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Colleen E. McGrath

The University of Western Ontario, cmcgrat2@uwo.ca

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Colleen McGrath¹  and Debbie Laliberte Rudman¹

Abstract

Research with older adults aging with vision loss has typically been informed by a biomedical theoretical framework. With a growing focus, however, on critical disability perspectives, which locates disability within the environment, new methods of data collection, such as participant observation, are needed. This article, which reports on the findings from a critical ethnographic study conducted with older adults with age-related vision loss (ARVL), aims to share those insights gained through participant observation and to demonstrate the utility of this method. Three insights were gained including the adaptive strategies tacitly employed to navigate the physical environment, a grounded understanding of social interactions that transpire in everyday contexts, and negating the presence of older adults with ARVL when accompanied by a perceived caregiver. The study findings unpack how participant observation can be used to understand social constructions of disability and gain a holistic understanding of environmental influences on the disability experience of older adults with ARVL.

Keywords

older adults, age-related vision loss, participant observation, critical disability perspective

Introduction

Older adults constitute the fastest growing low vision group within industrialized countries (Varma et al., 2016). Low vision is defined as a permanent “loss of visual acuity . . . not correctable by spectacles, contact lenses, or intraocular lenses” (Spafford, Laliberte Rudman, Leipter, Klinger, & Huot, 2010, p. 580). Age-related vision loss (ARVL) is the umbrella term commonly used to describe a grouping of diagnostic conditions including macular degeneration, diabetic retinopathy, and glaucoma (Watson, 2001). Similar to other areas of study addressing disability in later life, ARVL research has been largely informed through a theoretical lens consistent with biomedicine. For example, an abundance of research has focused on the association between ARVL and activity limitations in the areas of self-care (Berger & Porell, 2008; Grue et al., 2008; Knudtson, Klein, Klein, Cruickshanks, & Lee, 2011), leisure (Boerner & Wang, 2010; Desrosiers et al., 2009), and productivity (Alma et al., 2011; Lamoureux et al., 2007). Consistent with a biomedical lens, this research has tended to focus at the level of the individual, wherein the disability is assumed to exist within the individual’s impaired visual system and the notion that

there is something “wrong” with the individual’s body (Albrecht, 1992; McGrath & Laliberte Rudman, 2013; Smart, 2006–2007). Although the biomedical model of disability has long dominated conceptions of disability in medical and rehabilitation science (Imrie, 1997), its overmedicalized and individualist framing of disability as an individual phenomenon (Shakespeare, 2010) fails to acknowledge the influence of physical, social, cultural, political, and institutional environmental factors that ultimately shape the disability experience (Ells, 2001). This trend of individualizing disability is also seen in the field of geriatric medicine, wherein older age is equated with senescence (Katz, 1996), decline, and deterioration (Gilleard & Higgs, 2011), as well as chronic illness (Cole, 1992), thereby leading to, what has been termed, the

¹ School of Occupational Therapy, Western University, London, Ontario, Canada

Corresponding Author:

Colleen McGrath, Western University, 1201 Western Road, London, Ontario, Canada N6G 1H1.

Email: cmcgrat2@uwo.ca



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biomedicalization of aging (Estes, Wallace, Linkins, & Binney, 2001). In response to this, critical disability perspectives are emerging given their focus on obtaining more complex understandings of disability in later life that shift beyond individualistic frameworks.

The term critical disability perspective is used to refer to an ever-growing number of theoretical frameworks that employ critical social theory to reconceptualize disability as environmentally shaped by physical, social, cultural, political, and institutional forces (Hosking, 2008). Contemporary critical disability perspectives have certain shared assumptions. One significant assumption of these perspectives is the view that disability is a social construct rather than a direct or immediate result of impairment, thereby supporting the idea that “disabilities are physically based but socially constructed” (Grue et al., 2008, p. 35). This means that although individuals may experience certain functional limitations as a result of their impairment, the greatest challenge stems from those environmental constraints faced, whether social, physical, attitudinal, political, or institutional. This assumption moves away from a biomedical conceptualization of disability, which locates disability within individuals and their bodies, and instead takes up a conceptualization that emphasizes how constructions of disability are environmentally produced and sustained.

Given this shift associated with critical disability perspectives, new methods of data collection are needed that capture the transactional nature of environmental influences which, in turn, shape the production of disability for older adults with ARVL. Participant observation, a hallmark of ethnographic research, provides one possible method that can be used to understand the “everydayness” of life in ways that situate ongoing activity in relation to environmental features (McLees, 2013). At the same time, participant observation makes explicit the transaction between individuals and their physical, social, cultural, political, and institutional environment.

There is ample evidence of the use of participant observation in older adult research, particularly in ethnographic studies. For example, participant observation has been used to investigate end of life care (Emilsdottir & Gustafsdottir, 2011), engagement in meaningful occupation within a nursing home (Mondaca, Josephsson, Borell, Katz, & Rosenberg, 2019), notions of independence (Portacolone, 2011), experiences of place (Cruz, 2006), Tai Chi (Docker, 2006), volition in everyday occupation (Raber, Teitelman, Watts, & Kielhofner, 2010), and advance care planning (Jeong, Higgins, & McMillan, 2011), to name a few. However, as it relates to research focused on ARVL, most qualitative research has adopted an interviewing approach or focus groups, with participation observation being scarcely utilized, with a few notable and recent exceptions. For example, Barstow, Warren, Thaker, Hallman, and Batts (2015) explored how low vision and comorbid chronic conditions influenced occupational therapy intervention by surveying 59 occupational therapists, as well as eight older adults with vision loss who participated in one face-to-face semistructured interview and a field observation session. During the observation session, participants were

observed engaging in one routine activity of daily living in a typical location such as their home. Further, Berger (2012) completed two semistructured interviews and engaged in one participant observation session with 26 older adults (aged 70 years and older) with vision loss to see the relationship between low vision and leisure engagement. Completed after the first interview, participants engaged in a leisure activity of their choice including in-home activities such as baking, knitting, and hosting a stamping party as well as out-of-home activities such as going to a museum, sitting by the water, bowling, and attending an exercise class. The observation visits provided rich insight into the strategies, challenges, and experiences of the participants related to their performance in leisure occupations.

Despite the long-standing use of participant observation within qualitative research, it has rarely been used to critically unpack social constructions of disability or to gain critical understandings of the ways in which environments shape experiences of disability and the active ways in which older adults with ARVL negotiate environmental influences to continue to engage meaningfully in their desired occupations. For the purposes of this article, occupation refers to those things that a person needs to do, wants to do, or is expected to do and may include self-care (dressing, bathing, eating), leisure (reading, playing sports), or productivity (working, going to school, volunteering). As such, this article illustrates the contributions of participant observation to a broader critical ethnographic study. Critical ethnography is focused on eliciting the research participants’ point of view and understanding their world, while at the same time challenging taken-for-granted assumptions and questioning the prevailing status quo and dominant power structures within a particular culture which serve to constrict marginalized people’s lives (Cook, 2005; Simon & Dippo, 1986; Thomas, 1993). This broader critical ethnographic study drew upon critical disability perspectives to uncover how the environment (including physical, social, cultural, political, and institutional factors) influenced the occupational engagement of older adults with ARVL. The study further challenged those environmental barriers faced by older adults with ARVL in an effort to ultimately develop recommendations to support more vision-friendly spaces (for full study findings, see McGrath, Laliberte Rudman, Polgar, Spafford, & Trentham, 2016; McGrath, Laliberte Rudman, Spafford, Trentham, & Polgar, 2017). In this article, however, the focus is on highlighting those specific insights gained through participant observation to demonstrate the utility of this method, particularly in relation to unpacking the tacit, seemingly mundane aspects of daily life that often remain unspoken as well as highlighting the ways in which environmental features shape the production of disability for the growing number of older adults aging with vision loss. This article will outline the origins of participant observation, describe how participant observation was used in a critical ethnographic study with older adults aging with vision loss, share the insights gained by using participant observation, outline the strengths and limitations of this method, and describe the ways forward

for those researchers who intend to take up participant observation in their own work.

Understanding the Origins and Evolution of Participant Observation

Participant observation involves the researcher immersed in the day-to-day tacit aspects of people's activities, rituals, and interactions (Dewalt & Dewalt, 2010) as a way to uncover or reconstruct their practices, performances, behaviors, and actions within a naturalistic setting (Kawulich, 2005; Mulhall, 2003). Participant observation is described as the "heart of ethnographic fieldwork" by allowing researchers the opportunity to experience with participants during those natural situations that comprise daily life (Bailliard, Aldrich, & Dickie, 2013; Dewalt & Dewalt, 2010). There are three guiding assumptions of participant observation including that (1) we can learn from observation, (2) being actively engaged in the lives of people brings the ethnographer closer to understanding the participants' point of view, and (3) achieving understanding of people and their behaviors is possible (Dewalt & Dewalt, 2010).

With its origins in anthropology, participant observation emerged during the late 19th century as an ethnographic field method for the study of small homogenous cultures (Dahlke, Hall, & Phinney, 2015). Early ethnographies were often underpinned by positivist epistemology, in which researchers sought to immerse themselves in the life of "the other" as a means to accurately record and represent a culture. Contemporary ethnographic studies, however, have expanded to include constructivist, interpretivist, and critical paradigmatic positions (Huot & Laliberte Rudman, 2015). From a constructivist, interpretivist, or critical paradigmatic lens, participant observation is not about accurately representing a particular culture, but rather attention is shifted toward observing the individual within their natural context to understand the ways in which elements of the social, economic, cultural, and political environment are constructed and, in particular, understand how such constructions ultimately both enable and constrain particular people or cultural groups (Cooney, 2006; Kushner & Morrow, 2003).

In turn, alternative ways of thinking about and doing participant observation have now emerged, which recognize aspects such as the unavoidable influence of the researcher, the co-constructed nature of what was observed, and the importance of researcher reflexivity. In particular, in the study to be presented in this article, an "observation of participation" approach was employed (Tedlock, 1991). In this approach, the researcher is not a detached and objective observer but rather is reflexive of their own participation and coexistence within the same context as the people they are observing (Bryman, 2001). It allows the researcher to be an active participant in the exchange, such that the researcher participates in almost everything that other people are doing as a means of learning cultural rules, behaviors, and norms, as well as experiencing contextual influences (Dewalt & Dewalt, 2010; Polit & Beck, 2010). It provides the researcher with a unique way of "knowing" because the researcher becomes a participant in what is observed.

There are many proposed benefits of using participant observation as a method of data collection which align well with the assumptions of critical disability perspectives. For example, participant observation provides a step beyond interviews as "frequently people do not tell an interviewer all the things he might want to know" (Becker & Geer, 1957, p. 30). This may happen for a variety of reasons. For example, so many facets of daily lives are so seemingly mundane, that many people would not think to tell an interviewer, either because they assume it is unimportant or may not even be consciously aware of it. Participant observation, however, allows researchers to observe these more tacit, and often overlooked, aspects that comprise a person's performance of occupation. Indeed, it "affords access to the 'backstage culture'" (Demunck & Sobo, 1998, p. 43) by allowing researchers to engage in those "unscheduled events" that provide rich understanding of people's behaviors, rituals, and norms (Timeseena, 2009). It is particularly important to tap into these tacit and seemingly mundane aspects of occupation because it provides a clearer picture of the nuanced ways in which people perform occupation. Another benefit of participant observation, of particular relevance to enhancing understanding of the environmental production of disability, is that it enables an examination of the transactions between people and their environments. For example, researchers are able to observe, firsthand, not only how an individual interacts with their physical environment but also how the social environment, such as family, friends, neighbors, strangers, and service personnel interact with the person. In this way, participant observation moves "beyond interpersonal elements of relational situations" to examine other factors such as "place, objects, environmental features, traditions, history, politics, culture, and economics" (Bailliard et al., 2013, p. 165).

Enacting Participant Observation in a Critical Ethnographic Study

The findings of this article are grounded in a broader critical ethnographic study, which was focused on understanding how the environment (including physical, social, cultural, political, and institutional) influenced the participation of older adults with ARVL in their desired occupations (McGrath et al., 2016; McGrath et al., 2017). Participant recruitment occurred over a period of 9 months in a medium-sized Canadian city and its surrounding communities using in-person presentations, organizational contacts, and newspaper advertisements. To be eligible, participants had to be at least 75 years old, have received a diagnosis of ARVL (including age-related macular degeneration, glaucoma, and/or diabetic retinopathy), self-identify as experiencing functional impairments due to ARVL, and be able to communicate effectively in English. A total of 10 participants engaged in the study, including 2 males and 8 females, ranging in age from 76 to 91 years old. Ethics approval was provided by Western University Health Science Research Ethics Board. All participants provided written consent to participate.

Participants engaged in three methods of data collection, including an audio-taped narrative style interview, focusing on the participants' story of living with ARVL; a participant observation session; and a semistructured in-depth interview, in which the focus was on expanding on ideas generated during the narrative interview and participant observation sessions as it related to the impact of various physical, social, cultural, political, and institutional environmental factors on daily activity engagement.

One observation session was completed with each participant as the second method of data collection. For this session, each participant was asked to think about a possible occupation he or she would like to participate in with the researcher. The participant observation session was focused on a self-chosen occupation instead of arbitrarily "hanging out" to ensure it was meaningful to the participants. They were called within 1 week of the narrative interview to discuss the occupation and set up a time and place to meet. If the participant was unable to choose an occupation, a few suggestions were made based on occupations that had been identified during the narrative interview; however, the final decision was made by the participant. The researcher participated in each occupation chosen by the older adult. Seven of the participants chose occupations that occurred in the community including going to the mall, going for a walk, taking the bus to a craft program, grocery shopping, going out to eat at a restaurant, going to the pharmacy, and going to the bank. Some of the participants engaged in a combination of these occupations during a single trip. The three remaining participants chose occupations that allowed them to remain in their homes including attending a Braille lesson, learning to use an audio book player, and cooking a meal together. Sessions, on average, were between 60 and 90 min long.

During the participant observation sessions, the first author was an active contributor and not merely a passive observer (Adler & Adler, 1987). To encourage ongoing critical reflexivity regarding the first author's positionality and the emerging findings, the second author, in her capacity as a doctoral supervisor, engaged in collective dialogue during the analysis of the data, to challenge the first author's assumptions and encourage new ways of "seeing" the data. Due to the active nature of the occupations chosen, many of which occurred in the local neighborhood, audio recordings were impractical. Instead, detailed field notes were taken, from memory, immediately following each observation. The field notes included direct observations, conversations with the participant, and key reflections made by the researcher. Field notes were framed within a comprehensive fieldwork guide building on the note-taking method of Emerson, Fretz, and Shaw (1995). This note-taking method requires the systematic and comprehensive description of everything that happens at a particular point in time. Specifically, the research team used the question format proposed by Spradley (1980) which included a critical exploration of the following modified questions:

1. *Space*: What physical space or places are utilized?
2. *Actors*: Who are the people involved in the interaction?

3. *Activity*: What is the occupation being performed? Describe the environmental context. How is the researcher involved in the performance of the occupation?
4. *Object*: Are there any physical objects present during the performance of the occupation?
5. *Act*: What actions are being performed during the occupation? By which parties? What are people saying (include direct quotes if relevant)?
6. *Time*: What is the sequencing of events as it pertains to the occupation?
7. *Goal*: What is the end goal that the individual is trying to accomplish?
8. *Feelings*: What emotions are felt/expressed by the individual? What emotions are felt by the researcher in relationship to the interaction?
9. *Services*: What resources and/or services are necessary to support the occupation?

A consistent approach to data analysis was adopted for all data including the narrative interview, the observation visit, and the semistructured in-depth interviews. To ensure maximum immersion within "the context of the interactions" (Carspecken, 1996, p. 149), each observation field note was read individually to develop a rich understanding of the data before drawing comparisons between data sets or across participants. Both low-level (open) and high-level (theoretical) codes were applied to each of the field notes generated from the participant observation sessions, before codes were collapsed into relevant categories and themes.

Insights Gained Through Participant Observation Methods

While the full findings of the study have been reported elsewhere (McGrath et al., 2016; McGrath et al., 2017), this article aims to share those insights gained through the participant observation sessions. By utilizing participant observation, the researchers were able to understand the more nuanced and tacit ways in which older adults with ARVL navigate their physical, social, cultural, political, and institutional environments in order to engage in meaningful occupation, as well as the ways in which environmental elements served to shape facilitators and boundaries to their engagement. By co-engaging in the occupations, the participant observation sessions also led to more in-depth verbal discussions of any issues observed during the final semistructured in-depth interview. Specifically, this article focuses on three insights gained through the use of participant observation including (1) the adaptive strategies tacitly employed to navigate the physical environment, (2) a grounded understanding of social interactions that transpire in everyday contexts, and (3) negating the presence of older adults with ARVL when accompanied by a perceived caregiver. Quotes from participants are identified using codes (P1, P2, etc.). To protect participant anonymity, the names of persons and places, including streets and landmarks, have been removed.

Purposeful use of “I” has been integrated throughout the results section partly to establish the active voice and presence of the ethnographer within the observation sessions but more so to make explicit the relational and situational character of participant observation.

The Adaptive Strategies Tacitly Employed to Navigate the Physical Environment

Although superficially discussed in both their narrative and semistructured interviews, many of the strategies employed by older adults with ARVL to navigate their physical environments were then observed during the participant observation sessions. The participant observation sessions extended beyond the interviews to reveal those tacit and seemingly mundane strategies participants employed to navigate their physical environments.

Going to familiar places and spaces was a strategy frequently employed by the participants, to feel an increased sense of comfort when traveling in the community. The participant observation sessions provided firsthand insight into why participants gravitated toward familiar places/spaces. For example, during his observation visit, P3 chose to bring me to a shopping mall much further away from his home, as it was the mall he frequented most often prior to his vision loss. As a result, he had developed a mental map of where stores were located. Utilizing this mental map strategy allowed P3 to visualize the space, including where landmarks were located, the location of entrances/exits, when to anticipate changes in flooring type, and the approximate number of steps before turning right or left. Similarly, for her observation visit, P6 and I went to a small grocery store chain, not only because it was less expensive but also because P6 knew where all of the items were located. Although this sense of familiarity was important to P6, she also discussed the frequency with which the store moved their products around, which was a great source of frustration.

As it related to navigating their physical environments, the participants also demonstrated the important role planning played in enabling their performance of occupation. Indeed, planning took significant cognitive effort and time to enable activities that might otherwise be taken-for-granted and spontaneous in the absence of ARVL. For example, P6 needed to use the bus during our observation visit, and she knew precisely when it would arrive and the combination of routes that we needed to take to get to our destination. When I asked P6 about this, she described learning the bus system before losing her vision and how important it is to be good at planning when you have vision loss, so that you do not end up in an unfamiliar place. For P3, a seemingly minor change in plans created a significant challenge. During his observation visit, P3 took accessible transit and found himself dropped off at a different entrance to the mall than he had previously planned for, leaving him feeling disoriented. This was particularly distressing for P3 who relies on visualizing a space that he remembers from before his vision loss as a strategy to assist with navigation.

In an effort to more seamlessly navigate their physical environments, participants were observed to use a variety of compensatory strategies including exercising caution, counting, and using landmarks for navigation. The strategy of using caution was particularly relevant when participants were required to cross busy intersections. For example, I consistently observed P2 looking left and right at least 3 times before crossing, which he later explained was because he is looking for headlights and listening for traffic surges to ensure no vehicles are approaching. P9 was observed to make eye contact with drivers preparing to make a right-hand turn at the crosswalk in front of her apartment building. Although P9 explained that she has always been cautious at crosswalks, her strategy of looking motorists in the eye started a few weeks prior to our observation visit because a woman from her building was struck and died at that same crosswalk. Counting was another strategy observed during the observation visits. For example, P3 counted the number of steps he takes from the side of his building to where the walkway turns toward the city sidewalk, while P8 counted the number of streets she crosses over from her apartment building to know when she has reached the street her bank is located on. This strategy required a great deal of concentration, thereby requiring me to minimize my interactions with the participants during their counting process. Using landmarks is another strategy that participants were observed to use to navigate both indoor and outdoor spaces. For example, P3 used the grass (on the left) and rocks (on the right) to ensure he stayed on the pathway leading from his building to the sidewalk, while P4 memorized the location of trees and a fire hydrant to be able to know when to turn a corner or when she will meet an obstacle. To maintain himself in a straight line when we passed a mall store entrance, P3, rather creatively, followed the grout lines in the tile floors. He would find a grout line that ran parallel to the entrance until he reached the wall again. All of these compensatory strategies required significant effort on the part of the older adult to concentrate and exhibit the upmost caution, and the level of detail observed was much greater than what was described during the initial interviews. These findings could be perceived as consistent with a biomedical lens, in that if disability is assumed to exist within the individual’s impaired visual system, then it is expected that the older adult develop individualized strategies for coping. However, it was the physical environmental barriers that ultimately shaped the disability experience and required the taking up of adaptive strategies to successfully navigate the physical environment, which is in line with critical disability perspectives.

A Grounded Understanding of Social Interactions That Transpire in Everyday Contexts

Observation sessions enabled me to observe the participants engage in those social interactions that tend to be more informal and are often spontaneous in nature, including, as defined by Gardner (2011), relationships of proximity (i.e., with

neighbors), relationships of service (i.e., with business or service personnel), and relationships of chance (strangers). Although these social interactions were touched on during the narrative and semistructured interview, the participant observation sessions opened up space for richer discussion and to observe these interactions firsthand.

Although participants frequently discussed their relationships with neighbors, only one interaction was observed with P1 and a neighbor that she termed a “busy body.” A woman from the building entered P1’s home, without knocking, during our participant observation session and began to unpack groceries she had purchased for P1. She described each item that she bought and how much money she spent, frequently interrupting P1 as she did so. P1 was observed to roll her eyes during the interaction. After the visitor left, P1 explained that she had not asked the neighbor to buy any groceries for her as she prefers to use the service at the grocery store, whereby she calls in her order and they purchase the items and deliver it to her house. She also described how upset she gets when this woman just enters her home without knocking. P1 would like to tell this woman that her help is neither needed nor appreciated, but she does not want to be rude as P1 feels that the woman is well intentioned, nor does she want to burn any bridges, as she may need this woman’s help down the line. For P1, this was not an isolated incident, as she said: “When you are ‘handicapped,’ this is what happens. People don’t listen to you but rather they do what they want.” This one interaction provided such rich insight into the complex negotiation P1 experiences trying to balance her desire for independence versus her need for assistance, which is a struggle many older adults with ARVL face (McGrath et al., 2016).

Interactions with service personnel, namely, bus drivers and store employees, were typically brief and included both positive and negative interactions. One challenge that participants experienced centered on the unpredictability in terms of level of support older adults with ARVL receive when they travel into the surrounding community. For example, during a bus trip with P2, I observed the bus driver lower the bus to enable P2 to load his walker and waited for P2 to take a seat before moving; however, this was not the case on the bus ride home. Similarly, the bus driver began driving before P6 was seated, causing her to stumble as she reached her seat. Participants also experienced situations in which store employees did not appropriately accommodate for their needs as a person with ARVL, thereby requiring them to navigate unpredictable social environments. For example, P10 always went to her local convenience store to purchase bread because the employees knew her and were aware of her low vision, as P10 had previously disclosed her vision impairment and associated functional difficulties. On this occasion, the cashier automatically took the cloth bag P10 brought, placing the bread inside. P10 paid with a \$5 bill; however, when the cashier provided the change, she did not say out loud what change P10 was receiving, causing confusion. On the other hand, many participants experienced supportive and reliable relationships within the social environment. In fact, those positive social relationships were frequently the

reason participants continued visiting certain stores, banks, and restaurants. For example, P9 reported always going to the same coffee shop because the employees know her by name, and during our observation visit, they not only knew her name but also brought her order directly to the table, a service they don’t typically provide. Lastly, during a trip to the restaurant that P7 frequents every week on the same day, the waitress not only knew P7 by name but also moved the chair to accommodate her wheelchair and confirmed that she wanted “the special” without P7 needing to look at the menu.

Lastly, as it relates to interactions with strangers, the participants were observed to ask for help, particularly with those tasks perceived as unsafe or risky. For example, although P2 preferred being independent, he would ask strangers for assistance regarding whether the walk symbol was displayed at crosswalks, whether it was safe to cross the street/intersection, and which bus was approaching. Interestingly, strangers were also seen to initiate interactions with the participants. For example, there were a few instances where I observed people apologizing to P7, who used a power wheelchair in the community, if they were in her way. For example, a young couple were standing on the sidewalk waiting to cross the street, when P7 crossed from the other direction and was attempting to navigate past them on the sidewalk. Although where they were standing was fine, the couple apologized to P7 upon seeing her wheelchair and white cane. Similarly, while walking in the mall, a number of strangers were observed to all but jump out of P3’s way to ensure he had a clear path. In fact, at one point, P3 nearly knocked into a woman who was looking at a display at the front of a store. Upon seeing his walking stick, she automatically apologized even though P3 had technically walked into her. The same happened with a young mother attempting to bundle up her children prior to going outside. I needed to stop P3 as he was about to walk into the woman’s stroller. She rather immediately and profusely apologized, although again it was not technically her fault. In all of these interactions, I felt a general sense of pity was being directed at the older adults.

Negating the Presence of Older Adults With ARVL When Accompanied by a Perceived Caregiver

Not only did participant observation enable observation of how the participants interacted with their physical, social, cultural, political, and institutional environment, but it also provided a firsthand experience of how the social environment interacted with the first author, as the perceived caregiver of the older adult with vision loss.

Many people within the community specifically engaged me in discussion either about the participants or in lieu of speaking to them, seemingly assuming the person with ARVL was incapable of speaking for themselves. For example, during a craft session, I attended with P2, I was asked by one of the attendees, who was also visually impaired, who I was with and

when I indicated P2, she said “Oh are you his helper . . . because [P2] always brags about how independent he is at taking the bus.” I sensed resentment in her tone regarding the remaining independence that P2 is still perceived as having. Further, when I went to the bank with P8 and we had to wait approximately 15 min to use the “senior’s wicket,” the teller apologized to me for the wait and then asked me to come up to the wicket. She did not make any attempt to speak to P8 until it was clear that I was not going to be doing any of the speaking. Both of these interactions suggested a misinterpretation of the abilities of the older adults with ARVL who were perceived as incapable in the presence of a seemingly “normal” and younger companion. It may also speak to a general discomfort of able-bodied persons interacting with those who are perceived as disabled.

During the observation visits, I was the recipient of multiple nonverbal gestures from strangers within the social environment including nods, smiles, and a “thumbs-up” on one occasion. For example, during my trip to the mall with P3 some patrons, particularly older adults, would watch P3 with great interest, seemingly curious as to how P3 would navigate himself around the various obstacles. They would also nod or smile at myself as we passed. At one point, I was stopped by an older woman who told P3 how well he was doing and that she was proud of him and me for helping. Conversely, I also received looks of disapproval from strangers in the community during a particular outing with P8 to the bank. During the participant observation session, P8 had asked me to not intervene unless she specifically asked for my assistance. P8 bumped into multiple obstacles during our walk to the bank, though she was able to redirect herself each time, with the exception of one incident where P8 got turned around in front of the bank and asked for assistance from myself to get back onto the sidewalk. The number of disapproving looks I received from people as I stood by and allowed P8 to fumble were significant.

Discussion

One of the distinct benefits of participant observation in this critical ethnographic study was that it allowed the researchers to tap into those tacit and seemingly mundane aspects of occupation that are often overlooked when using more traditional qualitative data collection methods such as interviews or focus groups. The example of P3 going to his local mall best exemplifies this. For example, during his narrative interview, he discussed his preference for going to familiar places and the strategies he utilized to enable his successful engagement in those spaces. It was not until we journeyed to the mall together, however, that I was able to see how he utilized the strategy of creating a mental map to assist with navigation, how he used grout lines to navigate a straight line down the hallway, how he managed obstacles such as store displays, and how a seemingly insignificant problem, such as being dropped off at a different door, resulted in significant anxiety as it did not enable him to use the visualization technique he so heavily relied on. Another benefit of participant observation was that it enabled an examination of the transactions between people and their physical

and social environments. For example, a simple observation of how some bus drivers failed to wait for older adults with ARVL to be seated before driving demonstrates a rather profound misunderstanding of the needs of older adults with vision loss. Similarly, watching participants search for items in a grocery store because the layout of the store changed reflects a deeper institutional environmental issue of spaces not being created to be vision-friendly. It also potentially reflects the deep-seated cultural norm of maintaining independence, whereby participants would rather struggle to perform their desired occupations than ask for help. These findings are significant as it is only through understanding how people engage in their day-to-day occupations and the physical and social environmental challenges they face in doing so, that strategies can be developed to ensure more inclusive, accessible, and vision-friendly spaces/places that support the full engagement of older adults with ARVL. Moving forward, this speaks to the importance of researchers combining the more traditional methods of interviews, for example, with participant observation as a strategy to, more fully, unpack the complexity of human occupation.

An additional, and not necessarily anticipated, outcome of using participant observation in this critical ethnographic study was the insights gained in terms of the cultural environment, namely, in relation to attitudes and assumptions toward “disabled” older adults. In line with critical disability perspectives, participant observation provided rich insight into how power relations as well as ageist/ableist assumptions played out in everyday life for older adults with ARVL. For example, many of the interactions between the older adult participants and those in their social environment as well as how individuals interacted with me as the perceived caregiver demonstrated, firsthand, that people react to older adults, who they perceive as “disabled,” with a certain degree of fear or perhaps pity. It could reflect a generalized fear of aging or probably more likely a fear of aging with disability (Boudiny, 2013). Disability is commonly interpreted as a tragedy and pitied or feared by those perceived as able-bodied (Hughes, 2007). The “normal” body does not generally want to be reminded of its own sense of vulnerability and so there is a sense of underlying fear that one might experience the same physical frailty and social vulnerability that are so often stereotypically associated with the disabled body (Fitzgerald, 1997). The participant observation sessions also shed light on issues surrounding invisible disabilities. As a predominately invisible disability, unless a participant uses more obvious signifiers of vision loss such as a white cane, dark sunglasses, or “Traveler with Vision Loss” sign, participant observation allowed the researchers to gain insight into how people react to a person with vision loss when their vision challenges are made visible, either because of an assistive device the participant was using or because they choose to make their condition visible by disclosing it to strangers, family, friends, and neighbors. Lastly, this study demonstrated how structural issues, such as power imbalances, play out in the everyday lives of older adults with ARVL. For example, as the perceived caregiver, questions intended for the older adults with ARVL, or comments about them, were frequently directed

to me. This represented a clear power imbalance, whereby I was perceived as the young, able-bodied expert, while the older adults with ARVL, as a result of their age and perceived disability were rendered incapable of answering questions or directing their own care.

Perhaps of any methods used by ethnographers, participant observation raises the greatest number of ethical questions. Two common factors that cause controversy in participation observation include the role of the researcher and obtaining informed consent (Mulhall, 2003). For example, observational data are subject to researcher interpretation, as the researcher has nearly complete autonomy regarding what they observe and subsequently how it is analyzed and interpreted (Mulhall, 2003). Because the instrument for data collection in participant observation is a human, issues related to “gender, sexuality, ethnicity, class, and theoretical approach may affect observation, analysis, and interpretation” (Kawulich, 2005, p. 6). With respect to the researcher role, in an effort to acknowledge how my positionality influenced the data collection and analysis, I engaged in reflexive journaling throughout the observation process and engaged in peer debriefing, throughout the data collection and analysis stages, with the second author who was my doctoral supervisor at the time. It was also important for me to clearly articulate my theoretical framework, which was positioned in critical disability perspectives, as a way to acknowledge the ways in which I “see the world.” For researchers planning to use participant observation in their own research, transparency with respect to their paradigmatic positioning and their theoretical grounding will be important to ensure a greater level of research authenticity. As it relates to consent, a primary ethical consideration surrounds the participants being aware of the purpose of observation and that their actions, behaviors, and the information they share will be documented. Although participants were aware of my presence and consented to engage in the participant observation process, I did not attempt to record the sessions in situ nor did I make any notes. Instead, I reserved time for field notes immediately following each observation session. As such, there is a possibility that participants forgot or backgrounded, at times, that our observation sessions—including what they said and did—were being recorded. It is important for researchers moving forward using participant observation to be transparent about how the observation session will be recorded and analyzed. Lastly, there were inherent challenges with obtaining consent from all those who “enter[ed] into the field of observation” (Mulhall, 2003, p. 309) and so without their consent, there were limitations in terms of how data could be presented. There was also the challenge of explaining my presence to those who either interacted with me or inquired about why I was with a certain participant. In those situations where my presence was questioned, I ultimately deferred to the participant, providing them with the control to explain my presence however they felt comfortable. A final ethical tension arose for me when I observed participants engaging in an activity that put them at risk such as walking into a display, bumping into people on the sidewalk, or stepping off the curb. If a participant requested

that I be “hands-off,” I would allow them to struggle but always stepped in if a participant put themselves in imminent danger, such as when a participant stepped off the sidewalk into a busy intersection without the right of way. Discussing expectations of the participant observation session and the researcher’s involvement would be an important conversation for any researcher to have with their participants prior to engaging in any observation.

In addition to the ethical tensions that were contended with in this critical ethnographic study, there were benefits to using participant observation that strengthened the quality of the data collected. For example, the participants were able to self-choose a meaningful occupation that we participated in together. While rich observations would still have occurred from “hanging out,” the additional structure of focusing around a particular occupation coupled with using the note-taking method of Emerson et al. (1995) was helpful when it came to writing comprehensive field notes. Although allowing participants to self-choose a meaningful occupation was a strength of the study, it should be acknowledged that by only observing one meaningful occupation on 1 day, understandings gained were limited. Another strength of the participant observation was that I was an active member of each of these sessions and not a detached or passive observer. By taking on the “observation of participation” approach, I had a more comfortable interaction with the participants, one in which I could develop a greater sense of rapport. A final strength has to do with the positioning of the participant observation session as the second method of data collection. The narrative interview occurred first, allowing me to develop rapport with the participants and begin to understand their story of vision loss. With the semistructured interview positioned as the third, and final, data collection method, I was able to follow up on any observations that required further clarity or contextualization. Although this timing was beneficial for the purposes of building off the ideas shared by the participants during the first session, an overall critique of the study is that participant observation was not the main source of data but rather was one discrete session positioned between two verbal accounts.

In addition to the strengths, there were boundaries of using participant observation in this study, which researchers planning to take up participant observation in future studies should be particularly mindful of. For example, as a critical ethnographic study, the authors did not aim for generalizability of the findings but rather sought to provide rich, contextually situated findings that sensitized readers to those environmental elements that can shape and perpetuate disability. This limits, however, the application of the findings beyond this particular study. A further boundary was that there was only one observation session per participant. Deeper insights, however, would have been gained through multiple observation sessions with each participant. For example, in their study on how collective kitchens can contribute to food security, Engler-Stringer and Berenbaum (2007) conducted participant observation until data saturation was reached, with three of the collective kitchen groups being observed between 2 and 7 times. Similarly,

Corman (2018) engaged in over 34 separate ride-alongs, totaling 200 hr of observation over 11 months in order to better understand how paramedics work in and on their apparatus unit. Lastly, the authors did not engage in a formal member reflection process. Although the researcher did engage in ongoing discussion with the participants both during the observation session and the final semistructured in-depth interview, a formal process of member reflection would have helped to further ensure that there were no misunderstandings of the observations made by the researcher.

Conclusion

This critical ethnographic study effectively used participant observation to capture the transactional nature of environmental influences that shape the production of disability for older adults aging with vision loss. Three key insights were gained by using participant observation in this study including the adaptive strategies tacitly employed to navigate the physical environment, a grounded understanding of social interactions that transpire in everyday contexts, and negating the presence of older adults with ARVL when accompanied by a perceived caregiver. These findings provide helpful insights into how participant observation can be used to critically unpack social constructions of disability as well as to gain critical understandings of the ways in which environments shape experiences of disability and the active ways in which older adults with ARVL negotiate environmental influences to continue to engage meaningfully in their desired occupations.

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ORCID iD

Colleen McGrath  <https://orcid.org/0000-0003-0032-8092>

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