Walking Interviews and Wandering Behavior: Ethical Insights and Methodological Outcomes While Exploring the Perspectives of Older Adults Living With Dementia

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Abstract
While the use of walking interviews is not new in health care research, this method has not been used to study the wandering behavior of older adults living with dementia in long-term care (LTC) homes. The aim of this article is to describe ethical insights and consequential methodological outcomes when walking interviews were used as a means of exploring the perspectives of older adults living with mild to moderate dementia. We suggest that our use of walking interviews with older adults who presented with wandering behavior respected participants’ agency and, at times, placed the first author in the situation of “ethical vulnerability” in the roles of researcher and clinician. The first author, an experienced nurse clinician, walked with eight participants while interviewing them about why they walk and their intended destinations. Walking interviews provided the opportunity not only to interview participants but also to observe their walking behavior and interaction with others in the LTC home. Walking interviews with older adults living with dementia who are highly mobile in the LTC home acknowledge the primacy of the research participant and the researcher as learner.

Keywords
walking interview, dementia, long-term care homes, wandering behavior, researcher-clinician role, ethical insights

As a form of participant observation, walking interviews provide opportunities to explore participants’ perspectives and knowledge of where they live and create “a more spontaneous set of interactions” (Holton & Riley, 2014, p. 60). Generally speaking, participant observation not only allows researchers to “deliberately immerse” themselves in the world of the people being studied, but also to be part of their everyday “rhythms and routines” through observation (Anderson, 2004, p. 255). Walking interviews are a means of interacting with participants and determining the significance of location to individuals (Evans & Jones, 2011). This type of interview is commonly used by geographers, social scientists, and health researchers to examine the relationship between individuals and place (Anderson, 2004; Evans & Jones, 2011).

Evans and Jones (2011) suggest that walking interviews generate rich data and knowledge about participants’ connections to their environments, and they identify go-alongs, participatory, and bimbling as three types. The word “bimbling” originated in the British Army, meaning “aimlessly walking” or going for a walk as a means to have time away or disengage oneself from a stressful life situation (as cited in Anderson, 2004, p. 257). In bimbling, neither the researcher nor the participant knows the route, whereas for go-alongs and participatory walking interviews, the participant determines the route (Evans & Jones, 2011). The participatory walking interview is done with participants for the primary purpose of obtaining geographical information from their perspectives (Evans & Jones, 2011).

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Go-alongs, the most commonly used type of walking interview, include walking along (walk-alongs) and riding along (ride-alongs) with the participants (Kusenbach, 2003, p. 464). The go-along is a blend of interview and participant observation, where researchers follow participants in their movements (Butler & Derrett, 2014; Evans & Jones, 2011; Kusenbach, 2003). Researchers ask questions, listen and observe as participants walk and interact with their physical and social environment.

Walking interviews have been used with older adults living with dementia in the community to get a sense of the relationship between diminished cognition and the natural environment. A literature review by Keady et al. (2012) described research linking the experience of dementia with living in a neighborhood, noting “some interesting and innovative research methods that extend neighbourhood working, such as the ‘walking interview’” (p. 150). Eighteen key studies including four that used walking interviews or variants were identified. In terms of the links between living with dementia and the lived experience of neighborhoods, Keady et al. conclude that “…walking with participants can illuminate the practical and subjective experience of moving around a familiar zone or experience and the biographical connects it holds” (p. 160). They suggested viewing a long-term care (LTC) home as part of a neighborhood but not as a neighborhood of its own.

In summary, what is known about walking interviews and older adults living with dementia and their interactions with their environment is sited in community-based studies. What is not known is how walking interviews might be used in LTC homes to explore the perspectives of residents living with dementia who “wander” (or walk) in their environment. Our study reported here is of the “go-along” type and the first author accompanied LTC home residents living with dementia as they moved and interacted within their environment.

Wandering behavior is complex, with no commonly accepted definition. The definitions of wandering from the gerontological research literature range from aimless movement to goal-oriented movement (Cipriani et al., 2014). For the purpose of our study, wandering was described as walking because this term was commonly used and understood by residents and their families in LTC homes where our study was sited. It is our observation that “wandering” tends to be a pejorative term while walking (or even excessive walking) is not. Because the gerontological research literature mostly reports on wandering rather than walking, in this article, we will be using both these terms, as appropriate. Our study is the first known one to use walking interviews to explore older adults’ perspectives of their walking behavior within a LTC home.

Ingold and Lee (2008) suggested three productive outcomes of walking with interviewees: (1) walking as action establishes connectivity with the environment, (2) the routes selected allow for a mobile and dynamic understanding of places, and (3) walking with others creates a distinctive sociability. For our study, the third outcome was most relevant, and the sociability created a positive atmosphere for interviewing, interacting, and observing older adults who were living with mild to moderate dementia and who had been identified as “wanderers.” While we know from other research with older adults living with dementia that it is possible to ask about their perspectives and receive their answers, little research has been done directly with older adults who wander (Dewing, 2006; Tanner, 2012; Whitlatch et al., 2005). This might be because older adults living with dementia who are highly mobile may not respond to questions in the traditional sit-down interviewing approach.

Our contribution to scientific research was our use of walking interviews in LTC homes because to our knowledge, no other study has used walking interviews to explore wandering behavior of LTC residents living with dementia. The aim of our study was to gain a better understanding about wandering behavior by eliciting the perspectives of older adults living with mild to moderate dementia in LTC homes. The results of the study are available online (access https://doi.org/10.3928/19404921-20190522-01). Our research question was: How do older adults living with mild to moderate dementia in LTC homes perceive their own wandering behavior? So, the fit of the walking interview method with the research question was clear and observations recorded in a self-reflective journal augmented the walking interview data. The focus of this article is on the ethical insights and consequential methodological outcomes of using walking interviews to study wandering behavior and to provide recommendations related to the use of walking interviews in LTC home research.

**About the Study**

Our study was conducted in 2017 at two LTC homes in Winnipeg, Manitoba. Eight participants were recruited through initial contact with their family members. Older adults living with mild to moderate dementia with wandering behavior, age 65 or older with ability to answer simple questions, living in a LTC home for more than 2 months, and having a family member who visits more than once a month were the inclusion criteria. Participants who were able to sign their consent form did so. Also, family members signed proxy consents and provided information related to their relatives’ life history and previous walking activities. Families often reported that their relatives had been regular walkers either as a form of recreation or as a part of their daily life. During the walking interviews, ongoing verbal consent was obtained from participants. Ethical approval for the study was obtained from the University of Manitoba Education Nursing Research Ethics Board and the Winnipeg Regional Health Authority. All of the participants were assigned pseudonyms.

Of the eight participants, four (50%) were males and four (50%) were females and their ages ranged from 80 to 95 years old with the majority (n = 5, 62.5%) between 81 and 90 years of age (mean age of 86.63). Most participants were married (n = 5, 62.5%), and the remainder were divorced, single, and widowed. The dates of admission of the participants ranged from 2015 to 2017; five were admitted between May and August 2017, while the remaining three were admitted in
Funding body provides ethical principles and guidelines

The Canadian Institutes of Health Research, Canada’s national funding body provides ethical principles and guidelines through the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans. The principle of justice suggests that “...particular individuals, groups or communities [should not] be unfairly excluded from the potential benefits of research participation” (Government of Canada, 2015, p. 49). While some older adults living with cognitive impairment may lack the capacity to decide whether or not to participate in particular research initiatives... Yet the advancement of knowledge about their social, psychological and health experiences and needs may depend on their appropriate participation in research. (Government of Canada, 2015, p. 53)

Research on older adults living with dementia in LTC homes often relies on an authorized third party or family members to provide written consent as proxies (Government of Canada, 2015, p. 54). As indicated earlier, family members provided written consent but during the walking interviews, ongoing verbal consent was obtained from the participants. The first author asked participants if it was okay to walk with them and ask questions. For example, the first author asked Sarah, “Where are you going...can I come with you?” and Sarah replied, “Oh yes.” In addition, the first author was vigilant for signs of discomfort from participants. Participants’ requests to be alone or walk alone were honored during prewalking observations and walking interviews. As recorded in the self-reflective journal:

[Sam] seemed slightly agitated and confused, ... [was] in a hurry to get [to] somewhere, [he] wanted to leave [and] not receptive to questions from the researcher (me). I left [and] spoke to the nurse on the unit about my observations. I later approached [Sam] with the nurse and [Sam] seemed to settle [down]... I had conversations with him about his family as [he] kept repeating “I’m going to meet my wife.” We walked for a while around the facility.

Most of the participants seemed to enjoy the first author’s company as evidenced by their verbal and nonverbal behaviors. This is an excerpt from the self-reflective journal:

Lisa is a very pleasant, happy woman. She loved and really enjoyed walking, especially going outside and walking as a form of socialization. She also loved the company of animals. We stopped by to see a dog and the bird during her walk. She talked a lot about herself, family and the staff during the interview—said good things about her family and staff and how she loved [the LTC home].

One of the participants had aphasia, an impairment of the ability to communicate through speech. Although this participant was able to use some words, the first author also experienced some difficulty in verbally communicating with her but was able to build on nonverbal cues to gather information on her perspectives through observation. Participant observation provides the opportunity to include the perspectives of those who have physiological limitations in verbal communication to add to the body of knowledge on wandering behavior.
As indicated earlier, the gerontological research literature on wandering behavior has relied on families or staff members to provide insight on the reasons for wandering. Our study was inclusionary and gave primacy to what older adults living with dementia had to say about why they were walking and their intended destinations. This approach fits with the TCPS principles of inclusion and appropriate participation. Older adults living with dementia had an opportunity to speak for themselves (rather than through family and staff members as has been predominant in this area of study) about their perspectives on walking.

Ethical and methodological decisions intermingle during the course of research, that is, to say that every ethical decision has methodological outcomes that may alter the data collected. For example, the first author’s vigilance for participants’ discomfort meant her decisions not to begin the interview or to stop the interview either affected the data or resulted in lost data. While this vigilance is protocol for studies in general, it becomes more complicated when participants are living with dementia and experiencing cognitive changes in comprehension and expression. The first author is a skilled clinician having extended experience in the nursing care of older adults living with dementia in LTC homes. Her vigilance was acute (as will be described later) and her decisions were likely preemptive in comparison to nonclinically based researchers’ time frame. This is neither a negative finding nor a weakness of our study, but it must be acknowledged. Hibbert et al. (2014) have identified “ethical vulnerability” when the researcher engages in a research relationship where the participant comes first. This is the role of researcher not as “... expert, or a research partner, [but where] the researcher is understood as a learner” (Rhodes & Carlsen, 2018, p. 1298).

**Methodological Outcomes: Walking Interviews and Wandering Behavior**

As part of the data collection process, the first author deliberately instituted prewalking observations. The prewalking observations oriented her to the layout of the units, common areas for activities for participants, the location of exit doors, and the outside space of the LTC home. Time spent observing participants meant the first author also got better acquainted with participants and could discretely ease into their walking patterns for data collection. Later, when data were collected during the walking interviews, the first author used a digital audio recorder with a lapel-secured microphone. The “hands-free” lapel microphone minimized ambient noises and allowed the first author to focus her attention on the conversations with the participants without distractions from the audio recording process.

**Role Conflict**

Prior to conducting our research on wandering behavior, the researchers discussed potential conflict between the researcher and clinician roles, sometimes included in discussions about the “research-practice divide” (Rhodes & Carlsen, 2018). As anticipated, the first author experienced conflict between her researcher and clinician roles especially when participants became fatigued or placed themselves in unsafe or potential elopement situations. The first author’s primary role was as a researcher collecting data for a thesis and not as a clinician, a caregiver. Being a clinician was an asset because of her familiarity with the LTC home culture and her comfort with routines but at times, the first author had to dispense with researcher role and become an unofficial clinician. For example, during the walking interviews, the first author redirected some participants from entering other residents’ rooms to reduce the risks of resident-to-resident altercations. As recorded in the self-reflective journal, Sam was observed to be entering other residents’ rooms on several occasions, especially the first room on the unit and on one occasion, he went to the window and stated that he was trying to close the window, spotted holding the window handles.

Safety risks are very real in LTC homes and altercations and violence occur as a result of residents “trespassing” by entering into other residents’ rooms (boundary transgression) and intruding into their personal space (MacAndrew et al., 2017; Shinoda-Tagawa et al., 2004; Snellgrove et al., 2013). Family members in our study reported concerns about their relatives entering other residents’ rooms where they might be physically assaulted and injured. Some families reported that because of these occurrences, their relatives had been moved to a specialized dementia care unit. Altercations occur not only with other residents but have also been reported as directed toward staff (Brophy et al., 2019), although the first author never felt unsafe while redirecting participants. Her clinical expertise equipped her to gently and safely redirect participants but this might not have occurred for a researcher without this clinical background. From a methodological point, the first author’s redirections altered the participants’ walking behavior. Data were not collected on how walking behavior might have been specifically altered and this cannot be done retrospectively. We speculate that perhaps through redirection, an altercation was avoided and so this event was absent from our data. We remain steadfast in the decision to redirect, but we also acknowledge that this likely had consequences to the data that were collected or lost.

**Safety**

Safety was a concern in terms of participants’ boundary transgressions. Another safety concern was that some participants needed supervision when walking in the units’ exit areas and in less supervised areas such as the fenced-in courtyards. The first author intervened when participants verbalized and attempted to elope (escape) from the LTC home. These situations were distressing to the first author, and elopement and subsequent mishaps are distressing to residents and families (Aud, 2004).

In our study, family members expressed concerns about dire consequences of their relatives’ elopement including their getting lost and becoming dehydrated and confused. Elopement is
a major risk of wandering behavior with serious consequences to residents' morbidity and mortality (Ali et al., 2016; Aud, 2004).

One participant, Sam, told the first author while walking outdoors of the LTC home:

I know how to get through the fence... now I got to squeeze through that fence, I know how to do that too, I did it last week.

On other occasions, the first author observed that some participants had difficulty safely finding their way and so provided guidance to prevent falls and other injuries.

Here is an excerpt from the self-reflective journal:

I observed that Sarah had some difficulty with wayfinding. She wandered in a linear direction until she hit the wall or met with an obstruction, and then tried to turn around again. Sarah required occasional supervision during the walking interview to be safe in her walk and not bang or bump into objects or persons. The daughter also mentioned her concern with Sarah bumping into something when walking (described as banging into the wall before she turns and then when she hits the wall she turns and goes down until she hits the next wall).

For Sarah, the first author redirected her away from walls and other obstacles.

Fatigue

Another intervention implemented by the first author was related to fatigue, specifically by providing cues to participants to observe rest periods during the walking interviews. For example, one of the participants became short of breath while walking and was reminded to rest:

Researcher: It looks like you're getting tired, do you want to... go inside and take a rest?
John: Oh I don't know.
Researcher: Yeah, I think you should.
John: Yeah. A little out of breath.
Researcher: Yeah, I think maybe you should sit down and catch your breath.
John: Yeah. Usually it never bothers me the breath, but it does a little now getting older has taken its toll.

During the walking interview, another participant reported that his knees were sore. He stated that his pain medication “doesn’t help very much” so the first author encouraged him to rest his knees and speak to the nurse about his pain. This was recorded in the self-reflective journal:

[Dave] mentioned to me prior to the interview that he used to walk but not so much as his knees were sore. He takes some pain meds, which he stated doesn’t help very much. Pain might play a big role in the changes in his walking activity [lack of motivation to walk]. He needed education about getting some rest periods while walking and requesting pain meds as needed.

Participants’ fatigue was highly relevant for our study of wandering behavior and some participants walked extensively placing demands on their energy level and physical health. Although participants’ fatigue is relevant in most studies where interviews might be long or the participants frail or vulnerable, the occurrence of fatigue takes preeminence when the primary inclusion criterion is wandering behavior.

Discussion

This article discussed ethical insights and consequential methodological outcomes when walking interviews were used to explore the perspectives of older adults living with dementia in LTC homes. Walking interviews elicited participants’ perspectives as well the observation of their walking patterns and interaction with others and their environment. Importantly, walking interviews by their nature acknowledge that older adults living with dementia have a voice and can provide meaning to an activity that is often described in the gerontological research literature as aimless and without purpose. The use of walking interviews with older adults living with dementia respects those who are stigmatized and has the potential to explore “agency” (the capacity to act).

In our study, we identified ethical issues such as role conflict prior to conducting the research and retrospectively, we see this conflict in the context of participants’ safety (potential altercations and elopements) and fatigue. While we have acknowledged that ethical decisions meant methodological consequences, data loss, or alteration, we maintain that ethical actions are paramount in research and perhaps most complex when conducting research and learning from participants living with dementia in LTC homes. The first author’s actions as described amount to respecting the dignity, safety, and ongoing consent of these participants.

Recommendations

We recommend that researchers conducting studies in LTC homes incorporate walking interviews or ride along interviews (for participants in wheelchairs) along with the traditional sit-down interviews as a form of participant observation. Walking interviews are particularly suited for studying wandering/walking behavior, but they could also address research questions related to how LTC home residents living with dementia (or those not living with dementia) engage with their environment, their LTC home community. Walking interviews are a key to gaining residents’ perspectives. We also recommend that researchers using walking interviews might take from our experiences to be diligent about ongoing consent and vigilant to potential role conflicts that involve the safety and well-being of participants. Finally, we recommend a broad and in-depth discussion of ethical decisions and consequential methodological outcomes in the context of research with cognitively frail and vulnerable older adults. So often our reporting leaves unsaid the most important decisions that we make as researchers.
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