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Picturing Leisure: Using Photovoice to Understand the Experience of Leisure and Dementia

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Abstract

Interviews and participant observation are commonly used to explore the experience of dementia, yet may not adequately capture perspectives of persons with dementia as communication changes. We used photovoice (i.e., using cameras in qualitative research) along with interviews and participant observation to explore meanings of leisure for persons with dementia. We discuss our photovoice process and the challenges we encountered, including ethical concerns, difficulty using the equipment, forgetting the context of photos, and questioning self. Despite challenges, photovoice aided in cuing memory, planning for the interview, sharing stories, and capturing meaning. We recommend further exploration of photovoice with this population.

Keywords

Alzheimer's Disease, Dementia, Leisure, Phenomenology, Photovoice

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Picturing Leisure: Using Photovoice to Understand the Experience of Leisure and Dementia

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Interviews and participant observation are commonly used to explore the experience of dementia, yet may not adequately capture perspectives of persons with dementia as communication changes. We used photovoice (i.e., using cameras in qualitative research) along with interviews and participant observation to explore meanings of leisure for persons with dementia. We discuss our photovoice process and the challenges we encountered, including ethical concerns, difficulty using the equipment, forgetting the context of photos, and questioning self. Despite challenges, photovoice aided in cuing memory, planning for the interview, sharing stories, and capturing meaning. We recommend further exploration of photovoice with this population.

Keywords: Alzheimer's Disease, Dementia, Leisure, Phenomenology, Photovoice

In a growing body of research investigators are exploring the experience of dementia from those living with the disease (e.g., Beard, 2004; Beard, Knauss, & Moyer, 2009; Clare, Rowlands, & Quin, 2008; de Witt, Ploeg, & Black, 2009; MacQuarrie, 2005, Phinney, 2006). In these studies, the researchers frequently collect data using qualitative interviews and participant observation (e.g., Beard, 2004; Hubbard, Downs, & Tester, 2003; Nygard, 2006; Phinney, 1998; Phinney, Chaudhury, & O'Connor, 2007). These methods have been particularly fruitful in exploring how persons living with dementia experience their symptoms and how they manage daily life with memory loss. However, as communication can change with dementia, finding alternative ways to research the lived experience of memory loss becomes increasingly important.

This emergent body of knowledge focusing on the experiences of persons living with memory loss stems from Kitwood's (1997a) personhood approach to dementia. Personhood was developed as a counterdiscourse to the biomedical approach, which focuses on neuropathology, thereby neglecting the perspectives of those living with memory loss. The personhood paradigm resulted in a change in the way we think about dementia, leading to research that includes persons with dementia, rather than only relying on proxy voices from formal and informal care providers. Kitwood's reconceptualization of dementia was motivated by the desire to improve the lives of people living with dementia (Morton, 1999). Defined as "a standing or status bestowed upon one human being by others in the context of the relationship" (Kitwood, 1997a, p. 8), personhood acknowledges both individual values and possibilities for improving quality of life (Li & Orleans, 2002). According to Kitwood (1997a), personhood aims to include "...a richer range of evidence than the biomedical model...it provides a rationale for an approach to care that looks to more human than to medical solutions" (p. 2).

Kitwood (1997a) argues that personhood should be linked to feelings, emotions, and the ability to live in relationships. Recognition of the essential unity of all human beings regardless of differences in mental capabilities is vital to personhood. Personhood can be

maintained for individuals with dementia by enabling choice, using remaining abilities, through expression of feelings, and by living in the context of relationships (Kitwood, 1997a).

In developing personhood, Kitwood drew upon Buber's (1937) "I-Thou" perspective (Kitwood, 1997a; Morton, 1999). Buber contrasts "I-It" relationships with "I-Thou" relationships. I-It relationships are characterized by detachment (Kitwood, 1997a). I-Thou relationships imply "going out towards the other; self-discovery, spontaneity..." (p. 10). I-It relationships are ordinary and trivial, but I-Thou relationships rise above that, to include not only anxiety and suffering, but also fulfillment and joy (Kitwood, 1997a). Kitwood's approach to dementia calls for a move away from relating to persons living with dementia in the I-It mode to relating to them in the I-Thou mode, where the person is met with openness, tenderness, presence, and awareness. It is Kitwood's (1997b) belief that I-Thou relationships replenish personhood, which involves lowering our defences and allowing our true feelings to show.

As a result of the I-Thou-inspired personhood movement, we are beginning to understand the meaning of daily activities and occupations, including leisure. Literature suggests that leisure participation may be relevant to the experience of dementia (Beard et al., 2009; MacRae, 2010; Phinney et al., 2007) and important for maintaining identity and nurturing personhood for those living with dementia (Genoe, Dupuis, Keller, Schindel Martin, Cassolato, & Edwards, 2010; Genoe, 2009; Genoe & Dupuis, 2011; Murray Alzheimer Research and Education Program (MAREP), 2011). In particular, it is evident that engagement in therapeutic recreation programs in long-term care homes and day programs can have many benefits for persons in later stages of memory loss, including reductions in behaviours such as wandering or yelling, and an increase in alertness and socialization during participation in planned or prescribed therapeutic recreation programs (Buettner & Fitzsimmons, 2002; Buettner, Fitzsimmons, & Serdar, 2006; Buettner & Kolanowski, 2003; Fitzsimmons & Buettner, 2002; Kolanowski, Buettner, Costa, & Litaker, 2001; Kolanowski, Litaker, & Buettner, 2005; Sullivan, Pedlar, & Miller, 2002). Despite evidence of many benefits of these programs, little is known about how persons living with memory loss experience leisure and what meanings they attach to it. Nevertheless, recent research indicates that persons living with memory loss value meaningful leisure for a variety of reasons, including expressing oneself, finding balance, having fun, contributing in meaningful ways, freedom from stress, connection to loved ones, and opportunities for growth and development (MAREP, 2011). Participation in meaningful activity is valued among persons living with early stage memory loss (Beard et al., 2009; Phinney et al., 2007). Indeed, for some, engagement in meaningful activity is "the central driving force in their lives" (Phinney et al., 2007, p. 387).

Although the personhood approach to dementia privileges the voices of persons living with the disease, Nygard (2006) notes that interviews may not be adequate for understanding the experience of memory loss as communication changes over time. Furthermore, Stewart and Floyd (2004) call for greater use of visual methods in leisure research, arguing that "visual leisure is meant to enhance our ability to conceptualize people's leisure and to improve communication with the way we represent people's leisure" (pp. 448-449). Adopting personhood as our approach to dementia, we used photovoice to capture meanings of leisure among persons living with memory loss who may have difficulty communicating in traditional ways. We gave participants disposable cameras, and asked them to take photos of objects and subjects that were meaningful for their leisure. It was our hope that visual depictions of leisure would provide participants with a way to communicate meanings of leisure without having to rely solely on words and in ways that may not be captured in words alone. In this article, we discuss how participants used photovoice to capture the lived

experience of leisure and the challenges and advantages of using this method, along with recommendations for future research.

Photovoice

While visual research methods (e.g. photo elicitation) have been used to explore leisure in a variety of contexts (Hallman & Benbow, 2007; Johnson & Glover, 2011; Klitzing, 2004; Reynolds, Lim, & Prior, 2008), to our knowledge, photovoice has not been used to consider leisure within the context of dementia. Photovoice has a great deal of potential for exploring leisure within the context of dementia because it "...expands the forms of representation and the diversity of voices that help define, and improve our social, political, and health realities" (Wang, Cash, & Powers, 2000, p. 911). Photovoice provides a way to not only hear, but to see the participants' stories of leisure.

Photovoice is a participatory action research method in which participants are provided with cameras and given the opportunity to use photography to express, reflect, and communicate their everyday lives (Wang, 1999). It enables those most marginalized in our communities with a means to share their experiences and perspectives and enables researchers to see the world through the lenses of research participants. It "can affirm the ingenuity and perspective of society's most vulnerable populations" (Wang & Burris, 1997, p. 372). As a result of the focus on the use of images to better understand the lives and communities of marginalized individuals, photovoice has been used to explore a diversity of health issues and populations (Catalani & Minkler, 2010; Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009), such as women in rural China (Wang, 1999), traditional birth attendants in rural Guatemala (Cooper & Yarbrough, 2010), persons experiencing chronic pain (Baker & Wang, 2006), youth (Wang, Morrel-Samuel, Hutchison, Bell, & Pestronk, 2004), Tlcho mothers (Moffitt & Vollman, 2004), people who had experienced a spinal cord injury (Newman, 2010), people experiencing aphasia (Levin et al., 2007), and African American men (Ornelas, Amell, Tran, Royster, & Eng, 2009). We were only able to find one study that used photovoice as a means of capturing the experience of dementia for those living with it (see Wiersma, 2011).

Photovoice enables individuals to act as recorders of their lives and as agents of change (Wang & Burris, 1997). Participants can use the power of the visual image to communicate their life experiences (Wang et al., 2000). Through photovoice, researchers are afforded the opportunity to see the world from the view of others, and research participants have the chance to describe what their photos mean and reflect (Wang & Burris, 1997). Photos can enrich interviews with their capacity to generate multiple meanings and to trigger discussion (Clark-Ibáñez, 2004). Hagedorn (1994) summarizes the advantages of using photography in research:

Photographs invite open expression while maintaining concrete and explicit reference points. The images captured in photography invite people to take the lead in inquiry, facilitating their discussion of an experience. Photographic interviews elicit a unique return of insights that might otherwise be impossible to obtain with other techniques. Photographs sharpen memory and give the interview an immediate character of realistic construction and function. (p. 47)

Many benefits of the photovoice method have been documented. The use of photos in research has been shown to provide reflective opportunities for participants (Loeffler, 2004; Samuels, 2004). In particular, photovoice can provide persons living with dementia with an alternative way to consider their everyday lives and the role of leisure within daily life by

using a visual memory aid to reflect on their experiences and situations. Photos can also help build rapport between researchers and participants (Loeffler, 2004) by providing participants with something to focus on, thus easing anxiety (Clark-Ibáñez, 2004; Harper, 2002) and encouraging communication (Hagedorn, 1994; Loeffler, 2004). Photos can capture greater levels of detail about the emotional meaning of experience than words-only data collection (Loeffler, 2004). The use of photographs can be a means for expressing emotions (Radley & Taylor, 2003) and unidentified needs (Levin et al., 2007).

Photovoice researchers have demonstrated some of the motivations and advantages of using this method for research participants. Photovoice participants with chronic pain became involved in the research to help others better cope with pain, and to learn more about the physical and emotional experience of pain (Baker & Wang, 2006). When used with persons experiencing aphasia after a stroke, photovoice led to a new means of self-expression. Photos were shown to family and friends to express concerns and hopes about the present and future (Levin et al., 2007). Needs were identified and participants experienced empowerment as they expressed their concerns through photos, leading to feelings of control that had been lost in the medical model of treatment (Levin et al., 2007). Furthermore, the participants' photos were posted on a website, showing how persons living with aphasia can lead full lives. In this way participants were able to use their photos to challenge dominant perceptions and the stigma associated with illness.

Photovoice empowers research participants as they have control in deciding what to depict about their lives (Levin et al., 2007; Newman, 2010; Stewart & Floyd, 2004). This technique can increase feelings of competence as strengths and capabilities are discovered (Foster-Fishman, Nowell, Deacon, Nievar, & McCann, 2005). Photovoice gives participants freedom to express issues of importance to them and can stimulate discussion (Cooper & Yarbrough, 2010). Persons living with dementia might experience feelings of empowerment when using visual aids to tell their stories, especially if their abilities to communicate verbally have changed. The use of cameras to reveal experience might uncover hidden strengths and abilities and ensure that persons living with dementia are recognized as the experts of their own experiences. Adopting a critical reflection approach to photovoice in the context of leisure and dementia focuses on both positive and negative issues within the lives of persons living with dementia. Such an approach could portray the experience of dementia more holistically, moving away from the predominantly negative discourse surrounding dementia (Jolley & Benbow, 2000; Wiersma, 2011) and promoting positive identities for those living with the disease.

Purpose

The purpose of the original phenomenological study was to explore the meaning and experience of leisure within the context of early stage dementia using multiple methods, including the long interview (McCracken, 1988), participant observation, and photovoice. Since little is known about the meaning and experience of meaningful leisure within the context of dementia, we set out to understand how persons living with dementia experience the disease, how they experience leisure, what meanings they attach to leisure, and the role of leisure in maintaining identity. The findings addressing these questions have been published elsewhere (Genoe & Dupuis, 2011; Genoe & Dupuis, 2012). In this paper we focus on the experience of both the researchers and the participants in using photovoice in the dementia context, re-analyzing our data to understand the challenges and possibilities of using photovoice to understand the lived experience of dementia and leisure within that context.

Participants

Study participants included two men and two women living with early stage dementia in the community. They were recruited through early stage support groups and a dementia research program in Southwestern Ontario, Canada. Staff at the support groups and research program identified potential participants with early stage memory loss and provided them with information regarding the study, and four people who were interested in participating contacted the first author to be part of the study, or gave their contact information to the support group coordinator for us to contact them. No one who contacted the first author or gave their contact information to the coordinator, was excluded from the study, and all participants remained in the study until all data were collected.

Participants included Charles, Rita, Jack and Alice (pseudonyms have been provided to protect confidentiality). Charles was a 77 year old man who had been diagnosed with Alzheimer's disease about four years prior to our first meeting. Charles lived with his wife in an apartment complex for seniors. He was actively involved in choir and enjoyed playing games and watching movies, and reading fiction. Charles was living with Parkinson's disease and macular degeneration.

Rita was an 82 year old woman living in a condominium with her husband. She had been diagnosed with Alzheimer's disease one year prior to our first interview. She enjoyed spending time with her grandchildren, doing crossword puzzles, writing poetry, watching television, and playing cards.

Alice was a 59 year old retired nurse who had been diagnosed four years prior to our first interview. Alice was originally diagnosed with vascular dementia, but this was later changed to both vascular dementia and Alzheimer's disease. Alice lived on her own in an apartment, and advocated for persons with dementia, as well as enjoyed writing poetry, playing computer and card games, spending time with family and friends, doing crafts, reading fiction, caring for her cat, and feeding birds.

Jack was a 72 year old man who had been diagnosed with Alzheimer's disease two years prior to our first meeting. Jack lived with his wife in a small bungalow in a seniors' community. He enjoyed physical activity, and was an avid golfer. He played crokinole, darts, and carpet bowling. He and his wife enjoyed social dancing as well.

Methods

After obtaining ethical approval from the University Research Ethics Board, we followed Richardson and St. Pierre's (2005) notion of crystallization, and used three methods of data collection to understand the lived experience of leisure within the context of dementia from a variety of angles and sources. First, we conducted long interviews with the participants. The long interview is a series of interviews that aim to understand lived experience (McCracken, 1988). We interviewed each participant on four different occasions over a six month period. Second, using participant observation, we joined the participants in some of their favourite leisure activities, including physical activity, crafts, and games. Finally, using photovoice, we provided the participants with cameras and asked them to take photos of objects, subjects and spaces that were meaningful for their leisure. In this article, we will focus only on the photovoice data.

Photovoice Process

We gave participants 27-exposure disposable cameras with a built in flash at the end of the first interview and asked them to take photos of meaningful objects and experiences

relating to their leisure. Using disposable cameras can be challenging for older adults as manual dexterity is required to operate the camera (Kelly, Wakewich, Simmons, & Leipert, 2007). Therefore, we gave participants the option to use their own cameras if they preferred, however, all four participants chose to use the disposable cameras. We gave participants both written and verbal instructions regarding the operation of the camera. We had hoped that participants would take photos independently, yet three of them asked family members to take the photos so that they could be included in the photos engaging in leisure. As well, two participants asked us to take photos of them before the cameras were collected for processing. This could have influenced what the participants chose to photograph, however, Radley and Taylor (2003) found that assisting with photography increased knowledge about the context in which the photos were taken and awareness of the decision making process participants underwent when deciding what to photograph. The persons with memory loss decided which photos they wanted to take and set up the shots. Participants took between eight and 27 photos.

At our second meeting with participants (typically a participant observation session), we collected the cameras and developed the photos. We gave participants one set of photos and one compact disc with their photos on it and retained one set of photos and one compact disc for data analysis. As using photos alone contradicts the essence of photovoice, we asked participants to discuss (give voice) to their individual experience – participants narrated the meaning of the photos (Wang & Burris, 1997). Although photovoice researchers typically use group discussion to explore the photographs, Baker and Wang (2006) modified the method to work with individuals. In one-on-one interviews, we asked participants to tell us about their photos. This format negated the need for multiple group meetings to learn how to use the cameras or participate in public forums (see also Newman, 2010). In these interviews, we discussed the participants' photos to contextualize issues around leisure, including what was seen in the picture, what was really happening in the photo, and how the photo related to leisure and everyday life (Wang & Burris, 1997). Examples of questions asked of participants included: What do you see in this photo? Can you describe what is in the photo? What is meaningful to you about this photo? What does this photo say about your leisure? What does this photo say about your life now? What does this photo say about how you are? Data were digitally recorded and transcribed verbatim.

Data Analysis

In analyzing the data in order to uncover the challenges and possibilities of using photovoice in the dementia context, we used similar coding methods as was used in the original study, however we focused primarily on the photos, the narratives from the second interviews with participants, field notes and a reflexive journal that was maintained by the first author throughout the process. Field notes were recorded immediately following the interviews and participant observation sessions and included information such as the location of the interviews, whether others were present, mood and characteristics of the participant and first author, and what went well and what could be changed for next time. Suggestions for follow-up questions were also recorded (DeWalt & DeWalt, 2002; Patton, 2002). The reflexive journal was maintained throughout data collection and analysis, and included initial notes regarding analysis as connections between the data and the participants emerged (e.g. similarities and differences among the participants), as well as questions raised throughout data collection and analysis, and the first author's personal experiences with the research questions, interactions with participants, and epistemological and ontological positions (Bochner, 2000; Dupuis, 1999; Schwandt, 2007).

In our original analysis, we identified themes and subthemes related to the experience of dementia and the role of leisure within the context of dementia. However, in our re-analysis of the photovoice data, we looked specifically for themes regarding challenges and possibilities of using photovoice as a methodology. In the re-analysis, we used NVivo 8, and followed van Manen's (1997) detailed line by line coding. First, we read all data multiple times to get a sense of the experience of photovoice for the participants and for us as researchers. Second, we read each sentence carefully while considering what it revealed about the phenomena. Then, we identified themes along with appropriate phrases or statements that described the meaning of the themes. We compared themes in each transcript and field note for commonalities and differences and together we identified the themes that best described the participants' and our experiences of using photovoice with the participants. We reflected on themes that were not included and those that were not deemed essential to the experience of photovoice within the context of memory loss were removed. We discussed emerging themes and how they were interrelated and could be clustered together into broader expressions of the experience until we felt confident that the themes and their relationships adequately captured the both the challenges and possibilities of using photovoice within the dementia context. After the original analysis, we discussed and verified the findings with all participants to see if they agreed with our interpretations (Halldórsdóttir & Hamrin, 1997; Parsons, 1997; van Manen, 1997) and all participants agreed that our findings reflected their experiences. However, we were not able to return to the participants after this re-analysis of the data.

Results

Our original analysis revealed that participants experienced leisure within a complex paradox of challenge and hope characterized by struggling with change while tackling life with dementia. They experienced threats to identities but were able to use leisure to buffer these threats and uphold identities (see Genoe & Dupuis, 2011, and Genoe & Dupuis, 2012 for more details on these findings).

Photovoice provided unique insight into the participants' experiences of leisure. This distinctive way of communicating led to greater understanding of meanings of leisure in the context of dementia. Visual images provided persons living with dementia with a starting point for discussing the meaning of leisure and whether or not leisure has a role in sustaining identity and resisting the negative discourse surrounding dementia. Photos captured a variety of meanings of leisure within the context of dementia for the participants.

The photos, along with their narratives, revealed how leisure was experienced as paradoxical. As abilities changed because of memory loss, so too did the participants' ability to participate in leisure to the same extent that they had prior to diagnosis. Nevertheless, leisure was valued by the participants because they used it to cope with the changes they were experiencing, maintain their relationships with family and friends, sustain remaining abilities and slow progression of dementia, and to create positive memories of themselves for their loved ones.

Challenges of Photovoice

Challenges arose in using photovoice with persons living with memory loss. These included photographing ethically, struggling with equipment, forgetting the context of photos, and questioning self and abilities.

Photographing ethically. Photovoice presents a unique set of ethical concerns that are not found in words-only interviews. Attention must be paid to issues of consent,

ownership of photos, and intrusion (Wang & Redwood-Jones, 2001). Informed consent is pertinent in photovoice. In addition to providing informed consent to participate in the study, consent was required from human subjects in the photos. We asked participants to obtain consent from any person they wished to photograph, and to have them indicate their willingness to have their image appear in the study and in any resulting publications. We also obtained consent from participants to use their photos in the project and subsequent publications. Participants own the negatives of photos that they took, and must give permission, and be given credit, in publications. Photovoice participants should avoid intrusion on individuals, groups, neighbourhoods, and communities. As well, the participants needed to be careful not to place the subjects of their photographs in false light. The rights of the subject might be compromised if the interpretation of the events conflicts with his or her thoughts or feelings (Wang & Redwood-Jones, 2001).

Although most of these ethical guidelines did not pose challenges for this study, obtaining informed consent from human subjects of the photos did. Participants received copies of an information letter and consent form explaining the study to individuals or guardians of persons they wished to photograph. Some of the participants had difficulty understanding that consent was required from any person who appeared in a photo taken for the purpose of this study. In most cases, a family member ensured that consent was obtained, but one participant did not ask for consent, and we were unable to use her photos with other people in them: “She seemed to have more difficulty with the consent forms than the others, and they hadn’t been signed” (reflexive journal). Unfortunately, many of these photos vividly highlighted valued leisure time spent with her family, particularly grandchildren. While we were able to use her photos as a jumping-off point to discuss leisure with her family, we were unable to use the photos publically.

Struggling with equipment. Participants faced challenges in using the cameras themselves. Disposable cameras are small, with instructions written in small print. Although relatively simple to use, they do require a few steps to take the photo (e.g., holding the flash button until the light turns red, indicating the flash is ready, taking the photo, winding the film manually). Charles, who was also diagnosed with Parkinson’s disease and macular degeneration, was unable to use the camera and asked his wife to take the photos: “Um...I didn’t take any pictures myself, because two reasons...one is being able to see clearly.” The cameras had limited range (i.e., the photographer must stand 3 meters away from the subject), no zoom feature, and the flash was not automatic, occasionally making it difficult to capture what the participant wanted to portray in the photo. In figure 1, Alice was taking a photo of the birds on her neighbour’s balcony, because feeding the birds had become a valued leisure activity since being diagnosed with dementia. However, the limited range of the camera did not allow her to zoom in on the birds, making the birds very difficult to find in the photo. When looking at the photo, Alice said: “Now this one didn’t really catch everything, but it was, as you can see I feed the birds. And there’s the two doves” (pointing to the doves on the edge of the photo).

Forgetting the context of photos. Closely related to struggling with equipment, forgetting posed another challenge. Sometimes, participants could not remember what a photo represented to them or why they had taken it and were unable to discuss the meaning of the photo with us. For example, Rita was surprised to discover a photo of herself vacuuming, a chore that she disliked, among her leisure activities. When asked if she was vacuuming in the photo, she replied:

Yes I was. How about that. That doesn’t happen very often either (laughs). I have a cleaning lady that comes in, yeah, yeah, that’s what I’m doing. I don’t

know what that is, well I guess it's in here somewhere. Yeah. I didn't remember that picture being taken.

Figure 1: Alice takes a photo of the birds on her balcony



The lack of detail in the photographs contributed to forgetting because participants were occasionally unable to recall exactly what it was they had intended to portray with a particular shot:

it was uh, I'm wondering if it was uh... gosh what's that... restaurant, I can't think of it now. It's downtown here... uh, no it doesn't look like that either, I have no idea where this is. I'll have to ask my daughter sometime. (Rita)

Charles did not recognize what he was doing in many photos, and took some time to recall what he wanted to say about each photo, sometimes trying to guess what he was doing in the photo: "Hmm...(studies the photo) I'm back in my corner. But I can't remember whether I was reading."

Additionally, participants occasionally forgot to photograph their favorite leisure activities. During our discussions with Rita, we came to understand how much she loved to write poetry on her computer. However, when we began exploring her photos with her, this activity was not illustrated in any of her photos. Rita had not thought to take a photo that would reflect the importance of this activity for her. When asked if she had taken a photo of the computer, Rita replied: "Yeah, yeah...never thought about that. Yeah." Following the interview, the first author wrote in her reflexive journal: "Unfortunately we didn't get to talk much about her poetry, which is her favourite hobby, because she hadn't taken a photo of her computer, but we did talk about it at the end." When asked further about her poetry, Rita replied:

I love poetry. I love reading other people's poetry, and um, and I like writing it. Ah, I feel really good when I'm typing it out and, and uh, and it may not be all good, it's you know, but, to me it's good, because it's done, done something for me, and my kids like it, and you know, that's I've given it to friends, and stuff like that.

Questioning self and abilities. Participants felt unsure of their photos and whether or not they were taking pictures of the “right” thing, or taking photos of what we wanted to see: “I probably didn't do what you wanted for some of them” (Rita). Indeed, Charles questioned whether he should be part of the study at all since he experienced multiple illnesses that affected his ability to use the camera. Family members who took the photos were also unsure if they were taking photos of the “right” thing, or whether or not the photos would turn out. Occasionally, multiple shots of one scene were photographed because the photographer tried to get the best shot. Reassuring the participants that there was no right or wrong and that the photos did not have to be works of art helped ease their uncertainty of their ability to participate in the study. Despite concern about whether the photos were ‘good enough’, participants enjoyed seeing their photos and discussing them.

Possibilities of Photovoice

There were many possibilities associated with using photovoice that far outweighed the challenges. Photovoice was useful for planning ahead and cuing memory, sharing stories through photos, and capturing multilayered meaning.

Figure 2: Charles is pole walking



Planning ahead and cuing memory. Memory loss can impact the ability to participate in interviews because persons with dementia might have difficulty remembering answers to questions, which can cause feelings of embarrassment (Hubbard et al., 2003; Nygard, 2006). Photovoice might help to ease this difficulty because the brain responds differently to both verbal and visual information. Accordingly, photovoice might be useful for

prompting reflection and thought among persons with dementia in ways that words alone cannot. Indeed, photovoice gave participants control over the topics to be discussed (i.e., which leisure activities they wanted to discuss) and opportunity for reflection and preparation for our discussion. Some participants planned ahead when taking the photos and felt better prepared to discuss them in the interviews: “Um, I thought ahead of time of what I do for leisure before you came. I wondered what are we going to talk about. I wrote down most of what of the situations that I took pictures of” (Charles).

In addition to planning ahead prior to the interview, using photos might have allowed participants to access memories with greater ease, as they can provide opportunities for reflection, recollection, and description (Samuels, 2004). Often people with dementia rely on memory cues, such as calendars, lists, and timers, to cope with memory loss (Clare, 2002; Gillies, 2000; Parsons-Suhl, Johnson, McCann, & Solbert, 2008; Phinney, et al., 2007; Preston, Marshall, & Bucks 2007; Van Dijkhuizen, Clare, & Pearce, 2006). In this study, the use of the participants’ photographs in the interview allowed for reflection on both frustrations and joys of a particular leisure activity. For Charles, seeing certain photos prompted him not only to tell us about his leisure, but to show us how he adapted it to fit his changing abilities. In the photo, Charles is sitting in his favourite chair reading using a device he created to hold a book still to accommodate the tremors that resulted from Parkinson’s disease. When Charles saw the photo during the interview, he proceeded to show the interviewer with much pride how the device worked and went on to explain how he had designed the device in order to continue to enjoy one of his favorite activities. In another photo, Charles is using poles to go for a walk, which helped him maintain his balance. After seeing the photo, he showed the interviewer how to use the walking poles in his apartment (see figure 2). Later, when asked how he felt about using the photos as part of the study, Charles said: “that might not have come up at all had I not taken pictures of it and thought about what do we want to think of as leisure”. Jack also used the photos to remind him how he engaged in physical activity. Using one of his photos, Jack demonstrated how he worked on muscle strengthening in a stretch and tone fitness class (see figure 3):

Figure 3: Jack is stretching to maintain flexibility



. . . and this. . . is stretching. . . It's, it's all you doing, all we're doing there is coming down, coming down, coming down, coming down (demonstrates a squatting exercise) coming, touch the chair, and then, come up, come up, come up, come up (comes back up from squatting exercise) until you're back to where you started. And the slower you do it, it's, the harder it is. Because if you just go down and up and down and up you're not really stretching. . .

Sharing stories through photos. Although there might be nothing inherently interesting in the photos themselves (Clark-Ibáñez, 2004), photos encourage communication between the researcher and the participants (Hagedorn, 1994; Loeffler, 2004) and can capture greater levels of detail about the emotional meaning of experience than words-only data collection (Loeffler, 2004). The use of photos encouraged story telling around leisure and dementia. After Alice looked at her photos for the first time, she told us: "It's kind of nice when I look at them now. They all have a story when I really look at them. I was kind of hoping for that. And there it is." Two of the participants were particularly excited to talk about their photos and what the photos represented to them. Following one interview, the first author wrote in her reflexive journal,

[the participant] also found a great deal to talk about in each photo. She commented on how each photo really meant more than she thought it would when she took them, even though she did put a lot of thought and consideration into what she wanted to take.

Alice took a photo of her cat (see figure 4), which reminded her to tell the story of how she adopted the cat with the help of a friend:

Figure 4: Alice's cat



And ironically when um, I was accepted for the adoption, that was a long process, because they weren't sure because of my memory loss that I'd be able to take care of her. And on my fixed income that I'd be able to meet her health

care needs so my friend had quite a long discussion with them and told them how wild [my pet bird] was, and I got him tamed so where he'd walk up and down my arm. So that kind of sealed the deal I think that yes I was capable.

The photo represented not just her cat, which was a valued part of her leisure, but also how she had to advocate, with the help of a friend, for herself and others with dementia, that she had many abilities and was able to look after the cat. Photos prompted the telling of stories for other participants as well. This illuminated continued strengths and abilities. Jack's photo of himself playing the violin prompted stories of re-learning to play after diagnosis. Rita's photo of herself with her granddaughter led to stories of her relationship with her granddaughter and games they played together.

Capturing multilayered meaning. The photos portrayed the multidimensional nature of leisure in the lives of the participants. Photos reflected the participants' perceptions of themselves including their abilities, their determination, and the ways they adapted to having an illness causing dementia. Photos also highlighted the changes they experienced as a result of dementia and depicted the importance of leisure in their lives as well as the struggles they experienced as a result of memory loss. The photographs depicted a variety of meanings – the multilayered nature of leisure for the participants.

Through photovoice, the participants were able to show us who they were rather than just tell us who they perceived themselves to be. We asked Jack what his photo of himself stretching said about him and he responded: "That I'm being, being uh, very active...yes it is [important for my identity]." Alice included a photo of herself having coffee with a friend. For her the photo represented that she was a "people person", who felt most like herself when spending time with others:

One who enjoys being with people. Um, caring and sharing, um as you can tell by that photo, I'm very happy so obviously, um, it's a very positive experience to be with people. I've always been a people person so I think this is when you'll see me smile the most. When I'm with others.

Photos also represented the participants' determination to fight dementia. They took photos of leisure activities that they felt helped them maintain their abilities for longer periods of time, including playing cards, playing darts, doing jigsaw and crossword puzzles, reading, and using the computer. These photos also represented the participants' resolve to continue to do activities they love even when they become more difficult. Alice and Jack both took photos of a jigsaw puzzle to represent engaging in mentally stimulating activities to maintain abilities. More importantly, the photo represented a refusal to give up even when activities became more challenging:

The sense of completion, the sense of um...the beauty of it coming together. And the challenge of getting the right piece. And it really is incredible. It takes a lot of patience, it's not for everyone to do. But it seems I've been given the patience of Job because I won't give up. So, it kind of nurtures, 'cause I can't get angry at it or I've destroyed what I've already done. So it's not that you can throw it or, if you get angry because you are only hurting yourself so it's just demonstrates where you can increase your patience about doing a project and not just give up right away. So sort of as a nurturing and learning and redefining what was normal for you before. Normal for me before.

The photograph not only emphasized determination, but also how the participant learned to accept herself and her changing abilities and live with what she called her “new normal”.

Photos also captured relationships with family and friends. Relationships with grandchildren were particularly important, and two participants included photos of themselves with their granddaughters. Eating out with friends and family was a common leisure activities, and all participants included photos of themselves sharing a meal with loved ones. Another photo portrays Alice playing a dice game with a friend. Alice used the photo to describe their relationship and what that relationship meant to her:

Well right there when you look at it you can see how [my friend] and I are close. Um, she’s very relaxed, that’s herself, she’s just a loving caring person, and um, just from the photo you know how much she cares about me.

Relationships become especially important for those living with dementia when social support becomes critical to living well with dementia. Charles asked his wife to take a photo of him playing a dice game that the two of them enjoyed together. The photo was meaningful for him, as it represented his relationship with his wife and how he appreciates the support he gets from her:

[My wife] and I often play the dice game while we’re eating. At least once a day. One meal a day. And again, it’s, we’re doing something together that we both enjoy. And she is extremely helpful when I can, when I have trouble counting and sort of forget the rules of the game, which happens frequently.

The photo represented how their caring relationship spilled over into leisure, enabling the participant to continue to engage in an activity that he and his wife enjoy doing together.

The photos also represented the changes that the participants experienced as a result of dementia. Looking at the photos and discussing them reminded the participants of how their abilities had changed and how they have adapted their activities to continue to participate. The photo of the dice game reminded Charles that he needed more prompts and cues to follow the rules of games than he did before:

When I throw the dice then I say “...is this my first or my second or my third throw?” and so she has to help me, and the same way with counting. I have a lot of trouble counting. And um I never did before.

By using photos, the participants were able to prepare for, recall, and share their stories about their experience of dementia and what leisure meant for them in that context, the challenges, changes and suffering as well as the joy, love, acceptance, perseverance, and continued abilities they experienced.

Discussion and Conclusion

As our understandings of leisure within the context of memory loss are just beginning to develop, finding ways to move beyond explorations of the benefits and impacts of therapeutic recreation to a broader understanding of meanings and experiences of leisure is vital. Photovoice provided us with one way to include participants with memory loss in leisure research from a personhood perspective. Visual leisure research has provided insight into multiple dimensions of leisure, including how people cope with stress (Klitzing, 2005), challenges and opportunities for physical activity (Fleury et al., 2009), family leisure

(Hallman & Benbow, 2007), and community leisure spaces (Johnson & Glover, 2011). In using photovoice, we discovered the multidimensional, paradoxical nature of leisure within the context of dementia.

Our findings demonstrate that photovoice is a useful method for understanding meanings of leisure among persons living with memory loss. In particular, photovoice enabled us to adopt Buber's (1937) I-thou perspective, in keeping with personhood (Kitwood, 1997a). We encouraged participants to use and portray their abilities and strengths instead of focusing on deficits and losses and to focus on what was most meaningful to them. They demonstrated their capacities in choosing which activities to portray and setting up the shots. Participants decided what to depict and share about their lives, which helped us to develop strong relationships where we acknowledged both the challenges participants faced in leisure as a result of having memory loss, and the fulfillment and joy they experienced through leisure while living with memory loss. Furthermore, photos revealed how leisure contributed to personhood and identity among our participants as they used photos to discuss feelings and emotions related to participation in leisure activities and demonstrated the role of leisure in living within the context of relationships by depicting engagement in leisure with family and friends. In particular, participants were able to highlight through their photos the many ways that leisure helped them maintain and affirm valued and positive aspects of themselves to themselves and others around them (Genoe & Dupuis, 2011).

Viewing their photos brought forth mixed emotions in the participants, prompting the telling of stories that acknowledged how their leisure was changing as a result of dementia, but also portraying how the participants worked hard to maintain their abilities for as long as possible. The photos and their accompanying narratives highlighted both positive and negative aspects of life with memory loss. Indeed, words-only interviews might not have captured the contradictory experience of leisure as photos sparked discussion on both the meaning of the leisure activities portrayed in the photos, the challenges in maintaining involvement in those activities, and the positive feelings that resulted from conquering a new challenge or working hard to maintain involvement in leisure.

Researchers have critiqued traditional research approaches and called for alternative methodologies that provide creative ways of reflecting diverse experiences and translating new understandings into practice (Dupuis et al., 2011; Kontos & Naglie, 2007; Richardson & St. Pierre, 2005). Artistic representations of lived experiences, such as through photography, "shed light on oppression, challenge dominant stereotypes and myths, spark critical thinking and reflection, and provide insight into the perspectives of those who are suffering or have been silenced" (Dupuis et al., 2011, p. 106). The photos created by persons with dementia in this study challenged a deficit approach to understanding dementia and can be used to facilitate personal and social change.

The challenges of using photovoice with persons with memory loss were relatively minimal and not uncommon among other photovoice studies. Issues of informed consent could be resolved by asking participants to avoid taking photos of other people, or the use of an image editing software program in which faces or other identifying features can be removed or blurred. Alternatively, participants could be provided with a short check-list they could refer to when taking photos that would remind them to obtain written consent for use of the images in the photos.

Difficulty using equipment might be overcome with better equipment and careful instructions for using cameras. Participants in this study found it helpful to have a companion, in many cases a family member, help them set up and take the photographs. The participants wanted to be included in their photos and had others (family members or friends) take photos for them (cf., Klitzing, 2004). Involving family was helpful for the participants who had difficulty with operating the camera or remembering to get informed consent. Frith and

Harcourt (2007) noted that using photography in research can become a collective task to capture significant events and experiences. The reality for many people with dementia is that support is often needed and interdependent relationships are valued as a means of maintaining autonomy and continuing to be engaged in their communities (Dupuis, 2010; Nolan et al., 2002, 2004). Finding ways to enable and support persons with dementia in creating their photo representations of their experiences is needed, particularly for those in later stages of dementia. Frith and Harcourt (2007) also noted that involving other family members in the photographing process can cause tension and participants could lose control over their photos. This did not appear to be problematic in this study, but it could be considered in future research. Providing family care partners with instructions that ensure they understand the importance of allowing the person with dementia to make the decisions on what to photograph may be one option, but it will be important to identify other ways to support persons with dementia.

Forgetting the context of photos may be overcome by reducing the amount of time between taking the photos and discussing them. The use of digital cameras would allow persons with dementia to view their photos as they take them and, for those able, allow them to make a few notes about the photos they want to discuss in interviews or focus groups. This would also give participants a chance to look at the photo and see if it captures what they had intended, and delete or retake the photo if necessary. Memory may also be enabled by using small video cameras, where participants could record their thoughts and feelings about their images while capturing them. Forgetting or missing some photos is common across research involving photos (Burles, 2010; Frith & Harcourt, 2007) and also emerged as an issue in this study. It became clear to us how important it is to not only explore with participants the photos they have captured, but also what is missing and what other images they would have taken if they had the opportunity. Asking these questions provided an alternative way to facilitate discussion around other aspects of the participants' lives that were meaningful to them but were not reflected in the photos.

Concern by participants over the quality of photos taken is also not unique to this study. Frith and Harcourt (2007) noted that their participants, women undergoing chemotherapy, were also concerned about taking "good" photos. Our participants expressed worries that they were not capturing the "right" photos. It is important that researchers address these concerns by emphasizing the creative nature of the methodology and that there is no right or wrong way of doing photovoice. Persons with dementia may need encouragement throughout the process to lessen these concerns and assure them that whatever they choose to do will provide insight into their experiences. This may mean checking in with participants over the period they are taking their photographs to answer questions and reassure them. The important thing to reiterate is for them to capture experiences and aspects of their lives important to them in a way that makes sense to them.

Novel ways of collecting data with persons living with memory loss are needed to better understand their experiences. In his discussion of the challenges of interviews, Nunakoosing (2005) asked,

How do we involve people with no voices, people with weak voices, and people with incomprehensible voices in the interview? How are the stories of the very young, the people with cognitive impairments, the people with contaminable illnesses, and the strangers going to be told? (p. 705)

Photovoice might be one way to include persons living with dementia in leisure research in addition to the traditional interview and participant observation methods, particularly as participants used photos to highlight their strengths and capacities. Wiersma (2011) notes that

photovoice is one way to conduct research with persons living with memory loss, rather than for them. Furthermore, Wiersma suggests that using photovoice can provide “opportunities for preservation of self” (p. 215), both personally and at a societal level as stigma and negative discourse surrounding memory loss are challenged through realistic portrayals of memory loss. We aimed to challenge that discourse and put a personal face on memory loss through the creation of a slideshow, depicting both positive and negative aspects of living with dementia through their photos and their words. The slide show was shared with participants and their service providers, as well as broader academic and practitioner audiences¹.

We found photovoice to be a particularly rich way to converse with participants about their experiences and meanings of leisure. Finding ways to adapt photovoice to use throughout the dementia journey could continue to inform our perspectives regarding life with memory loss, and provide a way for persons living with dementia to identify their leisure needs as communication becomes more challenging.

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¹ The slideshow is available for viewing at <http://www.marep.uwaterloo.ca/other/>

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