

Article

Photo-Elicitation with Autodriving in Research with Individuals with Mild to Moderate Alzheimer's Disease: Advantages and Challenges

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Abstract

Recent research indicates that people with Alzheimer's disease (AD) can meaningfully report on their life. As a result, there is an increasing interest in finding ways to involve persons with AD in qualitative research to ensure their perspectives and experiences are included. However, researchers have largely depended on interview or observation methods to inform their study, acknowledging concern regarding capacity for expressive language. This article reports on the use of photography, specifically photo-elicitation with autodriving, in a qualitative study of happiness in persons with mild to moderate AD, and it explores the opportunities and challenges of using this methodology in this population. Results demonstrate that while photo-elicitation can be an effective tool for the researcher to use to understand the world of the individual with AD, it also presents practical challenges. Thoughtful application of this methodology can overcome these challenges, providing a richer level of understanding than interview alone can generate.

Keywords: photo-elicitation, Alzheimer's disease, qualitative research, dementia, photographs

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In Alzheimer's disease (AD), as in other diseases without a cure, the improvement of quality of life (QoL) is an important treatment goal in an effort to reduce suffering. Historically, the majority of the research in QoL and dementia has used appraisals provided by proxy informants (Steeman, Dierckx de Casterlé, Godderis, & Grypdonck, 2006). More recent studies have suggested the proxy-informant and patient perception of QoL ratings may differ significantly (Ready, Ott, & Grace, 2004). The importance of the subjective experience of people with AD in the assessment of QoL has been acknowledged, but how best to include their understanding is still being explored (Moyle, Murfield, Griffiths, & Venturato, 2012). Cognitive limitations such as diminished memory and language impairment might curtail access to narrative reports and minimize the usefulness of interviews. Non-traditional methodological strategies for including the perspective of the individual with AD are needed, and these strategies should compensate for limitations, respect the person's right to participate in research, and protect the integrity of the research itself. One such example of a more inclusive methodology is the diary interview used by Bartlett (2012) to research the life of persons with AD. Bartlett (2012) modified and expanded the traditional diary interview method to allow participants to keep either a written, photo, or audio diary. This change allowed respondents with AD to take an active role and have greater control in the research process.

The use of photography offers a method to explore the subjective experience of AD, as it allows persons with limited expressive language capacity to provide a visual image of their life. By selecting the subject matter to be photographed, participants choose the information they share and the representation of their life and experience. This article builds on the work of Bartlett (2012) by describing the use of photo-elicitation with autodiving, a method in which photographs used in research interviews are taken by the participant (Heisley & Levy, 1991), as a way to communicate the thoughts and experiences of happiness in a sample of people with AD. The purpose of this article is to report the benefits and challenges of autodiving as experienced while conducting a qualitative study with individuals diagnosed with mild to moderate Alzheimer's disease.

Photo-Elicitation

The use of photographs during an interview to encourage dialogue is known as *photo-elicitation*, first named in an article published by researcher and photographer John Collier in 1957 (Harper, 2002). Bateson and Mead (1942) became the first to use pictures as the primary recording device in their research of the Balinese culture in the 1930s and 1940s (Jacknis, 1988). Collier (1957) later expanded the role of photography in research by using pictures as an aid to the interview process and found that photographs served to jog memory, stimulate emotions, and help "the interview to proceed on its meaningful way" (p. 859).

More recently, photographs have been used to look at social issues (Alexander, 2013; Harper, 2002; Radley & Taylor, 2003), to explore the experiences of children and adolescents (Mandleco, 2013), and to shed light on the subjective experience of mental illness (Sandu, Ives, Birchwood, & Upthegrove, 2013). Erdner, Andersson, Magnusson, and Lutzen (2009) used photographs to study people with long-term mental illness, and they noted that photography provides a bridge for those with cognitive limitations, offering a fuller picture of the individual's world by supplying information that might not have been obtained through interview only. The term *photo-elicitation*, also referred to as photo interviewing (Hurworth, 2003), is used when photographs serve as the basis of an in-depth interview. Photographs can be created by the researcher or participant, the latter being a more inductive approach known as *autodiving* (Heisley & Levy, 1991) to indicate that the interview is guided or "driven" by examination of the participant's own photographs (Hurworth, 2003). Autodiving has also been referred to as reflexive photography (Douglas,

1998), photo novella (Wang & Burris, 1994), and more recently as photovoice, a methodology which uses participants' photographs to create social change (Hurworth, 2003).

This article reports on the use of autodiving as a method of data collection in a qualitative study of happiness in a sample of 12 community-dwelling persons diagnosed with mild to moderate AD by a geriatrician. As a research method, photography can be communicative because it incites and conveys meaning, and generative because new understandings might be created and deeper insight obtained through discussions and analysis of the photographs (Close, 2007). For persons with AD, photographs can serve as memory triggers and improve the individual's ability to reflect and dialogue and allow others to see the world through his or her eyes (Close, 2007). In this study, photographs were obtained through autodiving to allow each participant to capture the reality of his or her life. Participants were asked to take pictures representing situations and events that either inhibit or support the experience of happiness. The pictures served as the starting point for an in-depth, semi-structured interview, at which time the elements of each individual's reality associated with happiness were elicited. In this way, the photographs and the ensuing dialogue allowed me to "see" the experience of happiness as the participant viewed it and to connect happiness contextually to the individual's social world. Although two forms of data were involved in this study, photographs and interviews, only the interviews were coded and analyzed.

At the time of this study (2012), a search of CINAHL, PsycINFO, and PubMed revealed no previous research utilizing photo-elicitation with autodiving in persons with dementia. Hulko (2009) utilized photo-elicitation *without* autodiving in a study in which she used photographs of individuals interacting with the social community to explore the social world of people with dementia. Hulko (2009) described the use of photographs as "instrumental" (p. 134) in the development of theory and supported the use of photographs in researching people with dementia. Building upon Hulko's use of photography, this article reports on a study using autodiving as a research method in persons with dementia and identifies the benefits and challenges experienced in the research process.

Context of Current Research

The number of people directly and indirectly impacted by AD is staggering. In the United States alone, over 5 million people were living with AD in 2012, with an additional 15.4 million family and friends providing care to persons with AD and other dementias (Alzheimer's Association, 2013). Worldwide, the estimate of the number of people living with AD is expected to rise from 35.5 million in 2012 to 65.7 million by 2030 (Alzheimer's Disease International, 2012). Each individual living with AD confronts uncertainties about his or her future health and prognosis. In mild AD, the individual might struggle with memory loss but still remain able to communicate and participate meaningfully in a social context as well as in some personal care and daily living activities. In severe AD, responsive behaviors might significantly limit an individual's ability to function independently. In general, people with AD and other dementias have high rates of psychiatric symptoms, including depression, when compared with people who have normal cognitive function (Alzheimer's Disease International, 2012).

Maintaining optimal emotional health is an important treatment goal in an effort to improve QoL and reduce disability and suffering (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Prince, Acosta, Castro-Costa, Jackson, & Shaji, 2009). The majority of the research in QoL and dementia report on positive affect as measured on various QoL tools (Brod, Stewart, Sands, & Walton 1999; Logsdon, Gibbons, McCurry, & Teri, 2002; Moyle, Callister, Venturato, & Adams, 2007). In doing so, positive affect might be separated from the contextualized experience of the

responder, producing information concerning the amount of measured attributes but offering limited insights regarding the qualities themselves.

Additionally, past concern that AD limits an individual's cognitive and communicative abilities has led to the use of information obtained from the proxy caregivers rather than the person with dementia, thus producing useful but limited information from the "outsider" perspective (Steeman et al., 2006). More recent studies have suggested that persons with dementia can report on their own lived experiences, which offers a richer and more in-depth understanding of the factors associated with QoL (Diaz-Ponce & Cahill, 2013; Dröes et al., 2006). As a result, increasing effort has been made to include the voice of the person with dementia in qualitative and mixed-method research (Cahill et al., 2004; Katsuno, 2005; Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterlé, 2007). In multiple studies, a general feeling of happiness has been identified as a factor associated with QoL (Byrne-Davis, Bennett, & Wilcock, 2006; Dröes et al., 2006; Moyle et al., 2007). However, at the time of this study no qualitative study had focused exclusively on the experience of happiness in mild to moderate AD.

Current research suggests the importance of continued exploration into the relevance of happiness for optimal health (Linley, Joseph, Harrington, & Wood, 2006). Positive emotions, including happiness, not only indicate a person's inner optimal well-being but may also motivate engagement with the surrounding community and environment (Danner, Snowdon, & Friesen, 2001; Wilson et al., 2002). This is especially significant in light of research suggesting an association between cognitive stimulation, defined by Clare and Woods (2004) as the engagement in a variety of activities aimed to enhance cognition and social functioning, and benefits to cognition, well-being, and quality of life in AD (Aguirre, Woods, Spector, & Orrell, 2013; Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006).

The aim of my qualitative study was to unpack the concept of happiness with regard to factors that promote resilience, the role of positive experiences, and the effects of positive relationships. To this end, photo-elicitation was used to explore the phenomenon of happiness from the internal perspective of an individual with AD. The purpose of this article is to explore the benefits and challenges in using photo-elicitation and autodiving with individuals diagnosed with mild to moderate Alzheimer's disease.

Research Design and Data Analysis

My methodology was informed by symbolic interactionism (Blumer, 1969), principles of interpretive description theory (Thorne, Kirkham, & MacDonald-Emes, 1997), and positive psychology (Seligman & Csikszentmihalyi, 2000). Symbolic interaction originates from the work of George Herbert Mead and falls under the umbrella of interpretivism (Crotty, 1998). Symbolic interactionism presumes that humans exist in a world of objects and act towards things on the basis of the meanings those things have to them; that the meanings of those things is derived from social interactions; and that those meanings are modified through an interpretive process so that "social reality" is dependent on social interaction (Blumer, 1969). Shott (1979) suggested that from the perspective of symbolic interactionism, emotions are the complex product of learning, interpretation, and social influence. In this study, happiness is symbolic—we symbolize it to ourselves and each other, and the symbolic meaning constructs the experience for ourselves. Symbolic interactionism invites the researcher to look closely at the research participants' interpretations of their actions and situations, including happiness (Charmaz, 1990).

In this qualitative study, photos were taken by the study participants, people living with mild to moderate AD, as a method of data collection. The photographs and the semi-structured interviews

describing their meaning were the symbolic representations of the participant's experience of happiness. Transcripts of interviews were analyzed using interpretivist theory (Thorne et al., 1997) to gain access to the participant's understanding of happiness. Interviews were digitally recorded and professionally transcribed. Transcripts were read and re-read several times to ensure accuracy, coded line-by-line, and analyzed as completed, staying close to the data. Through a process of constant comparison of codes, transcripts were analyzed staying close to the data until saturation was attained (Corbin & Strauss, 2008). Once all individual transcripts had been coded, repeating patterns of similarities and differences were identified over all the transcripts from which themes emerged that were shared by the participants. Themes were then discussed with a colleague who is experienced in qualitative analysis and was familiar with the study and data.

Participants

Participants were recruited by referrals from geriatricians in two communities in the Northeast United States in accordance with Institutional Review Board guidelines. A letter describing the study and inclusion criteria and requesting referrals to the study was sent to geriatricians listed in public records and professional organizations in these two communities. The inclusion criteria for the participating individuals with AD were: English-speaking adults age 70 or older, living in the community with a family member or an identified caregiver, and diagnosed with mild to moderate AD at least four months prior to referral. To be accepted to the study, participants had to be capable and willing to express themselves verbally and score between 3 and 7 on the Short Portable Mental Status Questionnaire (SPMSQ) at the initial meeting to ensure mild to moderate level of AD at the time of the study. The 10-item SPMSQ developed by Pfeiffer (1975) is widely used to evaluate orientation, memory, and concentration.

Seventeen individuals with AD were referred to this study, 12 of whom met inclusion criteria and participated in the research. Five individuals were not accepted in the study: one was excluded because he lived outside the state, one was unable to communicate, and three scored less than 3 on the SPMSQ. All participants were able to take photos and answer questions.

Procedure

After receiving contact information from the referring provider, each participant was contacted by me via telephone. During the initial phone call, the study was explained to the individual, who was then asked if he or she would be willing to participate in a study of happiness. An appointment was set for an initial in-person meeting at that time. Permission was also obtained from the participant to contact the family member or caregiver to explain the study and invite him or her to attend the initial meeting.

At the first meeting, the study was again explained. Each participant was asked questions to ensure his or her understanding of the study and consent was then obtained. The SPMSQ was administered to all persons with AD at the initial meeting. The first four participants were given a twelve-exposure disposable camera for approximately one week and asked to take pictures representing situations that inhibit or support the experience of happiness. Each participant with AD was accompanied by his or her caregiver to assist with logistical concerns such as transportation or difficulty operating the camera. Two additional meeting dates and times were established—the first in approximately seven days to pick up the cameras for film development, and a final meeting for the interview approximately three days after film pickup. For these four participants, the final interview occurred approximately 7-10 days after the cameras were first distributed.

Interviews and data collection occurred concurrently. As discussed further below, it became apparent after the first four interviews that participants had difficulty remembering the rationale for image selection. As a result, the research design was changed, and the final eight respondents were accompanied by me rather than a caregiver when taking pictures. These last eight participants were contacted and consented in the same fashion as the initial four individuals. At the first meeting, a date and time was set to take pictures within three days. The individuals took pictures using my digital camera or their camera phone. The pictures were then downloaded onto my computer and printed out on a digital printer. The final meeting occurred within two to three days after the pictures were taken. In this way, I met with each of the 12 participants three times during the study. All 12 participants were instructed to take pictures representing happiness.

Semi-structured, open-ended questions were asked in the interview. The photographs were placed on a table one at a time, and the participant was invited to tell me about each picture and explain how the picture represented happiness. With each picture, I asked the person with AD the initial question: “In what way does this picture represent happiness to you?” From that point on, the discussion of the picture was led by the participant’s narrative. At the conclusion of the interview, field notes documenting the observations and overall impressions of the researcher were written. Personal notes were kept in a reflexive journal. Photographs were numbered to correspond to the taped interview. The photographs were not coded or analyzed in this study. They were solely used as a catalyst for discussion at the final meeting. Ultimately, interviews with the participants suggested that the experience of happiness is connected to one’s ability to live in a manner consistent with lifelong values. These findings will be reported elsewhere. The focus of this current article is to report on the merits and challenges of asking people living with AD to use a camera.

Benefits of Autodriving with Persons with AD

The use of photo-elicitation with autodriving for data collection in research with persons with AD offers several advantages. As a methodology, it provides a concrete representation of an abstract concept—in this case the participant’s experience of happiness, thus allowing me to see what could not be communicated with words. The photos served as the basis of a conversation from which the researcher extrapolated an understanding of the experience later confirmed through discourse.

This methodology also offers benefits to the participants. The inclusion and active engagement of the participants in picture-taking make them partners in the research process. In this study, the ability of the individual to control his or her photographs supported the personhood of the individual by providing an opportunity for the expression of self, the loss of which has been linked to the appearance and progression of AD symptoms (Kitwood, 1997). In addition, the photographs and the ensuing dialogue provided the participant an opportunity to reflect on the experience and therefore reflect on his or her life, which resulted in the development of meaning and insight for both the researcher and the participant. For example, one participant spoke about being teased and ostracized by other children because she was unable to participate in physical activity. As she discussed her need to “be busy,” she realized the need to be active was in part a response to that piece of her life story. This is just one of several instances where a new insight was revealed to the participant. In this way, meaning was conveyed and insight developed for both the researcher and the participant.

Methodological Challenges and Lessons Learned

Autodriving can be an effective tool in understanding the world of the individual with AD, but it is not without practical challenges. In this section, I report the challenges experienced firsthand in one study: limited fine motor skills, shifting memories, and lack of reflexivity. Information found in the literature pertaining to these themes is included to add to the understanding of the challenges experienced. I also discuss the difficulty of negotiating the role of the researcher-clinician.

Challenge of Data Collection: Physical Limitations

My initial assumption was that traditional film cameras would be more familiar to the participants and therefore easier to operate, but this proved to be incorrect. Although traditional film-based cameras were familiar, age-related physical changes made their use difficult for some participants. The operation of any camera requires adequate vision, hand strength, and fine motor skills to press buttons and turn small dials. Visual impairments made seeing and differentiating buttons difficult for some individuals. One participant living with arthritis had difficulty turning the dial to advance the film. For some individuals, these challenges proved to be significant obstacles to picture taking and led to frustration and anxiety.

The unfamiliarity of the digital camera posed different problems. Some participants were uncomfortable using the camera's monitor rather than a viewfinder to take the picture. For others, the weight of the camera made it difficult to hold. Lastly, the digital camera was viewed by some as a complicated electronic device that they believed themselves incapable of using. Camera phones proved to be a comfortable alternative for some participants who reported looking at photographs of their grandchildren on camera phones. As a result, some felt more comfortable looking at the image they were photographing on the cell phone screen and handling the phone than they did with the digital camera.

Lessons learned.

During the initial meeting, I allowed ample time to assess each participant's comfort and camera preference, to practice using the camera, and to modify the camera as needed to ensure ability and ease of use. I found that putting colored tape on the essential buttons allowed for easy identification of important buttons, and also made it easier to communicate clear instructions on camera use. For example, directing someone to "push the red button" was easier to understand than "push the button closest to the center" when two black buttons were next to each other.

Turning the dial to advance film on the disposable camera was problematic for some who reported pain and limited fine motor skills. Switching to a non-disposable camera may offer a familiar option with an easier mechanism. Having a choice of a traditional camera, a digital camera, and a camera phone was important to enable each participant to find a suitable option. Providing detailed notes in large font to explain the use of each camera was frequently needed. By offering participants a choice of camera types and providing simple directions in large print, all participants were able to take pictures without assistance. Still, physical challenges may limit one's ability to participate in studies using autodrivng and should be considered when determining participant inclusion criteria. This may be especially important if autodrivng is to be used with persons in the moderate to severe stages of AD where medical comorbidities may be more common and have more impact than in earlier stages (Doraiswamy, Leon, Cummings, Marin, & Neumann, 2002).

Challenge of Data Collection: Shifting Memories

Data collection occurred over a total of seven months. The process was reviewed after the initial four interviews were completed. During that review, it became apparent that at the interview which occurred approximately one week after taking the pictures, all four persons with AD had difficulty remembering both the experience of taking the picture and the rationale for its selection. In one instance, granddaughter Rachel accompanied participant Laura during picture-taking and recorded Laura's reasons for each photo. Rachel's notes reported meanings for three of the nine pictures taken, which were different than those expressed by Laura during the interview six days later. The inability of these four participants to remember taking the photographs is not surprising given that AD is a complex neurological disease with multiple symptoms, including memory impairment (Blazer & Steffens, 2009).

As a result of the initial review, the methodology was changed and the last eight participants were accompanied by me rather than a caregiver when taking the pictures. The pictures were taken by the participant using my digital camera, a disposable camera, or their camera phone. Photos were downloaded onto my computer and printed out on a digital printer. The final meeting occurred within two to three days after the pictures were taken, rather than the approximate 7-10 day timeframe for the initial four participants. This modification allowed me to document the expressed rationale for the image selection as it occurred. For example, a picture of flowers was taken and reported to represent happiness felt while gardening. Still, even with this change, five of the final eight participants had difficulty remembering taking the picture.

While memory impairment is a well-documented and prominent feature of AD, it is progressive in nature; Cottrell and Schulz (1993) have reported that memory deficits are not necessarily a barrier to experiencing the "here and now." The individual can still accurately report the experiences of the present time although be unable to report past experiences. Memory impairment is less problematic in this study as the focus is on the co-construction of the experience rather than treating the photo as a representation of objective truth. All of the participants with AD were able to connect the image with a feeling of happiness and speak to the experience of happiness. Thus, through dialogue, the picture of the flower was found to represent not just the act of gardening, but the connection to a "healthier" self.

Lessons learned.

Alzheimer's disease is a heterogeneous disease with many different presentations and different levels of physical, cognitive, and memory impairment (Blazer & Steffens, 2009). Assume memory impairment to be a significant part of the illness for all participants regardless of how they present initially. Communicate frequently via telephone and in writing. Confirm all appointments in the manner each participant prefers. At each meeting, I left reminder notes in large font indicating the date, time, and place of our next meeting and confirmed the appointment the day before. Allow sufficient time at each meeting to restate the purpose of the study and review previous events. This is especially important at the time of the interview to allow the participant to become comfortable with the researcher and the conversation to develop at a pace determined by the participant.

Minimizing the time between taking the photographs and the interview may reduce, but probably not erase, the challenges posed by memory impairment. Have a system in place that will yield a finished photograph quickly regardless of camera choice. For the final eight participants, I offered to print the pictures on my computer and return later that day for the interview. In each case this offer was rejected due to fatigue. Participants generally reported feeling tired after 60-90 minutes.

Balance the benefit of a shortened time between taking the photos and interview with the strength and energy of the participant. Finally, competing activities such as medical appointments can also limit the participant's availability and add to the delay of the final interview. Select the date for taking the pictures and date for the interview at the initial meeting to minimize delay due to scheduling conflicts.

Challenge of Self Report: Reflexivity

A third challenge of data collection became obvious when I started to accompany each person for picture-taking. Photographs were used in this study as a method of gaining access to the experience of happiness by a person with AD. However, when participants were asked to identify an item or subject to photograph that represented happiness, some individuals asked me for suggestions. The reason for this might have been difficulty in abstract thought, self-doubt, fear of making a mistake, or desire to please me. Regardless of the reason, the presence and input from anyone assisting the individual will be represented in the picture taken.

Photographs and the ensuing interviews provide a valuable source of data in qualitative research. The tenets of symbolic interactionism recognize both as co-constructions of the researcher and the participant, the implication for this method being the acknowledgment of both the inability to remove and the need to understand the influence of the person assisting with the picture-taking. It would also be reasonable to extrapolate this insight to how researchers and clinicians view the information obtained from the caregivers who serve as proxy reporters for, or interpreters of, the subjective experiences of people with AD. Thus the symbolic interaction perspective offers a way to connect the person's experience back to the social context, linking his or her personal values with social context in a way that is missing from other theories and methods.

Lessons learned.

Trustworthiness of findings is at risk if the study findings are altered by the biases or perspective of the researcher (Lincoln & Guba, 1985). The first three respondents I accompanied in this study asked for my input when choosing the photo subject or sought my approval of the subject selected. When I did not provide the assistance they requested, the participant appeared uncertain and uncomfortable making a decision. Explaining at the outset that my opinion of the photo subject was not relevant and compromised the integrity of the study minimized participant requests for my input. Maintaining a slower pace allowed the participant to reflect and then select a subject for the photograph. Finally, I paid special attention to my influence on the photograph taken by maintaining a self-reflexive consciousness, cognizant of the impact of my words and actions on their choice of subject matter. I documented methodological decisions and personal reflections of research experiences in a reflexive journal, which allowed me to reflect on what was occurring throughout the research process, including picture taking.

Challenge to Researcher-Clinician: Shifting Roles and Perspectives

A fourth and significant challenge for me during this research was negotiating my dual role—that is, my professional role as clinician and my role as researcher. As a geriatric psychiatric mental health nurse practitioner, I counsel and treat clients with AD and their families. As a researcher, my role is that of an impartial observer and recorder. None of the research subjects were my clients, and no interviews occurred in my office. Still, the interview might be perceived by the participant as therapeutic given the one-on-one attention, the personal nature of the topic, and the interpersonal skills that are part of my training and practice and that might have carried over into the interview. Garland, McCabe, and Yeh (2008) reported that this phenomenon can also occur

with trained interviewers who are selected for their interpersonal skills. Hellstrom, Nolan, Lennart, and Lundh (2007) suggested that establishing good relationships might be especially important in research involving people with AD; they suggested that time should be spent building rapport, trust, warmth, and empathy. These factors might influence the participants' understanding of the interview as therapeutic irrespective of any study explanation provided.

Not only can the shift in orientation from clinician to researcher impact the participant, it led to some internal role confusion for me. Yanos and Ziedonis (2006) adeptly described this role confusion as a “clash between the clinical mandate to act in the patient’s best interest (beneficence) and the scientific mandate to pursue truth with all appropriate rigor (scientific autonomy)” (p. 251). Being positioned at the intersection of research and clinical practice is both exciting, in that it can result in the development of clinically relevant research, and concerning because of possible ethical and role conflicts.

There are several benefits of this dual role. At the most fundamental level, a clinician possesses an understanding of the mental health-care system based on experience in that system and can therefore provide insights into the “real-world” experience for staff and clients. Serving as a bridge between theoretical knowledge and practical application can lead to clinically relevant research and the development of evidence-based treatments. Yanos and Ziedonis (2006) have suggested that the clinician-researcher can facilitate the dissemination and implementation of evidence-based treatments into routine clinical practice by communicating their importance in terms understood and valued by staff and administrators and by developing strategies to incorporate empirically validated treatments into clinical settings.

Ethical concerns can arise in the clinician-researcher role (Yanos & Ziedonis, 2006). I struggled with the dissonance between my desire to act in the individual’s best interest in a clinical sense juxtaposed to the research directive to remain neutral so as to understand the experience of the individual without the distraction of my own thoughts and beliefs. An example of this dilemma was the experience of hearing a participant share the frustration of the lived experience of AD and wanting to either offer support or suggest interventions.

Lessons learned.

To address role conflict, Yanos and Ziedonis (2006) have advocated the development of an integrated clinical and research identity to balance the responsibilities of researcher and clinician. Yanos and Ziedonis (2006) suggested that to do so requires introspection, examination of the moral principles that guide one’s practice, and an understanding of the importance of research and clinical practice in meeting that principle. Throughout this study, I used reflexive journaling and discourse with a mentoring researcher-clinician to gain awareness of my self, my actions, and the potential for misconception of the research interview as a therapeutic intervention. Reflecting on these themes in a reflexive journal and in the discussions with my mentor helped me to maintain a more objective stance with the participants and a balance between science and practice.

Yanos and Ziedonis (2006) recommended that research trainees participate in programs exploring ethical dilemmas to increase knowledge and awareness. Existing literature addressing the development of an integrated identity (Miller & Rosenstein, 2003; Miller, Rosenstein, DeRenzo, 1998; Yanos & Ziedonis, 2006) offers a good starting point for independent study. Researcher-clinicians should consider the ethical complexities of the dual role early in the research planning stage and incorporate mechanisms such as journaling and mentorship in the research design to reduce potential conflicts of interest and increase ethical clarity.

Conclusions

Alzheimer's disease is a debilitating neurological disease that affects cognition, including impairment of memory and language skills. Data required to understand the lived experience in AD may be culled from the expression of the experiences of individuals with the disease. Unfortunately, cognitive impairment can limit the ability for individuals with AD to express their thoughts and feelings through conventional dialogue. Photo-elicitation with autodriving offers a way to explore the everyday experience of living with mild to moderate AD by providing a methodology that is present-focused, subjective, and co-constructive. As a therapeutic tool, photographs obtained through autodriving may provide information leading to the development of person-centered interventions and programs that support happiness and improve quality of life. As a research tool, it might have implications for the development of meaningful outcome measures in the assessment of quality of life. Photo-elicitation with autodriving is not without challenges, but with thoughtful application of this methodology these challenges can be overcome, supplying a richer level of understanding than can be generated by interview alone.

References

- Aguirre, E., Woods, R. T., Spector, A., & Orrell, M. (2013). Cognitive stimulation for dementia: A systematic review of the evidence of effectiveness from randomised controlled trials. *Ageing Research Reviews, 12*(1), 253–262.
- Alexander, V. D. (2013). Views of the neighbourhood: A photo-elicitation study of the built environment. *Sociological Research Online, 18*(1). doi:10.5153/sro.2832
- Alzheimer's Association. (2013). *2013 Alzheimer's disease facts and figures*. Retrieved from http://www.alz.org/downloads/facts_figures_2013.pdf
- Alzheimer's Disease International. (2012). *World Alzheimer report 2012: Overcoming the stigma of dementia*. Retrieved from <http://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>
- Bartlett, R. (2012). Modifying the diary interview method to research the lives of people with dementia. *Qualitative Health Research, 22*(12), 1717–1726. doi:10.1177/1049732312462240
- Bateson, G., & Mead, M. (1947). *Balinese character: A photographic analysis*. New York, NY: New York Academy of Sciences.
- Blazer, D., & Steffens, D. (2009). *Textbook of geriatric psychiatry* (4th ed.). Washington, DC: American Psychiatric Publishing.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Brod, M., Stewart, A., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *Gerontologist, 39*, 25–35.
- Byrne-Davis, L. M., Bennett, P. D., & Wilcock, G. K. (2006). How are quality of life ratings made? Toward a model of quality of life in people with dementia. *Quality of Life Research, 15*(5), 855–865.
- Cahill, S., Begley, E., Topo, P., Saarikalle, K., Macijauskiene, J., Budraitiene, A., ... Jones, K. (2004). "I know where this is going and I know it won't go back": Hearing the individual's voice in dementia quality of life assessments. *Dementia, 3*, 313–330.
- Charmaz, K. (1990). "Discovering" chronic illness: Using grounded theory. *Social Science & Medicine, 30*(11), 1161–1172.
- Clare, L., & Woods, R. T. (2004). Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: A review. *Neuropsychological Rehabilitation, 14*(4), 385–401.
- Close, H. (2007). The use of photography as a qualitative research tool. *Nurse Researcher, 15*, 27–36.

- Collier, J. (1957). Photography in anthropology: A report on two experiments. *American Anthropologist*, 59, 843–859.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.
- Cottrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *Gerontologist*, 33, 205–211.
- Crotty, M. (1998). *The foundations of social research*. Thousand Oaks, CA: Sage.
- Danner, D., Snowdon, D., & Friesen, W. (2001). Positive emotions in early life and longevity: Findings from the nun study. *Journal of Personality and Social Psychology*, 80, 804–813.
- Diaz-Ponce, A., & Cahill, S. (2013). Dementia and quality-of-life issues in older people. In C. Phellas (Ed.), *Aging in European societies* (pp. 97–115). New York, NY: Springer.
- Doraiswamy, P. M., Leon, J., Cummings, J. L., Marin, D., & Neumann, P. J. (2002). Prevalence and impact of medical comorbidity in Alzheimer's disease. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57(3), M173–M177.
- Douglas, K. B. (1998). Impressions: African American first-year students' perceptions of a predominantly white university. *Journal of Negro Education*, 67(4), 416–431.
- Dröes, R. M., Boelens-Van Der Knoop, E. C., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., ... Schölzel-Dorenbos, C. J. M. (2006). Quality of life in dementia in perspective. An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*, 5(4), 533–558.
- Erdner, A., Andersson, L., Magnusson, A., & Lutzen, K. (2009). Varying views of life among people with long-term mental illness. *Journal of Psychiatric and Mental Health Nursing*, 16, 54–60.
- Garland, A. F., McCabe, K. M., & Yeh, M. (2008). Ethical challenges in practice-based mental health services research: Examples from research with children and families. *Clinical Psychology: Science & Practice*, 15, 118–124.
- Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010). A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: The COPE randomized trial. *JAMA*, 304(9), 983–991. doi:10.1001/jama.2010.1253
- Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies*, 17, 13–26.
- Heisley, D. D., & Levy, S. J. (1991). Autodriving: A photoelicitation technique. *Journal of Consumer Research*, 18(3), 257–272.
- Hellstrom, I., Nolan, M., Lennart, N., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14, 608–618.

- Hulko, W. (2009). From “not a big deal” to “hellish”: Experiences of older people with dementia. *Journal of Aging Studies*, 23, 131–144.
- Hurworth, R. (2003). Photo-interviewing for research. *Social Research Update*, 40, 1–4.
- Jacknis, I. (1988). Margaret Mead and Gregory Bateson in Bali: Their use of photography and film. *Cultural Anthropology*, 3, 160–177.
- Katsuno, T. (2005). Dementia from the inside: How people with early-stage dementia evaluate their quality of life. *Ageing & Society*, 25, 197–214.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Philadelphia, PA: Open University Press.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. London, United Kingdom: Sage.
- Linley, P., Joseph, S., Harrington, S., & Wood, A. M. (2006). Positive psychology: Past, present, and (possible) future. *Journal of Positive Psychology*, 1, 3–16.
- Logsdon, R., Gibbons, L., McCurry, S., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, 65, 510–519.
- Mandleco, B. (2013). Research with children as participants: Photo elicitation. *Journal for Specialists in Pediatric Nursing*, 18(1), 78–82.
- Miller, F., & Rosenstein, D. (2003). The therapeutic orientation to clinical trials. *New England Journal of Medicine*, 348(14), 1383–1385.
- Miller, F., Rosenstein, D., & DeRenzo, E. (1998). Professional integrity in clinical research. *JAMA*, 280(16), 1449–1454. doi:10.1001/jama.280.16.1449
- Moyle, W., Callister, M., Venturato, L., & Adams, T. (2007). Quality of life and dementia. The voice of the person with dementia. *Dementia*, 6, 175–191.
- Moyle, W., Murfield, J. E., Griffiths, S. G., & Venturato, L. (2012). Assessing quality of life of older people with dementia: A comparison of quantitative self-report and proxy accounts. *Journal of Advanced Nursing*, 68(10), 2237–2246.
- Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatrics Society*, 23, 433–441.
- Prince, M., Acosta, D., Castro-Costa, E., Jackson, J., & Shaji, K. (2009). Packages of care for dementia in low- and middle-income countries. *PLoS Med*, 6(11). doi:10.1371/journal.pmed.1000176
- Radley, A., & Taylor, D. (2003). Images of recovery: A photo-elicitation study on the hospital ward. *Qualitative Health Research*, 13, 77–99.
- Ready, R., Ott, B., & Grace, J. (2004). Patient versus informant perspectives on quality of life in mild cognitive impairment and Alzheimer’s disease. *International Journal of Geriatric Psychiatry*, 19, 256–265.

- Sandhu, A., Ives, J., Birchwood, M., & Upthegrove, R. (2013). The subjective experience and phenomenology of depression following first episode psychosis: A qualitative study using photo-elicitation. *Journal of Affective Disorders, 149*, 166–174. doi:10.1016/j.jad.2013.01.018
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist, 55*(1), 5–14.
- Shott, S. (1979). Emotion and social life: A symbolic interactionist analysis. *American Journal of Sociology, 84*(6), 1317–1334.
- Steehan, E., Dierckx de Casterlé, B., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: A review of qualitative studies. *Journal of Advanced Nursing, 54*(6), 722–738.
- Steehan, E., Godderis, J., Grypdonck, M., De Bal, N., & Dierckx de Casterlé, B. (2007). Living with dementia from the perspective of older people: Is it a positive story? *Aging & Mental Health, 11*(2), 119–130.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health, 20*(2), 169–177.
- Wang, C., & Burris, M. (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly, 21*(2), 171–186.
- Wilson, R., Mendes de Leon, C., Barnes, L., Schneider, J., Bienias, J., Evans, D., & Bennett, D. (2002). Participation in cognitively stimulating activities and risk of incident Alzheimer disease. *JAMA, 287*, 742–748. doi:10.1001/jama.287.6.742
- Woods, B., Thorgrimsen, L., Spector, A., Royan, L., & Orrell, M. (2006). Improved quality of life and cognitive stimulation therapy in dementia. *Aging & Mental Health, 10*(3), 219–226.
- Yanos, P., & Ziedonis, D. (2006). The patient-oriented clinician-researcher: Advantages and challenges of being a double agent. *Psychiatric Services, 57*, 249–259.