A guide to ensure client participation in research on people who suffer from dementia

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Methodieken ClientenParticipatie

Lectoraat Autonomie en participatie van chronisch zieken

July 2016

Background

Dementia is, within Western countries, a problem on the rise. For example; an estimated 5.2 million people of 65 years and older suffer from dementia in the U.S. This number is expected to triple in the next 40 years, which will also be the case in Europe. The magnitude of this problem on the rise and the consequences have a significant impact on healthcare – costs –, quality of life of patients and caregivers.

Therefore, much research is needed concerning diagnosis, treatment, quality of life in people with dementia. However, people with dementia are one of the most excluded groups from research (Hellström, Nolan, Nordenfelt & Lundh, 2007). In particular, knowledge about perceptions and experiences of people with dementia regarding quality of care is lacking. Several reasons for this exclusion are the stigmas these people are subjected to, based on their cognitive impairment, frailty and loss of autonomy. Other key obstacles to involving people with dementia are: unable to provide informed consent to participate in research, engage in effective and trustworthy communication, and ensure validity of the data (Carmody, Traynor, & Marchetti, 2015). Ethics of involving people with dementia are also a point of attention, which will be addressed later in this report.

Yet, how can we conclude what is best for people with dementia, when we do not listen to what they have to say. After all, who else would know what it is like to have the disease? (Hellström et al., 2007, Robinson). Unfortunately people with dementia are often excluded from research and their voice is often ignored. Participation of people with dementia in research is rare but needed.

At this moment, research focuses on experiences of people with moderate to severe dementia is mostly derived from observational and questionnaire-based studies (Clare, Rowlands, Bruce, Surr, & Downs, 2008).

Involving people with dementia has many benefits. It can lead to a better fit between health care and people with dementia, which eventually leads to a better quality of life (Van Baalen, Vingerhoets, Sixma & Lange, 2010). Participation of people with dementia may be a way to decrease the stigmatization attached to this group. Only the people themselves could provide insight about experiences of care. Also, participation could lead to more autonomy and empowerment for people with dementia (Van Baalen et al, 2010). Especially people with early-stage, mild, dementia are able to participate in several forms of qualitative research methods, such as interviews or focus groups. The information provided has been shown to be meaningfully interpretable by others. People with dementia are according to many specialists and authors, perfectly capable of participating in research and expressing their feelings and talk about experiences with sufficient clarity (Van Baalen et al, 2010).

Ladder of participation model

To determine when and how a client can participate in research, a model has been developed, called the *participation ladder* (Arnstein, 1969). The participation ladder distinguishes different steps of participation and defines the level of participation. The higher on the ladder, the more influence the client has in research. Within the programme Methods of patient and public participation we use the ladder of Brinkhost and colleagues. The steps are based on Arnsteins model but simplified. Step 1: information, the client is being informed about the research. Step 2: consultation, the professional wants to know the opinion of the client. Step 3: advice, the professional listens to ideas of the client.

Step 4: partnership, the collaboration is based on equality. Step 5:client is in controle, the client determines goals / priorities of research (Binkhorst, Posma & Lobenstein, 2009).

To enable participation of people with dementia in research, this guide provides an overview of

- *Informed consent*
- *Types of design suitable*
- *Practical guidelines*

Informed consent: what to do

A problem in involving people with dementia in research is informed consent. A researcher can never be sure the patient is 100% informed and thus the goal of informed consent should be to maximally inform the patient. Approaches applied currently to ensure consent are too reliant on cognitive ability and could be harmful or threatening to the person with dementia.

A possible alternative to the traditional, exclusionary, consent method is the **process consent method** (Dewing, 2007). Achieving consent starts with checking whether permission to access the person with dementia has been gained from staff, relatives or other named persons. This is not proxy consent; it is merely permission for access. After permission, the basis for consent is established. This entails that the capacity to consent should be explored (e.g. person's level of wellbeing, how to recognize a person's therapeutic need, how a person consents to other activities). Then, the researcher should seek an initial consent for the specific research with the person with dementia. Generally, this step consists of providing information about the research.

The participants and family will sign the informed consent. Additional to this declaration, assent will be asked of the participants for specific research sections during the study. The person with dementia does not have to be informed about the entire research project; merely about a delimited part of the research, such as an interview. If the participant does not give permission for the specific part, the participant is excluded from this part of the study, even though he or she signed the initial declaration of consent (called: dissent). This person might be approached at a later point of time. The consent is recorded on tape to ensure transparency. If needed, family members or caregivers will be informed about particularities which occurred during research.

The definitions of assent and dissent (Slaughter, Cole, Jennings, Reimer, 2007):

Assent : 'the agreement to participate in research based upon less than full understanding' and 'the initial and ongoing willingness of the participants themselves to participate'.
Dissent : 'dissent has been equated with refusal to participate even when the proxy provides consent'.

Data collection methods

Several designs can be appropriate to use when involving people with dementia in research. For people with cognitive impairments, one can use both qualitative and quantitative research methods.

Possible designs used to involve clients with dementia in research:

- Individual interviews
- Questionnaires
- Focus group interviews
- Observations
- Proxy reports

Interview

The most common method when involving people with dementia is an interview. A face-to-face interview enhances the possibility to access meanings, perspectives, interpretations and embrace individual differences. These aspects are particularly important when doing research with people with dementia for they allow the assurance of a complete assessment of data. An interview can be used as research method for people with mild to moderate dementia.

An interview is more time-consuming than self-administration, both in terms of staff and respondent burden, but the savings of time needed to follow up on missing data and non-returned self-administered forms may somewhat offset these higher costs (Stewart et al., 1996). Interviews lead to rich and in-depth data, since the researcher can clarify the meaning of questions, ask for comprehension of questions and the interviewee can make spontaneous reflections. The researcher can adapt the questions to the communication style and ensure complete assessment of the data (Van Baalen et al., 2010).

However, a traditional research interview could be experienced as stressful for people with dementia (Bartlett, 2012). A reason for this could be concerns about being recorded and sounding inarticulate. In research, people with dementia, and other serious illnesses, could be more vulnerable and prone to marginalization. For this reason, other types of designs or adjustments to the traditional interview method could be used to involve people with dementia and get to know more about their feelings and quality of life.

People with dementia often are not able to participate in regular interviews (of approximately one hour). Therefore, more interviews could be conducted to gather the needed date. If interviews are conducted more than once, they need to be spaced close together to benefit memory (Clarke & Keady, 2002).

When using interviews as the research method, there exists a risk of receiving social desirable information, and a risk of interviewer bias (Van Baalen et al., 2010).

Questionnaires / self report

Questionnaires can be used to measure the quality of life in people with dementia. Two questionnaires which are often used for this goal are the Dementia Quality of Life questionnaire (DQOL) and the Quality of Life in Alzheimer's Disease questionnaire (QOL-AD) (Moyle, Murfield, Griffiths & Venturato, 2010). The questionnaires can be self-reported or be administered by a researcher / professional in an interview.
Questionnaires may be used to assess quality of life in people with mild to moderate dementia.

Advantages of this method is that it ensures confidentiality, anonymity and reliability.
It may however be problematic for these people to complete a questionnaire due to their cognitive problems and possible vision problems, reading or language problems as evidenced by the considerable number of missing data when self-administration is used (Stewart et al., 1996). Filling in the questionnaire could be too demanding or distressing for the person, which has to be taken into account when using this method.

Focus group

Another design to gather information from people with dementia is a focus group interview. This method can provide insight into how and why people think as they do (Van Baalen et al., 2010). Focus group interviews are used to provide information on how and why people think as they do. This method is particularly used for people with mild dementia.

A focus group interview is a less threatening method to hear and react to experiences of people with dementia. It is the interaction between people with dementia which could lead to more insight into feelings, since it can trigger recall of similar events or feelings.

Some disadvantages of the focus group interview are that they are time-consuming, and could be too stressful for people with dementia (Van Baalen et al., 2010).

Photo elicitation

People with limited expressive language capacity, which is one of the symptoms of dementia, can benefit from the use of photography to explore subjective experiences (Shell, 2014). In this type of research, photographs serve as the basis for an in-depth interview. People with dementia take photographs themselves, however, the researcher can choose the subject matter to be photographed and the people with dementia, choose the information they share via the photographs and the representation of their life and experiences. Photography can provide a bridge for people with dementia, since it offers a more complete picture of the individual's world by supplying information that might not have been obtained through interview only.

Photography can be communicative because it incites and conveys meaning. It can also be generative because new understanding might be created and deeper insight obtained through discussions about the photography. Photographs can serve as memory triggers and improve the person's ability to reflect and allow others to see the world through his or her eyes.

In a photo elicitation interview, open-ended questions are asked about the photographs. One photograph at a time is placed on the table. The participant is then asked to tell about each picture and how the picture for example represents happiness or sadness (Shell, 2014).

A disadvantage could be the use of the camera for people with dementia. Also, the time between taking the picture and the in-depth interview is difficult due to memory loss. Reflection regarding choices on what to photograph could be difficult as well for people with dementia, relating to difficulties in abstract thought (Shell, 2014).

Solicited diary method

A different design which could be used to involve people with dementia is the solicited diary method (Bartlett, 2012). This is a method in which people are asked to keep a regular record of their experiences over a period of time. It captures rich data on personal motives, feelings and beliefs in an unobtrusive way.

There are many advantages to the solicited diary method. Researchers can obtain specific, recent information when memory or recall might pose a problem. People with dementia who write in a diary can report on thoughts and feelings in their own way, on their own time and wherever they feel comfortable. Writing can be beneficial for people with early dementia, through rediscovering their sense of self, and releasing complex emotions by naming them. The diary method can offer participants the opportunity to take some control over the content and pace of data collection. When using the diary method, the person with dementia can play a role in the interpretation of the data themselves. The relationship of the person with dementia and the research study is stronger when using this method than when using a traditional interview.

A limitation could be that this method makes the people with dementia aware of their diminishing skills. It could also be difficult what to record in their diaries. Respondent fatigue could be another disadvantage of the method (Bartlett, 2012).

Observation

Observations are a research method which can also be used in research on people with dementia. This method can be used in mild, moderate and severe dementia. Its advantages include that spontaneous reflections can be made and rich, in-depth data can be gathered (Van Baalen et al., 2010).

However, it is a time-consuming method and requires a high personnel and therefore cost investment (in collecting and analyzing the data).

Proxy report

Dementia research is also often based on proxy reports. The reason to include proxies in research, and not the person with dementia is to prevent distress in the person with dementia and thus to protect the patient (Hellström et al., 2007). However, research has shown that there often are great discrepancies between the assessments made by the person with dementia and their proxy (Moyle, Murfield, Griffiths & Venturato, 2012). For example, the person with dementia is in general more positive about the quality of life than the proxy. There exists a difference in the quality of life perception between proxies and people with dementia. In research, it is favorable to involve the people with dementia themselves. For example, research has shown that proxies rate the quality of life lower than the people with dementia, who are, in general, more positive about the quality of their life (Moyle et al., 2012).

Practical guidelines

There is no one-size-fits-all approach in involving people with dementia in research. However, there are some aspects to which a researcher should pay attention when studying experiences from people with dementia.

A safe context is one of the most important aspects in dementia research. A good relationship should be built between researcher and participant. To build a good relationship, time is needed. A hit and run approach should be avoided at all costs. To reduce power inequalities, one needs a relationship based on trust, warmth and empathy (Hellström et al., 2007).

Several other practical guidelines are

Communication (Van Baalen et al., 2010, pp: 122-123)**:**

- Begin with relatively straightforward questions
- Avoid abstract notions, and questions relating to time and frequency
- Use stimulus materials to discuss abstractions
- Third-party approach: asking person with dementia how they would describe the care offered to a third person, such as a friend
- Attending to non-verbal cues and accepting the emotional reality of the words of the person with dementia
- Show person with dementia a picture of a person who they do not know, but with whom they might be able to identify in some way. Then say: ‘Let’s imagine that this lady is coming to live here. What do you think she might feel about that?’ Other questions might be ‘What would she want to know about living here? What sorts of concerns might she have?’
- Use the term ‘memory problems’ rather than ‘dementia’ as a more sensitive way to explore issues relating to the participants’ dementia
- Allow time for person with dementia to understand what is being said (it can take five times longer to process information even with moderate dementia) and make sure that people understand before moving the conversation on
- Persons with dementia often speak metaphorically
- Use short sentences and do not carry double messages in them
- Carry out a pilot study to ascertain respondents’ communication skills and decide whether alternative format questions are required
- Before assessing the interview, use test questions to serve as the primary method of assessing the respondent’s ability to comprehend a structured answer form
- Use the schedule flexibly, modifying the order and content of questions as appropriate
- Comprehension of questions and selection of appropriate responses can be facilitated by the use of explicit instructions, face-to-face administration by a trained interviewer, and use of visual cues to remind the respondent of the response options
- Use clear language, focused questions and visual aids such as photographs
- Keep questions short, use familiar words, avoid compound sentences, and avoid double negatives
- Questionnaires need to be readable by those who have vision problems, so allow sufficient space on the page and use a large print size (font size 14)

Guaranteeing comfort of person with dementia (Van Baalen et al., 2010, pp: 123-124)**:**

- Try to establish a good relationship, based on trust, warmth and empathy
- Interview on more than one occasion for this allows effects of anxiety which may be present during a first interview to recede and enables the researcher to assess the consistency of the views of the people who have dementia across time
- Short interviews are recommended for patients with dementia since patients tire easily
- Adapt the length of each interview to the person with dementia's capacity to concentrate
- When possible or preferable to conduct longer interviews, include pauses and relaxed small talk to allow the person with dementia to rest
- Use open questions regarding what person with dementia usually does and what they think about particular issues in their daily life
- Questions that contain a time frame may need to be modified to a very short time frame
- Leave the person with dementia with a sense of achievement, and find a positive subject on which to conclude
- Continue to show interest in the person with dementia after the more formal part of the interview has finished if a lasting positive impression is to be created, and a 'hit and run' approach should be avoided at all costs
- Give people a choice of time. Preferable is to conduct interviews before lunch, when people with dementia are often likely to be more alert

Guaranteeing validity (Van Baalen et al., 2010, pp: 124)**:**

- Use an individualized approach: different methods depending on individual preferences and on severity of dementia
- Follow-up interviews can enrich and validate findings
- Vary the direction of item wording so that high scores do not always have the same meaning

Practical tips for

Interviews (Van Baalen et al., 2010, pp: 124):

- The interview should be held in a familiar surrounding (Bamford, 1998) with minimal background noise
- Time schedule for data collection must be very flexible
- Involve gatekeepers as a resource to the research process and in supporting persons with dementia into research
- For some people with dementia, the symptoms of cognitive impairment can vary during the day. It is therefore important to consider what time of day a participant is most alert to optimize the interview.

Focus group interviews (Van Baalen et al., 2010, pp: 125):

- Requires a skilled facilitator to ensure that those people with verbal competence are not heard at the expense of others who have less ability to express their needs.
- Use small, pre-existing groups to reassure that people are with familiar faces.

- Have some basic props to orientate people to the subject being discussed such as photographs and posters.
- The facilitators should ideally be known to the group and be skilled in communicating with people with dementia.
- If any of the participants are hard of hearing, make sure one of the facilitators sits beside the person to guarantee the questions are heard.
- Ideally the facilitators should have some knowledge of the personal circumstance of the participants, as this information can be used to frame questions more pertinently.
- Allow time for views to be expressed. Meet for a second or third time, if necessary.
- Do not overload the sessions with a variety of different concepts. Keep to one or two themes.

Aftercare

Continuing to show interest in the people with dementia after the research is done is relevant for a positive impression of the research. A ‘hit and run’ approach should be avoided at all costs (Van Baalen et al., 2010). The aftercare is thus a relevant part. A practical tip for the aftercare would be to organize a small final meeting for people with dementia, proxies, professionals, management in which results and experiences are presented. the people with dementia should be at the center of this meeting (Jans, Zadelhoff, & Moser, 2013, pp: 24).

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