From wandering to wayfaring: Reconsidering movement in people with dementia in long-term care

Megan E Graham
Carleton University, Ottawa, Ontario, Canada

Abstract

The movement of people with dementia in long-term care continues to be an issue of concern among clinicians, caregivers and families. This article will examine the social construction "wandering" and its association with pathology, risk discourse and surveillance technologies. Further, the article will explore the recent shift from the term "wanderer" to the phrase "people who like to walk" in person-centred dementia care. Engaging with Ingold's concept of movement as wayfaring, an alternative becoming-centred understanding of movement and its significance for people with dementia will be presented and illustrated through a case study. The paper concludes that depathologizing movement opens the possibility to see movement in people with dementia as an intention to be alive and to grow, rather than as a product of disease and deterioration. Suggestions for future research and implications for care interventions are discussed.

Keywords

Alzheimer's disease, dementia, movement, wandering, wayfaring, becoming, long-term care, identity, phenomenology

Movement in people with dementia is a phenomenon that needs to be better understood in terms of individual experience. When a person with dementia moves, a particular set of concerns arise that would not arise if the person was not known to have dementia. These concerns come from an understanding of dementia that pathologizes the body and as a result pathologizes its movements. When a person without dementia goes for a walk, it is called going for a stroll, getting some fresh air, or exercising. When a person with dementia goes for a walk beyond prescribed parameters, it is typically called wandering, exit-seeking, or elopement. I am not suggesting that concerns about an individual's health and safety are

Corresponding author:
Megan E Graham, Carleton University, 1125 Colonel By Drive, Ottawa, Ontario K1S 5B6, Canada.
Email: megangraham@cmail.carleton.ca

not real. Loseke (2003) argues the objective conditions continue to be real whilst the social construction is examined. There are certainly people whose movements negatively affect their health and safety, and the privacy, psychological well-being, and safety of others around them. This paper highlights the social construction of movement among people living with dementia in long-term care and proposes a phenomenological perspective from which to consider the social meaning and subjective experience of movement from the perspective of the person living with dementia.

Out of the discourse of person-centred care, a dignity-centred language shift has taken place. The person-centred care approach reflects what outside caregivers think is good for the person living with dementia, while the person-directed care approach learns what is good directly from the individual through verbal and non-verbal expressions, close observations and life history (Power, 2010, 2014). Some care institutions continue to follow person-centred care. In person-centred care, the term "wandering" has been replaced with the phrase "people who like to walk" (Frandsen, 2009; Ulrich, 2005; Vinita White, 2010). This shift is not universal, as some Alzheimer and dementia support organizations and academic forums continue to use the term "wandering." This is particularly the case among more biomedically oriented groups, such as medical journals, nursing journals, forums and regulatory agencies of long-term care residences and Alzheimer support organizations. The ongoing tension between movement as wandering and movement as liking and needing to walk signals a need for further inquiry into how the movement of people with dementia is conceptualized and then what the implications are for care. In so doing, a lacuna is exposed: the experience of the person with dementia. As caregivers, family, and various forums discuss the movement from their perspective, the phenomenological experience of the person with dementia gets short-shrift.

This paper will first take up the ways in which movement of people with dementia has been socially constructed through biomedical discourse and more recently through the discourse of person-centred care. It will then turn to the phenomenology of movement of people with dementia, offering a set of analytic tools based on Ingold's (2011) concept of "wayfaring" to better access the experience of movement for people with dementia. A case study drawn from ongoing fieldwork at a long-term care facility in Ontario, Canada, will be presented to illustrate a phenomenological approach to thinking about movement from the perspective of the person living with dementia.

Wandering as a social construction

It has been argued that reality as we know and make sense of it is a social construction. The social construction perspective is concerned with how we understand the world and the meaning people create in the world (Loseke, 2003). Something in the world can be said to be socially constructed when people form an idea about the world which becomes institutionalized over time, becoming a taken-for-granted part of the social world. Movement among people with dementia has been defined as a social problem called "wandering." Wandering has been socially constructed as a problem primarily through the language of biomedicine. Loseke (2003) states that defining a social problem does not deny the objective reality of the condition. Thus, we can explore how movement among people with dementia has been socially constructed without denying that some forms of movement pose real dangers to individuals with dementia and those around them, and create challenges for caregivers.

Scholars have long examined the struggle to understand what it will be like and what it means to become old in both Western society (Herskovits, 1995; Lock, 2005, 2011, 2013) and elsewhere in the world (Chatterji, 1998; Cohen, 1994, 1995, 1998; Harding & Palfrey, 1997; Lamb, 2000; Leibing, 2002, 2005, 2008, 2009, 2010; Leibing & Cohen, 2006). As a biomedical construct, dementia has become something that some people believe can be genetically tested for, staved off through mind puzzles, and treated with pharmaceutical medications (Lock, 2005, 2011, 2013). Leibing (2008) contends that "biologization" (a shift in biomedicine) has flattened out the psyche and that biomedicine has reduced the "somatic individuality," or depth, of people with Alzheimer's to the corporeal space of the brain. She traces the history of Alzheimer's disease and the personhood movement (the shift away from non-person to the "person within") from the 1960s through the 1990s, to the more recent trend of biomedicalization and the shift toward memory and behaviour. For the purposes of this paper, it is important to highlight the significance of "behaviours" in dementia care, under which undesired movement (e.g. "wandering") is subsumed. At the institutional level, an ethos and care culture forms around understandings of dementia and Alzheimer's disease (Brodwin, 2013). The label "having Alzheimer's" or "having dementia" influences perceptions about everything an individual does, including movement (Kitwood, 1988, 1990, 1997a, 1997b). As the body of the person with dementia is pathologized by the biomedical discourse, it is no wonder that its movements have been subjected to the same interpretation.

Wandering in people living with dementia has been categorized in several ways (Algase, Moore, Vandeweerd, & Gavin-Dreshnack, 2007; Halek & Bartholomeyczik, 2012; Lester, Garite, & Kohen, 2012). Halek and Bartholomeyczik (2012) argue that the phenomenon of wandering is too complex for definition; however, wandering is characterized by particular behaviours that relatives and care professionals find difficult to manage. Following Cohen-Mansfield, Marx, and Rosenthal (1989), it is important to note that the term "agitation" is often used to encompass many types of behaviours in people living with dementia. Movements are one of these behavioural expressions. In the last 15 years more attention has been paid to the drive to move itself. As a "drive to move," wandering includes: running away, excessive walking, pacing, or aimless walking back and forth, attempting to get outside, eloping, looking for others, inability to sit down, inability to focus during meals, and walking in and out of other residents' rooms. Halek and Bartholomeyczik (2012) also surveyed the subtypes of wandering that have been published in the literature. They note that two universal characteristics are present in every description or definition: moving in a certain space and being cognitively impaired. Definitions of wandering also include measures of how much and where a person moves in space, level of disorientation, and time of day. The authors conclude that wandering has no clear aetiology, and its definitions are imprecise, ambiguous and over-related to dementia-associated behaviours. Movement among people living with dementia is socially constructed through a biomedical understanding of dementia that pathologizes the body and consequently its movements as well. Ultimately, these problematic terms prevent us from understanding the human needs that underlie behaviours.

Movement is stigmatized by its association with the symptoms of dementia and by its location under the auspices of biomedicine. Dementia has been adopted by biomedicine and is being increasingly understood through the biomedical lens. Cipriani, Lucetti, Nuti, and Danti (2014) note that although wandering behaviour sounds innocent, it takes on medical significance in terms of outcomes, such as getting lost, malnutrition, weight loss, fatigue,

sleep disturbance, social isolation, earlier institutionalization, and injury. In broad strokes, movement is considered hazardous to the individual with dementia and those around him/her. Some forms of movement are harmful, particularly in the under recognized public health problem of resident-to-resident aggression, abuse, and mistreatment, which extends to caregivers and other elders (Aud, 2004; Caspi, 2013; Shinoda-Tagawa et al., 2004); however, the construction of movement as a pathology should be carefully considered.

Lester, Garite, and Kohen (2012) document risk factors for wandering, including cognitive impairment, older age, male sex, poor sleep patterns, agitation, aggression, and a more socially active and outgoing premorbid lifestyle. Residents in wheelchairs were also considered at risk of wandering. Whether on foot or on wheels, measures have been devised to assess people's movement. For example, the above authors suggest that an individual's risk of wandering should be assessed using one or more of the following scales: the Cohen-Mansfield Agitation Inventory (CMAI), the Rating Scale for Aggressive Behavior in the Elderly (RAGE), the Neuropsychiatric Inventory (NPI), the Revised Algase Wandering Scale (RAWS) and its version for community and long-term care settings (RAWS-CV and RAWS-LTC).

The phenomenon of wandering is continually constructed by people without dementia in relation to the impaired body that suffers cognitive, temporal and spatial disorder. This is particularly true for families that have people with dementia living at home, and for care professionals. Recently, innovative technological devices have been developed for surveilling and managing the movement of people with dementia (Bantry White & Montgomery, 2014a, 2014b; Sposaro, Danielson, & Tyson, 2010). For example, the *iWander* Android application offers remote monitoring to caregivers by using a GPS-based service and a Bayesian network to detect non-normal activity, or wandering. The application runs constantly and uses pre-programmed information such as a person's age and level of dementia, information gathered by the device (safe zones, GPS, time of day, and weather), and user feedback (response to a prompt: ''Are you okay?'') to calculate the probability that a person is wandering (Sposaro et al., 2010). Real-time movement monitoring systems in long-term care, such as the Vigil Dementia System, identify a person's immediate location and allow staff to intervene if the person is, or people around him or her are, at risk of harm (Caspi, 2014). Tools and technologies simultaneously provide the crucial means to ensure residents' safety, but one can also consider the ways in which they contribute to the social construction of movement in people with dementia.

Caution must be heeded. As Bantry White and Montgomery (2014b) note, wandering is a neglected area of research and the great challenge is to think about movement in a different way, bringing about a more in-depth understanding of walking activity and wandering behaviour. Feil (2012) reminds us that people in long-term care are busy wrapping up loose ends so that they may die in peace. She argues that in order to help the individual, the whole person should be considered from the perspective of unmet needs that motivate behaviour. Indeed, understanding the reason *in* a person's movement helps to move beyond the ''symptom'' to find deeper meanings. For example, Feil (2012) illustrates how movement can help someone relive a sense of usefulness they felt when they were working, moving their hands and feet as they would have at their jobs. Repeatedly, authors note the ambiguity of ''wandering'' definition and description. With the absence of an understanding of the person with dementia's experience of movement, the concept of movement in dementia will continue to be pathologized.

As a facet of dementia, movement becomes a behaviour symptom to be assessed and managed. Movement as wandering is closely associated with disease in popular discourse. Depending on the perspective of the organization, information pamphlets are written with more or less emphasis on movement as pathology. For example, the Alzheimer Society of Niagara Region (2013) in Canada and the Alzheimer's Society (2013) in the United Kingdom both published online information sheets about movement in people with dementia and Alzheimer's disease. In the former case, movement is categorized as "wandering," which is then broken down into six types of wandering: "recreational wandering," "tactile wandering," "environmentally cued wandering," "reminiscent/ fantasy wandering," agitated/purposeful wandering" and "internally cued wandering." The most benign movement has been labelled "recreational wandering," for "people [who] may have been active before or may be used to taking walks. [The] person is usually calm unless stopped, and wandering recurs regularly, seeming to fill a need for exercise" (Alzheimer Society of Niagara Region, 2013). It is explained that, "sometimes people with dementia like to walk because it is one of the few things they can still do without having their losses show. However, wandering can become a problem. Some people with dementia go through a hypermotor stage (6 to 9 months) when they are constantly on the move..." (Alzheimer Society of Niagara Region, 2013, p. 1). Indeed, movement can be detrimental to the health and safety of people with dementia. Some people with dementia walk continuously for very long periods of time until they become exhausted and incur injuries, putting them at higher risk for falls. This reality must be recognized. At the same time, we should consider how movement can be framed as pathology through biomedicalization and look for approaches to better understand the individual experience of movement.

A somewhat different approach is evident in the online material on movement provided by the Alzheimer's Society in the United Kingdom. The shift away from movement as pathology is deliberate and can be seen in both the language selected and the content offered. For example, in the title, movement is more colloquially labelled "walking about" and in the body of the text phrases such as "people who like to walk" are used and quotation marks are added to the term "wandering." It is noted that this term is unhelpful because "it suggests aimlessness, whereas the walking about often does have a purpose" (Alzheimer's Society, 2013). Rather than a nosology of wandering, the myriad reasons a person with dementia may walk around are emphasized. The information sheet seems to normalize movement by suggesting common reasons why people with dementia move, to which people without dementia can relate (e.g. moving to relive pain and discomfort, to use up energy, to relieve boredom, etc.). This reflects a more person-centred approach to movement than the Canadian example, reflecting different cultural shift towards person-centred care in the two countries. Still missing from the equation is the experience of movement from the perspective of the person living with dementia.

From "wandering" to "people who like to walk" in person-centred care

The person-centred care movement and culture change in long-term care settings are well known among dementia care facilities in the United Kingdom and increasingly in North America (Simmons & Rahman, 2014). Person-centred care is considered to be the gold standard in health care quality (Berwick, 2002). The person-centred approach comes from

Carl Rogers' client-centred psychotherapy which emphasizes the importance of seeing the person as the expert on him or herself. The therapist becomes a facilitator for the client's self-actualization. The person-centred approach was introduced to the field of dementia by Professor Tom Kitwood in 1988 to highlight communication and relationships and distinguish this from medical and behavioural management. Brooker (2004) outlined the four major elements of person-centred care as follows: (i) valuing people with dementia and those who care for them; (ii) treating people as individuals; (iii) looking at the world from the perspective of the person with dementia; and (iv) having a positive social environment in which the person living with dementia can experience relative wellbeing. The person-centred approach emphasizes human rights, equality and social justice. In the United States and Canada, The Eden Alternative and the Green House (both developed by Dr William Thomas), and the Pioneer Network place the person with dementia at the centre of care with rights and opportunities to contribute to daily life in long-term care settings, rather than only receive services (Thomas, 1996; Vinita White, 2010).

The Pioneer Network is an American grass roots network of individuals who are interested in cultivating a new culture of aging in long-term care and community-based settings. Fagan (2003) documented the origins and mandate of the Pioneer Network in great detail. This approach recognizes that values, beliefs, and practices at all levels of an organization must change in order to create culture change within the organization. As part of the culture change movement, the Pioneer Network refocused language to personalize care (Frandsen, 2009; Ulrich, 2005; Vinita White, 2010). Dignity language that is more respectful of the person is used in addressing people and discussing care. The Pioneer Network's focus on dignity language is meant to re-direct the way in which people are described and labelled. A significant language shift is the move from ''wanderers'' to ''people who like to walk'' (Vinita White, 2010). Schoeneman (2009) included additional shifts: ''ambulation, wandering'' to ''walking,'' and ''eloped, escaped, elopement'' to ''left the building, unescorted exiting.'' Following Caspi (2013), replacing the language of symptoms with person-directed terms interrupts the perpetuation of the deterministic biomedical view with terms such as ''behaviour expressions'' rather than ''behaviours'' that support the whole person and promote a psychosocial approach to care by recognizing the influence of the social and physical environment. The shift in language has not been universally adopted. This is evidenced by scholarly journal articles and popular publications, such as the Alzheimer Society ''Wandering'' publication and the Alzheimer's Society ''Walking About'' publication, which refer directly to wandering and discuss walking as a symptom of dementia.

Person-centred care is accompanied by concerns about person-environment-fit and the restructuring of nursing home architecture to facilitate ''wayfinding'' for people with dementia (Caspi, 2014; Chiu, Algase, Liang, Liu, & Lin, 2005; Lawton, 1977; Marquardt & Schmieg, 2009; Passini, Pigot, Rainville, & Tetreault, 2000). Wayfinding refers to a person's ability to mentally imagine or represent a physical setting and to situate him or herself spatially within that representation (Passini et al., 2000). Loss orientation and inability to reach destinations are the primary reason for institutionalization of people with dementia. Wayfinding is assessed using scales such as the Global Deterioration Scale (GDS) (Reisberg, 1985), once again associating movement with pathology. ''Dementia-friendly architecture'' has been studied by researchers to assess therapeutic environmental design and its impact on the well-being of people with dementia (Marquardt & Schmieg, 2009). Simple circuitous loops and continuous paths are popular designs that promote

orientation and wayfinding in small units. Some of the literature on architecture and dementia care continues to use the term wandering (Marquardt & Schmieg, 2009). Thus, wayfinding should not be taken as a direct derivative of the Pioneer Network approach; however, the findings of the research findings support the person-centred approach, including the Eden Alternative and the Green House (Caspi, 2014). Those interested in wayfinding appear to be concerned with people's experience in space, arguing that small-scale environments support residents' efforts to navigate to their destination, move without assistive devices, maximize eye contact between staff and residents, and improve staff detection and intervention in aggression between residents (Caspi, 2014, 2015; Verbeek & Rossum, 2008).

Environmental changes, such as providing safe walking areas, improve the living conditions of people living with dementia in long-term care. Efforts to design environments suitable for movement should continuously take into account the subjective experience of movement from the resident's perspective. Subjective experience of movement is markedly absent from the literature on dementia care in long-term care settings. In response to Bantry White and Montgomery's (2014b) call for a more in-depth understanding of movement among people with dementia, I will use Ingold's (2011) concept of wayfaring to reconceptualise movement among people with dementia.

Wayfaring: A phenomenological approach to movement in dementia

It has been recognized that a holistic understanding of the person with dementia in terms of identity and sociality offers insights that biomedical models and deficit-focused neuropsychological tests cannot (Kitwood, 1997b; Lyman, 1989; Sabat 2005; Sabat & Harré, 1992, 1994; Twigg & Buse, 2013). Personhood is an aspect of the dementia experience that medical tests cannot asses. Personhood encompasses the personal, relational, existential, and the moral as embodied day-to-day negotiations of self. In the context of dementia care, Kitwood (1997b) defined personhood as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p. 8). From anthropologists Conklin and Morgan (1996), we learn that personhood is a complex concept in societies. Just as we are vexed by the coming into social being of a young person with a young human body, we are equally vexed by the coming into social being of an older person with an older human body. Conklin and Morgan assert that, "personhood is a social category that is inherently dynamic; people invoke certain ideas about how persons are constituted to legitimate their actions and position themselves in relation to others" (1996, p. 659). Approaches to care are legitimated and justified based on how societies understand aging people and aging bodies. To illustrate the necessity of critically engaging the notion of personhood and its socially constructed nature in relation to approaches to care for people with dementia, the following caution from Jackson and Karp (1990) is informative:

> Formalized notions of personhood are not to be construed as descriptive of a static, preordained, social world; they are instrumentalities which people actively use in constructing and reconstructing a world which adjusts values and goals inherited from the past to the problems and exigencies which comprise their social existence in the here and now. (p. 28)

Person-centred care is inherently an outside-in perspective that is always in the process of constructing what is meant by the "person" being cared for. This requires the constant

adjustment of values and goals, including how person-centred care is construed. The purpose of this approach is to meet the challenges of dementia care in the best way possible. However, perhaps there is a way to accomplish the same end through an understanding of lived experience. Building upon the call for a deeper understanding of movement, this paper also responds to the call for increased attention to embodiment as a way to emphasize the social significance of expressions and meanings of movement in the experience of dementia (Kontos, 2005; Kontos & Nagalie, 2006; Kontos & Martin, 2013).

Drawing upon Merleau-Ponty (2012), the paradox of being alive is that we simultaneously have a body and are a body, but we are never entirely one or the other. The body can never fully be an object or a subject to itself. This means that we *have* a body that is socially constructed, ascribed with meanings by outsiders and by ourselves. The body that we have is objective and it can be assessed and managed. The body that we *are* cannot be so easily accessed from an outside perspective. The body that we *are* is the body we live *through* in the world.

As we move through the world, we relate to others and acquire knowledge through our bodies. The body is our vehicle of being-in-the-world and through the living body we are united with a particular milieu and our personal projects (Merleau-Ponty, 2012). This does not stop simply because the body that we have has been diagnosed with dementia. The body that we *are* continues to be sensible and sentient. Phenomenologists begin from the body and argue for an embodied perspective of being-in-the-world where the present is always in the process of becoming one's past and being filled by one's future: ''I never have an absolute possession of myself by myself, since the hollow of the future is always filled with a new present'' (Merleau-Ponty, 2012, p. 250). The body is an important point to carry forward, but being is not the endpoint of the discussion. Indeed, a consideration of *becoming* in dementia via movement can be unpacked using Ingold's (2011) concept of wayfaring.

Ingold (2011) approaches experience from an animic perception of the world, stressing the relational constitution of being and the primacy of movement. Drawing primarily upon Jakob von Uexküll's idea of the subjective universe (*umwelt*), Heidegger's concept of life as open with horizons of indeterminate possibilities beyond which humans live, and Deleuze's idea of lines of becoming, Ingold puts forth a new way to think about existence. He posits that human beings are wayfarers who inhabit the world through the embodied experience of movement. For Ingold, wayfaring is the most fundamental mode of being-in-the-world. Wherever there is life, there is movement of becoming. Its impulse is not to reach a terminus but to keep on going. ''The movement of life is specifically of becoming rather than being, of the incipience of renewal along a path rather than the extensivity of displacement in space'' (Ingold, 2011, p. 72). As wayfarers move through the world, they become their movement. The wayfarer *is* his or her movement in a phenomenal sense and also in terms of identity and social position. The lifeworld of an individual is constituted by the meshwork of relationships that take place along lines of movement.

For Ingold (2011), life is open-ended. The wayfarer moves through, not simply across, the world of horizons from which something *begins its presencing* (p. 147). Life is lived along lines, overflowing beyond parameters and borders thrown around it. Ingold argues that experience is not circumscribed by the restricted horizons of a life lived in a given place:

> Places, then, are like knots, and the threads from which they are tied are lines of wayfaring. A house, for example, is a place where the lines of its residents are tightly knotted together. But these lines are no more contained within the house than are threads contained within a knot.

> Rather, they trail beyond it, only to become caught up with other lines in other places, as are threads in other knots. (Ingold, 2011, p. 149)

Researchers in the field of long-term care and dementia recognize that physical environment has an impact on the experience of dementia. In particular, the topic of indoor movement and confinement is implicated in ethical and legal debates about civil rights and liberties of the elderly (Jackman, Emmett, Sharp, & Marshall, 2014; McMinn & Hinton, 2000; Schafer, 1988). Ingold's (2011) argument about the openness of life and movement as an existential matter can be used as a starting point from which movement in dementia can be discussed, much in the way that Vittoria's (1999) emphasis on adopting a "language of openings" opened discussions that the medical model's "language of limits" had closed (p. 362). With wayfaring in mind, it becomes possible to consider the movement of people with dementia as a more meaningful expression than the aimless, disease-driven behaviours articulated in biomedical models.

To illustrate this, I will present a case study from ongoing fieldwork at a long-term care facility in Ontario, Canada. Through a series of vignettes involving Robert, I will offer an alternative to the biomedical pathology-driven approach to movement, exploring Robert's movement in terms of his experience. The institutional review board of my academic institution approved the study (IRB #102012). Consent for participation was obtained through the long-term care facility and legally authorized representatives. All identifying information, such as names and places, has been changed to ensure participant anonymity. As a researcher associated with the creative arts team at the facility, I offered music and social visits to residents. I wore plain clothes and had an identity badge that signaled to residents that I was not a primary caregiver (e.g. a personal support worker, registered nurse, or doctor). Close observation and verbal expressions were documented through field notes after encounters, and during encounters when it was not intrusive. At each encounter with Robert, I explained that I was a researcher and offered a lay language explanation of the study. I also asked Robert each time I met with him if he would like to talk to or visit with me, allowing him the freedom to decline, which sometimes he did through verbal and non-verbal expressions. The data was analyzed using Ingold's (2011) concept of wayfaring in conjunction with the phenomenology of Merleau-Ponty (2012) and Straus (1966). Validity of the interpretations and conclusions was strengthened through thick description, iterative data analysis and seeking feedback from unit staff.

Case study: Robert

The resident in this case study will be referred to by the pseudonym, "Robert." Robert has been labelled a "wanderer." Robert is a 90-year-old man who has Alzheimer's disease. He has lived in the long-term care facility for more than five years. Staff members remarked that Robert is movement-based, coining the term "itchy feet syndrome" because he seems to be compelled to move. Since he is considered by care staff to be "exit-seeking," Robert wears an exit alert bracelet that sets off an alarm when he passes through the unit door which is not locked to residents. Following Merleau-Ponty (2012), direct experience is inaccessible and we must always perform a translation, through language or otherwise, to convey experience. In Robert's case, the fragmentation of language caused by Alzheimer's disease and aphasia requires that a subsequent translation be performed to make sense of his verbal expressions.

The vignettes that follow will illustrate movement in terms of its meaning for Robert, and the role movement plays in social positioning for himself and in relation to others.

"There," "now," "here": Positional spatiality and the language of becoming

When Robert is walking, and when he is sitting and preparing to stand up to start walking, he routinely uses the words "there," "now," and "here." When he initiates conversation, it is in the form a question, such as "Can I go now?," or "Can I go down there?" When responding to questions, his responses often involve directions, such as pointing down the hall and explaining that he has "gone down there, around the corner, and back here." The following vignette illustrates Robert's use of directions and positional spatiality:

> 4:15 p.m. I encounter Robert walking on his unit. Me: "Hi Robert!" Robert: "Hi there." Me: "How are you doing today?" Robert: "Oh, I'm alright." Me: "Do you mind if I walk with you for a bit?" Robert: "Is this the way we go now?" Me: "Sure." As we start walking together, side by side, Robert says: "That's the back way." I ask him: "Have you gone this way before?" Still in motion, Robert replies: "Yeah, but not by myself. I had two or three meetings since I lived here. Right there [pausing for a moment to point at the doors to the dining room and then turning his head to look at me]. You younger people..." I ask him: "What about us younger people?" Walking again, Robert says: "He was going good." As we come to a right angle turn to go down the next hall, Robert indicates with his right index finger the line of the corridor and says: "Now, here's the first part. Down there. Do you want to go there?" I reply: "Sure." Looking down the hallway, Robert says: "There's a lot of people going through there. Ready?" I answer: "Yes." As we are walking down the hall, Robert turns and remarks: "You're not much bigger than me." I reply: "That's right." Still walking, he asks me: "Where are you from?" I answer: "Toronto." Robert smiles and seems to light up and says: "That's wonderful, I live here, too!" As we come to the next corner, Robert looks both ways at the adjacent sitting room and the hall to the dining room, and asks: "Are we going down there now?" We continue to walk together into the dining room and sit down at the table where he has dinner.

According to Straus (1966), lived movement is a performance of movement, not simply a matter of mechanical physics and Cartesian philosophy. Everyday expressions such as "here," "now," "there," and "toward" articulate the experience of movement in terms of phenomenal spatial order that is lived in relation to the surrounding environment. Straus states, "If I intend to go from here to there, I must take a certain number of steps. The path is one, my action is one, and I myself am one in my attitude toward the world" (p. 51). When Robert asks about directions or indicates where he is going, his experience of lived movement reveals the phenomenon of direction, the phenomenon of change, and the phenomenon of becoming itself. "While on the trail one is always somewhere. But every 'somewhere' is on the way to somewhere else" (Ingold, 2011, p. 149). There is existential purpose in movement and it is fundamental to human existence.

From Merleau-Ponty (2012) we are reminded that the body is our means of having a world because it is through the body that we expand the reach of our intensions and gestures, take up residence in them and engage in the social milieu. Movement always takes place in relation to its background, and moments are only ever artificially separated from a single whole. "There," "now," and "here" can be understood as Robert's language of becoming, expressing his attitude toward the world and his intention to reach out into it.

As I walk alongside Robert, I am also a wayfarer, joining him on his path. Our bodies are both upright, and although his gait is assisted by a walker, we are two independent people

who stand face to face. Straus argues that to be "upright" in the world carries social meanings and values, such as those expressed by high and low, rise and decline, climbing and falling, superior and inferior, looking up to and despising (Straus, 1966). As we walk together and Robert compares himself to me in age ("you young people"), height ("you're not much bigger than me"), and locality ("where do you live?"), his upright posture and steady, quick gait equalize our status in the world as independent social actors. "In getting up, man gains his standing in the world" (Straus, 1966, p. 143). The upright movement reinscribes him as someone other than a person who is limited by dementia because in being upright, he gains the freedom to stand on his own feet and to walk. In rising to an upright position, he becomes an upstanding individual, both objectively and in terms of the social meanings that uprightness carries.

Movement, work and meeting unmet needs

Care staff on the unit say that Robert is always "on the go." Some have described him as having a "compulsion" to move, or more colloquially (as noted above), as having "itchy feet syndrome." Robert's tendency to walk into other residents' rooms is explained to those residents in terms of Robert's cognitive deficits. One resident, after telling me to "throw Robert out" of his room, remarked to me, "The people here say I should be nice to him because he doesn't know what he's doing." From a social constructionist perspective, these cultural definitions have an impact on the experience of dementia because identity is defined by social interactions and social environments (Kitwood, 1990; Lyman, 1989). It is important to be critical of malignant social positioning and to look at the whole person, their social milieu and the unmet human needs behind or within their movement (Feil, 2012; Sabat & Harré, 1994). The following vignette illustrates Robert's experience of movement, revealing a deeper connection to working:

> 6:45 p.m. As I enter the unit, I encounter Robert walking around the corner towards me. I say, "Hello," and he pauses in his path, saying me, "Can I go home? I'd rather go over there and just get out of here. I'm going. Are you going?" I ask Robert, "Which way are you going?" He replies, "I'm going down the hallway to come to my elbow [he means the corner, where there is a left hand turn] then come into Red Deer and that's the end." As we walk down the hall, I ask, "When you get to Red Deer what will you do?" Robert replies, "You take the milk you got here and I'll give it to... [his voice trails off and he chuckles]. I respond, "You're making a delivery?" Robert says, "Yeah. You don't mind that, eh?" I reply, "I don't mind that." Robert then says, "Let's get out of here. Can I go?" I nod and ask, "How are you going to get there?" Robert taps his hands on the handles of his walker and says, "I got a bike here." I ask him, "Do you like it?" Robert replies, "Yeah. That was pretty good. It's good because it has a twister and a stopper. You can get on this here and you can just flick it up." Still walking, I remark, "An easy ride" and Robert laughs, "Yeah. We'll stay with the good ones."

Having grown up a rural setting, Robert often references farms, repairs, caring for cows and other labour associated with agriculture. He also served in the military during World War II, and was responsible for servicing airplanes. Robert's walker has been both a bicycle and an "aircraft feeder filler" (his term). Illustrated here is an example of how Robert positions himself and constructs his storyline (Sabat & Harré, 1992). His identity as someone who fixes things, makes deliveries, and gets around on bicycles and aircraft manifests through his

fragmented language and his positioning of himself as markedly different from the malignant social positioning that is facilitated by biomedical language.

Merleau-Ponty's (2012) famous Schneider case, a former soldier with apraxia, illustrates how a person's movement can be inseparably connected to habitual action and affect. Schneider was able to salute (i.e. perform a concrete movement) when he had placed himself within the affective situation of the whole, embodying all of the aspects of being a solider that included marks of respect, such as the right hand combing his hair and the left hand holding a mirror, and the right hand hammering and the left hand holding a nail in place. Merleau-Ponty argues that Schneider embodies the total role of the solider, becoming not only the gesture of the salute, but also the myriad gestures that are intrinsic to a soldier's habitus. In the present context, Robert's upright movement seems to create for him the affective situation or background from which his verbal and non-verbal gestures flow. The wayfarer's body gives him a power for a certain world as he rises up to objects that call for a certain labour.

Following Feil (2012), Robert's movement may satisfy an unmet need to feel useful as he did when he was working. If the gestures associated with working are situation-dependent, then movement in an upright posture may construct the affective and symbolic aspects that support working gestures and feelings of usefulness. Ingold (2011) suggests that a wayfarer is changed by movement, different upon arrival than when he set out. While some people with dementia may not have a clear memory of the physical path they walked through, the emotional state (positive or negative) evoked along the way may remain. It is worthwhile to consider how movement might simultaneously express and fulfil unmet needs for people with dementia, and also consider the affect associated with both movement on one's own and movement in the context of social encounters.

Movement, identity and self-positioning in encounters with other residents

While spending time on the unit, I have had the opportunity to observe Robert's interactions with other residents. In most cases, these encounters are brief but concentrated as residents position themselves in relation to one another in the milieu of the long-term care space. Through the following two vignettes, I will examine Robert's experience of movement in terms of his own identity and self-positioning:

> 7:30 p.m. Robert walks down the hall and arrives at the corner room where I am sitting with a male resident, Doug. Robert asks Doug: "Do I have to go this way?" Doug replies: "I don't know where you have to go." Robert repeats his question: "Do I have to go this way?" Doug replies again: "I don't know where you have to go." Doug then turns to me and asks: "Who is this guy?" Robert says to Doug: "I just checked the books and it looks good to me." Doug looks confused and says: "What?" Robert seems to try to clarify his question, saying to Doug: "Your floor" [pointing to a spot on the floor next to Doug]. As Doug looks down at the floor, saying, "My floor? I don't know what it is..." Robert turns suddenly and quickly walks away from us down the hall and out of sight.

> 5:00 p.m. Robert and I are walking down the hall together and speaking to one another. When we reach a corner, a male resident, Jim, says hello to me from his recliner where he is watching television. We stop walking and Robert asks if Jim is my cousin or friend. I reply that he is a friend. Jim calls over to me, "Come over here! I'm doing nothing and I need help with it." I reply that I will return later and Jim says, "Alright." Robert turns to me and asks if he and I can "go there" [pointing towards the dining room]. I reply, "Yes," and as we start to walk to the dining

room, Robert turns suddenly to Jim and says in a stern voice, "Stop lying there like a baby and get up!" To which Jim shouts back, "Shut up!" The verbal exchange between Robert and Jim ends there and Robert and I continue to the dining room.

In both vignettes, Robert was addressing other male residents who were sitting down when he encountered them. Ingold (2011) asserts that the wayfarer sustains himself through active engagement with the world as it opens up along his path. The meshwork of relationship is not without friction. When Robert asserts his social position as someone who is upright and performing work, he in turn socially positions other residents – who are seated – by directing them or berating them for their reposed posture. As discussed earlier, Straus (1966) states that to be upright is not simply to stand, but to withstand and resist falling as one acts and suffers in the world. "In getting up, man gains his standing in the world" (1966, p. 143). In directing Doug, Robert asserted his authoritative status, and when reprimanding Jim for sitting, he again positioned himself as a person with superior status. Robert's uprightness incited an aggressive verbal incident between himself and Jim and could have triggered an incident with Doug. Aggressive behaviour between residents is often circumstance-driven (Caspi, 2015). Movement may be a contributing trigger for aggression between residents, particularly between those who can and cannot move on their own. Thus, in addition to potential feelings of independence and usefulness, Robert's subjective experience of movement may also include negative emotions.

In the upright vertical position, Robert is looking down at residents who are seated, while meeting care staff face to face. He can hold himself as separate from the group of residents and identify with the younger, able-bodied group of staff. Straus (1966) states that upright posture removes us from the ground and holds us aloof from our fellow men; these distances are gains and losses. Upright movement may open the possibility for Robert to identify with care staff, but in so doing he may risk alienating himself from relationships with other residents. I have observed that Robert does not seem to have friendships with other residents and he tends to position himself away from others. While sitting with Robert, he once said to me that the men on the unit stay back and that he "never bothers them at all." Acquiring a sense of belonging and building relationships appears to be a complex phenomenon in long-term care on units where there are differing capacities for uprightness and movement. Robert's experience of movement includes positive and negative emotions because of the nature of his encounters with other residents, care staff and auxiliary personnel through movement.

As illustrated in the above vignettes, the ability to become upright and to move through the world on one's own two feet can have deep meaning, far beyond what the term "wandering" allows. Movement as wayfaring gives us an approach to care that begins from the body and insists on life as continuous growth and possibility of experience. This person-directed approach provides a means by which people with dementia can reclaim a non-pathological and humane existence.

The way forward

This paper has discussed the ways in which the concept of movement in people with dementia has been socially constructed. Language reflects and shapes our social beliefs and normalizes understandings about others that become taken for granted, rather than critiqued. The biomedical discourse continues to use the term "wandering" despite its

ambiguity and pathological connotations. On the other hand, the person-centred care discourse in tandem with the Pioneer Network has introduced the phrase ''people who like to walk'' as part of a broader shift to language reflecting dignity, identity and personhood within the context of a whole person approach. This shift in language moves in the direction of depathologizing movement; however, the alternative wording does not access the phenomenological experience of the individual.

A continued effort to grasp the experience of movement for the person with dementia is required in order to address the lacuna in our understanding. This paper has argued that the most advantageous approach is to begin from the perspective that movement is fundamentally human activity, disassociating the movement of people in long-term care from their diagnoses of dementia. By depathologizing movement we open alternative avenues for understanding the experience of people with dementia. This paper acknowledges that there can be risks and dangers associated with movement in this population, but there is also an urgent need for a more person-directed and humane approach to movement.

This begins with reconceptualising the individual as first and foremost a human being in the world. Ingold's (2011) concept of wayfaring has been used to illustrate how movement is a fundamentally human aspect of being alive. To be alive is to keep going in the movement of becoming. We unfold and grow along our lines of movement, intersecting and entangling with the lines of others. The wayfarer *is* his movement in a more dynamic way than being-centred approaches have suggested. This paper proposes the notion of a becoming-centred approach to people with dementia. In so doing, movement is resignified as a healthy human activity.

Future research should consider movement in long-term care critically, from both theoretical and applied perspectives. Attention ought to be paid to residents' freedom of movement both indoors and outdoors. The building architecture and infrastructure need to support movement in the everyday context, as well as during infectious disease outbreaks and colder seasons when space for movement is limited. Approaches to resident care must take into account the deep personal and social meaning of movement and find ways to support freedom of movement. For example, applying the brakes on an individual's wheelchair should not be a habit because this may unnecessarily restrict someone's opportunity for expression, particularly during music programs where moving to the music may be part of the experience. As the culture of long-term care evolves, the topic of movement must stay in the forefront. If a becoming-centred approach is adopted and movement is depathologized, then the possibility is opened to see movement in people with dementia as an intention to be alive and to grow, rather than seeing their movement solely as a product of disease and deterioration. Not only does this relocate the focus of future research, but it also has implications for psychosocial interventions.

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Megan E Graham is a doctoral candidate in Anthropology at Carleton University, Canada. She holds a Masters in Anthropology and has a long standing interest in phenomenology, communication, media and the arts, particularly music, sound and voice. Current work focuses on the lived experience of dementia in long-term residential care settings, specifically looking at modes of communication and sociality among the residents and caregivers through engagement in the creative arts.