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Challenges in Conducting Qualitative Research with Persons with Dementia

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Abstract

Qualitative research can capture the meaningful experiences and life values of persons with dementia not reported in quantitative studies. This researcher shares personal experience of the challenges faced and the lessons learned while conducting a qualitative study of 15 persons with early stage Alzheimer's disease. The purpose of this paper is to discuss the issues concerning determination of capacity to consent to research, consent/assent, communication challenges, and trustworthiness of data when conducting a qualitative study of persons with dementia. Understanding communication challenges due to dementia is important to develop effective communication strategies, such as simplifying the structure of questions, allowing ample time for participant's response, using reminiscence, and redirecting the dialogue. This information will be valuable to researchers conducting future qualitative studies and the resulting contributions to the body of knowledge about Alzheimer's

Keywords

qualitative; interviewing; dementia; Alzheimer's

Dementia of the Alzheimer's type is the progressive loss of cognitive functions, such as memory, problem solving, attention, language, and reasoning; it is caused by the irreversible degeneration of brain cells (American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders [DSM-IV-TR], 2000). This disease affects approximately 5.2 million people in the United States with a projected four-fold increase by the year 2050 if no prevention or cure becomes available (Alzheimer's Association, 2008).

Persons with Alzheimer's dementia (AD) are lost in the traditional biomedical paradigm of research and practice (Penrod, Yu, et al., 2007) that focused on pathophysiology, diagnosis, behavioral and pharmacologic management; or on the impact of AD on caregivers. Little is known about the personal impact of the cognitive losses and how persons cope with their own cognitive losses. Consequently, there is a growing interest in conducting qualitative studies that capture the personal perspective of AD (Downs, 1997). Yet, few qualitative studies have been published and very little has been written about the challenges of conducting qualitative research in person with AD (Cotrell & Schulz, 1993). Thus the purpose of this article is to address some of these challenges and to share some lessons

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This article is dedicated to Dr. Robert G. Ferland, my first mentor.

learned from conducting a qualitative study that explored how persons with AD use spirituality as a coping mechanism. Specifically, it will discuss 1) obtaining informed consent, 2) effectively communicating with persons who have AD, and 3) ensuring credibility and dependability of data.

Although limited in number, qualitative research of lived experiences in persons with AD have revealed significant findings. First, they are aware of their cognitive decline, which is contrary to researchers' and clinicians' earlier understanding about the disease (Downs, 2005). Second, they can determine what is important to their quality of life (Katsuno, 2003; Matano, 2000). Third, they can describe how they cope with the stress of cognitive impairment (Phinney, Wallhagen, & Sands, 2002; Snyder, 2003). In addition, researchers have been able to capture individuals' meaningful experiences and life values not previously reported in quantitative studies (Moore & Hollett, 2003). This information is critical to researchers and clinicians who develop and test interventions for persons with AD to reduce stress, fears and anxieties and to improve their mental well-being and quality of life.

It is important for persons with AD to be included in research studies. Participating in research studies helps fulfills their need to be useful and productive (Bell & Troxel, 2001). Study participants shared that their contributions as research participants gave them a sense of purpose and usefulness (Katsuno, 2003; Matano, 2000). Another reason to include those with dementia in qualitative studies is that listening to their conversations emphasizes their value as a person and honors their personhood (Jonas-Simpson, 2001; Moore & Hollett, 2003). Persons with AD are able to inform researchers of their feelings, desires, and preferences; albeit the AD affects how well they communicate their thoughts and feelings (Bourgeois, 2002). Moreover, they have a right to have their expressed feelings taken seriously, as Bell & Troxel (1997) suggest in *"An Alzheimer's Disease Bill of Rights"*. In addition, offering choices to participate in research studies to persons with AD enhances their autonomy (Feinberg & Whitlatch, 2001).

Research Issues Related to Conducting Qualitative Studies in Persons with AD

Obtaining Informed Consent

Persons with AD are a vulnerable population because of their compromised decision-making ability. Thus, safeguarding their rights is a key issue in conducting research. An important concern is determining their capacity to give *consent* or *assent*. Capacity is the ability to understand the nature of the research, appreciate the consequences of participation, show ability to consider alternative choices, and show ability to make a reasoned choice (Lai & Karlawish, 2007). AD is not always associated with the lack of capacity for informed consent (Beck & Shue, 2003). The National Bioethics Advisory Commission (2001) recognizes this inconsistency and requires research protocols to include a method of determining capacity of the potential participants. In addition, the protocols must include a plan to reassess cognitive capacity if there appears to be a significant change of cognitive function. Several capacity assessment instruments exist although there is no widely accepted tool (Moore & Hollett, 2003).

If a potential participant lacks capacity to consent to a research study, then the researcher must seek consent from a surrogate or proxy decision-maker, usually a family caregiver, and seek assent from the participant. This method of "double-informed consent" follows a consensus recommendation from the Alzheimer's Association National Board of Directors (2004). Moreover, it permits persons with AD to participate in research and it promotes their autonomy (Beck & Shue, 2003). The researcher must affirm the participant's assent throughout the study (Alzheimer's Association, 2004). Since elderly family caregivers can also have some degree of cognitive impairment, the researcher must plan a cognitive capacity determination method for the proxy signing the consent.

Effectively Communicating

Qualitative research requires effective communication to optimize participant responses. First, a researcher needs a caring and respectful attitude toward those with AD. Being an attentive listener conveys this attitude to participants (Proctor, 2001). It is important to make eye contact, use a calm voice, and refrain from talking down to the participant, contradicting their statements, or quizzing about details (Bourgeois, 2002). Second, researchers need to understand the communication challenges for those with AD. Mild difficulties in word finding, abstract reasoning, and following complex conversations occur in the early stages of AD (Warchol, 2006). Individuals also experience fluctuating awareness and attention and concentration lapses in the early stages (Downs, 2005). In addition, it takes longer for individuals to register verbal stimuli such as interview questions. As AD progresses, there are increased deficits of word finding, memory deficits and difficulty staying on a conversation topic (Bourgeois).

Researchers should be knowledgeable of communication challenges and need to develop strategies to address these concerns with the caveat that the same strategy may not work in all situations (see Table 1). One strategy is to conduct interviews in a place that is familiar and comfortable to the participant to reduce anxiety related to unfamiliar surroundings and to control some distractions. Another strategy is to restructure interview questions to elicit more concrete thoughts from the participant and use terminology that is familiar and understandable to the participant (Moore & Hollett, 2003). In addition, the researcher must allow ample time for the participant to respond to a question or remark. If they are struggling to find a word, the researcher can reassure them (Bourgeois, 2002). Providing cues such as photos or using reminiscence to trigger memories may encourage the participants to share information (Robinson, 2000). A useful strategy to use when participants dwell on a topic, is to first validate the meaningfulness of their experience, and then gently redirect them to a different topic (Davis, 2005). Other authors discuss similar techniques of communicating with people with dementia. Ripich, Wykle, and Niles (1995) designed a training program that uses the acronym FOCUSED to identify these strategies: F= Face to face, O= Orientation, C=Continuity, U= Unsticking, S=Structure, E= Exchange and D=Direct.

Ensuring Credibility and Dependability of Data

An important issue to consider with qualitative AD research is how to ensure credibility and dependability of the data. Lincoln and Guba’s (1985) guidelines suggest increasing the amount of data, increasing time with the participants, and triangulating data. To increase the amount of data, larger samples may be needed to achieve data saturation, especially if interviewing elders with severe AD (Moore & Hollett, 2003). Samples sizes from published qualitative studies in the literature range from 7to 28 participants. In addition, multiple interviews may be necessary to obtain enough rich data, especially if the participants are in the more advanced stages of AD. For example, one researcher stated she needed two to five sessions for her sample of people with mild to moderate AD (Snyder, 2003). The third guideline directs attention toward the analysis of the data. The transcribed interviews may initially seem thin. However, by using multiple readings and triangulation of the interviews with the observations and field notes, the researcher can get a sense of the data in its wholeness (Moore & Hollett, 2003; Morris & Field, 1995).

Lessons Learned from Conducting a Qualitative Study

A qualitative study was conducted in a central Arkansas metropolitan area with a sample of 15 participants (8 females, 7 males) in whom AD has been diagnosed and who were living at home. These participants' mini-mental state exam ([MMSE] Folstein, Folstein, &McHugh, 1975) scores ranged from 21 to 26, indicating early stage AD. The experience of conducting a qualitative study of participants with early stage AD was the inspiration for this article.

Gaining Consent or Assent

Research services at the university IRB offered excellent resources for developing the informed consent for this vulnerable population. However, locating capacity assessment tools required a literature review. The MacArthur Competence Assessment Tool for Clinical Research (Applebaum & Grisso, 2001) has a high sensitivity and specificity with dementia residents who have a MMSE score > 16 (Karlawish, Casarett, & James, 2002); thus, it was chosen for the study. Researchers can purchase the instruction book for this tool from most book companies for a reasonable price. This tool provided a format to quantify potential participants' understanding of the research consent and was easily customized to reflect my study's consent form. The assessment tool, though straightforward, was lengthy and took approximately 30 minutes to administer. However, the additional time provided opportunity to establish rapport with the participants and observe their communication skills.

A family representative was requested to be present at the enrollment meeting either to sign as a witness if the participant had capacity to consent or to provide consent in case the participant did not have capacity to consent. In the latter case, having a third person, such as a research assistant present to witness the signature was important. Half of the participants in the study had capacity to sign the research consent. Participant consent or assent was confirmed before each interview session as recommended by the Alzheimer's Association (2004).

Optimizing Interviews

For some, AD commonly presents itself as an increased irritability in the afternoon or evening, known as sundowning. It may also disrupt sleep patterns resulting in decreased and fluctuating awareness in the morning. Therefore, to optimize the interview it is prudent to consider what time of day a participant is usually the most alert. Both the participants and their caregivers were keenly aware of this. They wanted the participants' interviews to be successful and asked to schedule the interviews accordingly. Seven participants wanted morning interviews and eight requested interviews in the early afternoon.

Confronting Communication Challenges

Acquiring knowledge from the literature about AD's effects on communication is helpful, but the researcher must also be open-minded and acknowledge that the effects of AD will be unique for each individual (Bourgeois, 2002; Davis, 2005). Moreover, researchers must be flexible to deal with the unpredictability of AD's effects. All interviews were conducted in the participants' homes. Before starting each interview, approximately 15 minutes was spent engaging in general conversation with the participant to build rapport. This also offered an opportunity to assess each participant's broad cognitive processing, communication ability, and general mood. For example, three participants were alert and responding well to the questions at their first interviews. A week later at the second visits they did not remember me and were slower to respond to questions.

An effective strategy to confront communication challenges is to restructure questions that may be too abstract for the participant to comprehend. The participants provided cues when they needed a more concrete question. For example, one participant in the study simply replied, “I don’t know exactly how to answer that. I don’t know. That’s hard to say.” Other participant cues were blank looks, participant-initiated change of topic or a long pause.

Even though there was a preexisting awareness that some participants might respond slowly to questions, the long pauses between the question and the participant’s reply were uncomfortable. There was a tendency to want to lead the response by suggesting answers. However, it is important to allow the participant ample time to answer, thus respecting their dignity. When the pause did not resolve and the participants seemed to be uncomfortable, reassurance was offered, as Bourgeois (2002) suggested. For example, the interviewer would say, “That’s alright; what can you tell me about …?” then the conversation resumed. In addition, a few participants in this study requested reassurance of their memory of an event from their caregiver: “I see my children about every weekend; is that right?”

A few participants responded with an unrelated topic to the interview question. For example, one participant was asked: “What helps you remember those appointments?” She replied,

> My closet is such a mess. That is one thing I’m going to start in the morning--,cleaning out the closet. Since I lost weight there is a lot of stuff I can’t wear. I lost 98 pounds! I worked so hard at doing it.

It was important to follow her to lead the conversation, which revealed a new meaningful topic of her accomplishment in overcoming health problems.

Reminiscence is another valuable interview strategy that can prompt participants’ memories during the interview and elicit information about a person’s history. As the participants in this study reminisced, they spoke eagerly with a stronger, clearer voice and a brighter affect. However, a person with AD may keep repeating the same story line, which occurred with a majority of my interviews. When this occurs, the researcher should validate their experience (Davis, 2005), and then gently redirect the conversation to other pertinent topics of the study. For example, one woman repeated the story about her family summer home five times within a 45-minute dialogue. This experience was obviously very meaningful to her. We were unable to move forward in the interview until that important experience to her was validated. The response to this woman was, “That was a wonderful time for you. Thank you for sharing that with me. Can you tell me about …?”

A final issue of concern is an ethical responsibility to minimize risks to the participants when conducting research. In this population, it is important to observe participants’ nonverbal signs of fatigue or anxiety during the interview (Moore & Hollett, 2003). When this occurs, the researcher can offer the participant a choice of continuing or stopping the interview. The subtle diminishing volume of two participants’ voices was observed and recognized as a sign of fatigue. An observation that was interpreted as anxiety was the repetitive rolling of a paper by one man and constantly shifting weight by a woman. These three participants chose to continue their interviews. Another participant was tearful during portions of the interview but chose to continue. He offered this explanation:

> I feel better about it inside, I guess. Being able to talk with you has helped me a whole lot. I think you have to get outside the family once in a while just to let yourself go and because you worry about yourself and you really don’t want your family to know about it because it’s sad.

The participants were asked one last question: “How do you feel about being in this study?” They all stated that they enjoyed taking part in research and that it gave them a purpose. For instance, they stated the following: “If anything I say can help others, then it’s a good thing”; “I still have a useful place, in my mind. I can still make people feel good”; and “I just hope it has given you something to work with." These statements highlighted the importance of conducting qualitative research with those living with AD.

Ensuring Credibility and Dependability of Data

The participants were interviewed in two or three sessions using an interview guide, beginning with the grand tour question, "Tell me how you feel about having Alzheimer's?" Each audiotaped interview lasted 20 to 60 minutes, depending on the depth of the topic and the participant's cognitive processing. The three participants with MMSE scores less than 22 had the shortest interviews and required the additional sessions to obtain enough rich data. This finding is consistent with Snyder's report (2003). Subsequent interviews should be conducted within three days to increase credibility.

The first impression of the transcribed interviews was that data were thin. However, after auditing the transcriptions and multiple readings of the transcriptions, the richness of the data was discovered. Using focused ethnography for a method of inquiry provided plentiful observational data to triangulate with the transcribed interviews.

Conclusion

As AD research shifts its focus to the persons with the disease, it is important to attest to the value of interviewing those with AD. Researchers need an attitude that persons with AD can contribute to the body of knowledge (Kitwood, 1997). Moreover, it is important to give a voice to persons with AD, acknowledging and respecting their value as a person (Jonas-Simpson, 2001; 2003).

Researchers must also confirm the feasibility of interviewing those with AD. First, qualitative researchers must address the ethical issues of assent and consent, (Moore & Hollett, 2003) and be vigilant to protect the participants' dignity. The MacArthur Competence Assessment Tool for Clinical Research (Applebaum & Grisso, 2001) is one instrument that researchers are using in AD research (Kim, Caine, Currier, Leibovici, & Ryan, 2001). Although the MacArthur Competence Assessment Tool has been used primarily in psychiatric research, it is easily adaptable for use with persons with AD. However, the researcher arbitrarily determines the cutoff score that establishes capacity; thus it is susceptible to researcher bias.

Second, qualitative researchers must consider the interviewing challenges related to the effects of AD on their participants. Using effective communication skills as previously discussed will facilitate successful interviews. Researchers should consider conducting pilot studies or working with another experienced qualitative researcher. This experience may offer opportunities to acquire a working knowledge of interviewing persons with dementia and to refine their communication strategies (Moore & Hollett, 2003). Using reminiscence is one strategy that should be incorporated in all qualitative interviews. Reminiscence encourages participants to share their accomplishments and joys, as well as some of their past sorrows (Robinson, 2000). Additionally, it may reveal what is important and meaningful in a person's life. Using personal items, photos, artwork, or religious symbols in a conversation, is a simple way to introduce reminiscence (Bouregeois, 2002).

Qualitative research literature suggests guidelines to ensure credibility and dependability of data (Lincoln & Guba, 1985). Future studies might involve participants with more severe AD. Those studies will probably require shorter but increased number of interviews per participant. Another suggestion is to increase observational time of participants to understand their communication abilities. To establish credibility and dependability, researchers might consider triangulation of the participants' interviews with the caregivers' interviews.

The foremost reason to include the voices of persons with AD in qualitative research is to understand the impact of this disease on their lives from their own perspective, so we can improve their quality of life. Effective communication requires the researcher's caring and respectful attitude toward persons with AD and skillful strategies to confront the communication challenges of their dementia.

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Table 1

Strategies to Optimize Communication with Persons with Dementia

Effects of Dementia	**Strategy**
Attention and concentration lapses	Conduct interview in place less distracting Redirect conversation
Decreased abstract reasoning	Restructure questions to concrete topics Use participant's wording
Difficulty word finding	Allow ample time to respond If participants seem uncomfortable, then offer reassurance and help them
Memory loss	Use reminiscence Provide cues
Repeating phrases	Validate meaning Redirect conversation
Fatigue or anxiety	Monitor for signs Offer to stop interview