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# Research into the Experience of Dementia: Methodological and Ethical Challenges

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**Abstract:** Conducting research in the field of dementia care can be fraught with moral and ethical dilemmas, particularly with regard to consent and capacity. These issues apply to all aspects of the research process and are an important consideration for the research to be considered ethical and of relevance to the future of dementia care. This article considers the importance of ethical issues in research involving people with dementia, with specific regard to consent and capacity and on minimising harm. Methodological suggestions are proposed which may assist in ensuring research is ethical and maximise participation of people with dementia. In conclusion, it is argued that consideration of these factors at a methodological level can increase the potential for engagement without compromising the wellbeing, dignity and protection of the person with dementia.

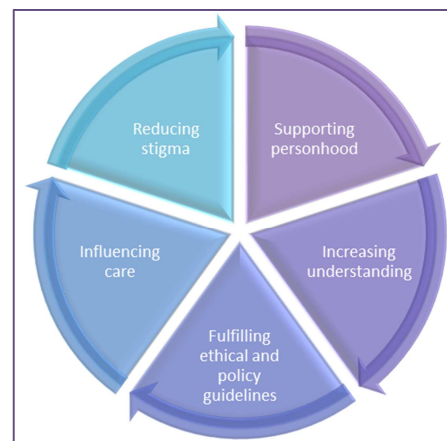
**Keywords:** Ethics, Dementia, Methodology, Research

## 1. Introduction

In recent years, there has been a shift in research within the field of dementia. Historically, the person with dementia was not included in the research process, and the research was done 'to' them, rather than 'with' them [1, 2]. This predominantly relates to the traditional ideation that a person with dementia had lost their 'self' and was no longer able to contribute to society (and equally the research process) [3]. However, this approach marginalised the person with dementia, and the dawn of the reconceptualised person centred models of dementia care has resulted in a shift in research methods which are now more inclusive of the person with dementia.

Research involving people with dementia provides a valuable insight into the lived experience of dementia, deepening knowledge of the illness and enabling the development of care practices in the field of dementia care [4, 5, 6, 7]. It provides valuable information on the perspectives and experiences of the people affected by dementia, broadening understanding of the illness from the more historical research which centred on the clinical effects of dementia and the impact of caring for a person with dementia on caregivers [8, 9, 7]. Figure 1 summarises the key

benefits of including people with dementia in the research process. However, there are many factors which need to be considered in order to protect the person with dementia and ensure that research is safe and ethical. These issues are complex, and consideration of these factors above and beyond the standard ethical requirements is required for research with people with dementia to be successful.



**Figure 1.** The benefits of involving people with dementia in research.

## 2. Capacity and Consent

The issue of capacity and consent is huge within the realm of dementia research, and this causes many obstacles for researchers to overcome in order to ensure that consent is obtained ethically and in order to protect the person with dementia. Consent is perhaps the most important aspect of research with anybody, not just people with dementia. This establishes whether the person actually wants to participate in the research [10]. There have been many debates and changes around the issue of consent over the past 20 years, but more recently a pattern is emerging whereby people with dementia are involved in the consent process to ensure that they are well informed and happy to proceed and continue in the study [6, 7, 11].

Informed consent is an essential element of most research with human participants (unless research is essentially covert), and is required for research to be ethically and legally compliant [12, 13]. The purpose of informed consent is primarily to ensure that the participants haven't been coerced or deceived into participating in the study, and to ensure safeguards are in place to protect those involved in the study [12, 13, 14]. Consent must be given freely and voluntarily, without influence or duress from others (e.g. researcher, health professional, family, friends), and must be given on the basis of the participants having received, understood, considered and agreed to the conditions of the study and the future implications of the research [13, 14]. Consent is often defined as the written agreement of an individual to participate in a research study [15], however considering the nature of dementia other methods of recording the consent may be required. Consent can only be truly classed as informed when the potential participant is able to understand the information presented to them and comprehend the implications of participating in the study [16].

One of the main concerns around the issue of consent is whether the person with dementia has capacity to give consent. Capacity is a legal term which is linked with the ability of an individual to understand information, make choices and communicate those choices to others [16]. All adults are presumed to have capacity until our ability to participate in society and make decisions regarding our welfare or property is called into question [17]. Capacity is described as a "dimensional quality of a person", i.e. it is measurable in the same way as blood pressure, weight and body mass index, and is considered a "precious component of personhood" [18, 19 p. 94]. The decisional capacity of a person is on a continuum of abilities: understanding (i.e. understanding the information regarding a research project); appreciation (i.e. recognising how the information relates to the person it applies to); reasoning (i.e. comparing options and understanding the consequences of the choices made); choice (i.e. expressing the choices made consistently) [20, 21, 22, 18].

When a person has dementia, in particular Alzheimer's Disease, they not only experience cognitive and functional

impairment, but also experience losses in terms of their ability to make decisions (i.e. decisional capacity) [18]. While the person with dementia may be able to express an interest in participating in research, the nature of the illness means that their ability to understand and appreciate the consequences of being involved in the study is impaired [16]. The limitations of the person's cognition increases the vulnerability and risk of exploitation of the person with dementia, which means that researchers must take extra care in ensuring that the person with dementia is engaged in the consent process and that all efforts have been made to ensure that they have understood what the study is about and what participation means in order to maintain their human rights and ensure research is ethical [23, 16]. While the person with dementia may have some limitations to their decision-making ability, they should not be excluded from research because of this. Hougham [24] states that many people with dementia are capable of engaging in what he calls 'consent discussions', and that people with mild cognitive impairment are able to make consent decisions which are equivocal to persons without neurological impairment [25].

### 2.1. The Importance of Information Presentation

One of the ways in which consent can be maximised is by ensuring that the information provided is appropriate for those who will read it. The Medical Research Council (MRC) [12] states that it is important that researchers consider how to present their information to potential participants, ensuring that the lifestyle, interests, needs, religious beliefs and priorities of that person are respected. The MRC also advocates the use of creative and resourceful methods of gaining consent when potential participants have difficulty understanding more traditional means of information about the study and are communicating their consent [12]. This is echoed by McKeown et al [6], who state that people with dementia are more able to make decisions around participating in research when a relevant approach is used. This is an important concept to consider when recruiting participants with dementia, as they may have capacity to consent but may have difficulty reading, processing and understanding large amounts of written information, and may have difficulty with reasoning, making judgements and communicating their decision [26]. In such circumstances, it may be necessary to present information in a different way that can be more easily understood e.g. pictorially, verbally. This is supported by the Health Research Authority (HRA), who state that information provided should be appropriate to the person's capacity of understanding [14]. An important consideration for the presentation of information is that of the language used. Primarily, any communication with a person with dementia should be accessible, simple and presented in layman's terms, avoiding abbreviations and acronyms [27].

### 2.2. Ongoing Consent

When including people with dementia in research, it is

widely recommended that consent is an ongoing process [e.g. 5, 12, 28, 6]. Several terms are used for this process i.e. ongoing consent, process consent, ongoing negotiated consent, continuous consent, but the philosophy is the same: consent is a process which happens throughout the research project to ensure that the person with dementia remains informed of the principles of the research and is happy to continue to be involved. This process is one of “continual renegotiations” and is used to determine whether participants are happy to remain in the research [29 p. 38, 26]. This is especially important when working with people with a memory deficit who may forget what the project is about and who may feel differently about the project as time passes because of further cognitive impairment/deterioration.

### 2.3. Negotiated Consent

Another method of gaining appropriate consent where capacity is limited is that of negotiated consent [30, 31]. Grout [31] argues that this method is a more progressive method of obtaining consent from people regardless of their age, disability or fluctuations in capacity, and it allows researchers to regard people with dementia as people with a valid and real view of their world. This approach recognises that people with impaired capacity may choose to share or defer the decision-making around whether to participate in research with another person of their choice (e.g. a spouse or descendent, health care professional) [31]. This approach eliminates the need for a proxy in situations where the person with dementia has limited capacity to consent, ensuring that they were involved in the decision over whether to consent to participate or not. Negotiated consent can be used to provide a person with an advocate in helping them make a decision and can be helpful in making those with limited capacity feel empowered [31].

### 2.4. Assent and Dissent

While consent is an important and necessary element for research to meet ethical requirements, researchers should also consider the notion of ‘assent’ when carrying out research, particularly when the participants may have difficulty in providing informed consent. Including the notion of assent/dissent in the process of research into dementia allows the person with dementia to express their own intentions regarding the research, and supports the personhood of participants who may otherwise be experiencing a diminishing choices and self-esteem in other areas of their lives [19]. Kim [32] states that the issues of consent within dementia research reinforce the need to consider assent and lack of dissent in conducting research with people with dementia, and that this should be an important ethical requirement.

Dissent is defined as “verbal or non-verbal indication of unwillingness to participate in study procedures” [33 p. 81]. The ways in which people may indicate that they do not wish to proceed vary according to the level of cognitive impairment they are experiencing, and while some may be

able to verbally state that they do not wish to continue, others may express this behaviourally e.g. by being uncooperative, showing signs of agitation, trying to leave, or emotionally e.g. by becoming distressed or unhappy [33]. Researchers should look for signs of dissent at all times during contacts with participants. A relationship built between the researcher, the participant and their carer should allow the researcher to develop knowledge of the person with dementia and how they communicate, which will help to identify any moments of dissent and will ensure that the research has a good ethical grounding.

Batchelor-Aselage et al. [34] proposed The Partnership of Consent Protocol, a method for establishing consent, assent and dissent. This protocol includes the person with dementia and their legal representatives (i.e. court-approved guardian, health care agent, spouse, adult children, parents, adult siblings, aunt, uncle, other adult kin) in the decision-making around consent for the research. It also involves the legal representatives and gatekeepers in the process of gaining assent and recognising dissent, outlining a clear pathway to follow if dissent is noted. This protocol focuses on the process of consent, assent and dissent as being one of partnership between the person with dementia, their legal representatives and the researcher.

## 3. Minimising Harm

When carrying out research, it is essential that safeguards are put into place to prevent harm to the participants. This is particularly important when the participants have any kind of cognitive impairment which could affect their decisional capacity. The factors discussed here are not exhaustive, and are considerations additional to the usual ethical safeguards in human research.

### 3.1. Accidental Diagnosis Disclosure

One of the most significant factors which can cause harm in dementia research is the issue of accidental diagnosis disclosure [23, 7, 2]. This occurs where the researcher inadvertently informs the person of their diagnosis, and is an issue which can cause significant distress. This may occur because the person was unaware of their diagnosis (i.e. has never been informed), has forgotten their diagnosis, or may be because the person has never had an assessment for diagnosis. This can happen through the researcher using the words ‘Alzheimer’s’ or ‘dementia’, or could even occur through discussing the symptoms of memory loss (a common symptom of dementia is loss of insight, which may mean that the person is not aware that they have a memory problem).

Pratt [23] suggests 5 ways of reducing the risk of accidental disclosure of diagnosis:

- i. Checking with key people (e.g. gatekeepers, carers) about the person’s understanding and knowledge of their diagnosis.
- ii. Not mentioning the diagnosis until the person does.
- iii. Finding ‘safe’ ways of discussing the symptoms the person experiences.

- iv. Prioritising safety above informed consent by taking measures to avoid accidental disclosure of diagnosis
- v. Informing key people of the research protocols

Pratt [23] suggests that the researcher allows the participant to instigate discussions around the symptoms of memory loss, and focuses on abilities rather than deficits during interviews by enquiring about feelings and experiences rather than facts. This will help to alleviate any feelings of distress which may be caused by asking the person to recall events/information which may not be accessible to them because of the cognitive impairment [23].

### 3.2. Unnecessary Reminders of Forgetfulness

As discussed by Pratt [23], asking a person with dementia to remember things may cause distress. As damage to the hippocampus in dementia causes the person to have difficulty in storing new information, this then makes it difficult for the person to recall events. In an interview situation, asking a person to recall something specific may cause them to feel under pressure and may cause them to experience distress. Pratt [23] suggests that the researcher should find creative methods to help the person discuss a topic which does not rely solely on their memory.

### 3.3. Taking Time

Pratt and Wilkinson [35] explain that people with dementia can vary in their performance from day to day (commonly described as 'good' and 'bad' days), may experience changes in their cognitive function over periods of time, and may take longer to feel safe enough to disclose information to researchers than participants without cognitive deficits. It is argued that spending longer periods of time with participants with dementia e.g. having several contacts over a period of time, not rushing interviews, has several benefits for the researcher and person with dementia [35]:

- i. allows the researcher to observe and understand the context that the person operates within
- ii. allows greater opportunity for understanding the person with dementia and their perspectives
- iii. provides the researcher with greater opportunity to interpret meaning from interviews
- iv. helps to build a rapport between the researcher and the person with dementia
- v. reduces stress for the person with dementia as they are allowing them time to express themselves without rushing them

### 3.4. Re-living Upsetting Events

Participants may find that certain topics and questions in interviews evoke memories which are distressing and may encroach on unresolved issues [36, 37]. This may be particularly relevant because people with dementia often experience a different reality to the one others around them experience, meaning that seemingly innocuous questions can evoke unexpected memories for a person. In this instance, it

is important to remain aware of the participant's behaviour and presentation during the interview, being mindful that distress can be shown in different ways and not just at the time of interview [38, 37].

## 4. Conclusion

Careful planning and attention to methodological issues around minimising harm and maximising opportunities for gaining consent can increase the potential for people with dementia to participate in dementia research. Involving people with dementia in the research process has many benefits, not least because it validates the personhood of the person with dementia and can help to reduce the stigma attached to the illness by illustrating that they are able to express their experiences, thoughts, feelings and opinions, regardless of their diagnosis. Failing to include people with dementia in research reinforces the negative stereotypes about dementia, particularly those around the belief that with a diagnosis of dementia brings incapacity and invalid experiences of life. Research which is inclusive of people with dementia challenges these stereotypes, and can help to change the ideology of society as a whole and encourages researchers and care providers to value the experiences of people with dementia.

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