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Participatory research

A method for process consent with persons who have dementia

JAN DEWING *University of Ulster, Northern Ireland, University of Northumbria, UK and Royal College of Nursing Institute, UK*

Abstract Consent theoretically threads through the whole qualitative research method, so getting this right can set the tone for person-centred relationships between researcher and participants. However, most attention has been given in the UK to cognitively biased informed consent and to consent taking place at the beginning of projects; and in North America to assent or the lack of objection. The method in this article is based on the premise that for persons with a dementia, informed consent becomes increasingly redundant and consequently exclusionary to them as persons. This article sets out and describes a method for consent that focuses on persons with dementia, traditionally excluded from consent and thus from research, and also refocuses on consent as a process that runs through the whole of a research project. It also suggests that use of this model can strengthen the assent process. Examples from two contrasting doctoral studies will be offered to illustrate the method in action. The first study investigates wandering in older persons with dementia living in a nursing home. The second study is a randomized control trial investigating an intervention for heel sores in older persons with dementia as patients on orthopaedic wards in a general hospital.

Keywords assent; capacity; dementia; participation; process consent; qualitative research

Introduction

The overall purpose of this article is to describe the process consent method in detail, to enable other researchers to critique it and to consider how it might be used within their own research practice. Thus, this article will present and discuss one method for developing increased participation with consent and assent in research with older persons who have dementia. The method set out here is designed for use with older persons who have

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a cognitive impairment (usually through a dementia) and changes in their capacity that would be expected to exclude them from giving informed consent. In this article, examples from two contrasting doctoral studies will be offered to illustrate the method in action. The first study is a phenomenological investigation of wandering in older people with dementia living in a nursing home in England. The second study is a randomized control trial (RCT) investigating an intervention for heel sores in older people with dementia who are patients on orthopaedic wards in a general hospital in Northern Ireland. All the examples provided in this article are taken over a time scale of several months, and are generally from different participants (who have been given a name in the case of the study on wandering) or different subject numbers (in the case of the RCT).

Participation in research

The process of developing partnerships with older people in research takes place against a background of academic research traditions and norms, which can present obstacles to collaboration in practice according to Reed, Weiner and Cook (2004). These authors argue there is a need to develop approaches of user participation in research shaped by philosophical, ethical and professional debates about partnership, but which also address pragmatic issues. There are now an increasing number of accounts about approaches and methods that can better enable the older person's participation in gerontological research. But it is often the practicalities or methods, about how participation is facilitated and enabled, that need more detailed and open discussion (see, for example, McKillop & Wilkinson, 2004).

At the heart of participation for older persons with dementia lies the thorny issue of consent and even assent. Despite the growing research on participation, many researchers are required to sacrifice their values about participation by older persons with dementia when it comes to consent, often to satisfy the demands of research ethics committees (Grout, 2004). Ethics committees have a large amount of control in the continuum of exclusion and inclusion. Ethics committees are generally regarded by members of the academic and research community, including qualitative researchers, as running on bio-ethical principles; whether this is true or not. Consequently, in many situations, older persons with dementia do become excluded from being involved in research as active participants, as ethics committees may feel it is practically too difficult to do, the risks are too great and where informed consent is not applicable there have been no other detailed options set out for them (Dewing & Pritchard, 2004). Whilst ethics committees have some responsibility for this situation,

gerontological researchers have perhaps been too ready to accept the so called gold standard of informed consent and thus slow to develop viable alternative methods acceptable to ethics committees and take risks with presenting ethics committees with alternative methodologies and methods. Although there are some accounts of alternative methods (for example Sachs, 1994; Barr, Closs, & Briggs, 2002).

Methodology

The methodology underpinning the process consent method has been described elsewhere (Dewing, 2002). In summary, it begins by rejecting a unilateral traditional competency-based approach to informed consent in research with many older people who have dementia. Primarily, this is because informed consent becomes increasingly exclusionary and is based on a required minimum level of cognitive competence assessed in a way that is generally both clinical and non situational specific. Process consent methodology and the method set out here presents a revisionist person-centred and inclusionary approach to consent, that values the interests of all parties involved, including above all the person with dementia. Although it contains elements of negotiated or tripartite methods as described by Grout (2004), Barr et al. (2002) and Moody (1992), this method moves beyond negotiated or tri-partite methods of consent because the person with dementia is the centre of the process.

The methodology is built on Gilligan's feminist ethics of care (Gilligan, 1982). Feminist ethics of care, of which there are several approaches and models, provide a powerful critique to traditional rights based frameworks where independence and autonomy take centre stage. An ethic of care stresses the importance of interdependence and connectedness through relationships (Lloyd, 2004). This is in line with calls from Nolan, Ryan, Enderby and Reid (2002) and Qureshi, Bamford, Nicholas, Patmore and Harris (2000) for a paradigm leap that involves greater attention to the inter-subjectivity of dementia and relational aspects of care. The method to be described here acknowledges that capacity is situational, that capacity can be present even after the usual legal threshold has been crossed and that it is often strengthened or even reinvigorated within an enabling and caring relationship. Further, it is suggested here, that a process consent method is a necessary requirement for person-centred research. McCormack (2003) for example, argues for five necessary conditions in order to have person-centred research. These conditions are: informed flexibility, sympathetic presence, negotiation, mutuality and transparency. These five conditions are incorporated within the process consent method.

Method

The origins of the method lie in the author's expertise in person-centred nursing practice with older persons who have dementia. The initial method, in a crude and untested format, was derived in and from nursing practice, and used as a coaching tool to enable other practitioners, in their day to day practice, by providing a structure and process for use with persons who had dementia. The express intention was, firstly, to seek consent prior to and during many nursing care activities that otherwise would have been carried out regardless of consent being given or withheld. Secondly, it aimed to enable practitioners to consider consent communicated through behaviour and non-verbal means by the person with dementia as being of equal value to the expressed wishes of supporters, such as carers. Although not common parlance in the UK, the North American notion of assent or of not objecting is often used in clinical practice by nurses as a basis for going ahead with nursing interventions.

The initial aim in testing the method within a qualitative research context was to develop a method suitable for using with older persons with a dementia, so that they could provide their own consent for inclusion in qualitative nursing research (Dewing, 2002; Dewing & Pritchard, 2004). In particular, the method was developed to be used in a doctoral study investigating wandering (Dewing, 2004). Prior to this, the process consent method was submitted as part of other research and systematic practice development work to several local ethics committees in England, Wales and Scotland over a 3–4 year period (for example Pritchard & Dewing, 2000; Walker, Dewar, Dewing, & Pritchard, 2001). The method and supporting documentation were further tested and refined between each submission as the result of being used in different research projects and in various settings. More recently it has been submitted by another nursing doctoral student to an ethics committee in Northern Ireland, where it is being used as part of a randomized control trial investigating heel sores in older people on orthopaedic wards. In all cases, the process consent method was accepted by the committees as either an acceptable alternative or a more appropriate method. In one case the committee asked for the researcher to attend a meeting to answer further questions. The ethics submissions included some additional focused and concise materials to that required in the application, to create the opportunity for a broader educative process for committee members.

An outline of the method

The method currently comprises five elements (see Box 1). They do not have to be seen as linear elements and the relationship between each

Box 1: The Process Consent Method
Background and preparation
Establishing the basis for capacity
Initial consent
Ongoing consent monitoring
Feedback and support

element can be fluid according to context and people involved. The method offers a pathway for researchers, but the process very much relies on the skill and expertise of the researcher in being able to engage with persons who have dementia and on their critical reflection skills. The fundamental question that the researcher needs to reflect on can be summarized as: 'is this person consenting?' There is a secondary question: 'does this person have (informed) appreciation of their consent?' And a third level question which asks 'is any lack of objection genuine?' Depending on the effects of dementia on the person, the latter questions cannot always be affirmatively answered and leave the researcher to engage in critical reflection. The former question should be affirmatively answered for the researcher to proceed.

One: Background and preparation

The first element in the method sets the scene by prompting the researcher to check they are not taking short cuts. In particular, it requires that the researcher clarifies that permission to access the person with dementia has been gained from staff, relatives or another named person. It is important to note that it is permission for access not proxy consent that is being asked for here. For some critiquing this method, there is obviously still an issue about even asking for permission from others and it does not eliminate the hurdle of relating and negotiating with a range of 'gatekeepers' (Bartlett & Martin, 2002). It may be that it is not always necessary to secure permission from another person who knows the person with dementia before approaching the person with dementia. However, it does enable persons deemed meaningful by the person with dementia and/or legally authorized representatives to be included in the process. The principle to be observed here is that the person-centred researcher should be transparent about their intentions to achieve process consent by including others who are of significance to the person with dementia and clarifying with them the purpose of that involvement. Seeking permission also acts to remind practitioners that they do have a legal and professional duty of care towards persons with dementia in their care to act in their best interests, and should neither give researchers carte blanche permission nor deny permission.

The first element of the method then prompts the researcher to have found out something about the biography of the person with dementia. Depending on the research, the culture and context of the setting and the skill of the researcher, it may or may not be essential to do this from other sources before meeting the person with dementia. However, it is suggested that as a minimum, the researcher has some cues about how the person usually presents themselves when in a relative state of well-being. This is because the initial social engagement should start when the person is in a state of well-being. A state of well-being with positive emotions can positively influence cognitive processing according to Damasio (2000). Approaching the person in a state of well-being means intrapersonal and environmental conditions are favouring the building up of trust between the person with dementia and the researcher. When the researcher is returning to the person for recurrent interactions, then this part of the initial process can often be brief. The initial engagement may be complex in that establishing how and when the person can be best approached (when they are at their optimum level of well-being and self confidence) can take some time as the following examples illustrate.

Example from wandering study (field notes):

> Ken gives very little away in his verbal or non-verbal communication. I am finding it challenging to establish when he is in and not in a state of well-being. Thus, he is different from the other possible participants. Perhaps his level of well-being is quite low most of the time and this is why I don't see observable changes? Or perhaps I'm not looking at the right indicators? What have I learnt about Ken so far?
>
> Ken is a man who seems reserved and formal. But at the same time he has not responded well to formal social contact from me. I have observed he moves on the outskirts of groups. He seems to dislike large groupings of residents and will try to walk around them. He does not like to be approached directly face to face but instead likes to come into space where other people are already occupied and not looking at him when he arrives. He is articulate in his own way. I have seen evidence of him making choices and decisions in the home. He chooses the when and where. Thus I have learnt I will need to be less direct to get along sidehim if any dialogue is to take place. I will also need to be more patient and wait for an opportunity to arise rather than feel I can generate it when it suits me.

Example from orthopaedic ward study (field notes):

> A 90 year old woman, alert but disorientated in time and place. She scored 9/10 on the MMS [Mini Mental Score]. The staff were not sure if she would participate or be able to give consent. I decided to talk with her and make an assessment. I explained the study to her, her daughter and granddaughter. She

read the adapted leaflet slowly and appeared to understand what she read but at the same time she referred to me by her granddaughter's name.

Two: Establishing the basis for consent

In the second element of the method (see Box 1) the researcher is primarily concerned with establishing the basis for capacity to consent and how this has been achieved. As capacity is situational and variable the researcher needs first to establish a basis for capacity to consent. It may be that an adapted informed consent process can be used. There are six other key factors to be considered in detail: this person's usual self-presentation; the person's usual level of ill/well-being; how a decrease in the level of this person's well-being may be triggered; how any decreasing level of well-being can be recognized; any significant conversation or behaviour that might be indicative of a deeper psychotherapeutic need/intervention and how the person usually 'consents' to other activities and procedures within their day-to-day life. This can be assessed through generating descriptions of how the level of well-being is recognized by an observer and where the usual level is situated. It is possible to make use of the scoring continuum similar to that in Dementia Care Mapping method ranging from −5 (severe ill-being) through to +5 (extreme well-being). Alternatively, generating a description of facial expressions for different levels of well-being can be a helpful tool. However this is achieved, it is necessary to spend some time and energy addressing how a measure of well-being and ill-being are to be captured, as it enables the researcher to feel more confident that they are getting to know the person behind the layers of patient/client/resident and dementia.

Example from orthopaedic ward study (field notes):

> [after reading information and a discussion] I was unsure about the capacity so I asked her if she would like to sign a consent form or if I should ask her daughter to do this on her behalf. I was told in no uncertain terms; 'why would my daughter sign the form, it's not her feet?' She went on to say how the nurses on the ward had asked her daughter to sign a form allowing bed-rails to be used and said 'she's not the one going to fall out of bed'.

This is an example where exploring process consent demonstrated that informed consent can materialize. Continuing with a clear and systematic approach, the process consent method will add credibility to any informed consent that has been achieved and help the researcher respond to any challenges about their decision making processes.

The method next requires identification of the triggers that influence a decrease in the level of well-being needs to take place. This is necessary so that the researcher has a conscious intentionality to act in a way that

maintains or promotes well-being. If the person with dementia does start moving into ill-being, there are ways in which the researcher can seek to address this. For example, by facilitating a change in the dynamics of the interaction or by conversation shift or, ultimately, by withdrawing where the person finds the interaction too demanding. Noting the ways in which a decreasing level of well-being can be recognized is necessary. Here it is useful to ascertain mild signs rather than extreme ones and to include behaviour, body language, verbal and non-verbal signs. Throughout the process, the researcher needs to note any significant conversation or behaviour that might be indicative of a deeper psychotherapeutic need and what the possible options of action are.

The question that needs to be answered in the element of establishing initial consent is: how does this person usually 'consent' to a range of activities within their day-to-day life? The researcher must consider existing assessments or opinions on capacity (Butterworth, 2005). Often these may take the form of a score obtained from a standardized cognitive assessment tool. If the score shows significant cognitive deficit this does not mean the researcher can assume that the person lacks capacity and should be excluded. Instead it challenges the researcher to find a way of trying to include the person. The poorer the score the more the researcher needs to sensitize their approach to the person's level of ability. It is also useful to know what scores have been obtained in case colleagues wish to challenge any decisions made in relation to participating in research.

Example from the orthopaedic ward study:

> A man (91 years of age) in an acute orthopaedic ward was given a Mini Mental Score of 3/10 following medical assessment. To the researcher, from reading this and other information in his medical records it seemed he would not be suitable to give informed consent or participate in process consent. On talking to the nurses who said this man was orientated, alert and behaving reasonably, the researcher decided to approach him. Before talking with him the researcher established from the nurses that the man was very gentle in his manner, quietly spoken and gave the impression of being very intelligent. The researcher established through following the process consent method that the man could read written information. He agreed to the researcher showing him what the assessment for the research study would involve and what the intervention aid was. He looked at, touched and talked about the intervention aid. When given the choice he wanted to sign a consent form.

In the above example the researcher was challenged by a medical colleague about the validity of the man's consent based on the test score. This same score had not prevented this man from being asked to give his informed consent for surgery.

Three: Initial consent

By the third element of the method (see Box 1 above), the researcher should be feeling confident enough to seek an initial consent for the specific research. Thus the consent process moves from what is known about consent and assent in general terms to its translation into the specific situation. The exact way of achieving this will vary. It will generally involve providing information for the person. Here the researcher needs to make an assessment about the person's cognitive abilities and preferred ways of taking on information. Sometimes slightly adapted written information is acceptable. For other participants, written information may need to be offered using computers or internet generated information, right through to highly modified or simplified down to single keywords with or without pictures. If, however, pictorial information, or actual props connected to the research are more suited to the person, then these should be provided to enable maximum capacity to be reached. In the study on wandering which was going to make use of videoing, pictures of the video camera and the actual camera and a notebook were used in the discussions with participants who were able to handle the props to help contextualize the discussion. Knight (2005) has commented positively on the use of video for consent purposes. In the study on the orthopaedic ward, the intervention, a heel boot, was available for the person with dementia to handle (Donnelly, 2004). In both cases the props enabled the person with dementia to ask questions, or a discussion to proceed in a more focused way.

The researcher should make extensive notes on the location, time, information given, props or equipment used, questions and answers. Ultimately, the researcher needs evidence to account for the methods they are using to indicate the person is giving consent. Critical reflection of what impressions were formed between the specific and generalist consent may ensure that there is consistency. For example, the researcher may critically reflect on the degree of consistency between facial expression or body language with how consent was given for inclusion in the research and how it is usually given in day to day life. Ensuring there is evidence of what assent or non-objection looks like on a day to day basis is also necessary to ensure that decisions are being made that cover the feeling state of the person (Damasio, 2000, 2004), and are not solely relying on the absence of verbal utterances or more active body movements indicating objection.

Four: Ongoing consent monitoring

In element four, the focus is on ensuring initial consent is revisited and re-established on every occasion or even within the same occasion. Again, this highlights the notion of consent as a process, supported by others

including Butterworth (2005) and Knight (2005). Here, the researcher needs to assess if ongoing consent is provided consistent to the initial consent, and if the person wishes to continue or their feelings about participation have changed. If not, then consent must be revisited in full. Any decision to continue, should the way of indicating consent be different, must be justified. Increasing the level of transparency can add to the process and may reassure ethics committees. This can be achieved by asking someone else known to the person to sit in as a validator. At the end of each conversation/interview the person's level of well-being can be noted. This can be done by providing a description of behaviour, verbal and non-verbal signs and relative well-being level that the researcher developed in the earlier parts of the process method. The method allows for an independent observer to track the well-being of the person with dementia at any point, should the setting support this. If there has been an independent observer their assessment needs to be noted. Again, tracking or assessment can be informal and unstructured or it may be highly structured using a specific method or tool such as Dementia Care Mapping.

Example from wandering study:

Situation 1:

> We were walking up the drive when Joan seemed to become aware of the digital video camera (DVC) in my hand. She looked at it a few times. Although she didn't say anything, it seemed like it was right to find out how she felt about the DVC. I told her that I had my camera on and was filming the scenery (at the same time I showed her the screen so she could see for herself). I asked her how she felt about me filming our conversation and that this meant she could be seen and her voice heard on the camera. Her reply was:
>
> 'You can do what you like with the camera.' As she said this, there was no warmth or enthusiasm on her face. As Joan's usual way of responding about something she feels comfortable with is to be enthusiastic and interested, I took this to mean she would tolerate the camera but did not welcome it there and then. Thus I felt she was not consenting. So I switched it off and said to her I had done so. She nodded her head and smiled at me. We carried on walking together.

Situation 2 (different occasion):

> I was standing at the gate with Joan. I showed her the camera and asked her if I could film whilst we were talking. I said that her voice and mine would be on the film but not her face or body. She said yes. I showed her the screen so she could see the pictures and she nodded with a relaxed smile. Her hand gesture was open and relaxed too. Her facial expression was lit up and she said 'oh good now I will be heard – at last!' [her voice was strong and clear].

Five: Feedback and support

Element five of the method asks the researcher to consider feedback and support. In some situations it may be necessary for the researcher to consider providing staff with some feedback about the person's well-being or on a particular concern. Feedback given to carers/staff needs to be thought about carefully. The researcher needs to plan what is to be said and how questions from staff or others such as representatives will be responded to. The primary responsibility is to ensure anything the person with dementia would wish to be kept confidential remains so. Where possible, feedback to be given to others should be agreed with the person with dementia beforehand so that they are included or take the lead if they choose.

The researcher must consider if the person with dementia needs support to make the transition back from the research/development context into another context such as their day-to-day environment. The researcher notes any interactions or interventions made with the person in order to achieve a transition/return back into another social relationship or their environment of care. The method also advocates a feedback loop whereby the researcher may need to provide feedback to others (such as a carer) or where carers may want to alert the researcher to a change in the person with dementia's well-being after the research encounter. This can be achieved through such means as a communication sheet, note book or an alert card system so the researcher can enquire with carers before resuming any research activities with the person on their next visit. Sometimes, the person with dementia has become so deeply focused on the researcher that the researcher stepping back and withdrawing can only be achieved with the involvement and seamless stepping forward of another person. Finally, in element five, if there are any issues for field notes or for discussion with a research supervisor or a principal investigator, these need to be noted whilst they are immediate.

Example from wandering study:

> There is a woman, not included in the study, who follows me around and wants to be in front of the camera. I've tested this out several times now. She seems to me to be 'posing' for her photo – so I'm guessing she likes having her picture taken. Although I'm trying to protect her privacy, I'm not sure what to do at the moment, as I don't know her very well?

Examples from the orthopaedic ward study:

> If the patient signed a consent form is this informed consent or not?
>
> What do I do about process consent when patients become confused post-operatively?

These and other concerns and issues were, at the time, challenging, as they happened in the field, but with critical reflection or supervision they were resolved.

Limitations of the method

This method of process consent is meant for use with those persons who have extremely limited capacity for informed consent, who would generally be thought to be incapable of legally informed consent by others but on observation can communicate and express their wishes. The method can also strengthen decision-making connected with assent. In this regard, the method can offer researchers and persons with dementia opportunities for involvement and inclusion in research that otherwise would have not been present. This opens up further opportunities for persons with dementia to have their voices heard (Goldsmith, 1996) and to experience agency as a vital part of personhood. Clearly there is still a cut off point in this method. There are occasions where some persons with dementia may lack capacity to make even small choices and decisions, or where assent is not clear or consistent to a required level. In this case, consent could be judged on how the person responds to a paced experiential involvement in the research. This, in effect, is what the process consent method advocates in all situations, but in this case it is drawn out to a pace that may better respond to the persons remaining abilities. This method does also emphasize the researcher having a greater expertise with sympathetic presence and having reflexive skills and moral decision-making skills (McCormack, 2003) which may have implications for preparation and supervision.

In the situation where the older person with dementia has very little capacity for expressing their consent through facial, behavioural and bodily communication, the need for the researcher to be open and transparent with decision-making is further heightened in order to avoid transgressing boundaries of trust. Having an independent researcher or skilled practitioner to analyse decision-making trails would be one way of achieving openness and transparency. The researcher always has the options of excluding the person or trying to keep the person included, if others known to the person can provide evidence to show that either exclusion or inclusion in the research would most likely have been what the person would have wished for themselves.

Obviously the method presented in this article requires further testing by others in a range of different types of qualitative research and in different settings, and needs subsequent further refining. The method is limited in another way which poses an ethical dilemma. Researchers begin social engagement with the person prior to gaining initial consent. In some

settings this may take several visits or weeks. Thus the researcher has already collected information about the person, either from others or though their own observations and interactions to begin the process of assessing their capacity. The method may appear limited given the requirement of time and perhaps the high level of person-centred expertise including communication skills required from researchers. The ability to be reflexive in the field is central to this method, and this may be challenging for novice researchers to achieve, especially if not combined with effective coaching from more experienced colleagues. Thus the method may not be suitable for use by less experienced researchers or those working in isolation.

Researchers need older people with dementia to participate in research, because without their involvement it is not possible to know as much as could be known about the problems and needs that are perhaps unique to people with dementia and their carers (Watson, 1994, p. 159). Achieving active participation involves risk taking to push forward boundaries. There are external limitations concerned with how much of a risk researchers are prepared to take when preparing submissions to research or other ethics committees that may have a bio-medicalized view of dementia, or feel a strong responsibility or paternalistic protection for persons with dementia who they might perceive as being highly vulnerable and generally beyond making choices and decisions of their own. As Bravo, Paquet and Dubois (2003) point out, as the amount of risk increases in a study, then key stakeholders (older people, researchers and ethics committee members) tend to increasingly believe proxy consent should be used. Although this finding was made in Canada, it could be equally applicable to other westernized countries. In countries where the role of carers in providing proxy consent is strengthened through legislation, this method, like others promoting direct involvement of the person with dementia, may have limited appeal to certain stakeholder groups (Beck and Shue, 2003). Vass et al. (2003) argue seeking proxy consent from carers was a means of protecting researchers against possible litigation. It is not within the remit of this article to debate the policy agendas underpinning research ethics, but researchers working with older persons with dementia, in different countries, will need to take greater account of legislation on capacity and other issues such as research governance as it comes into being (Beck & Shue, 2003; Gilhooly, 2005).

Summary

Whilst not without limitations, this method for process consent does seem to offer a valid and acceptable way for researchers to go about including a greater number of persons with dementia in research, from which they

otherwise might have been excluded. It can enable a greater and hopefully more meaningful level of involvement, and particularly more active participation in consent, from which they otherwise might have been sidelined or excluded. It also offers a means for deeper clarification of assent or non-objection. However, it does require researchers to take some risks with their practice.

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Biographical note

JAN DEWING primarily works as an Independent Consultant Nurse and undertakes a range of research, practice development and education projects related to care of older people, often with dementia. She is finishing her PhD studies and a thesis on how persons with dementia experience wandering.
[email: jan.dewing@btinternet.com]