

Reflections and Recommendations for Conducting In-Depth Interviews With People With Dementia

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Abstract

Despite the importance and advantages of including people with dementia in research, there are various challenges for researchers and participants to their involvement. This article draws on the literature and experiences of a diverse group of authors, including a person with dementia, to provide recommendations about conducting research with people with dementia. Particular attention is given to in-depth interviews as a qualitative technique. More specifically, topics discussed include interview guide preparation, recruitment, obtaining consent/assent, conducting effective interviews, analysis and interpretation of data, effective communication of research findings, and reflections and recommendations for maintaining researcher and participant health. Given the current obstacles to participation in research of people with dementia, this is a timely article providing useful insights to promote improved outcomes using in-depth interviews.

Keywords

dementia; qualitative interviews; research, participation; confidentiality/privacy; data collection and management; exploratory methods; relationships, research; Australia

Historically, people with dementia have been excluded from health and social research participation (Wilkinson, 2002). However, research incorporating the subjective experiences of people living with dementia¹ is on the rise (Clare, 2002; de Boer et al., 2007; von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012). Factors contributing to this increasing attention include acknowledgment that there is a need to address the power inequalities in the relationship people with dementia have with others (Wilkinson, 2002). This includes a recognition that exclusion from the research process can contribute to the objectification and negative stereotyping of people living with dementia (Cotrell & Schulz, 1993); people with dementia are capable of expressing their views, needs, and concerns (Hellström, Nolan, Nordenfelt, & Lundh, 2007; Smebye & Kirkevold, 2012); understanding the experiences of people with dementia is important for evidence-based service delivery; many people with dementia might desire to be involved in research (Abbato, 2015; Beard, 2004; de Boer et al., 2007; Dewing, 2002); and people with dementia might benefit from research involvement (Beard & Fox, 2008; Hellström et al., 2007). Many of the studies including people with dementia have used qualitative approaches. Benefits of qualitative approaches include the collaborative and inclusive nature, the flexible structure,

and the capacity to explore complex issues, such as mixed or ambiguous attitudes (Bond & Corner, 2001; Clare, 2002; Wilkinson, 2002).

The focus of this article is in-depth interviews, which are the most commonly known and widely employed qualitative research method (McIntosh & Morse, 2015; Seary & Liamputtong, 2001). In-depth interviews involve comprehensive conversations between the researcher and interviewee, which have an overall purpose prompted by the research aims, but are strongly guided by the interviewee's perceptions, opinions, and experiences (Dickson-Swift, James, Kippen, & Liamputtong, 2007; Minichiello, Aroni, Timewell & Alexander, 1995). More specifically, in-depth interviews aim to understand the participants' lived experience and, in this sense, are considered more complex than simply asking questions and talking to people (Seary & Liamputtong, 2001). Interviews have been favored as a method suitable for collecting data from

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people with dementia (Clarke & Keady, 2002), with an emerging body of research indicating other interview methods (such as focus groups) may be less suitable for this subgroup (Bamford & Bruce, 2000; Blackman et al., 2003).

Despite the acknowledged importance and advantages of including people with dementia in research, there are various challenges for both researchers and participants themselves when participating in in-depth interviews (Lloyd, Gatherer, & Kalsy, 2006). Fundamentally, the cognitive impairments inherent to the condition can make some people with dementia difficult to engage in the research process (Abbato, 2015; Dewing, 2002). More specifically, cognitive impairments implicated with dementia often involve memory difficulties, perceptual abnormalities, and communication challenges (Lloyd et al., 2006). Such impairment might result in vague speech, decreased vocabulary, poor reasoning of verbal information, confabulations or “pseudo-reminiscences,” perseverations, and confused word associations (Crisp, 1995; Haak, 2003; Hubbard, Downs, & Tester, 2003; Nygård, 2006). In addition, dementia is a progressive condition, meaning the capacity of a person with dementia to participate in a research interview is likely to decrease with the advancement of the disease. Together, these challenges have made some researchers question the credibility and reliability of including people with dementia in in-depth interviews (Abbato, 2015; Dewing, 2002). Furthermore, the behavioral difficulties (e.g., agitation, aggression, restlessness) that sometimes result from the cognitive changes can exacerbate the practical difficulties of involving people with dementia in in-depth interviews (Abbato, 2015).

Given the specific challenges, coupled with recognition of the importance of including people with dementia in research, there is a need for improved guidance for researchers regarding the conduct of in-depth interviews with people with dementia.

Method

In this article, we conducted a focused literature review of scholarly articles concerning approaches to conducting in-depth interviews with people with dementia. Recommendations presented throughout the article are derived from this review and also our own reflections in regard to the conduct of in-depth interviews. We have conducted various studies involving interviews with people with dementia and/or their carers² exploring issues such as understanding experiences of living in the community (Phillipson and Cridland), use of respite services (Phillipson and Cridland), the lived experience of dementia (Swaffer), and interviews to facilitate identification and mapping of dementia-friendly places and spaces

(Phillipson, Cridland, Brennan-Horley). The in-depth interview approaches have included conducting interviews with people with dementia and their carers together as well as separately. We have used various approaches to facilitate the interview process such as conducting “walk-about” with the participants within their home and community, using visual prompts, and mapping techniques (Phillipson, Cridland, Brennan-Horley). In addition, we have also worked with people with dementia and their carers in local dementia advisory groups and reference groups to inform research and community projects. Finally, Phillipson and Cridland have experience in the conduct of clinical interviews; the former as an allied health practitioner and the later as a psychologist. Swaffer is also living with dementia and so offers her unique perspectives as both a participant in research interviews and a facilitator of interviews with people with dementia.

Reflections presented throughout the article were derived from a range of methods, such as author field notes and research journal entries, debriefing following in-depth interviews, and meetings with people with dementia and carers. Furthermore, some reflections were derived from feedback from Swaffer regarding her experience of being involved in in-depth interviews and research processes (e.g., reflections about recruitment strategies, consent procedures, wording of interview questions, etc.).

The reflections and recommendations cover all stages of the research process for the conduct of in-depth interviews, including research preparation, data collection, data analysis, and dissemination of findings (see Figure 1). Consideration is also given to the health and well-being of researchers and participants across all stages of the research process. The model and guidelines were adapted from Cridland, Jones, Caputi, and Magee (2015) who presented recommendations for doing qualitative research with individuals living with autism spectrum disorder.

Preparation

Interview Guide Development

Adequate preparation of the interview guide is vital as it underpins the interview process and influences subsequent research stages (McIntosh & Morse, 2015; Minichiello et al., 1995). Given the range of considerations related to interviewing people with dementia, an appropriate interview guide is particularly important when conducting research with this population. For example, given the likelihood of memory impairments, it is particularly important when developing an interview guide to include an introductory statement to remind participants about the general focus of the interview.

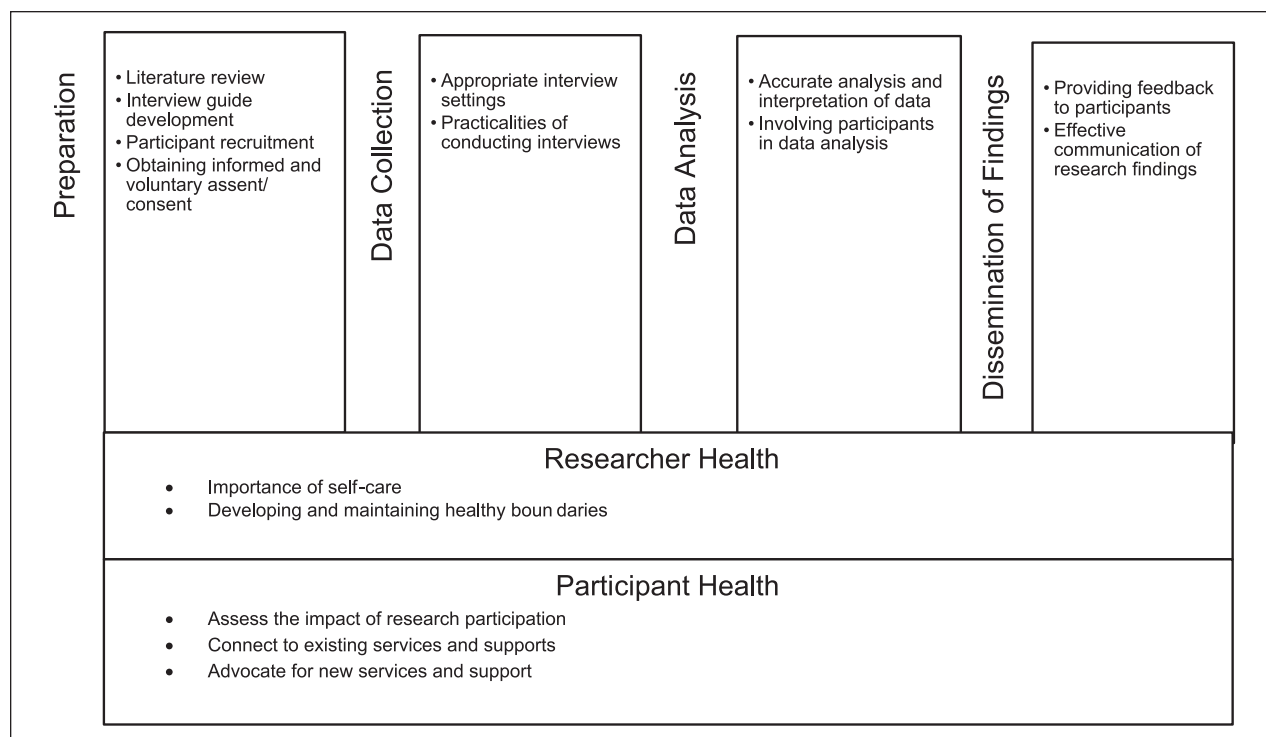


Figure 1. Stages of in-depth interviews discussed in the article.

Furthermore, it may be beneficial to repeat these “general statements” throughout the interview to ensure the participant retains a sense of the context for the interview. We have also found beginning interviews with a “warm-up” question to be helpful when interviewing this population, as it facilitates participants to “ease” into the conversation. This also allows the interviewer opportunity to develop a rapport with the person with dementia, which may be particularly important for this population.

From our experience, other useful considerations in interview guide development have included using appropriate language/dementia terminology when recruiting for participants, for example, not referring to them as recruits rather as “participants,” “experts,” “community member,” and so forth; using appropriate language/dementia terminology throughout the interview (e.g., avoiding referring to people with dementia as “sufferers”; Alzheimer’s Australia, n.d.b); and developing approaches to suit the capacity of individual participants (e.g., use of visual prompts, having joint interviews with the person/people who provide support, as so forth). We have also found providing a prelude to potentially challenging interview questions (e.g., “Some people find the next question difficult . . .”) and oscillating between challenging and less challenging topics to be helpful. Developing single-faceted interview questions is also imperative to help reduce the demands of the interview on participants. For example, asking “What do you like about living in

this house?” and then “Are there things you would like to modify in your house?” compared with “What do you like about living in this house or are there things you would like to modify?” Furthermore, using a balance of positively and negatively worded questions and avoiding leading questions is an important consideration with this population to normalize and encourage open discussion of potentially difficult topics and facilitate non-bias responses. An example of a leading question in a study focusing on the challenges of people with dementia driving would be “What challenges have you encountered when driving since your diagnosis of dementia?” opposed to a neutral question exploring the same issue, “What have been your experiences of driving recently?”

We recommend pilot testing the interview guide with people with dementia to identify areas of potential confusion or misinterpretation. Researchers may also connect with consumer groups of people with dementia to seek feedback on the interview guide (see Table 1, recommendation 1j for more details).

Participant Recruitment

Effective recruitment strategies are critical for obtaining an appropriate sample in all research studies (Dickson-Swift et al., 2007; Dickson-Swift, James, Kippen, & Liamputtong, 2008). However, many studies involving people with dementia recruit from dementia research

Table 1. Recommendations For Conducting Qualitative Interviews With People With Dementia.

	Research Stage	Recommendation	General Rationale	Rationale for Research With PWD
Ia.	Preparation: Interview guide development	Include an introductory statement and reminder statements periodically throughout the interview.	Introductory statements facilitates a clear and concise opening and remind participants of the general focus of the interview. Reminder statements incorporated at regular intervals reorient the participant to the interview focus.	Both introductory and reminder statements orient the PWD to the interview focus, which may be particularly relevant given the memory difficulties inherent to the condition. "Reminder cards" with brief summaries have been used with PWD (Clare, Roth, & Pratt, 2005)
Ib.	Preparation: Interview guide development	Begin interviews by building rapport and the use of a "warm-up" question.	Rapport building and a warm-up question help "set the scene" while also allowing participants to experience mastery and relax into the interview.	Time to establish the identity of the researcher and develop comfort are important to establish trust and context for PWD (see 2d for more information about rapport building). Facilitating mastery may decrease any apprehension or agitation, which is particularly relevant for this population.
Ic.	Preparation: Interview guide development	Use appropriate language	"Value-neutral" and sensitive language are important when conducting research with specific populations (e.g., individuals diagnosed with a health condition). It is beneficial and necessary to be flexible and use language preferred by individual participants.	Avoid terms which position PWD as "sufferers" or those "afflicted" by dementia (Beard, Knauss, & Moyer, 2009). PWD may use different terminology to refer to dementia (e.g., memory problem, Alzheimer's, and so forth; Clare, 2002; Clare, Roth, & Pratt, 2005; Garand, Longler, Connor, & Dew, 2009; Gillies, 2000).
I d.	Preparation: Interview guide development	Develop approaches to suit the capacity of each participant	Flexible interview approaches can be used to suit the capacity and needs of individual participants and help ensure participants who find complex approaches too demanding are not disempowered and/or declined from participating in the research.	Various approaches have been utilized with PWD to facilitate inclusion of those with more advanced conditions, such as preliminary interviews with carers (Clare, 2002); combining interviews with observations (Beard, 2004; Haak, 2003; Hubbard, Downs, & Tester, 2003); conducting follow-up interviews to review, clarify, and expand on issues discussed (Phinney, 1998); and triangulating interviews with contextual information such as medical records or carer perspectives (Clare, Rowlands, Bruce, Surr, & Downs, 2008). Co-occurring conditions (e.g., hearing or vision difficulties) may influence their capacity.
Ie.	Preparation: Interview guide development	Provide a prelude to challenging questions.	A prelude prepares participants for the upcoming question and normalizes any feelings of confusion or discomfort they may have.	Topics PWD may find challenging include the losses or difficulties associated with the condition and recalling recent events (Cotrell & Schulz, 1993).
If.	Preparation: Interview guide development	Structure interview guide to have challenging questions followed by easier topics.	Oscillating between challenging and less challenging topics can help reduce the emotional and psychological demands of the interview. "Easy" questions should foster mastery and relate in some way to the research topic (Minichiello, Aroni, Timewell, & Alexander, 1995).	"Easy" topics of conversation with PWD may involve reminiscing about past positive experiences.
Ig.	Preparation: Interview guide development	Develop single-faceted questions.	Single-faceted questions are easier for participants to understand and accurately interpret.	Single-faceted questions suit the processing style of PWD and facilitate accurate interpretation of questions (Harman & Clare, 2006; Nygård, 2006). Confusion caused by difficulty understanding multifaceted questions may disempower a PWD.
Ih.	Preparation: Interview guide development	Use both positively and negatively framed questions.	Using positively and negatively framed questions is good practice in all qualitative research. Such questions facilitate discussion of both rewarding and challenging experiences, attitudes, and feelings, and contribute to a balanced understanding of issues.	Interviews with PWD are likely to involve discussion of a range of positive, negative, and ambiguous experiences, attitudes, and feelings. In doing so, acknowledge that not all participants will share the range of experiences to help normalize and encourage open discussion.

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Table I. (continued)

	Research Stage	Recommendation	General Rationale	Rationale for Research With PWD
Ig	Preparation: Interview guide development	Consider the utility of visual aids or stimulus materials to prompt recall and response depth	The use of visual stimulus materials (e.g., photographs or maps) may assist with prompting recall and context when questions are not sufficient to gain a meaningful response.	Visual stimuli may be particularly relevant for prompting recall for PWD given the memory impairments inherent to the condition (see 2b for more information about visual stimuli).
Ii.	Preparation: Interview guide development	Avoid using leading questions.	All research studies have aims and hypotheses; however, it is important that interview questions do not elicit responses solely in support of these hypotheses.	When responding to questions, PWD may be likely to discuss things specific to the question posed rather than using that question as a platform on which to elaborate.
Ij.	Preparation: Interview guide development	Pilot test the interview guide.	Pilot testing the interview guide is helpful in estimating the time needed to conduct the interview and promote researcher familiarity with the interview guide.	Pilot testing with PWD may be useful in identifying potentially confusing questions or those open to misinterpretation. Researchers may also be able to connect with consumer groups (e.g., Dementia Alliance International [n.d.], and the Alzheimer's Australia Dementia Advisory Committee [n.d.-a]) to seek feedback about the interview guide and other project materials (e.g., participant information sheets).
Ik.	Preparation: Participant recruitment	Promote the study through a range of avenues, especially interpersonal channels.	Promoting the study through a range of avenues (such as community organizations and public venues) will increase the number of potential participants that the study is advertised to. Promoting the study through interpersonal channels is also likely to increase the responses.	Relevant places of recruitment for PWD may include dementia and aged care services, community social groups, general practitioner surgeries, volunteer organizations, and carers groups. Utilizing in-home services may facilitate recruitment of PWD who are not involved in community activities. Snowballing from recruited participants and encouraging staff and peers at services is also effective as PWD appreciate interpersonal channels of recruitment.
Il.	Preparation: Participant recruitment	Provide multiple methods of contact when advertising the study.	Providing multiple methods of contact gives potential participants flexibility in response options. Methods of contact may include a sign-up sheets, phone, text message services, email, or social media such as Facebook.	Methods of contact relying on social media or new technology may be less suitable/appealing for PWD; reliance on only these methods may result in sub-optimal and/or biased recruiting. The use of dedicated social marketing campaigns may assist with engagement (Gitlin et al.).
Im	Preparation: Participant recruitment	Provide clear and detailed information about the study in recruitment material.	Providing participants with detailed information about the study may facilitate interest. Relevant information may include study aims, participant requirements, study time frame (e.g., recruitment cutoff, data collection phases), and expected benefits of research.	Having limited information about the research may be a barrier for PWD and their carers participating in research (Connell, Shaw, Holmes, & Foster, 2001; Garand et al., 2009). Present detailed written information in a clearly structured format (e.g., bullet points) to facilitate interpretation by PWD.
In	Preparation: Participant recruitment	Provide a personal face to the project through face to face presentations to community forums/ groups	Presentations given by members of the research team to community audiences increase the personal face of the project.	Community information sessions is a useful strategy for encouraging research participation with this population (Author, 2015a) as it promotes familiarity with the research team.
Io.	Preparation: Participant recruitment	Include information about the expected positive outcomes of being involved in the study.	Being involved in in-depth interviews can be a rewarding and enriching experience for participants (Dickson-Swift, James, Kippen, & Liamputtong, 2007, 2008). Sharing this information with potential participants may increase their interest in being involved in the study. The broader community benefit of the project should also be promoted.	A significant barrier for PWD participating in research is the perception of limited benefit of doing so (Garand et al., 2009). Positive outcomes of being involved in in-depth interviews for PWD may include having an opportunity to discuss issues important to them, and having a sense of purpose by contributing to the scientific literature and potentially improving the quality of life of PWD (Beard & Fox, 2008; Garand et al., 2009; Gillies, 2000). Images that portray positive lived experiences of PWD in recruitment materials is also important (Garand et al., 2009).

(continued)

Table 1. (continued)

	Research Stage	Recommendation	General Rationale	Rationale for Research With PWD
1p.	Preparation: Obtaining informed and voluntary assent/consent	Organize a face-to-face “preliminary meeting” with potential participants to outline the study.	A preliminary meeting is useful for providing potential participants with written and verbal information about the study and requirements of participants (e.g., time commitment). It is also useful for answering participant questions and ensuring that research eligibility criteria are satisfied.	PWD may appreciate meeting the researcher prior to the interview to promote familiarity and build rapport (Cotrell & Schulz, 1993; Dalby Sperlinger, & Boddington, 2011; Dewing, 2002). During this meeting, explore what terminology they use to refer dementia and check whether they have the capacity required for the interview (Clare, 2002; Garand et al., 2009; Gillies, 2000). Providing participants with a list of topics to be discussed in the interview can be helpful to allow participants to prepare.
1q.	Preparation: Obtaining informed and voluntary assent/consent	Obtain informed assent from participants who are unable to provide formal consent.	While written assent from research participants deemed not competent may not be necessary to fulfill legal requirements of research, its inclusion is important to ensure all participants are voluntarily participating in the study and to promote a person-centered and inclusive approach.	Assent forms for PWD should have large printed text, appropriate language, and a “checklist” format, so important information is clearly outlined (Garand et al., 2009; Gillies, 2000). Allow PWD time to review the material at their own pace (Garand et al., 2009). In addition, having the option of writing initials or providing verbal assent is important for those who find writing difficult (Bamford & Bruce, 2000; Gillies, 2000).
1r.	Preparation: Obtaining informed and voluntary assent/consent	Remind participants of the research aims and participant commitments at each contact.	Discussing research aims and participant commitments regularly facilitates informed and voluntary assent/consent (van den Hoonaard, 2002).	Attend to verbal and non-verbal indicators that suggest that the PWD is wanting to participate in the research (Dewing, 2002; Graneheim & Jansson, 2006; Hubbard et al., 2003; Slaughter, Cole, Jennings, & Reimer, 2007).
1s.	Preparation: Obtaining informed and voluntary assent/consent	When conducting research with dyads, clearly outline confidentiality procedures.	Clearly outlining confidentiality issues ensures participants are aware that information provided during interviews will not be shared with other participants. This awareness may encourage openness during the interviews and prevent participants asking about other participants’ responses.	Participants may feel reluctant to speak openly about certain topics (e.g., challenging aspects of living with dementia) if they are uncertain whether their interviews will be shared with their carer. Having said that, the option of having a carer present for the interview may be preferred by some PWD (Cotrell & Schulz, 1993; Dalby et al., 2011; Nygård, 2006).
2a.	Data collection: Appropriate interview settings	Conduct interviews in an appropriate space within an appropriate setting	Semi-structured interviews are often conducted in a quiet room within participant homes. Alternative venues should be considered if there is no appropriate space within the residence or if participants and/or the researcher do not feel comfortable. Suitable alternative venues may include a quiet room in the researchers’ workplace or a bookable room in a community building, such as a library.	Conducting interviews in the homes of PWD is common as it is convenient (e.g., some participants may not drive) and avoids connotations of a clinical interview (Beard, 2004; Cotrell & Schulz, 1993; Garand et al., 2009; Watchman & Kerr, 2014). However, some PWD consider their home to be a private space or place of “refuge” and opt for a different location. The focus of the interview may also dictate the interview setting (Blackman, et al., 2003; Dewing, 2002; Olsson, Lampic, Skovdahl, & Engström, 2013).
2b.	Data collection: Appropriate interview settings	Use environmental cues to facilitate discussion.	Environmental cues can prompt or cue recall issues relevant to the interview. Furthermore, researchers may conduct a “walk-about” with the participant in a particular environment to facilitate the interview.	Use of environmental cues to facilitate discussion may be particularly helpful for PWD (Garand et al., 2009). If environmental cues are not possible, photos of relevant people, objects, or places may help prompt discussion (Abbato, 2015; Dewing, 2002; Watchman & Kerr, 2014).
2c.	Data collection: Practicalities of conducting interviews	Schedule interviews at a preferred time for participants.	Participants are more likely to be engaged in the interview process if it is conducted at a time suitable for them. To conduct interviews at appropriate timeslots, researchers should be flexible, such as conducting interviews outside of business hours (such as on weekends).	Engagement of PWD might be influenced by time of day (Cotrell & Schulz, 1993). Contacting the participant before the interview is recommended (Cotrell & Schulz, 1993). Willingness to reschedule is important for improving the quality of responses (e.g., minimal elaboration; Cotrell & Schulz, 1993; Garand et al., 2009; Nygård, 2006).

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	Research Stage	Recommendation	General Rationale	Rationale for Research With PWD
2d.	Data collection: Practicalities of conducting interviews	Take time to build rapport with participants.	The importance of rapport building in qualitative research is well established (Brinkmann, 2007; Lavis, 2010; van den Hoonaard, 2002). However, in building rapport, it is important to not just “do” rapport, where the researcher engages in “faking friendship” to obtain knowledge from the participant (Brinkmann, 2007).	Rapport building is essential given the highly personal nature of research topics (Cotrell & Schulz, 1993) and potential for PWD to provide researchers with information they assume they want to hear (Bond & Corner, 2001). Some studies recommend having multiple interviews with PWD to increase rapport (Clare et al., 2008; Graneheim & Jansson, 2006; Lloyd, Gatherer, & Kalsy, 2006).
2e.	Data collection: Practicalities of conducting interviews	Be aware of your rate of speech when asking interview questions.	Asking interview questions in a measured, slow pace facilitates accurate interpretation.	Slowed speech suits the processing style of PWD (Harman & Clare, 2006; Moore & Hollett, 2003; Nygård, 2006). PWD might require longer time to answer questions (Garand et al., 2009; Hubbard et al., 2003).
3a.	Data analysis: Accurate analysis and interpretation of data	Attend to issues that participants do not discuss.	There is a focus on what participants say in in-depth interviews. However, it is also important to reflect on issues not discussed.	Participants may find it difficult or even taboo to discuss the challenges of living with dementia, thus potentially presenting a biased perspective of their lived experience (Cotrell & Schulz, 1993).
3b.	Data analysis: Accurate analysis and interpretation of data	Have multiple researchers code the data.	The credibility of interview data analysis is improved with multiple researchers independently coding the data for comparison (Braun & Clarke, 2006).	Multiple coders are important in this field because it is common for researchers to have strong connections/investment with the research topic (Garand et al., 2009; Moore & Hollett, 2003) which could interfere with objective data analysis (Brinkmann, 2007; van den Hoonaard, 2002).
3c.	Data analysis: Involving participants in data analysis	Include participants in data analysis.	Including participants in data analysis facilitates the credibility of qualitative research. Involvement might include encouraging participants to brainstorm themes emerging from interviews, and/or inviting participants to read drafts of reports for feedback.	Studies involving PWD have indicated those with mild impairments are able to be involved in data analysis processes (Caddell & Claire, 2002; Clare, 2002). Furthermore, Clare (2002) reported that many PWD found this process to be meaningful and rewarding.
4a.	Dissemination of findings: Providing feedback to participants	Provide participants with written feedback about the study's findings.	Information sheets are an appropriate method for providing feedback to participants because they provide a succinct outline of information, they are a tangible resource for participants to refer to, and they are economical and practical.	Written feedback for PWD should have a structured format (i.e., headings, bullet points; Garand et al., 2009; Gillies, 2000) and be presented in an appropriately “simplified” manner to cater for cognitive and physical impairments (e.g., visual deficits) associated with the condition.
4b.	Dissemination of findings: Providing feedback to participants	Provide participants with the opportunity to come to a group feedback session.	Group feedback sessions are useful for conveying in-depth findings and providing participants with an opportunity for questions and comments.	Group feedback sessions give opportunity for participants to interact with other PWD.
4c.	Dissemination of findings: Providing feedback to participants	Reflect on the impact of being involved in the study with participants.	Reflections from the research team might include professional and/or personal insights, and challenges and rewards of conducting the research. Such reflections acknowledge the significance of participants sharing their experiences for the research.	Interview research investigating the experiences of PWD may involve highly personal experiences, meaning that the reflections from the research team about their experiences of being involved in the research might be particularly warranted.
4d.	Dissemination of findings: Effective communication of research findings	Share research findings with community members and groups.	Academic journals and conferences have their place in disseminating research findings; however, other avenues are also important (e.g., community forums, radio, newspaper, and television).	Relevant community groups for research focusing on PWD include dementia and aged care services, community social groups, retirement homes, and dementia research centers. Policy makers might also be relevant to target.
4e.	Dissemination of findings: Effective communication of research findings	Consider target audience when choosing journals to publish research findings.	Consider the intended target audience of the research when choosing journals to publish in rather than focusing on other research criteria such as the prestige of the journal.	Target audiences for research focusing on PWD include PWD, carers, families, clinicians, health practitioners, policymakers, and so forth.

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	Research Stage	Recommendation	General Rationale	Rationale for Research With PWD
5a.	Researcher health: Importance of self-care	Be involved in debriefing sessions to manage the emotional impact of conducting qualitative research about sensitive issues.	Debriefing sessions help researchers reflect on challenging experiences, discuss ways of improving research processes, and experience moral support (Rager, 2005a). Debriefing personnel include research team members and/or supervisors.	Researchers should not underestimate the emotional impact of conducting interviews with PWD, such as listening to difficult experiences and stories of loss, being present to emotional or behavioral "outbursts," and maintaining a supportive and non-judgmental attitude.
5b.	Researcher health: Importance of self-care	Maintain a journal to manage the emotional impact of conducting qualitative research.	Journal keeping has been shown to help manage the emotional impact of being involved in in-depth interviews and also promote reflective thinking (Rager, 2005a, 2005b).	As outlined in section 5a, managing the emotional impact of conducting interviews with PWD is an important issue in this research area. Journal keeping could be one strategy that assists with this.
5c.	Researcher health: Importance of self-care	Space interviews apart to manage the emotional impact of interviewing.	Organizing interviews over an extended period reduce the intensity of conducting the interviews and allow time for reflection between interviews.	Adequately spaced interviews may be particularly warranted when conducting interviews with PWD given the range of emotionally laden topics that might be inherent to the research topic.
5d.	Researcher health: Developing and maintaining healthy boundaries	Be aware of the potential for boundary confusions.	Boundary confusion can occur when researchers or participants become unclear around the researchers' primary role (i.e., to collect data). Strategies to minimize boundary confusion include clearly outlining the roles of the researcher prior to interviews, having multiple researchers attend interviews, having transcripts read by other researchers to monitor boundary maintenance, and ongoing debriefing sessions for researchers.	PWD might find it difficult to understand the unique role of a researcher, particularly when interviews are conducted in a supportive nature within their home, and when they involve emotionally laden topics. In addition, researchers themselves can become confused about their role, particularly if they have a personal connection to the research topic and/or professional roles other than a researcher (e.g., counselor, support worker).
5e.	Researcher health: Developing and maintaining healthy boundaries	Consider the differences in power in the roles of researchers and participants.	In in-depth interviews, it is acknowledged that participants are the expert in their own right as it is their personal experiences and opinions that are under investigation (Brinkmann, 2007).	Acknowledge the participants' unique role as "expert" as an individual with dementia. Such acknowledgment can facilitate participants' sense of mastery and highlight the value of sharing their experiences in research.
6a.	Participant health	Consider the impact that research participation can have on participant health	The research team should have a good knowledge of local care services and are able to provide information about these services required.	It should be acknowledged that in many cases, services for people with dementia may be lacking. Researchers should consider the extra responsibility to advocate for improvement in services for people where the research provides evidence of unmet need.

Note. PWD = people with dementia.

centers, meaning samples might not be representative of the general dementia community (Garand, Longler, Connor, & Dew, 2009). Thus, when recruiting people with dementia, it can be advantageous to promote the study through a broad range of community services and venues to facilitate obtaining an appropriate sample (Caddell & Claire, 2002). Others have found that use of frameworks such as social marketing are useful in promoting the benefits of participation in research for people with dementia using resonant messages and tailored communication channels (Nichols et al., 2004). From our experience, future success may stem from connecting directly with a global advocacy group, such as the Dementia Alliance International (n.d.) who are the peak

body for people with dementia, and whose membership is exclusive to people with a confirmed diagnosis of dementia, especially as most often trying to recruit through advocacy organizations has proven unsuccessful. Further to these, we recommend involving in-home services in reaching those people with dementia who are not actively involved in community activities to obtain an appropriate sample. Recruiting via a broad range of strategies and services may be particularly beneficial in avoiding potential "over-research" which can occur when researchers employ the same centers thus engaging the same people.

We also recommend using personalized recruitment approaches. Personalized recruitment approaches can include strategies such as community information sessions

held by relevant researchers and having information about the study provided to potential participants by service providers known to them. Using respectful and non-technical research language is crucial in these situations. Presentations given by members of the research team to community audiences increases the personal face of the project and can promote an increased response as people “know” who is trying to recruit them (Phillipson, Brennan-Horley, et al., 2015). For example, in a project involving in-depth interviews with people with dementia to understand their experiences of living in a community, the researchers delivered presentations at local retirement villages and community events to promote the study and recruit potential participants (Phillipson, Brennan-Horley, et al., 2015). Such approaches are recommended over traditional recruitment approaches with this population, which might be considered impersonal to people with dementia and/or rely on modern technology such as social media (which can result in sub-optimal and/or biased recruiting).

Engaging with dementia advocates, to support the recruitment process, may also prove helpful in engaging others with dementia to not only attend information sessions but also participate in the research. For example, the Join Dementia Research initiative (National Institute for Health Research, n.d.) in the United Kingdom links dementia researchers with members of the public who are willing to take part in studies. This initiative has reportedly been successful in promoting a 60% increase in people participating in dementia research in the past year (British Broadcasting Corporation [BBC], 2015).

Regardless of the recruitment strategies utilized, it is recommended to provide clear and detailed information about the study in recruitment material. Also, it can be advantageous to include information about the expected positive outcomes of being involved in the study, as research indicates that a significant barrier for people with dementia participating in research is the perception of limited benefit in doing so (Garand et al., 2009). This should include both the personal benefits of being involved (e.g., increased knowledge and understanding about dementia) and expected community benefits (e.g., information about how the research will be utilized to inform community programs or actions that could benefit people with dementia).

Furthermore, it is recommended to target the material to both people with dementia and their carer because, research and our own experience indicate, the carer is frequently the person to respond to study recruitment materials (Clarke & Keady, 2002; Connell, Shaw, Holmes, & Foster, 2001). More specifically, carers may be protective of the person with dementia and concerned that involvement in the research study might be confrontational and/or uncomfortable (Connell et al., 2001; Cotrell & Schulz, 1993); reassurance that the interview will be conducted

sensitively and professionally might be beneficial. For example, in our experience, some carers voice concern that the person they provide care for will become upset if involved in an in-depth interview about their experiences of living with dementia. However, when reassured about the nature of the interview and the positive outcomes reported by other participants, they are more willing to explore the interest of the person with dementia about being involved.

Obtaining Informed and Voluntary Consent/ Assent

Obtaining informed and voluntary consent is a necessary component of all research (Agre & Rapkin, 2003). Informed consent certifies individuals understand the aims of the study, what their participation involves, potential risks and benefits of being involved in the research, and expected outcomes of the study (Agre & Rapkin, 2003; van den Hoonaard, 2002). Informed consent is best conceptualized as an ongoing process, sought at all stages of research (Lloyd et al., 2006; Nygård, 2006; Smebye & Kirkevold, 2012; van den Hoonaard, 2002).

The ability of people with dementia to provide informed consent is a central issue to their involvement in research as the condition can impair an individual's capacity to make decisions (Agronin, 2014; Dewing, 2002; Moore & Hollett, 2003). However, it is imperative to consider that a diagnosis of dementia does not automatically mean someone is not competent to provide informed consent; rather, it is good practice to consider participants with dementia are competent to provide consent unless determined otherwise by a professional (Agronin, 2014; Kim, Karlawish, & Caine, 2002). If it is determined that a participant with dementia is unable to provide informed consent, it is important to involve them in assent procedures (Dewing, 2007). That is, while it may be the legal/ethical requirement to obtain “proxy” consent from an authorized proxy or representative on behalf of the person with dementia, this should not replace the principled approach of obtaining assent from the person with dementia themselves (Slaughter, Cole, Jennings, & Reimer, 2007). Such approaches are in-line with person-centered and inclusive research practices (Dewing, 2002). Furthermore, if formal assent procedures are not deemed appropriate, researchers should endeavor to determine whether verbal, non-verbal, and behavioral indicators suggest that the person with dementia is wanting to participate in the research (Bamford & Bruce, 2000; Dewing, 2002; Graneheim & Jansson, 2006; Slaughter et al., 2007).

There are several strategies which can be employed to facilitate obtaining informed and voluntary consent/assent such as having a face-to-face “preliminary meeting” with

potential participants to specifically discuss the study and build rapport (Cotrell & Schulz, 1993; Dalby, Sperlinger, & Boddington, 2011; Dewing, 2002; Hubbard et al., 2003), developing consent/assent forms which are tailored for people with dementia (Gillies, 2000), discussing research aims and participant commitments regularly throughout the interview process to encourage ongoing consent/assent (Agronin, 2014; Cacchione, 2011; Dewing, 2002; Hubbard et al., 2003), and clearly outlining confidentiality procedures. In addition to this, we have found use in verbally explaining the participant information sheets and consent forms (Phillipson, Cridland, Hall, & Smyth, 2015). For certain participants, this plain language verbal summary was found to maintain momentum and rapport rather than leaving the participant to read each and every page.

Data Collection

Appropriate Interview Settings

In this field of research, in-depth interviews are often conducted within the place of residence (Beard, 2004; Cotrell & Schulz, 1993; Garand et al., 2009; Nygård, 2006; Watchman & Kerr, 2014). Benefits of this approach include avoiding connotations of a clinical assessment, promoting familiarity for participants, gaining insight into the life of people with dementia, and having environmental cues which may facilitate the interview. For example, interviews about “life at home” conducted in the home facilitate reference to the environment and prompt recall in regard to aspects that may be important, challenging, enjoyable, and so forth.

The main challenge of conducting interviews within the home is ensuring interviews are completed in an appropriate private space to maintain participant confidentiality. Participants may not recognize the importance of conducting the interviews in a private space, particularly if they indicate that the relationship between the people with dementia and carer is “open” to discussing all issues. If this is the case, it is important to discuss the need and benefits of participant confidentiality (see Table 1, recommendation 1s for more details). Alternatively, it may be helpful to conduct joint or “dyad” interviews with the person with dementia and their carer, as the carer may be able to provide prompts for the person with dementia and/or clarify things the participant has mentioned (Pratt, 2002).

In some circumstances, it may be more suitable to conduct interviews outside of the home environment. Such circumstances include when the person with dementia considers their home to be a private space or “refuge” and/or when the focus of the interview dictates an alternate setting (Blackman et al., 2003; Dewing, 2002; Olsson et al., 2013). For example, if the focus of the

research is about involvement in the community, a suitable public place may be the best setting. In these instances, considering the interview environment may be beneficial. Factors such as low noise and a public venue with minimal distractions will support the person’s disabilities, and enhance the capacity of the participant.

Practicalities of Conducting Interviews

Numerous practical issues need to be considered when conducting qualitative research with people with dementia. Such issues include organizing interviews at an appropriate time of day for participants (e.g., avoiding late afternoon interviews when participants may be tired and/or considering impact of medication), contacting the participants or carer prior to the interview to check whether the person with dementia is willing to be involved in the interview, taking time to build rapport with the person, and conducting interviews at an appropriate pace (Cotrell & Schulz, 1993; Harman & Clare, 2006). Consideration of such issues during the planning stages of research will help facilitate effective interviews. In addition, it may be necessary to reflect on the processes in place during the data collection stages and make appropriate changes if warranted. Interview location may also impact on interview quality because of the stress of accessing and negotiating unfamiliar environments (Blackman et al., 2003; Dewing, 2002; Moore & Hollett, 2003; Olsson et al., 2013).

The skill base of interviewers is an important consideration in conductance of all in-depth interviews (Brinkmann, 2007). Generally, it is recommended that, at a minimum, interviewers are well acquainted with the interview guide and familiar with the interview process (Brinkmann, 2007; Minichiello et al., 1995). In addition, personality characteristics such as patience, an open and empathetic attitude, and an ability to listen are highly valued (Brinkmann, 2007). In the context of social research with people with dementia, it is also beneficial for researchers to have a clear understanding of the lived experience of dementia at different stages of the journey and to have gained some experience in strategies that may aide communication with people with dementia. One way to facilitate this, outside of face-to-face meetings with people with dementia, is to refer to articles, blogs, and books written by people with dementia (e.g., Dementia Diary Blog, 2015; Swaffer, 2015).

Data Analysis

Accurate Analysis and Interpretation of Data

When conducting in-depth interviews, data analysis and interpretation are overlapping, yet conceptually

different, processes. More specifically, analysis involves the breaking down of interview data, whereas interpretation illuminates a new way of understanding the interview data while remaining faithful to the original data (van den Hoonaard, 2002). It is important to note that the analysis and interpretation stages of in-depth interviews are influenced by all other stages of research, including preparation, data collection, transcribing, and reading of transcripts (van den Hoonaard, 2002).

There are multiple issues to be considered during data analysis and interpretation of in-depth interviews with people with dementia. These include reflecting on what participants discuss as well as issues they do not discuss in interviews and having multiple researchers involved in the analysis and interpretation of data (Caddell & Claire, 2002; Clare, 2002). Updating a research diary or reflective journal upon interview completion is encouraged to capture feelings and reflections as close as possible to the time they were experienced. This written record can be drawn upon as a further aide to interview analysis and interpretation (Garand et al., 2009; Moore & Hollett, 2003).

Involving Participants in Data Analysis

Involving participants in data analysis is a relatively recent concept with the rationale being to ensure data are accurate representations of the participants' experiences (Barbour, 2000; Braun & Clarke, 2006; van den Hoonaard, 2002). There can be benefits of including participants in data analysis, such as giving the opportunity to reflect on their interviews and brainstorm "themes" emerging from their interviews, and developing an appreciation of the research process. For example, a dementia advisory group (made up of participants from previous research interviews) in one of our projects underscored the additional insights gained from allowing participants to brainstorm and highlight the main themes arose from that research from their perspective (Phillipson, Brennan-Horley, et al., 2015; Phillipson, Cridland, et al., 2015). Furthermore, some participants may find such involvement to be rewarding and/or therapeutic.

Several studies have included participants with dementia in data analysis processes by asking participants (who had adequate memory of their interview) to review whether they felt the preliminary themes emerging from the interview data adequately captured the issues discussed (Caddell & Claire, 2002; Clare, 2002). Another study involved carers and/or other relevant people (e.g., staff at residential homes) in data analysis to explore whether the findings corresponded with their observations of the participants with dementia (Clare, Rowlands,

Bruce, Surr, & Downs, 2008). Possible challenges of involving participants and proxies in data analysis processes are issues with confidentiality and the possibility that participants may reflect on certain things they had said (e.g., challenging aspects of dementia) and express a desire for such aspects of the interview to not be included in analysis (Barbour, 2000). Such challenges may be managed by explaining confidentiality issues and normalizing experiences of discomfort when reading transcripts (Barbour, 2000).

Dissemination of Findings

Providing Feedback to Participants

Communicating feedback to participants about the results of research studies is not always considered a necessary component of the research process, beyond the publication of academic articles. However, there may be a range of benefits of taking a more comprehensive approach to dissemination and communication of results. First, feedback provides participants with findings of the study and overall outcomes of the research (e.g., policy changes, publications, funding, and so forth) that they may not otherwise have learned. In addition, people with dementia who participate in research are likely to have a genuine interest in the research outcomes and therefore appreciate feedback (Connell et al., 2001).

Feedback also acknowledges the significant commitment of participating in research, may facilitate participants having positive experiences of being involved in the interviews, and may also encourage future participation. Furthermore, providing feedback to participants may help consolidate research findings for the researcher and highlight the issues of importance for people with dementia (Keen & Todres, 2007). Feedback about research findings and outcomes may occur periodically or at the conclusion of the research, depending on the nature of the project. Furthermore, feedback to participants may be in the form of written information and/or feedback sessions.

People with dementia have said that being involved in research helps them feel valued and that they feel they are more engaged in meaningful activities by being involved; it also helps them feel good about themselves because they feel they are helping others in the future. For example, in an interview, Chris Roberts, a person with dementia commented (BBC, 2015),

What we then need is hope, and this is what research gives us. Taking part means I'm doing something constructive and worthwhile. I'm leaving something behind that might help others, if not myself. Any kind of research, small or large, brings with it hope that there may be a future.

Effective and Ethical Communication of Research Findings

The communication of qualitative research (including in-depth interview studies) is traditionally confined to academic journal articles and/or conference proceedings (Keen & Todres, 2007). This can often limit the application of research findings in facilitating positive change for the lives of those affected by the research—in this case, people with dementia. Put another way, the dissemination of research findings to practice is often seen as a task beyond the research process (Keen & Todres, 2007). However, we recommend considering the dissemination of research findings as an integral and ethical component of the research process (see Figure 1).

The intended target audience of the research is the criteria on which dissemination strategies should be based. Target audiences for research include people with dementia, carers, families, clinicians, health practitioners, policymakers, and so on. Therefore, dissemination strategies may include a range of approaches from presenting to local dementia and aged care services to key stakeholders such as governments and other policymakers. A multiple media approach to research dissemination—from printed reports and gray literature, to newspaper stories, blog posts, and social media—should be considered to enhance reach, especially among the wider community who may not otherwise become aware of the issues and lived experience of people with dementia. These forms of communication and engagement are critical to maximizing research impact and supporting the more active process of the translation of research evidence into policy, practice, and wider community engagement.

Researcher Health

Importance of Self-Care

Self-care involves a range of activities aimed at ensuring the physical, emotional, and psychological well-being of the researcher, such as exercise, social activities, hobbies, and traveling. The importance of self-care for researchers conducting in-depth interviews is recognized but often overlooked (Rager, 2005a, 2005b; Stamm, 1999). Researcher self-care is imperative across all aspects of the interview research process.

In discussing the potential for emotional effects of conducting in-depth interviews, it is not our intention to recommend that researchers guard against all emotional reactions to research. On the contrary, we recognize the important role of emotion in research using in-depth interview approaches (Brinkmann, 2007; Rager, 2005a, 2005b), such as the ability to empathetically consider the psychological world of participants. Rather, we recommend that researchers use strategies to manage the

possible negative emotional effects of conducting the interviews. Such strategies include being involved in debriefing sessions, maintaining a journal, organizing interviews with adequate spacing to reduce the intensity, permitting time for reflection, and considering the possible benefits of working within a research team. From our experiences, the emotional connection with participants' experience has also been a motivating factor for us to personally become more involved in advocacy efforts that may help to improve the experience of those living with dementia.

Developing and Maintaining Healthy Boundaries

When conducting in-depth interviews, it is common for researchers to negotiate multiple roles (such as data collector and empathetic listener; Lavis, 2010). In fact, these multiple roles are often considered necessary for conducting effective interview-based research; whereby the researcher must conduct ethical practices while also developing authentic relationships with participants (Lavis, 2010). Developing and maintaining healthy boundaries around researcher roles is critical for conducting research in this field, given the potential for role confusion that may result when involving people with dementia in research (Nygård, 2006).

Boundary confusion is a bidirectional process whereby misunderstandings from either the researchers or participants can result in inappropriate roles (Brinkmann, 2007). For example, an interviewer giving advice and/or discussing issues other than those directly related to the research topic. Strategies to help maintain healthy boundaries include a clear understanding for both researchers and participants about the role of the researcher and limitations to this role, and using various monitoring strategies such as other researchers attending the interviews or reading the transcripts. Another strategy involves permitting new researchers to accompany more experienced colleagues to interviews. This allows opportunity for experiencing how positive personality characteristics can affect the interview setting. Furthermore, exposing new researchers to what can at times be an emotionally charged environment alongside more experienced researchers can help them to develop emotional coping strategies before embarking upon their own fieldwork.

Participant Health

The potential impact of research participation is usually considered by researchers as part of the ethical considerations involved in the conduct of research. Such considerations usually include the consideration of risks, benefits, and consent (National Health and Medical

Research Council, 2015). We would suggest that there may be a need to consider participant health beyond these traditional realms. In one recent project (Phillipson, Brennan-Horley, et al., 2015), involvement in a research interview was the first time for some participants that they have been involved in an extended process of talking or reflecting on their circumstances and the impact of dementia on their lives and relationships. For some, this led to sadness, distress, or anger, which resulted in the person identifying the need for professional support or grief and loss counseling. To support participant health, it was essential as researchers that we had a good knowledge of local care services and were able to provide information about these services as required.

For others, it was the first time they had openly or publicly acknowledged that they had a diagnosis of dementia. In this sense, it was a “coming out” experience, which led them to desire contact with other people with dementia and to understand more about the way others with the disease were learning to live with their symptoms. In our local area, there were no active face-to-face support groups for people living with dementia, so we, as researchers, took up an advocacy role to support the creation of a local group. The initiation of this group was supported by Swaffer who lives with dementia, and was able to draw on her experience of the process that she had utilized to support the creation of a national dementia consumer advisory group—Dementia Alliance International. While others may find this point contentious, we believed this role was part of our ethical commitment to meeting the needs of our participants that were made evident as a result of their participation in the research process. An alternative to support the connection of people with dementia with others who are also living with the condition is to raise the awareness of online support groups (e.g., Dementia Alliance International, n.d.).

Table 1 provides detailed recommendations based on the issues discussed throughout the article. The recommendations are based on the literature and experiences from our involvement in semi-structured interviews with people with dementia.

Discussion

There are multiple imperatives to improve the participation of people with dementia in the research process. These include benefits for the person with dementia (Beard & Fox, 2008; Hellström et al., 2007), improved research outcomes (Abbato, 2015; Beard, 2004; de Boer et al., 2007; Dewing, 2002), and the need to improve the practice of researchers studying dementia (Cotrell & Schulz, 1993).

In this article, we have provided recommendations and reflections about conducting in-depth interviews with

people with dementia that considers the process from preparation, to data collection, data analysis, and dissemination of findings, and considers strategies to maintain and promote researcher and participant health throughout the process.

Although previous research had stressed the importance of the careful preparation of the interview guide for semi-structured interviews with people with dementia (Minichiello et al., 1995), this article has also highlighted the specific role of the interview guide in assisting researchers in the process of establishing a rapport within the interview process. The utility of providing strategies to support the disabilities caused by the symptoms of dementia, such as repetition and rephrasing of questions, developing single-faceted interview questions, and the use of visual prompts or stimulus material to prompt recall within the guide, is highlighted, along with the benefits of pilot testing the interview guide to identify areas for improvement. Table 1 provides useful features to consider when developing an interview guide, which might assist with the auditing of interview guides prior to piloting the guide with participants.

Strategies to promote participation in research by people with dementia have also been considered. Previous research has highlighted the potential benefit of promoting studies through not only hospital but also community channels (Caddell & Claire, 2002) or dedicated social marketing strategies (Nichols et al., 2004). In this article, we have extended this list of strategies from our own experience, highlighting the essential need to build trust and rapport with participants and their carers and also to promote the benefits of participation (both for the person themselves and the broader community). To achieve this, researchers must carefully consider the design of their studies to ensure they are maximizing participant benefit as part of the study objectives (see Crockett, Downey, Fuat Firat, Ozanne, & Pettigrew, 2013, for further reading regarding transformative consumer research approaches). The importance of strategies for promoting informed consent and/or assent and the consistency of these approaches with person-centered care philosophies is also emphasized (Bamford & Bruce, 2000; Dewing, 2002; Graneheim & Jansson, 2006; Slaughter et al., 2007).

This article clearly re-emphasizes the importance of considering the impact of place and time in the process of data collection with participants with dementia. Previous research has highlighted place considerations in the conduct of semi-structured interviews in regard to the impact on participant comfort, recall, and privacy (Blackman et al., 2003; Dewing, 2002; Olsson et al., 2013). In addition, this article also brings into greater focus the temporal aspects which should be considered during interviews including time for the researcher to build rapport with the person with dementia, the way that time of day might

impact on participant concentration and performance, “pacing” of the interview, and the need for the researcher to be periodically evaluating if the person with dementia would benefit from a “break” (Cotrell & Schulz, 1993; Harman & Clare, 2006).

Finally, the article considers the important interaction of skills, personal attributes, and knowledge that the researcher brings to the interview. In this, the characteristics of patience and empathy have been highlighted (Brinkmann, 2007). In addition, our recent experiences call us to suggest the benefit of researchers being equipped with knowledge of the lived experience of dementia at different stages of the journey, as well as skills which might aide their communication with people with dementia (Alzheimer’s Australia, n.d.-b, n.d.-c).

Looking beyond the use of specific analytic techniques, this article highlights the potential benefits of improving accuracy as well as adding further benefits for participants and/or their carers through involving them in data analysis (Caddell & Claire, 2002; Clare, 2002). This should be undertaken by researchers with an understanding of some of the challenges in doing so, such as confidentiality and discomfort that be associated with this level of involvement (Barbour, 2000).

In this article, we have posited that research which seeks to provide a mutually beneficial exchange for participants with dementia should consider feedback to participants a necessary part of the research process. Provision of participant feedback is likely to produce benefit to the person with dementia through acknowledgment of the significant commitment that they have made through their involvement in the research and, in addition, may produce an exchange which provides new insights or knowledge for the person with dementia and/or the researcher (Connell et al., 2001; Keen & Todres, 2007). From our recent research experience working with a local dementia advisory group (Phillipson, Brennan-Horley, et al., 2015), feedback for an audience with dementia should be timely, time-limited, and formatted to ensure the use of “dementia-friendly” language and the use of simplified data and/or diagrams to cater for the needs of an audience who are cognitively impaired and may also have visual deficits associated with the syndrome. Using visual aids such as a PowerPoint or printed sheets can also assist during the interview process, as a multisensory approach is more supportive of the cognitive and language disabilities of dementia. To maximize impact, researchers should also consider formats and channels for research dissemination to a variety of audience involved in the care of people with dementia including dementia and aged care services to key stakeholders such as governments and other policymakers.

Finally, the considerations of researcher and participant health are brought to the fore in this article. Both

acknowledge the potential impact of participation in in-depth interviews on the emotional and psychological well-being of both the researcher and the person with dementia. For the researcher, we suggest this can be supported through the maintenance of healthy boundaries and through strategies such as debriefing sessions, journaling, allowing time for reflection, and working within a research team or network. For the person with dementia, we believe the research process should be part of a response which contributes to their health and well-being through strategies which can connect people with dementia to relevant services and supports in response to needs that become evident during the research process.

A major challenge of conducting research in this field is obtaining a representative sample. First, recruitment of people with dementia is difficult as many of the commonly utilized methods of recruitment may not be suitable. Second, many of the participants responding to recruitment material may be a select group (e.g., more confident about engaging in research, motivated to help others, have come to terms with their diagnosis of dementia; Caddell & Claire, 2002; Cotrell & Schulz, 1993; Garand et al., 2009). Furthermore, attempts to understand more about the reasons why some people with dementia and/or carers choose not to participate in research are hindered by confidentiality issues and the need to respect their decision not to be involved in research (Cotrell & Schulz, 1993).

In addition, existing interview research has largely involved people with early stages of dementia (Beard, 2004; Caddell & Claire, 2002; Clare, 2002; Hubbard et al., 2003). However, there is also a need to explore the subjective experiences of people with moderate to severe levels of impairment (Clare et al., 2008; Cowdell, 2008). Such research will need to develop suitable strategies to match the capacity of such individuals and might benefit from utilizing approaches such as observation and interviews with carers (Clare et al., 2008).

Research exploring the experiences of people with dementia belonging to cultural minority groups is also lacking (Garand et al., 2009). In addition, while there have been some longitudinal interview studies involving people with dementia (e.g., Clare, 2002; Clare, Roth, & Pratt, 2005; Sabat, 2002), the vast majority are cross sectional. Longitudinal studies incorporating a “follow-up” have the potential to capture changes and adaptations in the lived experiences of people with dementia over time (Caddell & Claire, 2002; Cotrell & Schulz, 1993; Garand et al., 2009). Such studies might also assist us to generate a more holistic picture of the impact of research participation on the health and well-being of people with dementia.

Finally, the recent experiences of one author (Swaffer) suggest there may be value in further exploring the use of

other interview methods such as focus groups, especially if these groups can be facilitated by a researcher who is living with dementia. This is based on her recent pioneering work in the use of focus groups with those with dementia, who were very keen to take part when they knew it was another person with dementia facilitating the group.

Conclusion

Conducting in-depth interviews with people with dementia poses many challenges, as highlighted by the range of considerations discussed throughout. Clearly, there is more to be done around developing “dementia-friendly” interview methods to maximize these individuals’ capacities to share their perspectives and experiences, especially for those people with more advanced dementia (Dewing, 2002; Phinney, 1998). However, this article highlights that there is much that can be gained from supportive approaches that can assist researchers, which in turn will help to change the view of people living with dementia from a subgroup that need to be studied, to an appreciation of them as people whose perspectives can help us understand more about living with dementia (Cotrell & Schulz, 1993).

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Notes

1. The term *dementia* is used throughout this article to refer to people experiencing significant neurocognitive impairment involving cognitive domains such as memory, language, execution of purposeful movement, recognition, visuospatial function, and self-control (American Psychiatric Association, 2013). Furthermore, the term *dementia* is used throughout this article to refer to people with a diagnosis of Alzheimer’s disease, vascular dementia, Lewy Body disease, fronto-temporal dementia, dementia of the “mixed” type, and viral-induced dementias.
2. The term *carer* is used to describe the relationship between a person with dementia and the person/people who provide them support.

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