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## Safe and inclusive research practices for qualitative research involving people with dementia

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## **Safe and inclusive research practices for qualitative research involving people with dementia: A review of key issues and strategies**

### ABSTRACT

Developing strategies to ensure the safe participation of people with dementia in research is critical to support their wider inclusion in research and to advance knowledge in the areas of dementia policy and practice. **Objectives:** This literature review synthesizes and critically appraises different approaches to promote the safe participation of people with dementia in qualitative research. **Methods:** Two databases were searched for articles that discuss the methodological or ethical aspects of qualitative research involving people with dementia. We did not focus on informed consent or ethical review processes as these have been reviewed elsewhere. **Findings:** Key issues that impact participant safety include: language, gatekeepers, the research relationship, communication, dealing with distress, knowledge dissemination, and researcher skills. **Conclusion:** By synthesizing different approaches to safety and highlighting areas of debate, we hope to advance discussion and to contribute to the development of inclusive research methods.

Key Words: Dementia, Ethics, Inclusive Research, Qualitative Research Methods, Safety

In the absence of effective treatments, research into the care, quality of life, and social inclusion of persons with dementia has been identified as a global public health priority (World Health Organization, 2012). There is growing recognition that the development of effective policies and services requires an understanding of the perspectives of persons with dementia, yet they remain widely excluded from research (Beattie, Daker-White, Gilliard, & Means, 2004; Hellstrom, Nolan, Nordenfelt, & Lundh, 2007; Whitfield & Wismer, 2006; Wilkinson, 2002). Since the 1990s, researchers, advocacy organizations and people with dementia have challenged this, arguing that it reinforces negative stereotypes and contributes to social exclusion (Cotrell & Schulz, 1993; Downs, 1997; Hellstrom et al., 2007; Robinson, 2002; Wilkinson, 2002). In response, the body of qualitative research involving people with dementia has grown, and the methods used to engage with people with dementia have expanded from observation and interviews to include a wider range of methods and techniques (Bartlett, 2012; Tanner, 2012; Wiersma, 2011). This work provides compelling evidence that many people with dementia can actively participate in qualitative research and provide rich data on their experiences (Beuscher & Grando, 2009; Digby, Lee, & Williams, 2016; Hellstrom et al., 2007; Hubbard, Downs, & Tester, 2003; McKeown, Clarke, Ingleton, & Repper, 2010; Murphy, Jordan, Hunter, Cooney, & Casey, 2015; Pratt & Wilkinson, 2001; Wilkinson, 2002; Wilkinson & Milne, 2003). The effective inclusion of people with dementia in qualitative research, however, presents complex ethical and methodological issues that require critical examination and innovative solutions.

All research involving human subjects poses risks. In dementia research, these risks are heightened due to the profound stigma associated with the illness (Garand, Lingler, Conner, & Dew, 2009), the impaired cognition of participants, and the sensitive nature of discussing the illness experience (Hellstrom et al., 2007; Pesonen, Remes, & Isola, 2011). The ethical principles of non-maleficence and beneficence require researchers to protect the welfare of participants from any foreseeable harm and to weigh the benefits of participation against the potential risks. Developing strategies to ensure the safe participation of people with dementia is therefore critical to support their wider inclusion in research and to advance knowledge in the areas of dementia policy and practice (Hellstrom et al., 2007; Pratt, 2002; Wilkinson, 2002).

In her paper, 'Nobody's ever asked how I felt', Pratt (2002) applies the concept of safe practice to research involving people with dementia and argues that researchers should strive to create a safe research context. Other dementia scholars have also stressed the need to ensure safe research practices (Digby et al., 2016; Hellstrom et al., 2007; Wilkinson, 2002) and many have published work that reflects on their approaches to promoting safety and well-being, the challenges they have encountered, and possible solutions to these issues (Bartlett & Martin, 2002; Beuscher & Grando, 2009; Clarke & Keady, 2002; Dewing, 2002, 2007; Digby et al., 2016; Hellstrom et al., 2007; Holland & Kydd, 2015; Hubbard et al., 2003; McKeown et al., 2010; Murphy et al., 2015; Pesonen et al., 2011; Pratt, 2002; Wiersma, 2011). People with dementia have also written about their experiences of the research process (McKillop, 2002; McKillop & Wilkinson, 2004; Robinson, 2002) and developed guidelines for research involving people with dementia (Scottish Dementia Working Group Research Sub-Group, 2014).

As a result, the current literature offers a range of strategies to promote safe and inclusive practices for research involving persons with dementia. The approaches described in the literature provide practical guidance to help minimize discomfort and maximize the potential

benefits of participation. These strategies, however, have not been synthesized or critically reviewed.

Drawing on the concept of safe research practice advanced by Pratt (2002) and Hellstrom et al. (2007), this literature review synthesizes and critically appraises different approaches to promote the safe participation of people with dementia in qualitative research. Based on the ethical principles of beneficence and non-maleficence, we define safe research practices as the methods, strategies and techniques that minimize the potential harms of participating in research, support participant well-being and promote the benefits associated with participation (Ellsberg & Heise, 2002; McCosker, Barnard & Gerber, 2001). Informed consent processes and ethical review procedures are critical to participant safety. However, we chose not to include these issues in this review because of their scope and because they have been reviewed elsewhere (Beattie, 2009; Cubit, 2010; Sherratt, Soteriou, & Evans, 2007; Slaughter, Cole, & Jennings, 2007).

## **Methods**

Two electronic databases (CINHAL and MEDLINE) were searched for discussion and research papers that reflect on the methodological and ethical aspects of qualitative research involving people with dementia. These databases were selected for their coverage of qualitative health related research spanning medicine; nursing and allied health; and social sciences and humanities (Flemming & Briggs, 2006; Wright, Golder, & Lewis-Light, 2015). The search term 'dementia' was paired with combinations of the following search terms: 'research subjects', 'research ethics', 'ethics', 'consent', 'qualitative studies', 'qualitative research', and 'research methodology'. This was supplemented by reviewing the reference lists of retrieved publications. All searches were restricted to English language texts and there were no restrictions on publication dates. The first author reviewed the abstracts to identify articles containing a discussion of practical, methodological or ethical issues.

In order to capture the views of people with dementia, we also conducted a Web search to retrieve research and language guidelines published by organizations led by people with dementia. Two such sets of guidelines prepared by people with dementia were identified and included in the review (DEEP The Dementia Engagement and Empowerment Project, 2014; Scottish Dementia Working Group Research Sub-Group, 2014). The Dementia Engagement and Empowerment Project (DEEP) (2015) published guidelines on the use of language about dementia. The research subgroup of the Scottish Dementia Working Group developed core principles to guide research involving people with dementia (Scottish Dementia Working Group Research Sub-Group, 2014).

None of the retrieved articles focused specifically on participant safety, but many contained discussion of safety issues. Each article was read and examined for discussion related to the benefits and harms of participation, and strategies to promote safety and well-being. Notes were recoded for each article and then examined to identify themes. Articles that focused exclusively on informed consent processes or issues unrelated to safety were excluded. In total, 22 articles were included in the review. After compiling a preliminary list of themes, the first author re-read each article to capture discussion related to each theme. Those notes were then analysed to refine themes, compare approaches and to search for contradictions and debates. Additional literature on qualitative methods and research ethics was consulted in order to further examine and contextualize the themes that emerged from this review process (Corbin & Morse, 2003; Dickson-Swift, James, Kippen, & Liamputtong, 2007; Hewitt, 2007;

Kendall et al., 2010; Manderson, Bennett, & Andajani-Sutjahjo, 2006; Richards & Schwartz, 2002).

## **Findings**

The sections below explore each theme identified in the review process, followed by a discussion of debates, gaps in the literature and directions for future research. Figure 1 presents a summary of the safe research practices that emerged from this literature review.

### **Language and dementia disclosure**

#### *Avoiding stigmatizing language*

The question of how best to describe people with dementia who are subjects of qualitative research remains an important consideration for researchers. Commonly used terms and phrases such as ‘demented’ and ‘dementia victim’ reduce the person to his or her disease and reinforce the stigma associated with dementia. Several organizations have issued calls to end the use of stigmatizing language and identified appropriate and respectful terminology as well as terms to avoid (DEEP The Dementia Engagement and Empowerment Project, 2014; Scottish Dementia Working Group Research Sub-Group, 2014). Guidelines prepared by the Dementia Engagement and Empowerment Project (DEEP) (2015) recommend using the phrases person/people with dementia or person/people living with dementia. Terms to avoid include dementia sufferer, victim, senile, and demented (for a full list see: <http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>).

[Insert Figure 1 here]

#### *Dementia: a contested term*

In fact, the use of the word dementia is a contentious issue, and several scholars have voiced concern that it has the potential to cause harm if participants are unaware of having a dementia diagnosis (Bartlett & Martin, 2002; Heggstad, Nortvedt, & Slettebø, 2013; Pesonen et al., 2011; Pratt, 2002; Wiersma, 2011). Bartlett and Martin (2002) point out that even when participants have been diagnosed, health professionals may have used terms such as memory problems. Given the stigma associated with dementia, some people may not identify with the disease label (Garand et al., 2009). As a consequence of dementia, some participants may be unaware of their diagnosis at the time of the research encounter (Pratt, 2002).

This issue has sparked debate among dementia scholars about the ethical implications of using or avoiding the term dementia. If a person does not identify as having dementia, confronting them with a label of dementia in recruitment materials or during the course of an interview may cause considerable distress (Bartlett & Martin, 2002; Pesonen et al., 2011; Pratt, 2002). On the other hand, the principle of informed consent requires researchers to explain the purpose of the study and topics to be covered. Avoiding the term dementia can be seen as deceptive or paternalistic (Bartlett & Martin, 2002).

The literature offers several strategies to address this issue, though researchers acknowledge there are no simple solutions (Bartlett & Martin, 2002). Some researchers have chosen to avoid the term dementia, opting instead to use terms such as ‘memory problems’ or ‘memory loss’ (Bartlett & Martin, 2002; Hellstrom et al., 2007; Pesonen et al., 2011; Wiersma, 2011). Proponents of this approach have argued that these terms are more sensitive and carry less stigma (Hellstrom et al., 2007; Pesonen et al., 2011; Pratt, 2002).

Pratt (2002) and Heggstad et al. (2013) also suggest consulting with gatekeepers or carers to determine whether participants are aware of their diagnosis and receptive to talking about it. Heggstad et al. (2013) describe employing ‘situational sensitivity’, rather than a universal approach, when deciding whether to disclose the dementia focus of the research. To approach the topic in a sensitive and careful manner, Pratt (2002) further suggests talking about the symptoms of dementia before bringing up the diagnosis.

### *Issues to consider*

Concealing the dementia focus of a project and avoiding the term ‘dementia’ may protect participants from distress but it also raises several issues that warrant consideration. First, it can be argued that this approach constitutes deception and violates the principle of fully informed consent (Bartlett & Martin, 2002). Researchers who use terms like ‘memory problems’ during the course of research should consider how they plan to report their findings. Avoiding the term dementia during the research process, but then using it in presentations or publications could be viewed as deceptive and potentially harmful.

Second, it may not be possible to avoid talking about disease categories. For example, research examining the experiences of people with specific types of dementia such as Frontotemporal dementia may require explicit eligibility criteria as well as clear information about the purpose of the study. Using the term dementia may be necessary for research into dementia related policies, programs or initiatives such as the dementia friendly communities movement. In participatory projects where people with dementia are involved as stakeholders, using euphemisms may be inappropriate. In addition, terms such as ‘memory problems’ do not reflect the full range of symptoms of dementia, and may not be a suitable term for all research projects (Sachdev et al., 2014).

## **Negotiating with gatekeepers and identifying sources of support**

### *Gatekeepers*

The issue of gatekeeping has received considerable attention among dementia researchers, and the literature on this topic suggests ambivalence towards the role of gatekeepers. On one hand, gatekeepers can restrict access to participants and compromise participant autonomy (Bartlett & Martin, 2002). On the other hand, gatekeepers can provide valuable information about participants’ abilities and needs, support participants’ decision making processes, and provide support to participants who experience distress (Bartlett & Martin, 2002; Digby et al., 2016; Pratt, 2002).

Debates on the role of gatekeepers reflect the tension between protection from harm and respecting autonomy, and striking a balance can be challenging. Complicating the issue, the concept is used in the literature to refer to many different roles including ethical review boards, managers, health professionals, service providers and family members. These

positions have different interests and relationships to participants, and are not necessarily advocates or trusted supporters. While there can be considerable overlap, there are also important differences between gatekeepers who influence access to participants, and the people who support their participation in research.

While recognizing some of the pitfalls, Pratt (2002) remarks that enlisting the help of gatekeepers can promote safety and good research practice. Gatekeepers and carers often provide relevant information, such as a participant's awareness of a dementia diagnosis (Pratt, 2002), signs of well-being or ill-being (Dewing, 2002), capacity to consent (Bartlett & Martin, 2002), and any sensitive topics to avoid (McKillop & Wilkinson, 2004). When gatekeepers are informed and involved, they may also assist with communicating the study aims and ensuring participants understand the research process (Bartlett & Martin, 2002; Hellstrom et al., 2007; Pratt, 2002), and supporting participants who experience distress (Digby et al., 2016; Hellstrom et al., 2007; Pratt, 2002).

### *Identifying sources of support*

The Scottish Dementia Working Group (2014) recommends asking participants if they want someone to accompany them during the research process (Scottish Dementia Working Group Research Sub-Group, 2014). In addition to contributing their own perspectives, family members or friends can make participants feel more comfortable (Pesonen et al., 2011), and they may also offer emotional support and assistance with communication (Digby et al., 2016; Pratt, 2002). Enabling participants to decide what supports they require can promote safety and inclusivity, but it also raises some issues for consideration. For example, participants in Digby et al.'s (2016) study could nominate a trusted person to be present during interviews. During one interview a participant's wife provided support and comforted the participant when he experienced distress. In another situation, a family member dominated the interview, and appeared to undermine the participant's responses (Digby et al., 2016).

These examples highlight some of the potential complexities that can arise when family members or friends are involved in the research process. From a methodological perspective, joint interviews can be difficult to facilitate and to interpret. Participants may feel uncomfortable discussing their concerns in front of family members, and joint interviews are often unbalanced, with one person directing the conversation (Pesonen et al., 2011). On the other hand, family members or friends may contribute to the research process and outcomes by supporting participants, offering prompts, and providing additional insights (Kendall et al., 2010).

## **The Research Relationship**

### *Choosing the time and location of the research*

Allowing participants to choose the time, location and duration of interviews or other research meetings is recommended (Hubbard et al., 2003; McKillop & Wilkinson, 2004; Scottish Dementia Working Group Research Sub-Group, 2014). Research involving people living in the community often takes place within participants' homes or other familiar environments to maximize comfort (Bartlett, 2012; Beuscher & Grando, 2009; Hellstrom et al., 2007; McKillop & Wilkinson, 2004; Pesonen et al., 2011). McKillop and Wilkinson (2004) and the Scottish Dementia Working Group (2014) suggest consulting with participants

to determine what time they prefer to meet, and for how long. Nygård (2006) recommends adapting the duration of research meetings for each participant, and including the option of conducting multiple short interviews. Allowing choice and flexibility promotes inclusivity and it can also give participants some control over the research process (Hubbard et al., 2003; Nygård, 2006).

### *Developing rapport*

Developing rapport with research participants is considered essential in qualitative research (Corbin & Morse, 2003; Dickson-Swift et al., 2007; Nygård, 2006). Building trust and creating a comfortable atmosphere facilitates conversation and encourages participants to share personal information and experiences (Dickson-Swift et al., 2007). Developing trusting relationships can enhance participants' experiences of the research process, and can help to reduce the power inequalities between participants and researchers (Hellstrom et al., 2007).

In the literature reviewed here, building relationships and developing rapport is particularly emphasized. Researchers and people with dementia have identified several approaches to building rapport including meeting with participants before undertaking research (Hubbard et al., 2003), engaging in informal conversation before and after interviews (Beuscher & Grando, 2009; Hellstrom et al., 2007; McKillop & Wilkinson, 2004) and conducting research over several encounters (Hellstrom et al., 2007; Pesonen et al., 2011; Pratt, 2002). Tanner (2012) found that including people with dementia as co-researchers enhanced rapport and shared understanding, although the extent to which co-researchers and participants connected varied (Tanner, 2012). These strategies can ease participants' anxieties about the research process (Digby et al., 2016; McKillop & Wilkinson, 2004) and foster a supportive atmosphere where participants feel safe and not judged for any impairments they might have (Digby et al., 2016).

Spending time with participants also provides an opportunity for researchers to familiarize themselves with each person's cognitive and communication abilities, and to tailor their communication style and approach to each participant (Digby et al., 2016; Hubbard et al., 2003). Pratt (2002) conducted multiple interviews with participants, and found that her comfort level and communication skills improved with each subsequent interview. Hubbard (2003) used preliminary conversations to determine whether to conduct interviews or observation with each study participant. The Scottish Dementia Working Group (2010) recommends asking participants how they are feeling at the start of each meeting, and finding out if they require any supports. This initial conversation can help researchers assess participant well-being, identify any issues or concerns, and adapt their approach to accommodate each participant (Dewing, 2002; Hellstrom et al., 2007).

### *Clarifying roles*

Pesonen et al. (2011) and Pratt (2002) discuss the problem of role ambiguity and highlight the importance of clarifying the researcher's role throughout the research process. Cognitive problems may contribute to confusion about the role of the researcher, and participants may forget who the researchers is or the purpose of the study. Ensuring that participants understand the role of the researcher is essential to maintaining informed consent, and Pesonen et al. (2011) suggest paying close attention to participants' perception and



expectations of the researcher. In some cases, researchers may need to explain their position and the purpose of the study throughout the research encounter (Nygård, 2006; Pratt, 2002).

From the perspective of participants, the boundaries between researcher and practitioner may be blurred, particularly when the researcher is also a health practitioner, or when the research is conducted in a health or long-term care setting (Hewitt, 2007; Richards & Schwartz, 2002). Pratt (2002) and Pesonen et al. (2011) describe situations where participants sought advice about their condition, treatment options and available services. Navigating these types of questions can be particularly challenging, especially when participants appear to have unmet needs for support (Pesonen et al., 2011). Researchers with professional or clinical backgrounds may experience a role conflict, and struggle to balance their dual identities (Pesonen, 2011).

When participants ask questions that fall outside of the researcher's area of expertise, Pratt (2002) recommends re-establishing the position of the researcher and explaining the kinds of questions that he or she can and cannot answer. Pesonen et al. (2011) dealt with these situations by providing supportive feedback and referring participants to the appropriate services. Although limited, the available literature suggests that developing a plan to deal with role confusion, and bringing information on available services and resources can help to maintain ongoing consent and appropriate boundaries.

#### *Withdrawing from the relationship*

Given the time spent developing relationships, researchers should also consider how they plan to withdraw from the relationship (Hellstrom et al., 2007). This issue may be particularly salient in the context of dementia research as relationships are emphasized, and the risk of role confusion is heightened (McKeown et al., 2010; Pratt, 2002). Conducting research in participant's homes, engaging in informal conversation, and conveying empathy can further blur the boundaries between participants and researchers (Dickson Swift, 2007). In addition, some participants might experience a loss when a study terminates and the research relationship ends (Hewitt, 2007).

While this issue has been mentioned (Hellstrom et al., 2007; McKeown et al., 2010; Nygård, 2006), it has received little attention in the literature on dementia. Nygård (2006) advises clear communication about the parameters of the research relationship, and Hellstrom et al. (2007) suggest approaching the subject with "honesty and sincerity" (Hellstrom et al., 2007). Studies investigating sensitive topics might also consider following up with participants to debrief them and put them in touch with services that offer ongoing supports (Hewitt, 2007).

Research relationships vary and navigating the ending of relationships can be challenging (Dickson-Swift et al., 2007). Some research relationships end at the conclusion of a research project, while others may turn into friendships or research partnerships. In other cases, the researcher may decide to end a research encounter or withdraw a participant from the study if the participant is no longer able to provide informed consent or benefit from participation. Further examination of these issues from the perspectives of participants and researchers is required to develop sensitive and ethical approaches to relationship building and ending.

### **Communication and data collection**

#### *Communication strategies*

With the expansion of qualitative research to include participants with a wider range of communication abilities, researchers have reflected on the challenges that can arise, and the techniques that facilitate sensitive and effective communication (Beuscher & Grando, 2009; Digby et al., 2016; Hubbard et al., 2003; Murphy et al., 2015; Nygård, 2006; Pesonen et al., 2011; Pratt, 2002). Language and communication challenges associated with dementia vary considerably depending on the type of dementia and the person's level of disability. Individuals experience different cognitive and communication symptoms that progress at different rates, and for some these can fluctuate from day to day. As a result, there is no single method or strategy to accommodate the diversity of participants' needs and symptoms (Hubbard et al., 2003). Instead, scholars emphasize sensitive, attuned and flexible communication approaches that enable researchers to adapt and respond to participants' needs and abilities (Beuscher & Grando, 2009; Digby et al., 2016; Heggestad et al., 2013; Nygård, 2006).

As mentioned previously, developing rapport allows researchers to identify any communication issues, and to adapt their approach to each participant. This can include the wording of questions, as well as the timing and pace of interviews (Digby et al., 2016; Nygård, 2006). Allowing participants to direct the conversation and discuss issues that matter to them can minimize the power imbalance of the research relationship (Dickson-Swift et al., 2007; Digby et al., 2016). Digby et al. (2016) point out that in some instances, tangential stories function as a protective strategy for participants to avoid discussing sensitive topics, or subjects they have difficulty remembering. At the same time, researchers need to be able to support participants who are struggling to find words or to direct the conversation (Beuscher & Grando, 2009; Hubbard et al., 2003). Finding a balance between allowing time and freedom while also supporting the flow of conversation can be challenging (Hubbard et al., 2003).

#### *Preparing research questions*

In qualitative research, the emphasis on communication can present challenges for some people with dementia, and there is a risk that research questions and techniques will call attention to a person's impairments (Bartlett, 2012; Hubbard et al., 2003). Several scholars recommend designing questions that focus on participants' strengths, and avoiding questions that require recalling detailed information such as dates or the sequencing of events (Digby et al., 2016; Pratt, 2002). Many people with dementia can talk about their experiences and perspectives, so researchers are encouraged to focus questions around participants' experiences (Hellstrom et al., 2007; Pratt, 2002; Tanner, 2012). Providing demographic information can be difficult for some participants, and Pratt (2002) recommends exercising caution when including any demographic questions. Unless it is essential to the study, the use of cognitive tests is discouraged, as they can be profoundly distressing for people with cognitive impairment (Hellstrom et al., 2007). Methods that involve writing can also lead to distress if participants experience difficulties with written communication. Commenting on the diary interview method, Bartlett (2012) recommends informing participants of this possibility as part of the consent process.

#### *Factors that affect communication*

In a research context, a person's ability to understand and to communicate their perspective is influenced by several factors, and not simply their dementia (Digby et al., 2016; Hubbard et

al., 2003). Digby et al. (2016) point out that all individuals possess unique communication styles and abilities that can impact the research process, and cautions against attributing communication issues to the dementia itself. Hubbard et al. (2003) argue that a participant's ability to communicate is affected by the skills of the researcher, including their ability to listen and to understand. The particular research methods and techniques employed can also affect a participant's ability to communicate. Dewing (2002) points out the need to develop methods that enable communication with individuals who have more pronounced cognitive and communication impairments.

### **Dealing with distress**

Investigating sensitive topics places participants at risk for emotional and psychological distress, and researchers have an obligation to think through how they will respond to signs of distress (Pratt, 2002). Confusion or difficulty communicating and recalling events can also lead to distress or agitation (Hellstrom et al., 2007; Hubbard et al., 2003; Pesonen et al., 2011). For example, after taking a Mini-Mental State Examination (Tombaugh & McIntyre, 1992), a participant in Hellstrom et al.'s (2007) study described feeling stupid. In some cases, misunderstanding the role of the researcher can cause anxiety (Hellstrom et al., 2007; Pesonen et al., 2011).

Researchers are advised to look for verbal and non-verbal signs of distress or discomfort (Digby et al., 2016; Heggstad et al., 2013; Pesonen et al., 2011). Paying attention to body language is particularly important when communication is impaired, and is considered essential to maintaining on-going consent (Digby et al., 2016). Strategies to deal with signs of distress include offering breaks, offering to stop the interview or research process, and changing to a neutral topic. It is important to allow participants to talk through difficult issues, and participants often wish to continue even if the topic triggers difficult emotions (Moore & Hollett, 2003; Pesonen et al., 2011; Pratt, 2002). If a participant wishes to end the interview, Pratt (2002) suggests engaging in informal conversation until they no longer appear distressed. Ending interviews "on a positive note" by asking questions that focus on strengths and supports, and by engaging in informal interaction is widely recommended (Digby et al., 2016; Hellstrom et al., 2007; McKillop & Wilkinson, 2004; Murphy et al., 2015).

### **Feedback and knowledge dissemination**

Contributions to the literature from people with dementia underline the responsibility to provide updates on the study's progress, and to disseminate findings to relevant stakeholders (McKillop & Wilkinson, 2004; Robinson, 2002; Scottish Dementia Working Group Research Sub-Group, 2014). The Scottish Dementia Working Group (2014) cautions that people with dementia can feel used and devalued by researchers who do not report back to participants. The report recommends consulting with participants about when and how they wish to be informed of the study's progress, and whether they want a trusted person to be kept informed too. When conducting longitudinal studies, researchers may also consider keeping in contact with participants between interviews or when there is a break in the research process (Hellstrom et al., 2007). The Scottish Dementia Working Group (2014) and McKillop and Wilkinson (2004) point out that individuals have different preferences and expectations around feedback, and highlight the importance of clarifying and negotiating the process of communicating results.

While there is a growing push to include people with dementia in all aspects of the research process, the issue of knowledge dissemination has received little attention. The Scottish Dementia Working Group (2014) recommends sharing findings with relevant stakeholders, and engaging people with dementia in all aspects of the research process. Wiersma (2011) reflects on the challenges of representing people with dementia in research reports and including participants in the dissemination process. Consistent with a participatory approach, she sought input from participants on knowledge dissemination strategies and invited them to take part in crafting and presenting findings (Wiersma, 2011). More work is required to develop strategies for engaging participants in knowledge dissemination, and to consider the ethical and practical issues that can arise.

### **Researcher Knowledge and Skills**

In light of the complexities of the research process, McKeown et al. (2010) pose the question: “who should conduct research with people with dementia?” (p. 1940). According to the authors, the ethical complexity and sensitivity of dementia research demands particular knowledge and skills; skills which not all researchers possess (McKeown et al., 2010). Several scholars have commented on the importance of experience and skill (Beuscher & Grando, 2009; Digby et al., 2016; Heggstad et al., 2013; Hubbard et al., 2003), though the evidence in the area remains scant.

#### *Knowledge of dementia*

Several papers make the case for attaining sufficient knowledge of dementia before partaking in research, including the causes and symptoms of dementia, and the range of impacts of dementia on affected individuals. According to Hubbard et al. (2003), researchers should understand the potential effects of dementia on memory, decision-making capacity and emotions in order to identify issues as they arise and to adapt the research process. The Scottish Dementia Working Group (2014) urges researchers to learn about the various types of dementia and to recognize the heterogeneity of symptoms and experiences. Beuscher and Grando (2009), Digby et al. (2016), and Hubbard et al. (2003) argue that researchers should be aware of the range of communication challenges associated with dementia and should be prepared to accommodate participants’ communication abilities.

While knowledge of dementia is commonly described as essential (Digby et al., 2016; Hubbard et al., 2003), the issue of researcher training has not been considered in-depth. For example, the literature reviewed here does mention knowledge of some symptoms associated with dementia that could influence research participation such as behaviour changes and perceptual and motor impairments. Further research is necessary to determine the scope of knowledge required for dementia researchers and to develop training materials for those entering the field.

#### *Research and interpersonal skills*

Other skills and researcher attributes highlighted in the literature are not specific to dementia research, but reflect the interpersonal skills required to conduct qualitative research. In their discussion of risk and qualitative interviews, Corbin and Morse (2003) commented, ‘No one can predict what will be said in the course of an unstructured interview, the feelings it will provoke, or any long-lasting effects. Much depends on the ability of the interviewer to judge and respond to the emotional state of the participant.’ (p. 346-347). Researchers’ skills may

be particularly important in the context of dementia research given the sensitive nature of the subject matter, the potential for communication challenges, and the obligation to identify subtle signs of distress or lack of consent (Dewing, 2002; Digby et al., 2016; Hellstrom et al., 2007).

In addition to knowledge of qualitative methods and research ethics, pertinent researcher skills identified in the literature include verbal and non-verbal communication skills (Digby et al., 2016; Hubbard et al., 2003), active listening skills (Nygård, 2006), critical thinking skills, and reflexivity (Dewing, 2007; McKeown et al., 2010; Pesonen et al., 2011). Other researcher qualities thought to promote participant well-being and ethical practice include sensitivity (Digby et al., 2016), moral sensitivity (Heggestad et al., 2013), empathy (Digby et al., 2016; Hellstrom et al., 2007; Scottish Dementia Working Group Research Sub-Group, 2014), respect (Digby et al., 2016; Scottish Dementia Working Group Research Sub-Group, 2014) and authenticity (McKillop & Wilkinson, 2004).

### *Research and practical experience*

While some attributes such as sensitivity may be personality traits, other skills can be acquired through experience (Corbin & Morse, 2003). Hellstrom et al. (2007) suggest that the lead author's experience as a nurse working with people with dementia helped to ensure the interviews were relaxed and comfortable. Several others highlighted their clinical and research experience with people with dementia, commenting that it prepared them to communicate with participants, to adapt to their needs and abilities, and to navigate ethical issues (Beuscher & Grando, 2009; Digby et al., 2016; Heggestad et al., 2013; Hubbard et al., 2003; Pesonen et al., 2011).

One possibility for novice researchers is to work with or seek mentorship from more experienced dementia researchers (Beuscher & Grando, 2009; Dewing, 2002; McKeown et al., 2010). McKeown et al. (2010) point out that researchers and students can learn from experienced clinicians and suggests developing working relationships between academics and clinicians working in the field of dementia. Engaging in reflexive practice may also help researchers develop their skills, navigate ethical issues, and process any emotional challenges they experience (Heggestad et al., 2013; Pratt, 2002). Another promising strategy is to promote cooperation between academics and organizations that actively involve, or are led by people with dementia. For example, the Scottish Dementia Working Group has established links with researchers across the UK and collaborated with academic researchers to develop guidelines for research involving people with dementia (Scottish Dementia Working Group Research Sub-Group, 2014).

## **Discussion**

This review identified a range of issues that impact participant safety as well as strategies to minimize discomfort and maximize the potential benefits of participation. People with dementia form a diverse group, so approaches to promote safe research practice should be tailored to the study design, setting, and to individual participants. As such, the findings from this review are not intended to be prescriptive. Rather, the aim of this paper is to advance discussion of the practical and ethical dimensions of inclusive dementia research, and to identify new lines of inquiry.

The issue of dementia disclosure has received considerable attention. While there are no simple solutions to this issue, the discussion in the literature highlights the need to exercise caution when using a term that carries significant stigma. As awareness and diagnostic practices improve, and the movement to end the stigma associated with dementia gains momentum, the potential for the word dementia to cause harm may diminish. Still, a participant's awareness of their diagnosis is subject to change, and researchers are advised to think through how they plan to deal sensitively with participants who may be unaware of their diagnosis, as well as those who may reject the disease label (Bartlett & Martin, 2002).

Qualitative research is a social endeavour, and efforts to ensure participant well-being occur in the context of relationships. The literature suggests that participant safety is enhanced when researchers develop relationships that convey respect and reciprocity with participants and the people who support them (Hellstrom et al., 2007). At the same time, ethical issues can arise in the process of relationship building. Time spent developing rapport, establishing trust and engaging in informal conversations can blur the boundaries between researchers and participants (Dickson-Swift et al., 2007). Conducting research in participants' homes and displaying empathy and concern can also shift the relationship and increase the risk of role ambiguity (Corbin & Morse, 2003; Dickson-Swift et al., 2007). In this context, it is important for researchers to consider how they will withdraw from the relationship. While this issue has been raised, it has not been explored in-depth. We recommend further discussion of the practical and ethical aspects of relationship building and ending.

Strategies to uphold participant safety and ethical practice also have implications for researcher well-being and safety. Efforts to develop rapport and positive relationships can be emotionally taxing for researchers and may lead to attachments (Dickson-Swift et al., 2007; Pesonen et al., 2011). Hearing the stories of participants, witnessing suffering, and offering support can also affect researchers (Dickson-Swift et al., 2007). The task of resolving ethical issues and prioritizing participant safety can be challenging for researchers, and may have consequences for their well-being (Heggstad et al., 2013; Pesonen et al., 2011).

People with dementia have made important contributions to the literature on ethical practice. Papers written by people with dementia (McKillop & Wilkinson, 2004; Robinson, 2002) and the guidelines put forward by the Scottish Dementia Working Group (2014) emphasize the importance of feedback and knowledge dissemination. The Scottish Dementia Working Group (2014) also recommends consulting with participants to find out if they would like friends or family members involved in the research processes or updated about the study. Although researchers may already be employing this practice, it has so far received little attention in the literature.

The majority of literature reviewed here is based on the reflections of researchers; very few papers included the perspectives of participants living with dementia. The examples above highlight the importance of including the perspectives of people with dementia in discussions on research ethics and best practices. Their contributions to knowledge and ethical practice suggest that research safety is enhanced when people with dementia can influence the research process, and have a platform to express their views.

Qualitative research that includes people with dementia as participants has grown considerably over the last few decades, and now encompasses a wide range of methods and techniques. However, it should be noted that the majority of the research reviewed here

focused on methods of interviewing and observation. Despite the push to include people with dementia in all aspects of the research process, only three studies in this review employed participatory approaches (Bartlett, 2012; Tanner, 2012; Wiersma, 2011).

Participatory and collaborative approaches to research expand the role of participants and seek to reduce the power inequalities that structure traditional research processes (Bartlett, 2012; Beresford, 2002; Kitchin, 2010). Compared to other areas of health and social research, however, the participation of people with dementia in research and knowledge production remains relatively narrow. The few participatory studies identified in this review indicate that people with dementia can make significant contributions as co-researchers and collaborators. For example, Tanner (2012) observed that involving co-researchers with dementia helped to establish rapport and enhanced the interpretation of research findings. In order to support the wider engagement of people with dementia in the research process, further exploration of the strengths and challenges of participatory and collaborative methods is required.

Another significant gap in the research reviewed here is the lack of attention to minority groups and other categories of social identity beyond dementia. Research relationships and processes are influenced by multiple factors including participants' and researchers' age, gender, ethnicity, sexual orientation, socio-economic status, and dementia status (Hewitt, 2007; Manderson et al., 2006; Wilson & Neville, 2009). These factors affect social interactions and relations of power between researchers and participants (Hewitt, 2007; Manderson et al., 2006). There is a growing call for research that includes the perspectives and voices of people with dementia from different populations and minority groups (McGovern, 2014; O'Connor, Phinney, & Hulko, 2010). Meeting this challenge requires the development of safe and inclusive research approaches that are sensitive to and respectful of the needs and concerns of different populations.

## **Conclusion**

In the past, concerns about emotional harm and potential exploitation have been used to justify the exclusion of people with dementia from research and reliance on proxy accounts (Hellstrom et al., 2007). During the 1990s and early 2000s, researchers began to challenge the assumption that participation is inevitably harmful (Wilkinson, 2002). Since then, inclusive approaches to dementia research have expanded, and more and more researchers have reflected on the ethical dimensions of the research process. People with dementia have also entered the debate, writing about their experiences as research participants and developing guidelines for researchers.

The available evidence suggests that participation in qualitative research can contribute to well-being and social inclusion (Hellstrom et al., 2007; Wilkinson, 2002; Tanner, 2013), but it also carries risks. Participants' experiences of harm reflect the risks inherent to qualitative research on sensitive topics, and are not necessarily specific to dementia. At the same time, including people with dementia adds complexities to the research process, and research practices must meet high standards to ensure their welfare is protected. Attending to these issues is critical to support the wider inclusion of people with dementia in research.

This review identified key issues that emerge in the context of qualitative research involving people with dementia, as well as strategies and techniques proposed by researchers and

people living with dementia to prevent harm and to promote well-being. However, the available evidence remains anecdotal, and largely confined to the perspectives and observations of researchers. Seeking the perspectives of people with dementia through further collaboration and research is required to advance understanding of safe research practices and to support the development of inclusive and participatory approaches to research.



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- Use respectful terminology and avoid stigmatizing language
- Develop a plan to communicate sensitively with participants who may be unaware of their dementia diagnosis
- Consult with participants (and/or carers where appropriate) to identify sources of support
- When possible, allow participants to choose the time, location and duration of the research encounter
- Take time to foster rapport and develop a strategy to withdraw from the research relationship
- Consider the problem of role ambiguity, and take steps to ensure that participants understand the role of the researcher
- Tailor interview questions and communication styles to participants' communication abilities
- Develop a strategy to deal with participant distress, and pay attention to verbal and non-verbal signs of distress
- Consider researcher safety, and identify strategies and resources to deal with ethical issues and emotional challenges
- Consult with participants about their preferences and expectations for communicating results, and ensure that findings are shared with participants and relevant stakeholders
- Novice researchers may consider seeking guidance from more experienced researchers, clinicians or people living with dementia

**Figure 1.** Safe research practices identified in the literature