions were adapted from Birchall and Simmons (2004), which applied the participation chain to social housing and community care participants. The question: If there were something else you could be doing, would this put you off participating? yielded a unanimous ‘no’. The questionnaire is available from the first author on request.

The fourth focus group The elements of the participation chain were adapted iteratively for a fourth focus group, and were examined more directly and with a greater focus on participation and motivation. Additional questions asked were: What made you decide to participate today? Can you identify any benefits to participating? Can you identify any barriers to participating in research, either for you or the person you live with? What resources do you need to participate? Would it be useful to have training? The same themes appeared, but were more prevalent.

Individualistic motivation

■ ‘You want to know more about research and developments and hear from the experts’ (FG4, C).
■ ‘Whether we are being guinea pigs and I don’t mind that at all for research’ (FG4, P).
This group was keen to discuss in detail negative aspects of research participation:
■ ‘The downside to the participation is that we haven’t ever had any results’ (FG4, C).
■ ‘Sometimes I feel I don’t want to hear another word about dementia. I’ve had enough. I do enough’ (FG4, C).
■ ‘The other problem is a lot of the couples I know their husbands have toilet problems and need to get to a toilet quick but you know it limits where you can go and what you can do, you know, going out’ (FG4, C).
■ ‘Not too early in the morning because it takes me hours to get ready and you know’ (FG4, C).
■ ‘Well, I’ve been up since what, about 7 o’clock just to come here for 11’ (FG4, C).

Collectivistic motivation

■ ‘We are part of something bigger than that and there is a researcher attached to this at the university and it feels like our experience matters on a wider field as well as of great benefit now for us’ (FG4, C).
■ ‘It’s nice to be able to relax in the company of people who understand’ (FG4, P).

Mobilisation

■ ‘We’ve been involved with a pilot scheme of Global Positioning System because my wife went AWOL one night, which caused a bit of uproar one way and another’ (FG4, C).
■ ‘I think some people are just horrified at the thought and I can’t see why but that’s something that needs to be thought about, why people are so against the idea and I think it’s probably that they just don’t realise what it’s all about’ (FG4, C).

Resources

■ ‘You’re not looking to gain but you don’t want to be out of pocket at the same time. Sometimes we’re lucky that my husband is at a day centre today but if he wasn’t I would have had to arrange care’ (FG4, C).
■ ‘Also they would discuss it with their groups perhaps before they went. Build up a little more confidence, you know, I’ll go if you go’ (FG4, C).
The statement that ‘being asked’ was an important factor in their decision to participate in the focus group appeared consistently:
■ ‘There was such a nice person phoning me up and I just got talked into it – does that answer it? (laughter)’ (FG4, P).
■ ‘Well being asked and seeing it as somewhere to say how I feel about it and find out how other people feel about it’ (FG4, C).
■ ‘So I say when this focus group was mentioned, I thought, “oh, in for a penny, in for a pound”’ (FG4, C).

Discussion

Study limitations include the possibility of selection bias. Participants had already shown an interest in dementia research because they were drawn from the SDRIR. Therefore, non-participants were not studied. Understanding why people do not participate would be useful for further dementia research, with the ultimate aim of including 10 per cent of those with a diagnosis (DH 2012).
The strengths of this study are that time was spent on the primary analysis of the first three FGs and, through an iterative process, the questions for the fourth group were subsequently shaped. The questions were well designed, fit for purpose and focused. The study also provides a ‘proof of concept’; that using a theory originally intended for a different group in the social care sector can be adapted for use with people with dementia and their carers.
Themes from the participation chain model appeared spontaneously in interactions between members about taking part in focus groups. Anger at the sense of deprivation – for example, people...
thought they were not getting access to treatments that worked or services that were appropriate or missing out on a happy retirement with their spouse because of dementia – and the limited drug treatment opportunities in this area of research proved strong motivating factors for participation. However, ‘being asked’ was unanimously agreed as the best motivator to participation, while a sense that research results were not communicated to participants was a strong negative factor against future participation.

‘Being asked’ was an interesting finding considering that brain tissue donation was discussed. In all the focus groups, no participants said they would not consider brain tissue donation either for themselves or for the people they advocated for. There was considerable discussion on this issue but in all four of the groups the consensus was that participants would consider brain tissue donation. Most said they had not previously considered this option of engaging in research.

The participation chain model identifies elements that may be common to engagement in many types of dementia research. Elad et al. (2000) studied caregivers’ role in patients with dementia participating in pharmaceutical studies. The main reason caregivers gave for encouraging participation was the belief it would help or improve patients’ dementia. The primary reason for refusal was worry about potential side effects of drugs, such as physical illness. Mastwyk et al. (2003), also studying caregivers, identified a desire for improvement in patients, possible cure and living a good quality life for longer as prime motivating factors. This was reflected in the present study by the perception that not participating in dementia research was a form of deprivation.

Grill and Karlawish (2010) examined the challenges of successfully recruiting and retaining people in Alzheimer’s disease clinical trials. They found a number of positive factors associated with research involvement for people with dementia and their carers: having access to informed consent; gaining access to new treatments; and feelings of altruism. Factors that put people off engaging in research included: having a comorbid physical illness; not knowing what trials were available to them; risk of side effects; risk of allocation to the placebo arm; intrusive procedures such as lumbar puncture; and excessive travel. This point was also highlighted by McMurdo et al. (2011) who emphasised the importance of planning and logistics in optimising research participation in older people.

This finding was echoed in the present study in discussions about the careful consideration needed when planning the time and place for research so that people could attend.

Further insights into participation were gleaned by Grill et al. (2013), who found that people with dementia who had enrolled with a spouse carer were less likely to drop out of the study. It was hypothesised that people who did not have a spouse partner would require more input from the study team to participate and to prevent drop out during the research. Therefore, many of the practical considerations described by the groups in the present study are likely to be equally important for carers, such as good facilities with ease of toilet access, ease of parking and not starting too early.

Connell et al. (2001) identified cultural differences in caregivers’ attitudes to family members with Alzheimer’s disease participating in dementia research. For example, in their study of African-American and white caregivers they noted scepticism about the research process and suspicion in attitudes about medical treatment and help-seeking in the African-Americans, whereas the white caregivers were more concerned about problems with procedures and tests and lack of time and resources.

Researchers must be sensitive to barriers to participation that may be cultural in origin and consider how they can encourage meaningful participation. Participants in the present study, for example, still felt a sense of stigma surrounding dementia. Smith et al. (2009) stressed the importance of direct communication with potential participants in their project on user involvement in a systematic review. Minogue et al. (2005) found that by contacting people directly the number willing to be involved increased. In the present study ‘being asked’ was an important motivator to participation. This is corroborated by Verba et al.’s (2000) rational action theory, which suggested that those most likely to participate were those who were asked.

A 30-month qualitative research project, led by the National Council for Voluntary Organisations in partnership with the Institute for Volunteering Research and Involve, investigated ‘how and why individuals get involved and stay involved in different forms of participation, to improve knowledge and understanding of people’s pathways into and through participation and of the factors that shape their participation over time’ (Brodie et al. 2011).

Although not specific to dementia research, the findings (Box 1, page 36) are relevant when considering the motivations and understanding of people with dementia and their carers in participating in dementia research. Smith et al. (2008) found that there was much to learn about what user involvement is, what works best and why, and the importance of researchers’ own education and training. Minogue et al. (2005) found that service
users involved in research thought the experience enjoyable and valuable and that the numbers participating because of their direct involvement increased. However, a cost, which was reflected in the present study, is that lack of feedback was perceived as a negative issue: ‘it would be good if we had some feedback but no one gives you any’ (FG2, P).

Identifying and rectifying negative aspects of research participation, such as lack of feedback, is useful in planning research and affects motivation to participate. Connell et al (2001) found that lack of feedback on short and long-term results in previous study participation had put off family members from encouraging their relatives’ participation in future studies. Understanding people’s motivation to participate and predicting who will participate will have the final outcome of allowing research projects to be completed with minimal people failing to complete the study. This will increase the strength, validity and cost effectiveness of these projects.

Implications for practice
The implications for nursing practice are fourfold. First, it is important that nurses do not assume that people with dementia, or their carers, will lack motivation to be part of research. Second, nurses should be aware that motivation in itself is not a potent enough factor to ensure participation. It is essential that the desire to participate is amplified through nurses’ ability to mobilise a research resource, for example, to be aware of potential research studies and inform patients based on the views they have expressed about research. Third, they need to be aware of the powerful effect of ‘being asked’ to participate once motivation has been established. Finally, they need to consider what provisions need to be made, for example, transport, to aid participation. In these respects, research may not be different to engagement in other therapeutic relationships with patients. This hypothesis warrants further investigation.

Conclusion
This study used the participation chain model to explore why some people with dementia and their carers take part in research and barriers to participation. Focus group participants were supportive of dementia research. They highlighted that being asked to participate was an important factor in engaging them, as were practical considerations about access and transport. Understanding what motivates people to participate can be increased by applying the theory-based approach of the participation chain. This model could be applied to inform future research.

References


