

Exploring Social Citizenship in the Context of Leisure in Residential Care Settings

by

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Authors Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Dominant stigmatizing narratives of dementia emphasize tragedy, the loss of self, and portray people living with dementia (PLwD) as ‘unagentic’ and ‘failed’ aging subjects. Due to this stigma and the medicalized structure of long-term care (LTC) settings, recreation and leisure are often focused on therapeutic goals or managing “difficult behaviours,” rather than recognizing residents’ desires and aspirations. A social citizenship framework challenges these deficit-based views by recognizing PLwD as active agents with rights, histories, and competencies, while relational citizenship highlights the role of relationships in shaping agency. Although leisure has the potential to either support or undermine social and relational citizenship, existing research has focused almost exclusively on community-based settings, leaving LTC contexts largely unexplored. This study addresses this gap by using an ethnographic approach to narrative inquiry and narrative citizenship to support PLwD in telling their own stories, an opportunity they are often denied in research due to stigma and assumptions about capacity. More specifically it explored how leisure practices in LTC shape social and relational citizenship for PLwD living in these settings. Through fieldwork in a LTC institution in Southern Ontario, I conducted participant observation of leisure programs and research conversations with both PLwD and recreation staff. Four stories reflect the experiences of PLwD and the staff who support them in this LTC setting: *Holding onto Selfhood*, *The Right to Choose*, *Beyond Isolation*, and *Negotiating Freedom and Care*. This study provides insights into how LTC environments can be reimaged through a relational model of care that intentionally supports the social and relational citizenship of residents by prioritizing interdependence, shared agency, and reciprocal relationships over individualized, person-centred approaches.

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Chapter 1: Setting the Stage

Introduction

Dementia is highly stigmatized. Dominant stigmatizing narratives of dementia emphasize the tragedy of it, the complete loss of self, and construct people living with dementia as ‘unagentic’ and ‘failed’ aging subjects (Dupuis et al., 2012a; Kontos, 2012). It is often this stigma that gives shape to the most repressing or disabling aspects of the condition (Knifton & Yates, 2019; Mitchell et al., 2013). The two dominant stigmatizing discourses surrounding people with dementia are biomedicine and ‘dementia as a tragedy’ (Kontos et al., 2020; Mitchell et al., 2020). Within the biomedicine discourse, people with dementia are reduced to their neurological impairment. The medicalization of dementia encourages medical solutions while downplaying the social and political contexts of dementia. Discourses surrounding ‘dementia as tragedy’ make the assumption that neurological impairment is at the core of dementia leading to a total erasure of the self upon diagnosis (Kontos et al., 2020; Mitchell et al., 2020).

Both stigmatizing discourses shape individual and societal understandings of dementia, interpersonal relationships, and the structure and experience of life and care. These representations have enormous consequences for people living with dementia and their family members, impacting an individual’s identity construction and leading to fear, social exclusion and isolation, abuse, neglect, pre-mature death, and even suicide (Conrad & Baker, 2010; Mitchell et al., 2013). For example, public stigma resulting from these dominant discourses form common beliefs or stereotypes targeting dementia, such as the belief that people with dementia are dangerous or lack competence (Cohen et al., 2009; O’Connor & McFadden, 2012). These stereotypes lead to negative emotional reactions towards people with dementia. It has been found that fear is a frequent emotional reaction towards people with dementia (O’Connor & McFadden,

2012; Phillipson et al., 2012; Piver et al., 2013) along with anxiety (Cohen et al., 2009), shame (Piver et al., 2013), pity (O'Connor & McFadden, 2012; Werner et al., 2012) and disgust (Werner et al., 2010). These negative emotional reactions (prejudice) lead to discriminatory behaviours. The most common form of discrimination within the general public was found to be social distancing, particularly the avoidance of people living with dementia (Nguyen & Li, 2020).

In addition to public stigma, these dominant discourses can also lead to negative manifestations of the self. In a study examining self-stigma in people living with dementia, researchers indicated the association between perceived stigma level and an individual's physical health, anxiety, depression, self-esteem, personal control, social support, understanding and assistance, and activity participation (Burgener et al., 2015). Anxiety was consistently considered the key factor for denial, social withdrawal, and help-seeking delay of people living with dementia and their family care partners (Nguyen & Li, 2020).

Partly due to the stigma associated with dementia and the lack of resources to support people in ageing in their own homes, many people living with dementia end up spending their last years in a long-term care (LTC) home. Nearly 90% of LTC residents in Ontario have some form of cognitive impairment and nearly 70% are diagnosed with dementia (Carroll, 2021). In LTC, stigma associated with taken-for-granted assumptions that people with dementia lose their selfhood and their ability to know and express their needs frequently leads health carepartners to negate the preferences of people living with dementia (Sutherland et al., 2022). As mentioned previously, broader systems and stigmatizing discourses shape everyday practices related to the care of people living with dementia in these settings. As a result, residents living with dementia are typically identified as passive recipients of care (Bartlett & O'Connor, 2007) and social interactions become superficial (Knight & Mellor, 2007). Due to the medicalized structure of

LTC, recreation and leisure are often focused on targeting therapeutic goals or managing ‘difficult behaviours’ rather than recognizing residents’ desires and aspirations (Dupuis et al., 2012b; Dupuis et al., 2012c). Residents are provided a variety of social programs, but typically these programs are planned and implemented using a ‘task-oriented’, scheduled approach (Katz, 2000), without input from residents. This is an example of institutionalized recreation, a term used to describe this formally administered approach to psychological programming in LTC that underscores the marginalization and stigma associated with residents (Wiersma & Dupuis, 2010). As a result, loneliness and unmet needs for belonging are common experiences of residents in LTC, linked with numerous negative consequences including interpersonal violence (O’Connor & McFadden, 2012). The World Health Organization (2002) defines interpersonal violence as “violence between individuals, including physical, sexual, or emotional abuse, and threats of violence” (*Types of Violence Section*). It can be argued that behavioural responses of residents stem from a fundamental struggle to be included as influential members of an individual’s community (Theurer et al., 2015).

Despite dominant approaches to leisure and recreation in LTC, leisure has the potential to support culture change and create spaces that are open and accepting of difference (Fortune & Dupuis, 2018; Fortune & Whyte, 2011). In fact, people living with dementia themselves have indicated that leisure is essential for creating a life worth living and to flourishing, including people living with dementia in LTC (Dupuis et al., 2024). However, due to the stigma surrounding cognitive impairment, there is often a lack of meaningful activity as well as a lack of choice and control for people living with dementia within their leisure pursuits. A study found that 45% of residents with dementia participated in few or no activities, 20% participated occasionally and 12% attended activities that were inappropriate or incongruent with their

interests (Buettner & Fitzsimmons, 2003). Another study found that aside from the time spent receiving care, residents spent only two minutes within a six-hour period interacting with other residents or staff (Sharp, 2007). Ultimately, stigma creates institutional bodies (Wiersma & Dupuis, 2010) and results in the loss of social citizenship status for people living with dementia in LTC.

My Story

When I began working as a recreation professional in a LTC institution in May of 2020, in the midst of COVID-19, I was exposed to the harsh realities of life for residents in LTC settings, especially during a pandemic. Residents were unable to leave their rooms to eat, toilet or even bathe during outbreaks. Although these measures may have reduced risk of infection, they also presented their own health risks through the devastating impacts on residents' social connections (Chu et al., 2020; Stall et al., 2020). Comparable to a prison, many people living with dementia felt as though they were being punished when not recognizing the reasoning behind the strict protocols being imposed. When residents began exploring outside of their rooms, what is commonly referred to as 'wandering', security guards were hired for residents labelled as difficult. For example, Mabel¹, who was living with dementia, had a security guard sitting outside of her room during a COVID-19 outbreak. Before moving to a LTC institution, Mabel loved to go on a walk every evening around her neighbourhood. Now, when innocently trying to leave her room to go for a walk, she would be stopped by the security guard. Mabel was not permitted to go outside for months, and the institution quickly constructed her as a 'difficult', 'problematic' resident when she began resisting the restrictions imposed on her. Mabel loved to

¹ Names have been changed

walk, to clean, to socialize, and to help others, and was punished when she tried to continue those valued pursuits.

Due to COVID-19 restrictions, programs became strictly 1:1, providing me with the opportunity to really get to know the residents and learn their life stories. Mabel became one of my best friends. I loved hearing about her life and getting to know her. As a result of this close bond, I was often called when Mabel was being so-called ‘problematic’. Stereotyping often results in misinterpretations of personal expressions of experiences and inappropriate social treatment (Dupuis et al., 2012b; Scholl and Sabat, 2008). I remember one morning; I sat down to read the 24-hour report that would show me the documentation completed since my last shift. When I got to the section on Mabel, it was filled with negative comments. So negative, that if I did not know Mabel already, I admittedly would have been nervous to approach her. Her report described her as violent, harsh, difficult, stating that she swore at and abused staff. I realized that the individuals writing this report did not know Mabel’s life history. For example, when Mabel was upset with her new seating arrangement at dinner, staff reported her as difficult; they scolded her telling her she would have to leave the dining room and get no food if she was not quiet. After reading this, I looked at her seating arrangement and noticed that Mabel had been seated at a table with all males, one of whom would often shout sporadically. Mabel had a history of sexual assault from a male family member, and I immediately suggested she sit elsewhere. After being surrounded by a group of women, Mabel began to socialize and enjoy her mealtimes once again. Documentation is very important to creating a long-lasting construction of someone and the organizational format of this documentation tells a story where emphasis is placed on symptoms, behaviours, and clinical treatments rather than the person and their life history (Bartlett, O’Connor, 2010; Peter, 2000).

I believe Mabel to be one of the kindest, most caring people I have ever met in my life, however, she also knew how to stand up for herself. Mabel never remembered my name, only ever calling me her buddy. She knew my face as a person who was kind to her. She also knew the faces of those who were not kind to her, whispering in my ear when someone walked by “oh she’s just awful.” I began to take note that individuals she described as awful were those who were quick to snap; “get back into your room, Mabel” rather than “Mabel, there is a pandemic, and we must stay isolated for your safety.” When Mabel was treated as less than, she would get angry and who could blame her? Mabel wanted to be treated as a person and a valued citizen not a prisoner in her own home.

The relationships I have formed with people living with dementia have drastically changed my life. I have new perspectives on what it means to be a person living with dementia and a much greater respect for the deep complexity of this experience. However, the more time I took to get to know residents on a personal level, the more I struggled to do my job according to the structure of the institution. Often, the programs that I was running had functional goals, and did not consider residents’ perspectives. While some find joy in activities, feelings of loneliness and depression persist, and the absence of resident input reinforces the stereotype of passive care recipients (Theurer et al., 2015). When residents were not motivated to participate, I was told to run these programs anyway since the recreation staff could not veer away from the schedule on the monthly calendar. There was no room for flexibility and spontaneity. With little recreation staff in the home, I began to experience feelings of burnout. The programs were not meeting the emotional needs of residents. I found myself missing breaks and staying late in an attempt to provide residents with meaningful social connection. I began to realize that I was experiencing

systematic barriers to providing the quality of care I wanted to provide and that this experience was not uncommon among LTC staff.

Having meaningful interactions with residents is what motivated me to continue my work and learn more about the culture change movement in LTC and how I could contribute. Having the opportunity to explore social citizenship in the context of dementia through my graduate work has offered me some promise, revealing ways in which individuals can work in collaboration with people living with dementia to enhance the experiences of residents and leisure in LTC. I drew on a social citizenship lens to explore with people living with dementia the ways leisure may support or threaten their citizenship in LTC.

Towards a Social Citizenship Approach in Dementia

Critique of traditional understandings/approaches to personhood and person-centred care

Historic definitions of personhood (and citizenship) exclude people living with dementia. In the 17th century, the human body was viewed as merely passive, and the brain was assumed to be the sole organ responsible for the functions in which the self is identified (Kontos et al., 2017). Post (2000) argued that in a ‘hyper cognitive society’, cognition is prized to the point where other equally valuable aspects of being human are no longer valued. This was exemplified by criteria for assigning the status of person to a human being provided by Quintin (1973), which included: consciousness and self-consciousness, morality (living by principles and accounting for one’s own actions), rationality, agency, and the capacity to form and hold social relationships. This conceptualization of personhood is problematic for people living with dementia, and coupled with the stigma I described earlier, greatly contributes to the dominant discourse today that dementia results in the total loss of self, which is then accompanied by assumptions of loss of agency and citizenship status (Kontos et al., 2017). These assumptions have deep

consequences in the lives of people living with dementia who are viewed as no-longer being able to contribute to society and are therefore often treated as non-persons and passive recipients of care (Peoples et al., 2022). As individuals continue to be in relation with people living with dementia, they can continue to challenge this discourse.

Shifts have been made in understandings of what it means to be a person; it is now recognized that the mind and body are deeply intertwined (Bartlett & O'Connor, 2010). In the 1980's, Tom Kitwood re-conceptualized personhood in the context of dementia as socially constructed by and within a person's interactional environment (Kitwood, 1997). Kitwood stressed the importance of interpersonal relationships to personhood, stating that how we treat an individual, what he termed the malignant social psychology (e.g., disempowerment, infantilization, intimidation, labelling, invalidation, objectification, etc.) threatens personhood and results in the loss of personhood (Bartlett & O'Connor, 2010). Thus, Kitwood (1997, p. 8) 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." Kitwood and others advocated for the need for person-centred care is in the promotion of personhood (Dewing, 2008).

However, person-centred care has been critiqued for excluding others involved in the care process such as care partners and family members, not fully capturing the interdependence and reciprocities that underpin caring relationships (Dupuis et al. 2012b; Jonas-Simpson et al., 2022) and for ignoring the broader social context in which the dementia experience is occurring (Dewing, 2008; Jonas-Simpson et al., 2022). Although Kitwood (1997) acknowledged the dementia experience as relational, his definition places the maintenance of personhood on those who are cognitively intact (Bartlett & O'Connor, 2010). It is important to recognize that people

with dementia have agency; people with dementia continue to be relational beings and are not only influenced by, but also influence, interpersonal and social relationships (Bartlett & O'Connor, 2010). Given the critiques of person-centred care, especially in terms of how it is practiced, there have been calls to adopt more relationship-centred care approaches. However, the focus of these approaches continues to be on care relationships as opposed to other forms of relationships such as friendships (Bartlett & O'Connor, 2010). This continues to create a power imbalance whereby the person living with dementia is positioned as the one who needs care rather than a part of a reciprocal relationship that recognizes the relational capacities of people living with dementia (Bartlett & O'Connor, 2010). Though the lens of personhood has provided value in challenging the stigma and discrimination associated with dementia (Bartlett, O'Connor, 2007), it is also important to consider how stereotypes, prejudice and discrimination manifest at broader organizational, systematic, and societal levels (Bartlett & O'Connor, 2010). Though useful, the lens of personhood is not sufficient in understanding and responding to the stigma surrounding dementia and how this influences organizational policies and systematic structures of LTC.

Social Citizenship in the Context of Dementia

Personhood on its own is an apolitical term, where social citizenship is utilized to promote the status of discriminated groups of people (such as people living with dementia) to that of an equal citizen (Bartlett & O'Connor, 2007). The tendency to emphasize the collective experience of people living with dementia as an oppressed group can simplify experiences and therefore be counterproductive. However, recognizing people with dementia as a cultural group that is marginalized is important for political mobilization (Bartlett & O'Connor, 2010). While personhood highlights the uniqueness of human experience, citizenship is about the collective

where discussions surround power, and particularly the lack of power afforded to people living with dementia in relation to others (Bartlett & O'Connor, 2010).

Similar to historically changing definitions of personhood, views of citizenship have altered as well. Within traditional views of citizenship, difference is overlooked, and it is assumed that one must be cognitively able to be considered a citizen (Bartlett & O'Connor, 2010). An alternative understanding of citizenship recognizes difference in that there is no fixed or proper way to be a citizen (Bartlett & O'Connor, 2010). When further distinguishing between active and passive modes of citizenship, injustices that occur at structural levels become apparent. From this perspective, citizenship is not the degree to which an individual participates but the extent to which an individual's rights are recognized and upheld (Bartlett & O'Connor, 2010). A passive mode of citizenship can be described as people getting what they are entitled to and have a right to expect as an equal citizen (Bartlett & O'Connor, 2010). Active citizenship is about an individual participating in decisions that affect not only their life but the lives of those around them (Bartlett & O'Connor, 2010). When considering the definition of passive citizenship, attention is drawn to not only the practices and policies that support citizenship rights, but also the discriminatory practices and policies that threaten citizenship. Critically, this means that those who may lack cognizance or physical ability to actively participate in civic life are not disenfranchised; they are still seen and treated as valued citizens (Bartlett & O'Connor, 2010). A social citizenship lens can therefore provide all involved in the care process the opportunity to form a more dynamic, politically informed understanding of dementia that challenges dominant discourses (Bartlett & O'Connor, 2010). For example, rather than viewing 'behaviours' of a person with dementia as unintentional and as a normalized part of the disease process, a social citizenship approach recognizes the complex nature of personal expressions and actions (Dupuis

et al., 2012b). Utilizing this lens requires individuals to explore and understand actions at the personal, interactional, environmental, and broader sociopolitical levels understanding that ‘the best response cannot be assumed to be best situated at the individual level’ (Bartlett & O’Connor, 2010, p. 92).

Bartlett and O’Connor (2010) were the first to argue for the need for a social citizenship approach in the context of dementia. They drew on several theories and disciplines, including critical gerontology, disability studies, feminism, and critical psychiatry, to put forward an alternative understanding of social citizenship for persons living with dementia. A critical gerontological stance questions why something is the way that it is, particularly for older adults, with the intent to improve the domain of practice on which established norms and ways of thinking are based (Bartlett & O’Connor, 2010). This perspective assists in the critical analysis of how structural issues influence the day-to-day lives of older adults, including people living with dementia (Bartlett & O’Connor, 2010). Within the disability studies field, a critical perspective emphasizes and examines the problems in society, such as physical and attitudinal barriers, that oppress and discriminate against – disable – people, rather than focusing the conversation on the individual and their impairment (Bartlett & O’Connor, 2010). In the context of dementia, critical disability theories, especially relational critical disability theories (Thomas, 2004), are important to not only take into account political, social, and structural barriers, but barriers caused by impairment through recognizing the impact of the neurodegenerative changes that are happening to a person living with dementia (Bartlett & O’Connor, 2010). Feminism offers a critical lens related to social positioning and intersectionality, providing language for understanding stigma and power within the context of ageism, disability, gender, and socio-economic status as a few examples (Bartlett & O’Connor, 2010). Feminist ethics also draw attention to problematics with

how care has been conceptualized, including the dichotomy between giving and receiving care, and provided a more dynamic, relational understanding of care (Bartlett & O'Connor, 2010; Jonas-Simpson et al., 2022). Finally, critical psychiatry explores the relationship between psychiatry, social exclusion, and coercion (Bracken & Thomas, 2005). Critical psychiatry can be described as a movement or critique against traditional mental health services and assumptions about the experiences of people with mental health conditions (Bartlett & O'Connor, 2010).

Informed by these theories and disciplines, Bartlett and O'Connor presented a conceptual framework of social citizenship that recognizes people living with dementia as active agents with rights, history and competencies (Bartlett & O'Connor, 2010). Social citizenship is defined as follows in the context of dementia:

A relationship, practice or status in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level (Bartlett & O'Connor, 2010, p. 37).

This framework works to expand thinking and practice beyond the focus on personhood put forward by Kitwood (1997) through six components: growth, social positions, purpose, participation, solidarity, and freedom from discrimination.

The first component describes the shift from comfort to growth. Within a social citizenship approach, comfort and a sense of security are not enough; people must also have opportunities to grow and evolve (Bartlett & O'Connor, 2010). People living with dementia themselves have identified having opportunities for growth as important to flourishing (Dupuis et al., 2024). The idea of growth recognizes people's inner hopes, desires and capacity to contribute to life, moving

away from the dominant discourse of loss and despair that accompanies a diagnosis of dementia (Bartlett & O'Connor, 2010).

The second component describes the shift from identity to social positions. It was initially assumed that a diagnosis of dementia resulted in a loss of identity or 'self' (Bartlett & O'Connor, 2010). This view has been widely challenged, and it is now accepted that the loss of identity is a potential hazard (due to stigma surrounding dementia) rather than an inevitable consequence (Schweitzer & Bruce, 2008). However, the notion of the term 'identity' is problematic in that it fails to acknowledge the multiple identities or positions that a person living with dementia may occupy (Bartlett & O'Connor, 2010). Dementia is just one aspect of an individual's identity and, like all individuals, people living with dementia hold multiple identities. However, Bartlett and O'Connor (2010) argue that pluralizing this component is not sufficient. Bartlett and O'Connor (2010) state although discussions surrounding identity are important, they are conceptually inadequate. To capture the complexities of individuals social locations in the world and how these are reflected in term of rights and responses, Bartlett and O'Connor (2010) suggest the notion of 'social positions' is conceptually richer and more useful to a social citizenship framework than the notion of 'identity'. The notion of social positions provides space for reflecting on how different identities are positioned in a social context. In the context of LTC, individuals can consider how residents or people living with dementia are socially positioned within this space, often unfortunately as lesser citizens.

The third component describes the shift from occupation to purpose. The term 'occupation' is closely aligned to the notion of 'doing' rather than meaning (Bartlett & O'Connor, 2010). People living with dementia do not talk of needing occupation but rather of needing a purpose and meaning in life (Dupuis et al., 2024).

The fourth component describes the shift from inclusion to participation. Bartlett and O'Connor (2010) argue that individuals need to consider the involvement of people living with dementia in their own lives and decisions in a much more active way than the notions of 'inclusion' encourages, and in a much broader range of decisions and debates than previously considered. Dupuis et al., (2012d) also argued for the need to actively include people living with dementia in decision-making, and worked with people living with dementia, family members and professionals to develop the authentic partnership model to support this. Participation also involves recognizing people's diverse abilities and that individual participation will look different depending on retained abilities, personal histories, and opportunities made available (Bartlett & O'Connor, 2010).

The fifth component, from attachment to solidarity, explains that the concept of attachment assumes that a person living with dementia psychologically connects with something. That something is where the power and energy will lie (Bartlett & O'Connor, 2010). Secondly, the term attachment seeks to explain experiences in purely emotional terms without considering broader sociopolitical relations (Bartlett & O'Connor, 2010). Solidarity is defined as uniting with others to make a difference both in terms of the shape of society as a whole and in terms of the individual needs of citizens (Bartlett & O'Connor, 2010). The idea of solidarity apprehends that some people can and will want to take responsibility for others and that certain individuals connect with each other on a political, as well as emotional level (Bartlett & O'Connor, 2010).

The sixth and final component describes the shift from love to freedom from discrimination. Bartlett and O'Connor (2010) argue that people with dementia are entitled to experience freedom from discrimination as well as love. Love in itself is not sufficient especially when it manifests as protectionism, paternalism and control. Instead, it must be considered how, even in the most

loving of relationships or care environments, an individual's rights and entitlements can be easily undermined (Bartlett & O'Connor, 2010).

Together, these six components work to facilitate and support expansions in thinking and practice. It (re)positions the person living with dementia as an active agent with rights and a fluid degree of responsibility, and provides language when taking a more critical perspective, which is urgently needed in dementia studies (Bartlett & O'Connor, 2010). Discrimination against people with dementia can occur at different levels. Specifically, within LTC, discrimination against people living with dementia can occur in various ways. At a micro level, some staff members may hold negative attitudes or misconceptions about dementia resulting from stigma, leading to unequal treatment or neglect of residents with dementia. At a macro level, policies and regulations within the LTC system may not prioritize the specific needs of people living with dementia, resulting in inadequate resources, limited access to specialized care, or a lack of person-centred/relational care approaches. At a mezzo level, the culture and practices within specific LTC institutions can also contribute to discrimination. This can include an inaccessible environment, insufficient staff training on dementia care, or a focus on medical management rather than quality of life. Re-imagining dementia from a social citizenship lens has the potential to have impacts at the micro, mezzo, and macro levels influencing the unique everyday lives and experiences of people living with dementia as well as the overall dementia experience that is influenced by the larger socio-political context (Bartlett & O'Connor, 2010). Through social citizenship, people living with dementia can be recognized as active members of society with the right to participate in the decision-making process that affects their care and well-being. A social citizenship approach can advocate for policies and practices that prioritize the rights and needs of people living with dementia. By embracing the concept of social citizenship, individuals can

work towards creating environments that uphold the rights and dignity of people living with dementia.

Relational Citizenship in the Context of Dementia

Despite the numerous disciplines and theories used to contribute to the formation of social citizenship within dementia studies, there have still been critiques. Gaps in citizenship discourse include an absence of engagement with the insights of critical gerontology's theoretical sub-field of embodiment and dementia, specifically *embodied selfhood* (Kontos et al., 2017). Relational citizenship was developed to broaden and enrich the social citizenship discourse in the context of dementia by bringing attention to how the capacities and sense of the body are central to body-self/body-world relations (Kontos & Grigorovich, 2018a).

A number of scholars have stressed the relational nature of social citizenship (Dupuis et al., 2016b; Kontos et al., 2016, 2017). In fact, relationships are essential in realizing inclusion, solidarity, and citizenship for people living with dementia (Keyes et al., 2019). Relational citizenship, as developed by Kontos and colleagues (2016)

is a model that is premised on the importance of interdependence, reciprocity, and the support of persons with dementia as active partners in their own care ... [as well as emphasizing] the capacities, senses, and socio-cultural dispositions of the body [that] are central to self-expression, interdependence, and the reciprocal nature of engagement (pp. 182-183)

Relational citizenship emphasizes the significance of day-to-day relationships for people living with dementia (both beyond and within the care context). Similar to relationship-centre care (Nolan et al., 2004) and relational caring (Dupuis et al., 2024), the first tenant of relational citizenship, relationality, highlights the importance of mutual, reciprocal and interdependent

connections and the continued relational capacities of people living with dementia (Kontos et al., 2016). The myth of independence is damaging; dependency and caring exist within normative relational connections (Bartlett & O'Connor, 2010). Dualities such as dependent versus independent ignore the complexities of mutuality in relationships. 'Dependent' categorizes individuals as inferior and contributes to the lack of agency afforded to people living with dementia. Refocusing on the concept of interdependency works to recognize that even in situations where an individual may be dependent on another, the supporting individual is still getting something out of the relationship (Bartlett & O'Connor, 2010). When the relational capacities of people living with dementia are understood and valued, they are recognized for what they bring to relationships and are afforded opportunities to contribute to decision-making about their own lives and the lives of others.

The second tenet, embodied selfhood, is described by Kontos and Grigorovich (2018) as considering "both the pre-reflective intentionality of the body and its natural (pre-social) engagement with the world (the body's power of natural expression), as well as the ongoing socio-cultural relationship between the pre-reflective body and the world (history, culture, power and discourse)" (p. 718). The theory of corporeality provides the ontological foundation of the model of embodied selfhood (Kontos, 2004). Taking theoretical bearings from Merleau-Ponty's reconceptualization of perception (Merleau-Ponty & Smith, 1962) and Bourdieu's concept of habitus (Bourdieu, 1977), this theory advances a theory of selfhood through capturing the pre-reflective capacity of the body to seize upon and transform the perceptible into something meaningful (Kontos & Grigorovich, 2018b). Pre-reflective intentionality is not unconscious (Reuter, 1999), here, the body is intentional in its capacity to perceive and experience (Kontos, 2006), challenging assumptions surrounding loss of agency with a dementia diagnosis (Kontos &

Grigorovich, 2018a). Socio-cultural dispositions do not suppress the body's power of natural expression, although, postures, gestures, and movement of the body disclose a socio-cultural particularity shaped by a particular cultural and historical context; socio-cultural practices are always dependent on a basic level of intentionality (Kontos & Grigorovich, 2018b). In this sense, embodied selfhood is inherently relational where self-expressions are always intertwined with a shared world (Kontos & Grigorovich, 2018b).

It is a common misconception that agency can only be expressed through language. There are many embodied forms of communication and connection (Bartlett & O'Connor, 2010). Posture, touch, eye contact, and movement enable individuals who cannot otherwise express themselves to do so in interactions with others (Petherbridge, 2019). Kontos and colleagues (2016, p. 184) sum up how a relational citizenship approach expands understandings of social citizenship:

Our proposed relational citizenship model extends the concept of social citizenship by presuming that support of the central tenets of relationship-centred care (i.e. interdependence, reciprocity, and the support of persons with dementia as active partners in their own care) and embodied selfhood theory (i.e. the primordial body and socio-cultural dispositions as the primary agential source of interactive and communicative practices for persons living with dementia) are necessary to more inclusively grant citizenship entitlements to persons living with dementia in long-term residential care.

Given that embodied selfhood and relationality are fundamental to the human condition, it is essential that they be supported through sociopolitical institutions such as LTC institutions, and the organizational practices within these institutions (Kontos & Grigorovich, 2018a). Despite this being acknowledged within research, practice does not necessarily reflect this.

Narrative Citizenship

Narrative citizenship is vital in supporting the social and relational citizenship of people living with dementia by providing them with opportunities to actively shape and contribute to the narratives about their lives. However, traditionally, narrative research has focused on the textual aspects of stories told by people living with dementia, often overlooking the storytelling process and the significance of embodiment for sharing important aspects of lives, identity, and experiences (Hydén, 2013). This emphasis on textual narratives reflects a broader epistemological bias rooted in storytelling traditions in the Global North. Since Aristotle's *Poetics*, dominant Global North understandings of narrative have been defined by linear structures, coherence, and a clear beginning, middle and end (Aristotle, 1996). This emphasis has led to assumptions about incompetence or a lack of agency when people living with dementia struggle to conform to traditional narrative forms (Hydén, 2013). Such stereotypes, when internalized, can result in the exclusion of people living with dementia from epistemic practices, both by others and by the individuals themselves (Young et al., 2019). Epistemic injustice, defined as “wrong done to an individual, specifically in their capacity as a knower” (Fricker, 2007, p1), includes testimonial injustice, where a speaker's testimony is devalued by the listener, harming the speaker's role as a knower (Young et al., 2019). Qualitative research fundamentally seeks to challenge traditional assumptions about knowledge production (Denzin, 2017; Gray & Kontos, 2018). But, by adhering to traditional narrative norms, individuals risk excluding and marginalizing certain groups of storytellers, such as people living with dementia. People living with dementia have the right to contribute to stories told about them. In fact, the opportunity to express oneself is a fundamental human right (United Nations, 1948, Article 19; Jonas-Simpson

et al., 2022); as Bakhtin (1984) puts it, to be unheard, unrecognized, unremembered is “absolute death”.

Baldwin (2008) calls for the need of a ‘narrative citizenship’ that is given structural and organizational form. This means working to embed this concept within systems and practices that shape care, policies and institutions ensuring that individual narratives are valued and influence practice and decision-making rather than continuing to dismiss or silence these stories. Baldwin (2008) describes narrativity as an interpersonal activity in that some individuals find their stories marginalized and themselves as narrators dispossessed. In LTC settings more specifically, people living with dementia may find themselves narratively dispossessed with few opportunities to tell their own stories, resulting in the stories told about people living with dementia in LTC being constraining and oppressing (Baldwin, 2008). The stories constructed about Mable that I described earlier being a poignant example.

The organizational format of documentation tells a story where emphasis is often placed on symptoms, behaviours, and clinical treatments as opposed to the individual within a historical, cultural, and socio-political life context (Bartlett, O’Connor, 2010; Peter, 2000). Rather than acknowledging the individual’s life history, preferences, or individuality, documentation often reduces an individual to a symptom, contributing to a sense of narrative dispossession. This dispossession is not unique to people living with dementia; it parallels the historical suppression of Indigenous storytelling traditions within Global North academic and institutional settings. Kovach (2009) and Simpson (2014) argue that Indigenous storytelling is inherently relational and non-linear, yet Global North academic traditions have long privileged written, structured, and text-based narratives. This colonization of storytelling has led to the erasure of oral traditions as legitimate knowledge sources (Tuhiwai Smith, 1999). Similarly, stories told by people living

with dementia are often judged by their coherence and factual accuracy rather than their meaning and relational significance (Baldwin, 2015; Hydén, 2018). Through recognizing relational and embodied forms of storytelling, the exclusion of those whose stories do not conform to dominant Global North narrative norms can be challenged.

To further develop the concept of narrative citizenship, Baldwin (2008) states that a fundamental aspect of narrativity is the opportunity to tell one's own story, or otherwise, requires the maintenance of narrative agency. Baldwin (2008) provides two conditions in which narrative agency depends on:

1. "Being able to express oneself in a form that is recognizable as narrative, even if one's linguistic abilities are limited."
2. "Having the opportunity to express oneself narratively" (p. 225)

Supporting narrative agency requires attending to the various ways that people living with dementia communicate aspects of themselves and their experiences, especially through embodied expression and interdependent relationships. Baldwin (2008) suggests three ways that individuals might think about and support narrative agency that would include people living with dementia:

1. "To seek to narrativize other symbolic means of expression such as dance, movement and artistic expression."
2. "To look towards the joint authorship of narratives where the narrative process is shared by people living with dementia and those around them."
3. "To examine the contribution made by people with dementia to the narratives of others." (p. 225)

However, Baldwin (2008) points out that people living with dementia are more dependent on the narrative literacy of others than people without dementia and personal stories can become marginalized by grand narratives such as the loss of self that results from a diagnosis of dementia. For example, narratives, as generally conceptualized, often rely on language for its articulation even when verbal communication is limited (Booth & Booth, 1996; Goodley, 1996), restricting the narrative agency of certain groups of people (Baldwin 2006). One way of addressing this issue is to reframe our conceptualizations of narrative as chronological. A broader reframing of narrative must also recognize that storytelling is not inherently about linear progression or individual memory recall. Indigenous epistemologies have long embraced storytelling as a holistic and intergenerational practice, where meaning is not tied to chronological accuracy but rather to the relational process of knowledge transmission (Kovach, 2009; Simpson, 2014). If it is recognized that narratives are messy and not necessarily chronological, chronologically fragmented stories or repetition of stories by a person living with dementia can be understood as unaddressed, misunderstood, recurring meaning rather than merely as a result of forgetfulness or confusion (Baldwin, 2006). In this sense, narrative becomes related to meaning rather than time. This is where the narrative literacy of others becomes important. To understand a story and develop a narrative, individuals need to relate it to and with other stories (i.e., embodied expressions, co-constructed), building up a narrative map with the person living with dementia that is essential for understanding that person's experience (Baldwin, 2006). Individuals may also look to interpret other symbolic means of expression such as through the arts or through fashion (Baldwin, 2008). Taking the time to understand/co-construct an individual's story is another way of facilitating narrative agency for people living with dementia. In fact, Hydén (2013) argues that embodiment is less an individual expressive

phenomenon than it is an interactive resource. Here, the body becomes a shared, interactive tool in communication and social interactions. This means that bodily expressions are not only individual but also function as a resource that others can interpret, respond to, or engage with in social contexts (Hydén, 2013).

Within the context of social citizenship, Bartlett and O'Connor (2010) see narrative as being able to contribute to practice in four ways: as an empowering process, as a means towards essential insights, as an act of community building, and as a focus on change. Firstly, a narrative approach to practice can be empowering through positioning authority and control in the person telling the story (Bartlett & O'Connor, 2010), in this case people living with dementia. However, I do think this would still be dependent upon the narrative literacy of others, depending on where the person living with dementia is in the dementia journey. If a person living with dementia does not communicate in a chronological or verbal way, their stories may go unheard or be dismissed if those around them are not aware of the alternative forms of communication and different ways people with dementia can share important aspects of their experiences and tell their stories.

Secondly, listening to the stories of people living with dementia offers essential insight into the experiences of individuals (Bartlett & O'Connor, 2010). Not only do stories offer insight into personal experience, but they can also offer political insights and opportunities for people to reclaim power and assert authority over their lives and experiences (Bartlett & O'Connor, 2010).

A third way that narrative can be utilized in practice is as a tool for community building (Bartlett & O'Connor, 2010); narrative can be utilized to strengthen collective identity (Davis, 2002). Specifically, narratives facilitate the sharing of insights and perspectives, drawing together similarities with others (Bartlett & O'Connor, 2010). Although storytelling has transformative potential, it is often only utilized as a therapeutic activity. For example, storying

is often utilized as an intervention technique in LTC settings during reminiscing activities focused on stories as objective realities demanding acceptance rather than challenging and re-authoring these stories (Bartlett & O'Connor, 2010). As Ray (2000) notes, since individuals write themselves into being, by reinterpreting and rewriting life stories, this way of being can be changed.

Fourthly, narratives can support change and transformation (Bartlett & O'Connor, 2010). Personal stories reflect the beliefs, ideas and messages to which individuals have been exposed to through interactions within familial, social, political, economic, and cultural contexts (Bartlett & O'Connor, 2010). Therefore, these stories are often reflective of grand narratives. When given the opportunity to change the way a story is told, alternative stories can surface and grand narratives can be challenged. Counter narratives arise from the vantage point of those who have been historically marginalized (Mora, 2014) and are based on the actual experiences of people, leading to transformations.

An Ethnographic Approach to Narrative

While supporting and recognizing the self-expression of people living dementia through narrative agency is essential, it is equally important to question whose voice is truly represented in these stories and in what contexts (Gubrium & Holstein, 2009). Merely analyzing the internal structure of narratives may not fully reveal their meaning (Gubrium & Holstein, 2009). As mentioned, dementia is often constructed as identity consuming, and it is therefore often assumed that people living with dementia are incompetent, untrustworthy and incapable of speaking for themselves; they become non-persons. Taking an ethnographic approach to narrative seeks to move beyond evaluating stories solely based on individual factors like memory, rationality, or communicative skill (Gubrium & Holstein, 2009). Instead, this approach

focuses on understanding how stories are shaped by broader social, cultural, and environmental contexts (Gubrium & Holstein, 2009). It recognizes that narratives are not just personal recollections or expressions of logical thought but are deeply influenced by the circumstances in which they are told, including the relationships between the storyteller and the audience, as well as the cultural norms and expectations that surround the act of storytelling (Gubrium & Holstein, 2008). This perspective aims to capture a more holistic understanding of narratives by considering the interplay between individual experience and the social world (Gubrium & Holstein, 2009). Evaluating stories on an individual level therefore overlooks the social contexts that shape the act of storytelling (Gubrium & Holstein, 2009). Gubrium and Holstein (2009) contend that meanings and themes are inherently tied to the socially situated practice of storytelling. Narrative environments have the power to both challenge and validate various stories (Gubrium & Holstein, 2009). Although Baldwin (2008) emphasizes the importance of narrating one's own story as a core aspect of narrativity and recognizes narrativity as an interpersonal activity, an ethnographic approach to narrative practices moves beyond the reductionist goal of extracting a lived subject's 'own story' by recognizing the sociopolitical and environmental influences on storytelling. In this context, Gubrium and Holstein (2009) describe narrative control as factors that work to shape and condition storytelling. Two forms of control are considered: interactional control and institutional control (Gubrium & Holstein, 2009). Interactional control recognizes that narratives must be invited, incited or initiated (Gubrium & Holstein, 2009). Here, the influence over a conversation first starts by just being asked to tell your story, and also lies in how the patterns of interaction between individuals then work together to shape and develop narratives. For instance, the way people take turns speaking, respond to each-other, and contribute to the conversation determines how the narrative unfolds.

Institutional control refers to the way that institutions shape and influence the stories people tell and how they tell them (Gubrium & Holstein, 2009). This might mean emphasizing certain aspects of a story while minimizing others, or even preventing certain narratives from being told altogether. While this study aims to empower people living with dementia through providing individuals with narrative citizenship, narrative ethnography seeks to deepen our understanding of the relationship between narrative experience and meaning within a specific context. This requires researchers to be more inclusive and flexible in considering what constitutes appropriate data and how it should be analyzed, encouraging the integration of narrative inquiry with ethnographic methods—such as observation and interviewing. In order to support the social, relational and narrative citizenship of people living with dementia, considering all the ways they share their stories in the specific context of LTC settings, I utilized an ethnographic narrative approach in this research. The specific methods used will be discussed in Chapter 3.

Exploring Social/Relational Citizenship and Leisure in Long-Term Care Settings

Leisure can be an important space for recognizing and supporting the social and relational citizenship of people living with dementia (Dupuis et al., 2024). For example, in a community, arts-based project with people living with dementia, family members, community artists, and researchers, the arts played an important role in the “reclamation of citizenship for persons living with dementia and [fostered] the relational citizenship of all involved.” (Dupuis et al., 2016, p. 358). Leisure may be especially important to supporting the social and relational citizenship of people living with dementia in LTC institutions, given the additional losses associated with stigma they experience and the dominant culture of care they are embedded in. However, very little research has looked at how leisure within LTC institutions might support or undermine the social and relational citizenship of people living with dementia in those settings, particularly

from the perspectives of people living with dementia. In fact, most of the research on social citizenship has focused on people living with dementia in the community. My hope when I embarked on this study was that it would provide individuals with the opportunity to listen to the opinions and experiences of individuals who often go unheard, whether this be through language or more embodied forms of communication, challenging the stigma surrounding dementia and the loss of self.

Statement of Purpose

This study used narrative citizenship and ethnographic tools as a way to capture the stories of social and relational citizenship for people living with dementia in LTC settings. More specifically, it aimed to: 1) support the narrative agency of people living with dementia and advocate for more narrative approaches with people living with dementia by providing a space for them to contribute to the telling of their own stories, in their own unique ways; 2) gain a better understanding of the role leisure plays in supporting or undermining the social and relational citizenship of people living with dementia in the context of LTC institutions; and 3) raise awareness of the importance of social relational citizenship and narrative approaches to the culture change process in LTC institutions and ultimately advance a social and narrative citizenship approach in LTC settings. To achieve these aims, I explored the following four research questions:

1. How might leisure support or threaten the social and relational citizenship of people living with dementia in LTC institutions?
 - a. How is the narrative agency of people living with dementia supported or threatened in leisure spaces?
 - b. How does leisure support, or not, the six components of social citizenship?

- c. In what ways do leisure professionals support, or not, the social and relational citizenship of persons living with dementia in leisure programming?
2. How do residents living with dementia narrativize their lives and experiences, assert their social and relational citizenship, and contribute to the stories of others in leisure spaces?
3. What gets in the way of supporting the social and relational citizenship of persons living with dementia in LTC institutions?
4. What is necessary to support the social and relational citizenship of persons living with dementia in LTC institutions and advance a social, relational and narrative citizenship approach in these settings?

In Chapter 2, the literature review, I explore literature relevant to this study, including the structure of LTC and how this influences the experiences of people living with dementia in those settings, and current research on social citizenship in the context of dementia, both within the community and within LTC institutions. In Chapter 3, methods/methodology, I describe my research process including my methodology, methods for data collection, methods of analysis, and how I attended to rigour and ethics throughout my research process. In Chapter 4, I present my findings as four stories created from data collected from research conversations, observations, and informal interactions. In Chapter 5, I discuss how each of the four stories connects to components of social and relational citizenship and reveal personal, practical, theoretical, and methodological implications of this research before discussing the limitations of this project and what future research might entail.

Chapter 2: Contextualizing My Research

Introduction

This chapter will begin by providing a historical overview of the structure of the LTC system. From there, I will discuss the ways in which social citizenship is being explored in the context of dementia both within the community, and in LTC settings. I will also explore how individuals, including people living with dementia, are currently taking up a social citizenship lens and the importance of this research. This chapter will then explore spaces within social citizenship that individuals are looking to expand or develop further within research and practice. This review will highlight the lack of research done from a social citizenship perspective, particularly within LTC.

Structure of Long-Term Care

Between the 18th and 19th centuries, illness and disability became socially constructed as pathologies that had to be prevented, cured, and managed (Lawlor & Nale, 2014). In the 19th century, people living with dementia were considered ‘mad’ and were placed in mental asylums to obscure them from society. Medical labels and definitions function as tools of social control (Conrad & Baker, 2010), and individuals are managed by ‘experts’ through medical/social interventions and institutionalization (Mitchell et al., 2020). This medical knowledge is not necessarily given by nature, but is constructed and developed (Conrad & Baker, 2010). Medical discourses construct knowledge about the body and influence an individual’s meaning and experience of illness (Conrad & Baker, 2010), as well as how they are treated by others (Mitchell et al., 2013). As discussed in Chapter 1, while traditional views of personhood and citizenship have evolved, stigma surrounding dementia and aging persists, shaping policies and the structure of LTC institutions to this day.

Within Canada, LTC management is the responsibility of provinces and territories, where the federal government is responsible for regulating the homes and measuring performance. Implicit guidance comes from metrics governments use to measure and compare performance (Bartlett & O'Connor, 2010). The success of an institution is often measured on their ability to prevent adverse events or death, creating motivation and rationale for focusing on preventing behaviours that increase risk, even if this behaviour may improve quality of life (Bartlett & O'Connor, 2010). For example, a resident may wish to sit outside but may be prevented from doing so due to concerns about 'wandering' or because the terrain is deemed to be unsafe or slippery such as after a rainstorm. Attempting to control for every possible risk generates boredom, inactivity and social isolation for residents living in LTC institutions (Armstrong & Lowndes, 2018). Upon entering a LTC setting, residents lose control of so much of their lives and environment (Fortune & Whyte, 2011; Wiersma & Dupuis, 2010). Because of this rigid level of control, LTC institutions, similar to prisons, have been described as total institutions (Dupuis et al., 2005). Total institutions are characterized as depriving residents of their personal identity as well as limiting their sense of autonomy (Fortune & Whyte, 2011).

The COVID-19 pandemic further revealed inequities that exist within the LTC system. As a result of the medicalization of LTC, the central focus throughout the COVID-19 pandemic was on disease prevention (LeVasseur, 2021). In an attempt to protect LTC residents from COVID-19 infection, infection control measures included prohibiting visitors and restricting activities and interactions with other residents and staff in the home (Bethell et al., 2021). Separated from their loved ones and the important advocacy they provide due to social isolation policies, many older adults were left unattended for hours and many died alone, sometimes in their own filth (Monpetit, 2020). These strict isolation protocols severely restricted the autonomy of residents,

leading to serious mental health concerns and the worsening of dementia symptoms (LeVasseur, 2021). In response to both the concerns about the profound consequences of the stigma of dementia in society and inhumane practices rooted in the biomedical model in most dementia and LTC settings (Mitchell et al., 2013), researchers and professionals have called for the urgent need for culture change within these settings (Dupuis et al. 2016a).

There have been a variety of approaches and models advocated for and introduced to push culture change forward. Some approaches/models include: the Butterfly approach, the Eden Alternative, the Green House approach, and the Wellspring model (Armstrong & Lowndes, 2018). These approaches and models share many commonalities such as promoting smaller community-like homes and homelike environments, supporting the choice and autonomy of residents and staff, adopting holistic ‘person-centred’ approaches that emphasize quality of life for residents, nurturing strong interdependent relationships, the inclusion of families in care, and the elimination of hierarchical forms of governance/practice (Armstrong & Lowndes, 2018). However, there are also some differences. For example, the Wellspring approach focuses less on the design of the home where the Green House model emphasizes the built environment and requires ground up construction (Armstrong & Lowndes, 2018). As mentioned in my first chapter, others have advocated for alternative approaches to care, such as relationship-centred care and relational caring (Nolan et al., 2004; Dupuis et al., 2016) and authentic partnership approaches (Dupuis et al., 2012d). Though these approaches have offered critical advancements in the culture change movement, approaches in LTC institutions continue to draw on biomedical and/or person-centred approaches. Few if any are informed by a model of social citizenship/relational citizenship. I turn to a discussion on the research focused on social citizenship/relational citizenship in the context of dementia next.

Social Citizenship and Dementia Around the World

Mitchell et al., (2020) called for the ethical duty to promote, preserve and sustain the human flourishing of persons living with dementia by supporting their embodied and relational capabilities. As mentioned in Chapter 1, social citizenship has become a central focus within dementia studies in recent years, however the topic remains under-theorized (Peoples et al., 2022), especially in the context of LTC. In this section, I will describe and critically examine the conceptual and empirical literature focussed on social citizenship for people living with dementia. Most of the research on social citizenship focuses on people living with dementia in the community. I was able to find 23 articles focused on social citizenship in the context of people living with dementia in the community; only 8 articles focused on social citizenship in the context of LTC institutions were found.

Social Citizenship in Community

Research in the context of people living with dementia in the community suggests that older adults living with and without dementia participate in activities and places outside their home not only for health, functional, and mobility benefits but also as an important way to enact their social citizenship (Bartlett 2021; Nedlund et al., 2019). For example, Phinney et al. (2007) conducted an ethnographic study aimed at exploring how a community-based program, Paul's Club, could promote the social citizenship of people with young on-set dementia. Paul's Club is in Vancouver, Canada and has no formal connection with the health- or social-care system (Phinney et al., 2007). The findings of this study showed how the members of Paul's Club actively enacted their social citizenship through their everyday experiences such as walking, keeping the focus off dementia, supporting each other, creating a place of belonging, and claiming a place in the community (Phinney et al., 2023). Members of Paul's club reported

feeling emotionally safe in this non-medicalized atmosphere where the importance of participating together and emotional connection were valued and privileged. Members were viewed as “seeking the same things we all do: to have a role, to feel valued and respected, and to have connection with others” (Phinney et al., 2007, p. 385).

Given the importance of every day and community-life for supporting the social citizenship of people living with dementia, there have been global efforts to improve the everyday community life for *all* people living with dementia. ‘Dementia-friendly’ has been increasingly used in the international literature to describe approaches that include and support people living with dementia within their communities and wider society (Innes et al., 2021). However, it is important to note that many people living with dementia do not like the ‘dementia-friendly’ concept and some are turning to language of dementia inclusive, as seen in the *Promoting dementia-inclusive communities toolkit* created by the World Health Organization (<https://www.who.int/publications/i/item/9789290619314>). A dementia-friendly or dementia-inclusive community is defined as one that “possesses an inclusive and accessible community environment that optimizes opportunities for health, participation and security for all people, in order to ensure quality of life and dignity for people with dementia, their carers and families.” (World Health Organization, 2020, p.3). The movement is said to remind society that people with dementia have the same rights as everyone else to be treated with dignity and respect, to lead independent autonomous lives, and to continue to be active citizens in society whose opinions are heard and acted upon (Mitchell, 2012). Dementia-inclusive communities are critical to supporting the social citizenship and relational citizenship of people living with dementia.

Initially originating in Japan, dementia-friendly/inclusive communities is now a global agenda, especially in the UK, Europe, Canada and the United States (Bartlett, 2016). The

majority of what is known about the need for design and implementation of dementia-friendly/inclusive communities has emerged from the U.K, however, there has been very little empirical research testing the outcomes of dementia-friendly/inclusive community initiatives to determine if they are effective in improving the quality of life of people living with dementia (Silverman, 2021) or in supporting their social/relational citizenship. Some have also argued that the terms ‘dementia-friendly/inclusive’ and ‘dementia-friendly/inclusive communities’ are under theorized (Bartlett, 2016) and in need of further development. Bartlett (2016) suggested that citizenship studies may be used to advance the dementia-friendly/inclusive community agenda. Bartlett (2016) described citizenship as occurring in and enacted within ordinary places, such as everyday community activities and within the domestic sphere. Bartlett (2016) argued that the dementia friendly/inclusive community agenda is a relevant area of research and practice for several reasons: it has growing international appeal and currency; the agenda has implicit and explicit citizenship underpinnings; the agenda is in its infancy and has much room to be shaped and developed further; places for exclusion and inclusion are still undefined/unfolding; and because the role of non-state actors and ‘ordinary’ citizens living with dementia in the initiative remains unclear.

However, this movement does not come without critiques. Inadequate consultation with people living with dementia when working towards dementia-friendly/inclusive communities is one critique of this movement (Seetharaman & Chaudhury, 2020). Inadequate consultation of people living with dementia as well as the term dementia-friendly itself reflects a paternalistic viewpoint and results in reproduction of stigma by othering people living with dementia, creating a further divide between ‘us’ and ‘them’ (Peoples, 2022). In a study completed by Seetharaman and Chaudhury (2020), a participant living with dementia emphasized that misrepresenting

individuals living with dementia would have negative repercussions on the movement towards creating dementia-inclusive communities and perpetuate misinformation and inaccurate understandings of the experience of living with dementia. In my opinion, the term dementia-friendly is othering, reinforcing discriminatory attitudes. Efforts should instead be (re)-focused on addressing stigma and challenging dominant and harmful discourses of dementia. If dominant discourses are exposed and challenged, they might be eliminated, and then I believe communities could not only become dementia-friendly or dementia-inclusive but inclusive to all.

With few opportunities for people living with dementia to challenge the dominant discourses of dementia, research has demonstrated the power of the arts to create transformative spaces as well as spaces to support the social citizenship of all involved. Art-based methodologies open up spaces to make visible the abilities, power potentials, and talents of people living with dementia, contradicting dominant discourses and opening up possibilities for alternative narratives (Dupuis et al., 2016). There has been growing awareness of the power of the arts to support verbal and non-verbal creative self-expression and connection, affect, and the opportunity to participate in activities that are meaningful (Dupuis et al., 2016; Kontos & Grigorovich, 2018b; de Mediros & Swinnen, 2018). In a one-day workshop, Dupuis et al. (2016) worked with persons living with dementia and family members to interrogate the implications of the tragedy discourse and to begin to create an alternative discourse. People living with dementia and their family members were paired with visual and performance artists and researchers to co-create artistic reflections about what the individuals with dementia wanted to share with the world about themselves (Dupuis et al., 2016). This project supported the exercise of citizenship practice through the embodied practice of participatory arts and through the facilitation of storytelling (Dupuis et al., 2016). The authors of this study concluded that through the process, all were opened up to the

roles and power individuals have in supporting the citizenship of each other, saw new possibilities for actualizing relational citizenship, and came to understand how individuals could *do* citizenship differently (Dupuis et al., 2016).

Although this was a one-day workshop, there are art-based opportunities within the community for people living with dementia that are more permanent. For example, the Dotsa Bitove Wellness Academy (now known as The Bitove Method) inspires and facilitates expressions of the self in relationship through the arts and movement in an open, homelike environment (Mitchell et al., 2020). The academy is an assessment and therapy-free space that has an impact on all who engage with its community, including people living with dementia, care partners, staff, students, artists, and volunteers (Dupuis et al., 2025; Mitchell et al., 2020). Here, people living with dementia who are often excluded, alone and isolated are given opportunities to be in relationship and create art with others. Relational citizenship is demonstrated in their participation in the arts for life enrichment, in their expressions of joy and sadness, in asking someone to dance or in advocacy work and more (Mitchell et al., 2020).

Jonas-Simpson et al. (2022) conducted research on the experiences of diverse members at the Dotsa Bitove Wellness Academy. The authors of this study describe the importance of three concepts in the development of and study of the Academy: relationality, knowing otherwise, and embodied selfhood (Jonas-Simpson et al., 2022). This academy was created for people living with dementia seeking quality relationships, opportunities for creative self-expression, and learning through the arts, including music, theatre, painting, poetry and movement (Jonas-Simpson et al., 2022). Jonas-Simpson et al. (2022) identified three interwoven thematic patterns that reflect what it is like for different members to experience the relational ethic of care prominent at the Academy: freedom and fluid engagement inspire a connected spontaneous

liveliness, embracing difference invites discovery with generous inclusivity, and mutually affection brings forth trust and genuine expression. This study demonstrates the potential of arts-based practices grounded in relational caring to support the flourishing of all and challenges the dominant, stigmatizing discourses that result in people living with dementia often being excluded in communities as active citizens.

Although arts-based and creative initiatives can have positive relational and social citizenship benefits, the key for effective arts-based engagement is ensuring participants have meaningful opportunities to co-construct the experience and increase their agency while facilitating the social interaction, not only the activity (Robertson & McCall, 2020). In a study conducted by Robertson and McCall (2020), a creative activity toolkit was utilized to promote conversation and social interaction for people living with dementia in day centre and care home settings. The toolkit included a variety of activities including music, poetry and the visual arts (Robertson & McCall, 2020). However, there were instances when activities were prioritized over participant-led conversations. For example, when one participant wanted to talk about her family, this was overridden and ignored even when repeatedly asking volunteers “did you hear me?”. In this instance, this participant was trying to assert their agency and social citizenship, but rigid facilitation of the activity shut down this conversation (Robertson and McCall, 2020). It is important that activities, arts-based or otherwise, that support the relationality and social citizenship of people living with dementia provide a safe space for dialogue led by people living with dementia and that all involved have opportunities for the interrogation of stigma that may be held at the individual level. Unfortunately, few opportunities are available for individuals living with dementia to enact their citizenship in this way (Dupuis et al., 2016).

In a more recent study, Phinney and colleagues (2023) turned to an exploration of Dementia Without Borders, a singular creative community-based event held at the Peace Arch, an international park straddling the border between Washington and British Columbia. This festival was organized to address the stigma, discrimination, and social exclusion faced by people living with dementia that reduces quality of life and limits social participation (Phinney et al., 2023). It also is an excellent example of how these kinds of community events can showcase the social citizenship of people living with dementia. The event was planned to be flexible and responsive to opportunities for innovation, resulting in everyone feeling welcomed and a part of the event (Phinney et al., 2023). The festival had over 140 attendees from both the United States and Canada. The group was diverse in terms of ethnicity, race, gender, age, people living with dementia, people without dementia, family members, friends and children. It was made clear that this was not a health festival but rather a community artistry, a co-created performance that showed everyone new possibilities for what it might mean to live well with dementia. In doing so, it challenged dominant discourses and practices of dementia that maintain ‘us and them’ binaries. The heart of the event was a celebration of creative activities led by people living with dementia during and after a shared meal (Phinney et al., 2023). In fact, participation was an important value guiding the day and supporting one of the core tenants of social citizenship, from inclusion to participation. Although just a one-time event, this project has helped to raise awareness of the importance of social connection and community engagement for people living with dementia, while further exposing how community can both be a location of refuge and familiarity, and a place of peril and unfamiliarity for people living with dementia due to stigma and social exclusion (Phinney et al., 2023). These initiatives are not unique in that there are many

groups around the world resisting dominant discourses surrounding dementia, however many of these initiatives have not been observed within research.

In addition to explorations of social citizenship in art and creative events, researchers have also studied social citizenship in the context of community gardening. More specifically, a study conducted by Noone and Jenkins (2018) drew on the concepts of social citizenship and embodied selfhood in an exploration of the experience of community gardening from the perspectives of people living with dementia. The garden was located in the grounds of a community hall in Glasgow, Scotland, which hosted a day centre for people living with dementia (Noone & Jenkins, 2018). All 13 participants had a diagnosis of dementia and were willing and able to undertake the light physical activity associated with gardening (Noone & Jenkins, 2018). Gardening sessions were conducted weekly over a six-week period. Following each session, participants were invited to suggest activities incorporated into the subsequent session to encourage the collaborative nature of the project (Noone & Jenkins, 2018). As a result, all activities conducted during the project were selected by the participants (Noone & Jenkins, 2018). Here, researchers were able to demonstrate how people living with dementia are indeed able to express agency. They argued that empowering people living with dementia to demonstrate their agency using creative approaches is crucial to the delivery of effective and meaningful activities (Noone & Jenkins, 2018). This study demonstrated resistance by people living with dementia to the structures oppressing people living with dementia, as one participant stated, “I bet they didn’t think we’d do it!”, referring to the ability of people living with dementia to flourish beyond perceived stereotypes placed upon them (Noone & Jenkins, 2018). The authors concluded that gardening can be an effective vehicle for the promotion of social

citizenship and the expression of selfhood and agency in people living with dementia (Noone & Jenkins, 2018).

Social Citizenship through Advocacy

Understanding and supporting advocacy, campaigning, and activism among people living with dementia is important due to the positive impacts advocating can have on a person's psychological health, well-being, social identity, and the values and meaning advocating holds for individuals (Bartlett, 2014). Further, participating in advocacy is another way that people living with dementia both perform and demonstrate their social citizenship. In order to meaningfully involve and engage people living with dementia in decision-making processes and activism, community partners, providers, planners, as well as researchers and healthcare practitioners need to have a better understanding of the lived experiences of dementia and advocacy (Seetharaman & Chaudhury, 2020). Previous research on dementia and advocacy suggests factors that motivate people with dementia to advocate, including: coping with the progression of dementia, gaining quality and respect in society, regaining their identity as social citizens, and staying connected to the dementia community (Bartlett, 2014; Knauss & Moyer, 2006). Advocacy empowers persons living with dementia to educate others who may be unaware or have misconceptions/misunderstandings about dementia, thereby eliminating or reducing the stigma surrounding dementia (O'Connor et al., 2018). However, this research also demonstrates that the experience of being involved in advocacy while living with dementia also has its challenges and barriers, such as: the stigma faced in relation to misguided social attitudes and expectations (e.g., cognitively biased conceptualizations of competence), and not being consulted adequately on issues that are of direct relevance for people living with dementia (Seetharaman & Chaudhury, 2020). A study conducted by Seetharaman and Chaudhury (2020) found a number of

ways through which advocates living with dementia enact and position themselves as social citizens. In this study, participants were able to fight for freedom from stigma and discrimination through advocacy, express solidarity, derive purpose and meaning, and grow. However, participants had several stigmatizing and discriminatory encounters with project partners and collaborators, and the public, leading participants to feel that their opinions were not equally valued. Additionally, participants reported the experience of superficial and inadequate consultation as a barrier to meaningful engagement in their advocacy work (Seetharaman & Chaudhury, 2020).

Several initiatives around the world have been taken to address these barriers to inclusion in advocacy and decision-making for people living with dementia. For example, the Mental Capacity Act 2005 initiated in England and in Wales during 2007, enshrines a legal right to autonomy of people assumed to lack decision-making capacity, such as people living with dementia (Boyle, 2008). Before initiated, people living with dementia were often defined as lacking decision-making capacity, simply because of the presence of dementia, with little recognition for the capacity of people with dementia to exert agency and be involved in decision-making processes (Boyle, 2008). However, this law does not necessarily provide people living with dementia a right to have their decisions respected or facilitated (Boyle, 2008). The Mental Capacity Act 2005 Code of Practice cautions that a decision made in the ‘best interest’ of an individual may not necessarily accord with the person’s views, thus making these restricted rights only, as the views of the person living with dementia can be over-ridden by the decisions of others (Boyle, 2008). Including people living with dementia in decision-making is an important way to support their social citizenship.

To address the exclusion of people with dementia from decision-making, national/international collectives involving, and often lead by, people living with dementia and their care partners have been developed, such as The Scottish Dementia Working Group, Dementia Advocacy Canada, and the Dementia Alliance International (Innes et al., 2021). Here in Canada, the Murray Alzheimer Research and Education Program at the University of Waterloo was one of the first research institutions to engage people living with dementia actively in decision-making in all of its research and knowledge-in-action initiatives, by including people living with dementia as co-researchers and co-designers of their initiatives. Based on these initiatives, they worked together to develop the Authentic Partnership model, which outlines principles and enablers for supporting people living with dementia in participating actively and meaningfully in authentic partnership with others (Dupuis et al., 2012d). According to Dupuis et al. (2012d, p. 432), an authentic partnership approach:

- “Recognizes how persons with dementia have been silenced, excluded and oppressed, while at the same time recognizes the collective capacity they have to empower themselves and others (Foley, 2001; Freire, 1972, 1976);
- seeks to work in partnership with persons with dementia, their families and others to promote equality and social justice for all persons with dementia (Adams & Clarke, 1999; Foley, 2001; Freire, 1972);
- Views knowledge as power, and education and learning as important vehicles for social change, transformation and liberation (Findsen, 2007; Freire, 1972, 1976).
- challenges the supremacy of higher order or expert knowledge and instrumental rationality (Habermas, 1984) by acknowledging, valuing and incorporating the lived or experiential knowledge of our partners (Thomas, 1982); and

- incorporates a systematic process of critical reflection and dialogue in community with others, as all partners work collectively towards the realization of new possibilities (Freire, 1972; Habermas, 1984)”.

Another example, The Dementia Associate Panel, based on a social citizenship model, aims to provide a platform to work with and hear the voices of people living with dementia in a region of England (Innes et al., 2021). The use of the social citizenship model led participants to report a sense of empowerment to share their views that brought personal fulfilment and collective action (Innes et al., 2021). Participants were provided with opportunities to engage in research, education, public awareness campaigns, and community engagement, that supported their ambition of having a wider impact (Innes et al., 2021). In another example, a study by Russell (2020) aimed to explore how people living with dementia could contribute to improving educational initiatives about dementia in higher education. This study explored the experiences of four people living with dementia employed as “expert by lived experience tutors” on the Foundation Degree Course in Dementia Studies at a University in the United Kingdom. Feedback from students indicated the importance and significance of the tutor role in readdressing power imbalances and reversing traditional roles commenting on how this made a real shift in how people with dementia are perceived (Russell, 2020). However, despite a number of national and European initiatives, narratives surrounding dementia and the loss of self/agency are still the dominating discourses, indicating that this work is still in early development.

Enacting social citizenship through COVID-19

The COVID-19 pandemic was life altering to both those living with and without dementia. Although, as stated earlier, older adults were disproportionately affected by the pandemic, particularly older adults living in residential care settings; viewing older adults, including older

adults living with dementia, as wholly burdened by the pandemic discounts their social citizenship (Ali et al., 2023). Here, people living with dementia were positioned as only passive and helpless in the face of a public health-crisis (Ali et al., 2023). Dixon et al. (2022) note that people living with dementia are capable of taking steps to rebuild their worlds, even in situations such as the pandemic, fostering new friendships, engaging in opportunistic sociability, and endeavouring to keep places of importance reachable and accessible. In a study conducted by Dixon et al. (2022), the authors recognized challenges faced by people living with dementia throughout the COVID-19 pandemic such as reduced social contact, increased loneliness, loss of social routines, difficulties in accessing and trusting health services, and non-inclusive practices in public spaces. However, these researchers also found that participants responded actively to these challenges. Dixon et al., (2022) described multiple ways in which people with dementia resisted, coped, and adapted to challenges. These strategies included: maintaining and extending social networks, making the most of ‘nodding acquaintances’, learning new skills (for communication and hobbies), supporting others and engaging in reciprocal exchange, and valuing connection with peers. The authors concluded that support for people living with dementia should focus on utilizing people’s full capacities, supporting them in the acquisition of new knowledge and skills, in advocacy and support, and in creating supportive social and environmental circumstances for people living with dementia to promote their own well-being (Dixon et al., 2022). All of these initiatives would also recognize and support the social citizenship of people living with dementia.

The above section described several initiatives within research and practice that utilize a social citizenship lens to explore and support the social citizenship of people living with dementia living in community-settings. These studies focused on more active forms of

citizenship where people with dementia were directly involved in initiatives and decision-making processes that influenced not only their own lives but the lives of those around them. Although important and influential, being an active member of society is not the only thing that defines citizenship. The passive model of social citizenship is concerned with ‘people getting what they are entitled to or have a right to expect as an equal citizen’ without having to make public contributions (Kontos et al., 2017). Although some people with dementia may wish to remain involved in more active forms of citizenship, others may not. Much of the broader discussion surrounding social citizenship is focused on larger issues of social inclusion, rights and responsibilities reflecting an individual’s relationship to the society in which they live (Baldwin & Greason, 2016). For people living with dementia in LTC institutions, social citizenship may be enacted differently, and participation and engagement might be realized differently at different levels. As mentioned in the previous chapter, relational citizenship is a particularly important topic to be considered in the LTC context as it also takes into consideration the embodied selfhood of people living with dementia. By extending the concept of social citizenship to support the central tenants of relationship-centred care and embodied selfhood theory, the concept becomes more inclusive, recognizing the citizenship entitlements of people living with dementia later in the disease progression (Kontos et al., 2017). In the next section, I explore social citizenship in the context of LTC institutions.

Social Citizenship and Leisure in Long-Term Care

Dominant Approaches to Leisure in LTC institutions

Leisure has the potential to create spaces in LTC institutions to support the social citizenship of residents and people living with dementia in these settings. In order to understand the context of leisure and social interactions in LTC institutions, the next section will explore and critique

dominant approaches to leisure in LTC institutions and the possibilities of leisure to support or threaten the social citizenship of people living in those settings.

In a hyper-cognitive society, a diagnosis of dementia results in significant changes in power dynamics and relations for people labelled with it. Due to the assumption that persons living with dementia are incompetent and unable to contribute to decisions about their bodies, their lives or services and supports targeted at them, people living with dementia have been historically excluded from decision-making in LTC institutions (Bartlett & O'Connor, 2010), including decisions surrounding their leisure pursuits (Theurer et al., 2015). Leisure in the context of dementia is often implemented for therapeutic purposes, to enhance functional and cognitive abilities, and/or as non-pharmacological means to support social/behavioural change (Dupuis et al., 2012b; Kontos & Grigorovich, 2018a). For example, leisure and recreation is often used to manage misunderstood 'behaviours' of people living with dementia, often referred to as 'challenging' or 'disruptive' (Dupuis et al., 2012c). This approach overlooks how the personal expressions and actions of people living with dementia are not always symptomatic of dementia itself but rather are intentional and indicative of purposeful/meaningful communication (Dupuis et al., 2012c; Kontos & Grigorovich, 2018a). Because of this, residents in LTC institutions report a lack of meaning in their lives, limited opportunities for contribution, and feelings of frustration with paternalistic communication with staff (Theurer et al. 2015). With loneliness and depression prevalent in LTC, psychosocial care traditionally consists of light social events that are planned and implemented by staff without input from residents (Theurer et al., 2015).

Much of the research on leisure in the context of LTC is published in the therapeutic recreation literature. Therapeutic recreation (also called recreation therapy) is defined in many

different ways depending on how it is approached. Therapeutic Recreation Ontario (2023) defines therapeutic recreation as:

...a process that utilizes functional intervention, education and recreation participation to enable persons with physical, cognitive, emotional and/or social limitations to acquire and/or maintain the skills, knowledge and behaviours that will allow them to enjoy their leisure optimally, function independently with the least amount of assistance and participate as fully as possible in society. Therapeutic Recreation intervention is provided by trained professionals in clinical and/or community settings.

Although there have been calls for, and some movement towards, change in therapeutic recreation broadly (Anderson & Heyne, 2012; Mobily et al., 2015; Sylvester, 2015), the field of therapeutic recreation continues to be aligned with the medical model, where goals often centre around functional change. This is in sharp contrast to a significant body of literature that supports freedom, self-determination, and intrinsic motivation as compelling aspects of leisure (Mobily et al., 2015). In this sense, therapeutic recreation may exacerbate stigma and oppress persons living with illness and labelled with a disability through its medically oriented focus and approach instead of supporting leisure for life enrichment and addressing aspects of the social and built environment (Devine & Sylvester, 2009; Dupuis & Kontos, 2025; Mobily et al., 2015) that limit meaningful opportunities.

These standard approaches to therapeutic recreation have become normalized within the therapeutic recreation practice (Sylvester, 2015). Normalization becomes a constraint when practitioners internalize norms as natural and essential (Sylvester, 2015), shutting out new possibilities and approaches for practice. As a result, knowledge and practices that exist within therapeutic recreation often go unquestioned (Sylvester, 2015). In addition to the normalization

of therapeutic recreation practices, there is political power in a treatment driven ideology (Mobily et al., 2015). Some argue that in a healthcare system built upon the medical model, therapeutic recreation must appeal to medical professionals in order to remain relevant (Mobily et al., 2015). Whatever the case, therapeutic recreation is a historically complex sociocultural product that should not be taken for granted (Sylvester, 2015). To avoid *presentism*, the belief that the present is superior, one must constantly question current knowledge and practices (Sylvester, 2015).

The social construction of *normal* began in the 19th century in conjunction with the development of the bell curve (Mobily et al., 2015). The middle of the bell curve became the ideal and those on the lower deviation were viewed as needing to be fixed or cured (Mobily et al., 2015). The primary mission of the “troubled persons profession”, such as therapeutic recreation, became to mould an individual in the ideology of the dominant culture’s norms (Mobily et al., 2015, p. 49). Due to this history, societies are predisposed to understand disability as a personal tragedy (Mobily et al., 2015). Here, people with disabilities are seen as ‘broken’, objects to be repaired rather than human beings and citizens; ability becomes the ideological baseline by which humanness is determined thereby othering people with disabilities (Mobily et al., 2015). Intersecting with the stigma associated with disability, including dementia, stereotyping based on age is one of the most tolerated forms of social prejudice in Canada (Genoe & Whyte, 2015). Common stereotypes surrounding ageing bodies include the belief that it implies frailty, dependence, cognitive impairment, social isolation, depression, and asexual behaviour (Genoe & Whyte, 2015). These stereotypes contribute to the othering of older individuals and have seeped into social systems including health systems such as LTC, affecting the ways care is approached in those systems (Genoe & Whyte, 2015).

These stereotypes have deep consequences for older adults interacting with these systems, particularly if ageist beliefs become internalized and older adults accept these stereotypes as truth (Genoe & Whyte, 2015). For example, within many LTC institutions, there is an emphasis on biological survival over meaningful existence and engagement (Genoe & Whyte, 2015). Harmer and Orrell (2008) described how even when residents indicated activities that were meaningful to them, staff and family members emphasized and encouraged greater involvement in activities that maintained physical abilities. For people living with dementia, assumptions surrounding ability further limit the provision of meaningful engagement in LTC institutions. Stigma associated with dementia has impacts on residents and many individuals become resigned to maintaining a passive role and keeping their social interactions superficial (Knight & Mellor, 2007). As a result, persons living with dementia in LTC institutions are more likely not to be included in leisure, recreation and social activities and remain at the greatest risk of social isolation, loneliness, and depression. As a response to this, Theurer et al. (2015) called for a social revolution in residential care through an over-turning of the long-standing tradition of psychosocial care (such as provided by some therapeutic recreation programs) centred on superficial social programming to providing opportunities for emotional and meaningful social engagement.

Despite these standard approaches, some research has explored the important role that leisure can play to support culture change in LTC institutions. For example, Fortune and Dupuis (2018) explored the ways that leisure was supporting the values embedded in the culture change movement and were able to see how leisure can play an integral role in transforming LTC institutions into caring communities. Fortune and Dupuis (2018) identified five ways that illustrate leisure's capacity to contribute to caring LTC communities where everyone can derive

meaning and joy from their experiences and relationships: expanding person-centred and relational leisure opportunities, sharing power in decision-making, celebrating lives by seeing individuals in their broader life context, nurturing a relational community, and working collaboratively to navigate risk and address challenges. Leisure programs and practices can contribute to culture change by creating spaces for relationships between residents, team members, and family to develop and deepen (Fortune & Dupuis, 2018). However, unless intentionally planned with residents' choice and citizenship rights in mind, leisure in LTC institutions could end up reinforcing control and compliance (Klaassens & Merijering, 2015). Although this research demonstrates the different ways that leisure spaces can support culture change in LTC institutions, very little research has explored how leisure might support (or undermine) the social citizenship of residents and persons living with dementia in the context of LTC institutions. In the next section, I explore the importance of a social citizenship lens to supporting meaningful leisure in LTC institutions.

Addressing meaningful leisure in LTC – A Social Citizenship Approach

Sund et al. (2023) argued that although active aspects of citizenship and political influence are normally centred on public arenas of society, LTC institutions themselves are deeply ingrained in the political. More specifically, an activist lens of citizenship in LTC institutions recognizes residents' expressions and actions as holding transformative power; interpreting residents as intentional and capable shows us ways to support residents' efforts to practice their citizenship (Sund et al., 2023). Attempts to influence change can take form in more indirect and embodied forms of communication highlighting the importance of recognizing and paying attention to expressions of residents as possible acts of resistance rather than pathologizing such expressions as a symptom of dementia (Sund et al., 2023). Arts-based interventions have been employed in

the LTC setting in an attempt to embrace non-verbal communication, intersubjectivity, affect and embodied expression (Kontos & Grigorovich, 2018a).

Art-based Interventions.

Much of the research using a social citizenship lens in the context of LTC focuses on the arts. Traditional arts programs in LTC institutions are designed and implemented in the context of structured leisure and recreation therapy as a form of ‘maintenance entertainment’ that aims to ‘keep people happy’ (Basting, 2009) with little creative challenge (de Medeiros & Basting, 2014; Basting, 2009). For people living with dementia, common arts-based programs include music, art therapy, visual arts, and drama, and are most often administered as therapy (Kontos & Grigorovich, 2018a). However, Kontos and Martin (2013) argued that the arts are an important means of self-expression for people living with dementia as they draw on the body’s potentiality for innovation and creative action, supporting non-verbal communication and affect (Kontos & Martin, 2013). The model of relational citizenship brings further attention to how the capacities and sense of the body are central to body-self/body-world relations (Kontos & Grigorovich, 2018a).

Drawing on these ideas, an innovative dance program has been designed for people living with dementia in LTC institutions, the *Movement to Music* program (Kontos & Grigorovich, 2018a). The program is offered by teachers from Canada’s National Ballet School and is developed in partnership with Baycrest Health Sciences (Kontos & Grigorovich, 2018a). By applying the framework of relational citizenship, the authors propose that dance emerges from the non-conscious realm of habituation rather than conscious acquisition of principles and rules (Kontos & Grigorovich, 2018a). Dance can be described as a bodily form of consciousness or the body’s pre-reflective ability to direct itself toward the world and can serve as a unique platform

for non-verbal communication, emotions, and meaningful interaction, greatly enhancing the sense of relational citizenship in people living with dementia (Kontos & Grigorovich, 2018a). Kontos and Grigorovich (2018a) suggest that dance holds great significance for individuals with cognitive challenges as it enables individuals to interact with the world and others through their bodies. The experiences of dance for people living with dementia were showcased in the short video, *Dancer Not Dementia*: <https://youtu.be/gHIh4bFvmIk?si=MtYE2Tru1Urw8SAF>. Despite the potential of these dance programs to support the relational citizenship of people living with dementia, such programs are not offered systematically across LTC institutions, nor is dance supported through arts and leisure programming in ways that support embodied relationality (Kontos & Grigorovich, 2018a).

Music can also be an important means of self-expression for people living with dementia in LTC institutions. Musicality in general can be described as a bodily form of consciousness (Kontos & Grigorovich, 2018b). In an analysis done by Kontos and Grigorovich (2018b) of two people living with dementia in a LTC institution, the authors were able to demonstrate that musicality is embodied and persists despite even more severe cognitive impairment. Ongoing incorporation of musicality in the presence of cognitive impairment implies a profound understanding that extends beyond cognitive functions; it suggests a pre-reflective mastery of the world through complete immersion within it (Kontos & Grigorovich, 2018b). Expressing the self through music can be an important way to support the relational citizenship of persons living with dementia in LTC institutions. Yet, music in these settings (similar to dance) is often restricted to passive entertainment or its application as a therapeutic tool to improve ‘behaviours’ and cognitive functioning of residents, often through music therapy.

Kontos et al. (2017) drew on findings from a mixed-method study of specialized, red-nosed elder-clowns in a LTC institution to advance a model of relational citizenship for individuals living with dementia. Here, the authors aimed to examine how the core tenants of relational citizenship, embodied selfhood and relationality, might be supported at a micro-level of care (Kontos et al., 2017). Elder-clowning is an arts-based approach in dementia care. Therapeutic clowning began in the 1970s in the United States with children as the primary target. In the late 1990's, clowning had been adapted for specific use with the dementia population (Kontos et al., 2017). Elder-clowns distinguish themselves from therapeutic clowns by avoiding the traditional heavily made-up white-faced clown with exaggerated smile and oversized shoes, and rather keep their faces natural with minimal make-up and wear clothing that evokes an earlier era such as 1950s swing dresses (Kontos et al., 2017). Elder-clowns' activities rely upon a resident's biographical information such as life history, preferences and hobbies that are typically provided by the healthcare staff (Kontos et al., 2017). The central tenants of relational citizenship, embodied selfhood and relationality, were observed by researchers in the interactions between residents and elder-clowns. For example, embodied expressions of creativity were seen when one elder clown was able to interpret a resident's bodily movements as artistic expression and supported this, leading to a reciprocal creative exchange (Kontos et al., 2017). These interactions provide insight into how relational citizenship can be inclusively and fully supported in the context of LTC settings (Kontos et al., 2017).

Art created by people with dementia and works that transmit experience not only have the potential to change the way individuals think about dementia but also teach about the importance of human relations in general and about the depths of our own personhood (Windle et al., 2020). This was exemplified in the study mentioned previously by Dupuis et al. (2016) where people

with dementia and their family members worked with one visual and performance artist and a researcher to co-create an artistic reflection about what individuals living with dementia wanted to share with the world about themselves. Despite evidence that art-based initiatives have the potential to enable people with dementia to enact their citizenship, these programs are not widely implemented within LTC.

Peer Mentors.

In a one-of-a-kind study completed by Theurer et al. (2022), concepts of social citizenship were drawn upon when developing a peer mentoring program entitled the Java Mentorship program. In this program, volunteers, family from outside the residential setting and residents meet as a team, receive training and provide visits in pairs to residents who are lonely and socially isolated (Theurer et al., 2022). This program was designed to be inclusive of residents living with dementia and other cognitive challenges. Here, resident mentors with dementia are paired up with community mentors who provide support as needed (Theurer et al., 2022). The researchers described the experiences of being a mentor from the perspectives of residents living in LTC institutions and identified three overarching, inter-related themes from their analysis: helping others; helping ourselves; and building a bigger social world, facing challenges and learning together (Theurer et al., 2022). In addition to addressing concerns surrounding loneliness and social isolation often experienced in LTC settings, being a peer mentor may enable people living with dementia to regain their social position as social citizens by staying connected to and contributing to the community. Important to social citizenship/relational citizenship is the reciprocal nature of relationships. Some mentors in this study described the benefits of being a mentor as reciprocal, where mentors not only felt they were helping others but were receiving help themselves (Theurer et al., 2022). Some visits from mentors helped to

establish relationships with people outside of the program, extending their social world (Theurer et al., 2022). Peer mentoring demonstrates a form of active citizenship where people living with dementia are seen as being able to actively contribute to the community life.

Although this peer mentorship program may be an important way to support the social citizenship of residents living in LTC institutions, a few limitations were identified. This study failed to explore why isolated residents are isolated in the first place, potentially ignoring the larger social and environmental structures at play. It is also unclear if the mentees in this program had voluntarily signed up or if this program was forced upon individuals. Along with having a right to choose to participate, residents should also have the right to choose not to participate. Assuming that an individual requires/wants a peer mentor may undermine the citizenship of the mentee. Although social isolation is a persistent issue amongst residents living in LTC institutions, I fear that programs such as these may counteract tenants of citizenship if the choices of residents and persons living with dementia are not recognized and respected. It is also important to pay attention to the structures within the LTC culture that contribute to the lack of recognition and support of the social citizenship/relational citizenship of persons living within those settings.

Sexuality and Social Citizenship in LTC institutions.

Grigorovich and Kontos (2018) have explored supporting sexuality in residential care settings. Residents' sexual activity is rarely acknowledged or encouraged in LTC settings (Miles & Parker, 1999; Parker, 2007). In response, the authors propose an alternative to bioethics to guide decision-making in the context of sexuality in LTC institutions. This approach is grounded in a relational model of citizenship that reflects the importance of supporting the capacities, senses, and sociocultural dispositions of the body that are central to self-expression,

interdependence, and the relational nature of engagement (Grigorovich & Kontos, 2018). The embodied and relational ethic of sexuality upholds sexuality as fundamental to embodied self-expression (Grigorovich & Kontos, 2018), valuing sexual expression for its own sake, and recognizing it as a universal human need (Lottes, 2013). Grounding an ethic of sexuality in the relational model of citizenship broadens the goal of ethical decision-making from the duty to not only protect individuals from harm to the duty to also uphold and support the sexual rights of residents in LTC settings (Grigorovich & Kontos, 2018). Upholding positive rights to sexuality would include developing public health, professional training, and policy initiatives to raise awareness and to counteract the stigma that surrounds sexuality and dementia in later life (Grigorovich & Kontos, 2018). It would also require identification and correction of organizational practices in LTC institutions, and educational and organization initiatives that are sensitive to the complexity of balancing the rights of individual residents with those of other residents, as well as the rights of health-care professionals (Grigorovich & Kontos, 2018). Within a leisure setting, diverse leisure and social activities that are supportive of sexual expression and the formation of intimate relationships need to be adopted/developed (Grigorovich & Kontos, 2018).

Future Theoretical Advancements of Social Citizenship

As discussed in Chapter 1, a social citizenship lens has been critiqued for an absence of engagement with the insights of critical gerontology's theoretical sub field of embodiment and dementia, specifically embodied selfhood (Kontos et al., 2017). Despite theoretical research acknowledging that attempts to influence change can take form in more indirect and embodied forms of communication (Sund et al., 2023), there is little research to examine this in both community and LTC settings.

Additionally, researchers are calling for an advancement of social citizenship beyond humanism. Citizenship approaches to social justice have a mixed history, and as Bartlett and O'Connor (2010) acknowledge, there remains tensions within the application of citizenship-based thinking to contemporary dementia care policy and practice. Wolfe (2010) argues:

[M]ost of us would probably agree that ... people with disabilities deserve to be treated with respect and equality. But ... the philosophical and theoretical frameworks used by humanism to try and make good on those commitments reproduce the very kind of normative subjectivity – a specific concept of the human – that grounds discrimination against ... the disabled in the first place (xvi-xvii).

In short, by emphasizing normative conceptualizations of the human, social citizenship approaches can unintentionally reinforce a hierarchal system that categorizes beings based on their proximity to the human ideal (Jenkins, 2016). The term citizenship perpetuates a binary view, dividing individuals as citizens versus non-citizens. In addition, citizenship at its foundation is grounded in hegemonic ideologies that historically denied women's rights and recognition as citizens (Lister 1997, 1998). Critical posthumanism seeks to develop new ways of thinking about persons and personhood in ways that address hierarchies according to the human ideal (Jenkins, 2016). One approach described here is to replace the concept of the individual in dementia with that of the symbiont (Jenkins, 2016). Here, researchers are considering the role of dementia care in a technologically advancing society. Jenkins (2016) argues that contrary to existing models of care, which reflect the belief that there is no substitute for human touch, the idea that people living with dementia can and should form productive, meaningful and mutually beneficial relationships with machines (as well as other non-human beings), is central to the co-production of high-quality caring relationships. The use of artificial intelligence in care settings

is beginning to emerge. For example, Pan-European projects such as CompanionAble and Mobiserv have sought to create robots for use within residential care settings capable of inspiring interaction (Jenkins, 2016). The Japan-based company PARO was one of the first to pilot the use of robots in dementia care settings. PARO robots are designed to imitate baby seals and have been shown to lower blood pressure amongst older people in care environments (Robinson et al., 2015). Because this research is its infancy, it is unclear how human and non-human interactions and relationships might support (or not) the social citizenship of persons living with dementia. If approaches continue to focus on medical outcomes, such as lowering blood pressure, or reducing misunderstood expressions of people living with dementia, other potential outcomes might be missed. More research is needed in this area.

Moving Forward

In summary, the need to promote social citizenship is gaining recognition within the dementia care literature (Bartlett and O'Connor 2007) but remains under-theorized within dementia practice and research (Kontos et al., 2017). Some advances have been made in understanding what is meaningful to people living with dementia. For example, Peoples et al. (2022) completed a meta-study with the goal of investigating what people living with dementia perceive to enable or hinder social citizenship in everyday occupations. Four themes were identified: having rights acknowledged and seizing self-empowerment, experiencing stigma/marginalization, belonging and independence, and connecting with places of community and continuity (Peoples et al., 2022). However, much of the research conducted on social citizenship in the context of dementia has been conducted within a community setting and is focused on everyday occupations. The responses from people living with dementia in LTC institutions are likely to differ due to different socio-political and environmental influences within those settings. Additionally, very

little has taken into account relational citizenship or embodied methods of communication to support social citizenship in these settings. People living with more progressive forms of dementia and in LTC institutions have been largely excluded from the social citizenship research and discourse. Finally, very little research has explored how leisure might support or threaten the social and relational citizenship of people living with dementia in LTC institutions and therefore our understanding remains limited in this area.

With a theory of social citizenship still within its early developments, there is an opportunity to learn directly from people living with dementia in LTC institutions. To continue to advance the social citizenship lens, it is important to understand what is important to people living with dementia. A major aim of this research was to provide myself and others with the opportunity to learn from people living with dementia living in LTC institutions. Through acknowledging more embodied methods of communication and actions as purposeful and meaningful, I also aimed to understand how leisure is undermining and/or supporting citizenship within LTC institutions and how people living with dementia enact their social citizenship in leisure contexts within these settings. In my next chapter, I turn to how addressed the purpose and aims of this research.

Chapter 3: Methodology and Methods

Introduction

As a way to advocate for the rights of people living with dementia to be included in narrative research, I chose to draw on narrative inquiry as my methodology for this research. Narrative inquiry is a methodology that has been extensively described over the last three decades (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2019; Connelly & Clandinin, 1990; Risseman, 2008). Within this chapter, I begin by describing the turn to narrative inquiry as a research methodology. From here, I describe narrative inquiry as a storied and relational methodology to make the connection between where I am positioned theoretically and my chosen methodology for this study. In this section I briefly describe the philosophical underpinnings of narrative inquiry including the ontological and epistemological implications of this research methodology, which will help to situate my research within broader conversations about knowledge production. Here I will also discuss taking a decolonial approach to narrative inquiry, particularly in relation to resisting Global North epistemic norms of storytelling and knowledge production. In connection to social citizenship, I then describe narrative ethnography and its relevance in research with people living with dementia. Before outlining my research process, including my research setting, recruitment process, and the methods I utilized to collect stories, I describe relational ethics and how I maintained ethical relationships/processes throughout my inquiry process. This is followed by discussions on how I analyzed this data while maintaining my ontological/epistemological commitments and how I maintained rigour throughout my research.

The Turn to Narrative

Since the late 1980s and early 1990s, research in the social sciences has taken a narrative turn to studying experience (Pinnegar & Daynes, 2007). Pinnegar and Daynes (2007) describe four themes that are clear indicators of the movement toward narrative inquiry. These themes involve: changes in the relationships of researchers and research participants, kinds of data collected for a study, the focus of the study, and kinds of knowing embraced by the researcher (Pinnegar & Daynes, 2007). The first theme, relationship of researcher and researched, acknowledges that the researcher and the researched in a particular study are in relationship with each other and that both parties will learn and change in the encounter (Pinnegar & Daynes, 2007). The second theme, from numbers to words as data, describes the recognition that in translating experience to numeric codes researchers lose the nuances of experiences and relationships (Pinnegar & Daynes, 2007). The third theme, from the general to the particular, describes the understanding of the value of a particular experience, in a particular setting, involving particular people rather than a concern for generalizability (Pinnegar & Daynes, 2007). The fourth and final theme, blurring knowing, describes the turn from one way of knowing the world to an understanding that there are multiple ways of knowing and understanding human experience (Pinnegar & Daynes, 2007). Thus, narrative inquiry developed over time as a critique of positivist research where the goal is to locate a singular objective, Truth.

Clandinin (2013) makes clear that what separates narrative inquiry from other methodologies are the underpinning ontological and epistemological commitments. Clandinin (2013), however, points out that some forms of what is called *narrative analysis*, such as thematic analysis, linguistic analysis, structural analysis and visual analysis are used as methods within other qualitative research methodologies. Narrative inquiry, as its own methodology, has

developed important distinctions that have become guiding frames for what fits within the field of narrative inquiry (Clandinin, 2013). When working from a particular ontological and epistemological stance, narrative inquiry is a way of understanding and inquiring into experiences (Clandinin, 2013). It is deeply rooted in the dynamics of relationships and community, while also emphasizing knowledge that is co-created through relational and participatory practices. Engaging in narrative inquiry fosters an understanding of the complex relationships between individuals and their environments, creating space for transformative experiences.

Narrative Inquiry as a Storied and Relational Methodology

Narrative inquiry is rooted in Dewey's (1938) theory of experience, which frames experience as both personal and social, always unfolding within particular contexts. Dewey emphasized three central features of experience that underpin narrative research: the social dimension of inquiry, temporality of knowledge generation, and continuity that is not merely perceptual but ontological (Clandinin & Murphy, 2007). Here, individuals are always in relation, and always within a particular social context (Clandinin & Connelly, 2000). As Dewey wrote: "In an experience, things and events belonging to the world, physical and social, are transformed through the human context they enter, while the live creature is changed and developed through its intercourse with things previously external to it" (p. 251). Temporality in narrative inquiry refers to the way experiences are understood in relation to the past, present and future – not as fixed but as constantly evolving. Continuity speaks to how experiences grow out of one another and generate future experiences (Clandinin & Connelly, 2000; Clandinin & Rosie's, 2007). Dewey's relational ontology leads to epistemological implications, as knowledge is always socially and contextually produced. Thus, ontology and epistemology are understood as

intertwined. As a relational scholar grounded in social constructionism, I work from the understanding that knowledge is shaped through relationships, multiple truths coexist, and my understandings are influenced by my previous knowledge and experiences.

At its core, a story is a way of making meaning out of experience. Although other qualitative methodologies such as phenomenology are also utilized to understand experience, narrative inquiry is a unique methodology. Phenomenological research involves investigating phenomena through gaining an understanding of the essence of people's lived experiences, while narrative research involves capturing and interpreting stories to understand how people make sense of their experiences and perceptions. Many narrative researchers view human beings, the lives they live, and the world around them as texts (Randall & McKim, 2008). As Dupuis et al., (2016c) state:

In the day-to-day living of our lives, we story our lives and ourselves. In the reading of our lives over time, we come to understand ourselves more deeply and make meaning of our lives – how we come to make sense of our lives – through the patterns and changes in the themes our story embodies and the larger narrative contexts in which the story is embedded (p.329). Narrative inquiry is therefore concerned not only with individual experiences, but with the broader social, cultural, historical and political narratives within which individuals' experiences are constituted, shaped, expressed, and enacted. Stories are never told in isolation; they emerge through relationships and are embedded within power structures, norms, and collective histories (Frank, 2010).

Although narrative inquiry has been taken up in diverse ways, I am particularly drawn to approaches that resist rigid, pre-defined structures in favour of fluidity, uncertainty, and multiplicity in meaning-making (Frank, 2010). This is especially important when working with

people living with dementia whose stories may be nonlinear, fragmented, or expressed through gesture, affect, and embodiment. Even in these forms, stories offer profound meaning and insight (Baldwin, 2008; Kontos & Martin, 2013). Yet, while narrative inquiry critiques positivist assumptions, it has often remained situated within Global North epistemologies (Smith, 1999; Kovach, 2009). A decolonial approach invites us to question whose ways of knowing are valued, and how dominant research practices may marginalize alternative narrative forms. Indigenous and African oral traditions, for example, emphasize relationally, cyclical temporality, and communal storytelling (Archibald, 2008; Kovach, 2009; Smith 1999). A decolonial narrative inquiry expands what counts as storytelling to include embodied, emotional, and interactive forms, thereby challenging epistemic injustice (Fricker, 2007) and recognizing narrative agency in those whose voices have often been excluded (Baldwin, 2008). From this standpoint, a relational approach to narrative inquiry is not simply about collecting and analyzing stories. It involves co-constructing meaning in relationship with participants and attending to the social, cultural, and institutional contexts in which stories are told and lived (Clandinin, 2013; Frank, 2010). Stories are shaped through the research relationship itself, and the researcher's presence is always part of the inquiry.

Clandinin and Connelly (1998) outlined four key terms in narrative inquiry emerging from their view of experience as a storied phenomenon: living, telling, retelling, and reliving. People live out stories and tell stories of their living (Clandinin, 2007). As we retell our lived and told stories, we may begin to relive our stories. Through this process, we re-story ourselves and perhaps in this process begin to shift the institutional, social, and cultural narratives in which we are embedded (Clandinin, 2013). This can be especially powerful in dementia research, where

dominant narratives often frame dementia as loss or tragedy. Through narrative inquiry, these grand narratives can be challenged and re-authored (Bartlett & O'Connor, 2010).

Just as counter-narratives resist dominant ideologies, narrative inquiry also calls for a shift in how we engage with stories – not merely as objects of study but as relational acts of meaning making (Frank, 2010). Morris (2002) captures this shift through the idea of ‘thinking *with* stories’ as opposed to thinking *about* stories (Morris, 2002). Here, Morris (2002) emphasized that thinking involves a crucial collaboration with feeling. The concept of ‘thinking *with* stories’ is meant to oppose and modify (not replace) institutional Global North practice of thinking *about* stories where reason and emotion are viewed as binaries (Morris, 2002). Thinking with stories is primarily thinking relationally, as Clandinin (2013) describes: “as narrative inquirers, we become part of participants’ lives and they part of ours. Therefore, our lives – and who we are and becoming, on our and their landscape – are also under study” (p. 24). This perspective aligns with decolonial approaches, which emphasize that storytelling is not simply an act of representation but a way of knowing (Archibald, 2008; Kovach 2009; Tuhiwai Smith, 1999). Embracing diverse storytelling forms- including oral, embodied and collective narratives- expands how knowledge is understood and validated (Silko, 1996; Fricker, 2007).

Narrative inquiry is further guided by the three commonplaces: temporality, sociality, and place (Clandinin, 2013). Temporality involves attending to the past, present, and future of people, places, things and events under study. Carr (1986) highlights how “we are composing and constantly revising our autobiographies as we go along” (p. 76). Temporality then is always attending to someone’s experiences as well as our own in a particular time in relationship with the past and the future (Clandinin, 2013). Temporality in the context of dementia can be interesting and complex as past, present, and future can be experienced at the same time for

people living with dementia (Hydén, 2018). The sociality commonplace describes attending to both personal and social conditions. Carr (1986) points to the larger cultural, social, institutional and familial narratives that provide narrative contexts highlighting the embeddedness of each individual's experience in particular contexts as well as in particular times and places (Clandinin, 2013). Secondly, the sociality commonplace directs attention to the inquiry relationship between the researchers' and participants lives, where the researcher is not an objective observer in this situation but relationally embedded in it (Clandinin, 2013). The sociality commonplace in research with people living with dementia must recognize the continued relational capacities of people living with dementia and the diverse ways that people living with dementia reflect their relationality. The place commonplace reminds us that "all events take place some place" (Connelly & Clandinin, 2006, p. 480). People, place and stories are inextricably linked (Basso, 1996; Silko, 1996), meaning that place influences the self as well as personal and practical knowledge (Clandinin, 2013). For example, an individual who grows up in a city versus a small rural town will have different life experiences and different stories to tell because of those experiences. In the context of this study, institutional narratives of a particular LTC setting has influence on residents living within the setting. Individuals living in LTC settings may be narratively dispossessed and find their stories marginalized (Baldwin, 2008) when individual stories are not being listened to and are overwritten by institutional narratives.

Understanding narrative experience requires attention to both the individual and the social structures within which stories are lived and told. A purely individual approach risks de-contextualizing stories from the environments that shape them. An ethnographic approach to narrative – what Gubrium and Holstein (2009) term narrative ethnography – offers a way to situate stories within their broader interactional, institutional, and cultural contexts.

Narrative Ethnography

As discussed in Chapter 1, Gubrium and Holstein (2009) argue that it is no longer sufficient to evaluate stories solely on an individual level. Elements of narrative control—factors that enable or restrict certain stories from being told—might not be fully revealed when focusing only on individual narratives (Gubrium & Holstein, 2009). Narrative ethnography expands the scope of research to consider not just the internal themes, structures, and organization of stories, but also the external narratives and their contextual frameworks (Gubrium & Holstein, 2009). In this approach, storytelling itself becomes a significant meaning-making activity (Gubrium & Holstein, 2009). This shift in focus emphasizes the importance of examining the interactional and institutional levels of control, leading to a deeper understanding of the relationship between narrative experience and meaning (Gubrium & Holstein, 2009). By investigating these broader contexts, narrative ethnography aligns with social/relational citizenship as it reveals how external factors shape an individual's ability to assert narrative agency and participate meaningfully. Consequently, narrative ethnography goes beyond the narrative to investigate the context of its creation, encouraging the use of narrative methods alongside ethnographic tools like close observation and interviewing (Gubrium & Holstein, 2009). I was drawn to an ethnographic approach to narrative inquiry - narrative ethnography – as my methodology as it also reflects strategies for promoting social citizenship. I describe later in this Chapter how an ethnographic approach to narrative inquiry was specifically utilized in my research.

Research Plan and Process

I conducted my research within a LTC institution in an urban community in southern Ontario called Evergreen Manor². My research process included research conversations with people with

² Name of LTC institution has been changed

dementia living at Evergreen Manor and recreation professionals working within the home. I also observed leisure programs run by the recreation staff members who consented to participate in this project, and that resident participants were engaged in.

As mentioned earlier, I drew on narrative citizenship and an ethnographic approach to narrative inquiry in this research to support the co-constructed nature of storytelling for people living with dementia and capture the social dimensions of the story telling process. Although this research intended to support the narrative citizenship of people living with dementia by hearing their stories in the different ways they might express those stories, including the stories of the recreation staff was important to contextualising and filling out those stories. I also observed leisure programs the residents participated in so that I could experience first-hand how leisure might be supporting or limiting the social citizenship of people living with dementia in the setting. These observations also provided me with another opportunity to observe the embodied and non-verbal ways that people living with dementia might tell their stories and express their social citizenship. Both my research conversations and the observations helped me to understand how experiences and stories were being shaped by broader social, cultural, and environmental contexts within this particular home.

Relational Ethics

Before I turn to describing in more detail the setting where my research took place and the research process I employed in this study, it is important for me to talk about the relational ethics that guided my work throughout the process. As mentioned earlier in this Chapter, narrative inquiry is first and foremost a relational research methodology (Caine et al., 2013). As Clandinin (2007) wrote “the challenge for the narrative inquirer therefore is less one of achieving the highest possible grade of epistemic clarity and is instead how to integrate ethical and epistemic

concerns... how to put knowledge in the service of enhancing human experience” (p. 46). Thus, narrative inquiry is deeply ethical. In narrative inquiry, researchers intentionally come into relation with participants, with everyone being influenced by the process. Relational ethics shifts beyond an ethics of care where rather than ‘caring for’ researchers are moving towards a narrative inquiry relationship of ‘belonging and becoming with’ one another (Caine et al., 2019). Throughout my study, I remained aware of my own role in the inquiry, recognizing that I am not an objective observer but part of the relational process – my presence shaped the stories that were told and the setting shaped me and my experiences in the setting (Baldwin, 2008).

Relational ethics is premised on the idea that ethical decisions are made within the context of a relationship and involve mutual respect, engagement, embodied knowledge, environment, and uncertainty (Pollard, 2015). Mutual respect is one way to mitigate power differentials (Pollard, 2015). I was committed to attending to the overall quality of my relationships with study participants through bonding and sharing, and mutual respect that was based on the norms of equity and complementary reciprocity (Pollard, 2015). As a way to build relationships within the Evergreen Manor, I spent time immersing myself in the environment. This involved spending time with and getting to know potential resident participants, having lunch with the staff, volunteering to help at events that were not part of my observations, and even attending an outing when an additional set of hands was needed. I not only spent time interacting with the recreation staff and the participants of this project, but with many other individuals that occupy this space including community members, volunteers, family members, personal support workers, horticultural team members and more. Engagement recognizes the self as embodied, a self that is the product of relationships with others (Pollard, 2015). Throughout my time at my research site, I was careful not to project my own thoughts and opinions onto participants. Rather

than trying to put myself in the position of participants, I intentionally engaged with participants to better understand their experiences. I drew on my prior experiences working in LTC institutions and with persons living with dementia along with compassion to help guide ethical action.

The environment refers to the social context in which individuals are situated, recognizing that humans are social beings who are constantly affected by our relationships and social surroundings (Pollard, 2015). During this study, I was mindful of the social and physical spaces I and others in the home were interacting in and paid particular attention to how my own presence might be shaping the social and physical environment of the home as well as how the space might be influencing me.

Finally, uncertainty occurs when value-based questions create difficulty in making a decision (McPherson et al., 2004). Uncertainty explains that one must be aware that knowledge is constructed within the context of the situation and is incomplete (Pollard, 2015). I remained self-reflective throughout the study, continuously negotiating my research decisions and being mindful of the ethical relationships that developed as the study progressed. These relationships were renegotiated as participants renegotiated their own understanding and commitments to the project (Poole, 2021). Recognizing that I could not fully detach from the research, I aimed to reflect the mutual process of meaning-making in my work with participants. Reflexivity was crucial to maintaining an ethical research process, ensuring that participants shared their personal stories because they wanted to, rather than feeling compelled to do so.

When it comes to the ‘truth’, the most important aspect for me is the real emotional consequences that stem from how an individual perceives a particular phenomenon. It is not important to me that an individual is able to tell a story with complete ‘accuracy’. I would rather

capture their feelings and emotions. I aimed to support individuals in telling their own stories, not speak over them with my own interpretations. When speaking to participants, it was incredibly important to acknowledge that the COVID-19 pandemic was/is traumatizing for many residents, staff, and family members. I was sure to have sensitivity when discussing these topics with participants and deeply considered my impact. For me, this meant when formulating questions I considered what needs to be asked and what does not, respecting the privacy of individuals. I remained open and honest and set those boundaries with participants by having conversations about their right to not disclose certain information. Additionally, it was important that the participants understood exactly what I was doing. By this I mean my overall intent and purpose of the research and why I value their willingness to participate was made clear repeatedly throughout the time I spent at the home. I aimed to be as transparent about the research process as possible, explaining every stage to participants as necessary. When I set out to do this research, it was important to me that my research in some way supported the culture change movement needed in LTC institutions. I was open about my aims throughout this project and my desires to mobilize my findings to support change beyond the academic community in the future. It was important for me to remember that although this research is apart of my Master's program that will lead to future advancements in my own career, such as continuing education, I was not conducting this research solely to advance myself or to simply produce; I conducted this research to create meaning and change to support a population I care deeply about.

In summary, I aimed to be as transparent as possible throughout the entire research process not only with myself, but with everyone involved. I listened to and valued the stories of individuals. I strived to do *research with* people not *on* people and to never treat individuals as

objects I can pull information from for my own benefit. Most importantly, through this research, I want to give back to participants and create true meaning through my research.

Setting

The setting for this research is a not-for-profit, charitable organization owned and operated by a religious-affiliated organization. This unique organization is composed of four interconnected components: a LTC building, retirement living, life lease townhomes, and the Adult Day Program. While this research specifically took place at the LTC building (Evergreen Manor), all four of these components are deeply integrated within Evergreen Manor. For instance, individuals living in the lease townhomes may have spouses residing in Evergreen Manor, and all community members have access to the café located in the home.

Evergreen Manor itself provides long-term accommodation for 150 residents across three floors, divided into five home areas: Apple Glade, Birch Hollow, Spruce Valley, Elm Crest, and Cedar Haven³. Each home area includes a dining room, a TV room, a nursing station, and a recreation room equipped with desks and ample storage for supplies and space to support small group activities. Evergreen Manor is currently committed to a person-centred approach to care, partnering with educational institutions to encourage students to focus on individuals' unique stories, not just their diagnoses. This approach is guided by the Eden Alternative, which fosters a sense of purpose by engaging residents in meaningful activities and acknowledging their wisdom. While the Eden Alternative has advanced the culture change movement, its focus on person-centred care leaves room for further innovation through models of social or relational citizenship.

³ Names of home areas have been changed.

Upon entering Evergreen Manor, visitors are greeted by a bright, open space, the Lounge. Within this space, the reception desk, café, and a spacious seating area with couches, tables, and chairs create a welcoming atmosphere. I observed that families often gather here, filling the space with warmth and connection. Visitors are often welcomed by the friendly café staff and receptionists, but the true star of the lounge is Sunny, a lively cockatiel who delights passersby with his rendition of *If You're Happy and You Know It*. Sunny often draws families, particularly those with children, who stop to enjoy his cheerful performances. Nearby, a large fish tank filled with colourful fish invites visitors and residents to pause and watch.

As visitors turn left from the entrance to the home, they see that there are meeting rooms that I came to understand are used for care conferences and staff orientations, and a large community gathering space for day programs and large group programs such as church services. Continuing down this hallway leads to the management offices, supporting accessibility for staff and residents.

Continuing straight from the lounge is a secured back area, where a wheelchair-friendly path meanders through gardens, trees, and seating areas for reflection. The community garden, a standout feature, is accessible via the front entrance or a locked gate at the back. However, not all residents can freely visit the garden. For safety reasons, some residents wear alarm bracelets that trigger alerts if they try to leave the building, restricting their access without supervision. While these measures help prevent 'wandering', they also highlight the balance between ensuring safety and promoting autonomy. The gardens themselves include over thirty individual plots designed to promote sustainable, organic horticulture. These plots consist of 13 in-ground beds, 9 raised beds, and 5 grow towers that can be rented by residents, staff, or community members for a small fee from May through October. During the growing season, the gardens are vibrant with

a variety of flowers, vegetables, and herbs. Residents (including those living in the Town Homes and the Retirement Home) and visitors are encouraged to pick their own produce or blooms using the ‘pick-your-own-flower’ cart which is conveniently stocked with shears and vases to bring freshly cut flowers indoors.

To the right of the lounge, the five home areas provide warm and personalized living spaces. *Elm Crest*, located on the first floor is home to Rio, an orange tabby cat who often lounges in a cardboard box by the nurses’ station or visits residents who have taken responsibility for his care. While the presence of a nurses’ station reflects the clinical aspects of care, it coexists with efforts to create a more home-like setting, such as taking on care roles for Rio. Also to the right of the lounge is a gated outdoor area with tables, chairs, and greenery, offering space for fresh air, which residents on the Elm Crest can access. On the second floor there is a shared balcony between *Spruce Valley* and *Birch Hollow*, with doors wide enough for wheelchairs to fit through so that residents can access the outdoors from their floor. Another cat, known for occasionally donning crocheted hats, often greets residents and visitors on their way out of the elevator onto the second floor. The third floor, during my time there, housed the big bird aviary, though it rotates between home areas quarterly. This floor has the same layout as the second floor, with one secured home area to the left (Apple Glade) and another home area to the right (Cedar Heaven), with a balcony in between. However, residents of Apple Glade, a secured unit, do not have access to this shared space without supervision or permission. Apple Glade is the only unit in the home that is separated by a door and requires a code to enter and exit.

With its thoughtfully designed spaces and integration of pets, plants, and community activities, consistent with the Eden Alternative model, this LTC institution strives to create a homelike environment rather than a traditional institutional one. This contributes to a calm,

inviting atmosphere; however, there remain opportunities to further improve how the space supports meaningful engagement and relational caring, particularly through deeper integration of social and relational citizenship principles. I will talk more about this as I describe and interpret the stories told during this project.

Participant Recruitment /Sampling

People Living with Dementia.

Using purposeful sampling, I recruited six residents living with dementia at the LTC institution. Purposeful sampling is a technique widely used in qualitative research for the identification and selection of information-rich cases (Patton, 2002). I utilized criterion sampling to identify participants (Palinkas et al., 2015). The objective of this form of purposeful sampling is to identify and select cases that meet some predetermined criterion of importance. In the context of this study, residents had to be able to communicate verbally, at least to some degree, in English. In addition, residents had to have lived at the LTC institution for a period of at least three months. The move to a LTC facility can be particularly traumatic for residents (Wiersma, 2010). I wanted to ensure that residents had enough time to adjust to a new environment and to explore potential leisure pursuits within the home. To recruit people living with dementia, I worked with the recreation staff on all the home areas and recreation manager to identify eligible participants.

Initially, each recreation staff member printed out a list of all residents living on their designated home areas and highlighted the names of individuals on their home areas that they thought might be willing and eligible to participate. Once I had a list of potential residents, I spent time immersing myself in the environment, taking the time to casually interact with potential participants. When I first arrived at the home, there was a COVID outbreak on Elm

Crest, and I was not able to spend time in that area initially. However, I was able to spend time on the other four home areas, and after getting more comfortable in the environment and learning more about each resident, I selected five residents from these four home areas I had access to who all indicated an interest in participating in my research.

The Recreation Manager then assisted me in getting substitute decision maker (SDM) consent needed from four of these five residents. After sending my email script to these SDMs, I quickly heard back from four SDMs who were eager to have their relatives take part in the research. However, one of these four SDMs never did send back the consent form despite several follow up emails over a two-week period. I then selected a new participant who was interested in participating in my project and, after having a brief conversation with the newly selected participant and concluding that they would be interested in participating, the Recreation Manager provided me the contact information of their SDM. I quickly heard back and received consent from this resident's SDM, who was also excited to support their relative's participation.

After the COVID-19 outbreak on Elm Crest ended, I visited the floor to get to know residents and identify potential participants on that floor who might be interested in participating. The recreation staff member on the floor suggested a particular resident who might be interested, and I decided to sit down with this individual for a casual conversation. They were more than happy to chat, even mentioning that they were raised to "never turn down a conversation." Our talk was lively and engaging and we shared jokes and discussed recreation programs and the recreation staff member who facilitates them. When I asked if they would be interested in participating in my research project, they readily agreed. Following this, I approached the Recreation Manager to discuss contacting the resident's SDM. The manager informed me that the SDM would be visiting later that day, allowing me to speak with them in person.

When the SDM arrived, I introduced myself and explained the project while in the resident's room. However, the SDM immediately dismissed the idea, deciding on the resident's behalf that this was not something they would be interested in. Notably, this decision was made without consulting the resident, who was sitting right there and perfectly capable of responding. Instead, the SDM asserted that the resident would not be able to recall or provide the necessary information for the project. This interaction starkly illustrated the stigma surrounding dementia and its impact on narrative citizenship. Despite our earlier conversation, where the resident demonstrated clear memory by recalling the recreation staff member's name and various programs, the SDM's assumptions overshadowed the resident's voice. Even if the resident was unable to recall programs or specific details, this would not make their story any less valuable. I took this opportunity to explain that a key aim of the project is to challenge such stigma and emphasize the importance of giving people with dementia the chance to share their own stories. Yet, the SDM's insistence reflected a common, yet harmful, misunderstanding of dementia and its effect on autonomy and personhood.

After not receiving consent from this SDM, I worked with staff to identify a new possible participant. At this point, I had gotten to know one gentleman on this floor through casual conversations and interactions. I thought this individual might be interested in participating, though, I was not sure of their diagnosis. I was able to confirm that this resident did have a form of dementia. I then went to ask the resident if he would be interested in participating and he was happy to support the project. I emailed the SDM directly with the information letter and consent form. Quickly, the SDM replied back with the consent form signed.

The sixth and final participant was able to provide consent without the use of a SDM. I went to visit with this resident in their room to read them the information and consent form and

answer any questions they might have. At first, they were hesitant stating that they did not have anything bad to say about the home and may not be able to give me the answers I am looking for. I informed them that I simply wanted to hear about their thoughts and experiences, that there were no wrong answers, and that positive stories are equally as valuable. After answering some clarifying questions, this resident agreed to participate in this research project.

To sum up, six residents living with dementia at the research site participated in this study, four women and two men. Five required SDM consent and the sixth was able to consent on their own. The residents’ ages ranged from 59-95. The residents lived on one of the five home areas, with two residents living on the same home area on the second floor. The table below provides a brief overview of the six resident participants.

Participant Name⁴	Gender	Age	Home Area	Time Living at Home (as of October 2024)
Elaine	Female	95	Cedar Haven	1 year and 4 months
Daniel	Male	89	Birch Hollow	1 year and 2 months
Helen	Female	83	Spruce Valley	1 year and 8 months
June	Female	95	Birch Hollow	5 years and 7 months
Frank	Male	59	Elm Crest	2 years
Elizabeth	Female	66	Apple Glade	8 months

A former nurse, Elaine, took great pride in caring for her patients. Growing up in the country, she discovered a love for gardening- a passion that still brings her joy today. At Evergreen Manor, Elaine cherishes her time outdoors, especially in the gated backyard, where she enjoys visits with her family. Though she wishes they could visit more often, she finds comfort in their

⁴ Names have been changed.

time together. Elaine described herself as a loner, someone who enjoys her quiet moments but admits to feeling bored now and then. While she doesn't always join group activities, she likes being invited – it makes her feel included. Though reserved, Elaine is not one to be overlooked. When it comes to her choices, she makes her presence known, advocating for herself with quiet determination.

Daniel spent his career as a production manager at a newspaper, a job he speaks of with pride and admiration. He respected the company he worked for and held great regard for its leadership. Outside of work, Daniel and his wife share a love of golf and jazz music, and in the past often took trips to Toronto for Jazz shows- memories he treasures deeply. Family is at the heart of Daniel's life. His face lights up when he talks about his wife and three children, and he especially enjoys the simple tradition of picking flowers with his daughter to give to his wife or the nurses on his floor. Thoughtful and warm-hearted, Daniel finds happiness in life's quieter moments, particularly those spent with the people he loves.

Helen grew up on what she fondly calls "the funny farm," where she learned the value of hard work- driving a tractor, tending the land, and caring for animals. Cows were always her favourite. She often reminisces about her father, who balanced running the farm with his dedication to charity work with children. A framed photo of him hangs on her wall. Being outdoors still brings Helen joy, and she frequently talks about the sense of accomplishment she felt working on the farm. Her room is filled with photos of her children and grandchildren, whom she is immensely proud of. Helen described herself as a happy person, and it's evident in the way she smiles when speaking about her family and life on the farm.

June is as straightforward as they come, a quality she acknowledges has sometimes led to conflict. She grew up in the country and deeply values the time she spent outdoors and in her

garden growing vegetables. Now, she enjoys visits from her husband, three children, and grandchildren, though she insists they should never feel obligated to visit too often – she values her independence. She is not one for a large social circle, preferring to keep to herself, yet she enjoys joining group activities on her floor and engaging in casual conversations with staff. June values her independence but also appreciates moments of connections with others.

A natural leader, Frank thrives on bringing people together. He takes great pride in his accomplishments – graduating high school, earning his harness horse driving license, getting married, and raising three children. He often shares advice with his kids, encouraging them to build confidence by starting small and working their way up to bigger challenges. Frank sees himself as a strong speaker and an active participant in the world around him. Whether he’s chatting with fellow residents, joining group activities, or watching sports, he is always engaged. His energy and positive attitude make him a central figure in the community, someone who not only enjoys life but also inspires those around him.

Elizabeth described herself as a happy person, someone who finds joy in being around others. She loves going for walks, exploring, and spending time in the gardens, where she often admires the flowers. Before moving into LTC, she lived with her son, whom she speaks of with deep love and appreciation. He still visits her, which she is grateful for. However, Elizabeth is not entirely content with her living situation - she finds her roommate rude at times and prefers to keep to herself when it comes to other residents. Still, she remains optimistic, finding comfort in her connections with people, particularly staff, and in the moments she spends outdoors.

Recreation Staff.

I also recruited five recreation professionals working within the LTC institution, one from each home area, to participate in the project. Three of the recreationists were female and two

were male. These recreation professionals were the individuals running the leisure programs that were observed. To be eligible to participate, recreation professionals had to be able to communicate verbally in English. Additionally, I had initially stated that staff participants had to have worked at the home for at least three months. The rationale for this being that three months is a good amount of time for the recreation professionals to get to know how their particular department works and the resources available to them. I also thought this time would allow staff to get to know residents as the extent to which an individual knows a resident may influence how they support residents' social citizenship and personhood. However, this ended up not being relevant as the shortest amount of time any of the recreation staff had been at Evergreen Manor was 15 years. I shared the information letter and consent form with all recreation staff by email. I received two signatures over email while the remaining three requested that I gain their verbal consent in person. I let the recreation staff know that I would be available by either phone or email to answer any questions before or after signing consent. The table below gives a brief overview of the five recreation staff who consented to participate.

Participant Name⁵	Gender	Home Area	Time Working at this Home
Martha	Female	Spruce Valley	15 years
Luke	Male	Birch Hollow	24 years
Rebecca	Female	Cedar Haven	16 years
Ethan	Male	Elm Crest	28 years
Samantha	Female	Apple Glade	40 years (first 25 as PSW)

⁵ Names have been changed.

Once all recreation staff had signed the consent form, I had received assent/consent from the residents, and the SDM's consent where needed, I was able to begin observing leisure programs on the home areas.

Data Collection Methods: Capturing Stories

Participant Observations.

As described above, the ethnographic study of narrativity highlights the social dimensions of narratives. Within this approach, it is no longer sufficient to seek the meaning of narratives by examining their internal structure (Gubrium & Holstein, 2009). Narrative ethnography focuses on the contextual nature of stories, examining interactions and institutional structures to deepen understanding of the relationship between narrative, experience, and meaning (Gubrium & Holstein, 2009). Additionally, although narrative research has historically relied on spoken and written text, embodied methods of communication are also important to examine, especially for people living with dementia. Our stories are created through and within our bodies, but our bodies are also an important means by which individuals come to understand and share stories (Dupuis et al., 2016c) That is, our bodies are expressions of our stories, and our stories are expressions of our embodied experience of the world (Frank, 1991; Kontos & Martin, 2013; Phoenix & Sparkes, 2009). By examining bodily expressions in context, we not only come to understand important aspects of the self and lived experience, but also the features of our social world that trigger or limit bodily expressions (Kontos et al., 2015). Embodied self and expressions are an important aspect of relational citizenship and therefore important to consider.

I chose to begin with observations before completing any research conversations. When conducting research conversations with staff and residents, I wanted to have examples from observations to refer back to. I also wanted to continue to build rapport with resident and staff

participants during this time so that I could create a trusting environment when engaging in the research conversations with them. To complete the observation phase, I observed resident participants during their leisure pursuits organized by the home. More specifically, I identified and observed two recreation programs per resident, observing nine different recreation programs in total (one observation had two resident participants). This is outlined in the chart below:

Participant Name	Program Title(s)	Type of Program	Location
Elaine	Roman Catholic Mass Flower arranging	Large group Small Group	Community place (1 st floor) Recreation Room (Cedar Haven)
Daniel	Rock Music Bingo	Small group Small group	Dining Room (Birch Hollow) Dinning Room (Birch Hollow)
Helen	Opening Minds Through the Arts Farm Animals	Large Group Large group	Community Place (1 st floor) Gated backyard (1 st floor)
June	Bingo Dog Show	Small Group Large Group	Dining Room (Birch Hollow) Gated backyard (1 st floor)
Frank	Elvis Show Music on Patio	Large Group Small Group	Community Place (1 st floor) First floor gated patio.
Elizabeth	Bingo Elvis Show	Small Group Large Group	Recreation Room (Apple Glade) Community Place (1 st Floor)

I worked with residents and staff to determine what programs were being offered and which programs resident participants were most likely to participate in. It was important for me to respect the decisions and autonomy of residents participating in this research. There were a few occasions where I had planned an observation but the resident participants either chose not to participate or had other plans with family visitors. Even when no resident participants from this project were taking part in a program I had planned to observe, I joined the programs as a volunteer. This helped me to continue to build a strong rapport with recreation staff and other individuals within the home. An ethnographic approach to narrativity values personal connection and lived experience, which enhances understanding and enriches data collection (Goodall, 2004). Spending time in the environment fostered trust and authentic insights. After a few weeks of doing this, rather than being asked by staff and residents “who are you?”, I was greeted by many and welcomed into the environment. In addition, Baldwin (2008) suggests that stories can be articulated as much through movement as they can language. As mentioned earlier, the observations provided me with the opportunity to see how residents expressed important aspects of themselves and their social citizenship in social situations and through their leisure, and how the leisure they participated in supported and/or limited aspects of social citizenship.

Drawing on a social citizenship lens, I structured my observations around the six components of social citizenship and the opportunities provided to residents to experience growth, social positions, purpose, active participation, solidarity, and freedom from discrimination during leisure pursuits (Bartlett & O’Connor, 2010). I observed how these six components were facilitated and undermined through the structure of the leisure programs and through the actions of residents and recreation staff. When the social citizenship of residents was being undermined,

I was also able to observe signs of resistance, not only through verbal communication but also through more embodied methods of communication from residents.

While looking to observe the six components of social citizenship, I also looked to observe ways in which the narrative agency of people living with dementia was being supported.

Baldwin (2008) states that narrative agency is fundamental to being able to tell one's story. This narrative agency is dependent on being able to express oneself in a form that is recognizable as narrative, even if one's linguistic abilities are limited and having the opportunity to express oneself narratively (Baldwin, 2008). While completing observations, I observed if recreation programs provided the space for residents to express their narrative agency regardless of the ability to communicate verbally. For example, I looked to observe the narrative literacy of others and if staff/residents attended to non-verbal forms of communication during leisure programs.

Additionally, I was sure to leave space for residents to tell their own stories through our informal conversations during my observations.

Junker (1952) suggested a typology of roles from which the field researcher can choose: complete participant, participant as an observer, observer as a participant, and complete observer. The participant observer makes their presence known as a researcher and attempts to form relationships with the members of the group. This strategy, although most common, is most appropriate when the researcher has something in common with the members in the group (Van Der Hoonaard, 2012). If the investigator is visibly different from participants in meaningful ways, which is the case in the context of this study, the observer as participant is a more appropriate strategy (Van Der Hoonaard, 2012). The observer as participant also informs the members of the research setting that they are doing research but carries out a less involved role than the participant observer.

In the context of this study, it was important for me to recognize and acknowledge that I am not a member of this community. I participated actively in the leisure programs and supported the staff and residents in whatever ways they needed and seemed appropriate in the moment. My storyline in the home was the explanation I provided to individuals about the purpose of my research and how I wanted to participate. In my initial conversations with both resident participants and recreation staff, I had the opportunity to introduce myself and describe the purpose of my research. At the beginning of each observed session, I also provided a brief introduction of myself and my research and described how I would be helping out in the program while completing observations.

Once I entered the field, I was very attentive to my surroundings, making note of what I saw and how it made me feel (Van Der Hoonaard, 2012). To organize my thoughts throughout observations of the leisure programs, I took field notes. As Esterberg observed “writing is a way of making meaning” (2002, p.73). As I was making observations, I began to make sense of what I saw in my field notes. To collect field notes, I utilized my observation guide found in **Appendix C** to ensure that I was attending to the six components of social citizenship as well as aspects of narrative inquiry such as temporality, sociality and place. Although I utilized a guide to ensure I attended to the goals of my research, I was also flexible, allowing myself to observe things that I may not have expected to observe. During the observations of programs, I utilized this guide to first create jottings while in the field to help me remember details when writing up my full field notes after the sessions. My jotted notes consisted of brief notes, phrases, quotes, and key words that I heard/thought would help to jog my memory later on when I went to write up my full field notes. This process took practice, and I had to gauge the environment for when and how often it was appropriate to take notes. The more comfortable I became in the

environment, the more directly involved I found myself being in the programs. So, as time progressed, I took less jotted notes during the programs and instead was focusing on engaging with individuals, which felt more aligned with the relational approach I wanted to utilize in this research. When I was not able to take many jotted notes during an observation, I tried to sit down and take jotted notes immediately following a program before sitting down to reflect more deeply. When writing up my full field notes, I aimed to record as much detail as possible. At this point, I was careful to distinguish between what I actually observed and what I thought or felt about it (Van Der Hoonaard, 2012). I was also careful to distinguish between what people actually said and what had been paraphrased (Van Der Hoonaard, 2012).

Research Conversations.

Most narrative inquiries begin with the researcher engaged in conversations with participants who tell stories of their experiences (Clandinin, 2013). Here, the use of the word conversation rather than interview is intentional and purposeful. Conversations create a space for both the participant's and researcher's stories to be told (Clandinin, 2013) and recognize the relational, dialogical nature of these interactions (Watkins & Shulman, 2008). As opposed to interviews, conversations are flexible, and do not have the intention of being therapeutic, resolving issues, or providing answers to questions (Clandinin, 2013). The goal of these conversations was to support participants in telling their own stories and generating detailed accounts of experiences rather than brief answers or general statements (Risseman, 2008).

I drew from Holstein and Gubrium's (1995) relational approach titled 'the active interview' to support the participants in the telling of their stories. In alignment with a relational methodology, the active interview recognizes how participants and the researcher are both actively involved in the co-construction of knowledge. Similar to ethnographic approaches to narrative inquiry, this

approach also recognizes that each participant and the meanings of their experiences are not predefined but constructed in relation to the ongoing communicative contingencies of the back-and-forth conversational process (Holstein & Gubrium, 1995). An in-depth interview is an interactional process, more accurately described as ‘generating data’ than ‘collecting data’ (Mason, 2002). Holstein and Gubrium (1995) aim to strike a balance between not only *how* the meaning process unfolds in the research conversation but also *what* is being asked and conveyed. The *hows* of a research conversation refer to the interactional, narrative procedures of knowledge production, while the *what’s* pertain to the issues guiding the conversation, the content of questions, and the substantive information communicated by the respondent (Holstein & Gubrium, 1995). As a relational researcher, the *how* required that I intentionally attend to the relational processes of my interactions with participants. To reflect the relational and evolving nature of active research conversations, Pool (1975) emphasized “every interview is an interpersonal drama with a developing plot” (p. 193). As described earlier, narrative inquiry provides the opportunity to reject the status quo, opening up to new ways of being. Within the active interview, the goal is not to dictate interpretation through pre-determined agendas but to provide an environment conducive to the production of the range and complexity of meanings that address relevant issues (Holstein & Gubrium, 1995). Although participants actively construct and assemble answers in ways to tell their story, the active interviewer is responsible for inciting participants' answers and providing them with a measure of narrative guidance that maintains the necessary research focus (Holstein & Gubrium, 1995). Narrative complexity requires an interview format that accommodates contextual shifts and reflexivity (Holstein & Gubrium, 1995). The active interview therefore has two key aims: to gather information about *what* the research project is about and to explicate *how* knowledge concerning that topic is

narratively constructed (Holstein & Gubrium, 1995). As a relational researcher, I acknowledged that my research conversations were an important space to understand how participants understand their social world and to be social events that do more than simply extract data (Van Den Hoonaard, 2012). Such conversations can often encourage participants to think about their experiences in new ways and formulate ideas that they did not possess before the conversation began (Van Den Hoonaard, 2012).

For this study, I conducted research conversations with all participants within the research setting, prioritizing quiet and private spaces to create a comfortable environment for meaningful dialogue. Five of the six conversations with resident participants were held in their rooms to ensure privacy. For the sixth, a resident preferred to walk and spend time outside, so I adapted to their preference to facilitate a more natural and comfortable conversation setting in addition to acknowledging their preferences. Conversations with staff were conducted during their working hours in the recreation rooms. The recreation manager worked with me and the recreation staff to schedule these conversations into their calendars, balancing the staff's availability with their other responsibilities. Time for these conversations was limited, as staff often had to prepare for scheduled programs immediately afterward.

All research conversations were audio-recorded, with recordings securely stored locally and deleted after transcription and review. Conversations with resident participants ranged from 17 minutes and 37 seconds to 1 hour and 10 minutes, with shorter sessions occurring when participants expressed fatigue or a preference to stop. Conversations with recreation professionals ranged from 44 minutes and 51 seconds to 1 hour and 5 minutes. The flexible approach I used for the research conversations respected participants' preferences and the practical constraints of the staff.

A conversation guide was used to facilitate the telling of stories during the research conversations with both residents living with dementia and the recreation staff. The guide served as a prompt, reminding me of key topics to cover, questions to ask related to these topics, and areas to probe to support the telling of residents' and recreationists' stories. However, the primary goal of these conversations was to provide an opportunity for participants to share their stories in their own words and on their own terms. The term guide is used intentionally to reflect the flexibility of this approach, enabling me to adapt questions/prompts to suit a particular conversation and choose to add or omit questions not relevant to the story being told (Van Der Hoonard, 2012).

The first step in designing the conversation guide was to identify the broad categories of interest aligned with the study's research questions (Van Den Hoonard, 2012). The broad categories of interest for this study were linked to the following four research questions:

1. How might leisure support or threaten the social and relational citizenship of people living with dementia in LTC institutions?
2. How do residents living with dementia assert their social and relational citizenship in leisure spaces?
3. What gets in the way of supporting the social and relational citizenship of persons living with dementia in LTC institutions?
4. What is necessary to support the social and relational citizenship of persons living with dementia in LTC institutions and advance a social and relational citizenship approach in these settings?

The second step involved developing open-ended questions relevant to these categories. Since I have two different participant groups, I developed two different guides. Each guide addresses the

broad categories of interest but are tailored specifically to the population. When creating these guides, I considered how questions would flow together and was intentional in not outlining too many questions. Outlining too many questions can lead the researcher to feel rushed through the conversation instead of listening closely to responses and asking good follow up questions (Van Den Hoonaard, 2012). However, I did find that I struggled to get to some questions I wanted to ask when having research conversations with the recreation staff due to the scheduling of programs. When planning my conversation guides, I intentionally began with questions that might be easier to answer to help foster a comfortable environment and included probes to help participants elaborate, explain, or provide a story or example. For example, I started with questions that asked residents and recreation staff to describe themselves and what was important to them in their own words (e.g., Could you tell me a bit about yourself and what's important to you? How would you describe yourself or how would others describe you?)

In addition to the steps outlined above, I was intentional in utilizing aspects of social citizenship and narrative inquiry to help support residents and recreation staff in telling their stories. Where possible, I tried to incorporate aspects of the different components of social citizenship (i.e., growth, social position, purpose, participation, solidarity, freedom from discrimination) and the three commonplaces within narrative inquiry (i.e., temporality, place, and sociality). For example, I asked questions of residents such as: Do you feel like you have a sense of purpose here? If so, when do you feel that you have purpose here? Do you feel you can make your own decisions about what you participate in here? Recreation staff were asked related questions, such as: How do you use leisure and recreation to provide purpose and meaning in life for the residents, particularly those living with dementia? Can you give an example? Are people living with dementia actively involved in decision-making about programs? If yes, how so?

What does this look like? If no, what stands in the way of including people living with dementia in decision-making and creation of recreation programs? I also asked questions that attended to the past, present and future (i.e., What are some moments or times in your life that are important to you?) I also included questions that attended to personal and social conditions (i.e., Can you tell me about the friends you have here?) and to place (i.e., How would you describe this place?). While some aspects of temporality, place, and sociality were more evident during my observations, I sought to integrate them into the conversations wherever appropriate. My full research conversation guides are provided in Appendix A: Narrative Research Conversation Guide for Residents and Appendix B: Narrative Research Conversation Guide for Staff.

Research conversations were conducted with residents before staff. The purpose of this was to prioritize the stories told by the residents and then be able to contextualize and fill-out these stories with my conversations with recreation staff. As mentioned earlier, before speaking with residents, I first observed the recreation programs they participated in to better understand how leisure was structured and facilitated within the home. By conducting these conversations in stages, I aimed to contextualize resident narratives within the broader sociocultural environment of the LTC setting, gaining insight into both personal experiences and systemic practices and structural forces shaping experiences in the home.

Analysis of Narratives

Before beginning the analysis process, it was important for me to identify the difference between *analysis of narratives* and *narrative analysis*. Narrative analysis is where researchers gather descriptions of actions and events as data that are then used to generate stories (McCormack, 2004). This process explores individuals' understandings of their experience in the context of their everyday lives while simultaneously looking at the wider social/cultural contexts

(McCormack, 2004). Alternatively, analysis of narrative is where researchers seek stories as data and analyze the stories for themes that hold across stories (McCormack, 2004). For this study, I utilized analysis of narratives where I worked to identify common themes told through the research conversations with residents and recreation and staff and the field notes that were collected during observations.

For this study, I conducted a reflexive thematic analysis (TA) of my transcripts, observations notes, and other field notes, following Braun and Clarke's methodological guidance (Braun & Clarke, 2019, 2021). Reflexive TA is a qualitative approach that embraces the researcher's subjectivity and reflexivity and analytic resources, rather than treating them as biases to eliminate (Braun & Clarke, 2019). In reflexive TA, meaning is actively generated through the researcher's engagement with the data, and quality is judged by depth of interpretation, coherence, and transparency, rather than by notions of reliability or replicability (Braun & Clarke, 2021).

Throughout my analysis process, I engaged in ongoing reflexive practice, meeting regularly with my advisor to talk through emerging ideas and explore questions I had. These meetings were instrumental in clarifying my thinking, deepening my interpretation, and navigating the complexities of social citizenship in LTC.

Braun et al. (2022) outlined six flexible phases of reflexive TA, which I followed in analyzing all of my data. Phase 1, familiarization with the data (Braun et al., 2022), began with the transcription of verbal data. The transcription process helped me to become deeply familiar with the data stories told in the research conversations. Once all the research conversation data was transcribed, I re-familiarized myself with the rest of the data by reading through all field texts. During this phase, I began to pay attention to aspects of the data that began feeling familiar, or in

contrast, struck me as unfamiliar or surprising (Braun et al., 2022). I started taking notes and jotting down potential ideas that might later guide the development of codes and themes.

In the second phase, coding, I systematically worked through the data to generate initial codes (Braun et al., 2022). To stay grounded in my research questions, I kept them visible during analysis and used them to refer back to when identifying features of the data that seemed relevant. Following Braun et al.'s (2022) guidance, I approached coding inclusively, coding for as many potential patterns of meaning as possible, and allowing 'data' to be assigned to multiple codes when appropriate.

Additionally, during Phase 2 and throughout the analysis, I considered Murray's (2000) levels of analysis: personal, focusing on the lived experiences of the narrator; interpersonal, examining how narratives are co-created through dialogue; positional, highlighting differences in social positions between the narrator and the listener; and societal, addressing socially shared stories characteristic of specific communities and societies. These levels are interconnected and influence one another. For example, I paid attention to how individuals recognized and understood their selfhood, while also reflecting on the interview and observational contexts that shaped which stories participants felt able to share. I also examined how social positions affected the narratives and how social representations of dementia manifested within individual stories. These considerations were essential for understanding the broader socio-cultural and relational contexts of the narratives shared in this study.

In phase 3, constructing initial themes, I analyzed my codes and considered how different codes might combine to form overarching patterns of meaning, or preliminary themes (Braun et al., 2022). To support this process, I used a mind map to visually organize the codes into thematic clusters. I explored relationships between codes, between potential themes, and across

different thematic levels (e.g., main themes versus sub-themes). By the end of this phase, I had developed an initial sense of the significance of the patterns of meaning I was beginning to construct in relation to social citizenship and narrative analysis, while also remaining open to refining or discarding themes as needed.

In Phase 4, reviewing and refining themes, I reviewed the preliminary themes against the entire data set to assess their coherence and relevance (Braun et al., 2022). This involved revisiting coded data extracts within each theme and refining the themes to better reflect the complexity of participants' stories. Some candidate themes were merged, split, or substantially reworked. I evaluated each theme not only for internal consistency but also for its connection to the broader concepts of social, relational, and narrative citizenship, ensuring alignment with the ontological and epistemological commitments of narrative inquiry.

Next, phase 5, defining and naming themes, I carefully defined the core essence of each theme, articulating the specific story each theme conveyed (Braun et al., 2022). This involved detailed analytic work to refine the boundaries and scope of each theme, and to ensure clarity in how each theme related to the research questions. I drew connections to the six components of social citizenship, the principles of relational and narrative citizenship, and Murray's (2000) levels of analysis. Where appropriate, I also identified sub-themes that captured important nuances within the larger patterns of meaning.

Finally, I moved into the writing phase, producing the narrative accounts, where the themes were woven into coherent narrative accounts (Braun et al., 2022). Writing served not just as a means of presenting findings, but as a continuation of the analytic process itself. Through writing, I further refined the thematic structure, combining or collapsing aspects of earlier themes and sub-themes where it enhanced coherence and interpretive depth. Ultimately, this

process led to the construction of four main, interconnected narrative accounts, each containing multiple interrelated sub-stories. These narratives sought to convey the complexity of how social and relational citizenship were shaped within the long-term care environment.

Attending to Rigour

Social constructionist traditions in qualitative research provide unique and innovative approaches to understanding, critiquing and deconstructing our own constructed realities (Berbary & Boles, 2014). However, this does not come without critiques, where a more improvisational approach to research can be mistaken for an ‘anything is research’ mentality (Berbary & Boles, 2014). As discussed earlier in this chapter, Berbary and Boles (2014) proposed an eight-point scaffold for humanist research with the goal of providing the structure and fluidity to research that satisfies some scholar’s calls for rigorous methodology as well as their desire to push towards an acceptance of more fluid, creative and improvisational forms of qualitative inquiry. Throughout my study, I adhered to this scaffolding, ensuring that each step of my research process was interconnected as much as possible.

Additionally, De Witt and Ploeg (2006) provide a framework of expressions of rigour for interpretive phenomenological research, based on the work of Van Manen, Madison and various nursing scholars. Although phenomenology was not my chosen methodology, this framework was still relevant to my narrative inquiry approach. This framework describes expressions of rigour as balanced between representing the research process and outcome of the study (De Witt & Ploeg, 2006). These expressions include: balanced integration, openness, concreteness, resonance and actualization (De Witt & Ploeg, 2006). Balanced integration describes the intertwining of philosophical concepts in methods and findings, that is balancing between the voices of participants and philosophical explanation (De Witt & Ploeg, 2006). In my study, I

aimed to balance between the stories told by participants with the philosophical insights represented through the lens of social citizenship and narrative inquiry. Openness describes being transparent about decisions throughout the study (De Witt & Ploeg, 2006), which I maintained by clearly explaining my methodological choices and the analysis process of identifying themes. Concreteness pertains to the practical application of the study's findings (De Witt & Ploeg, 2006), which I address in the final chapter of this thesis. Resonance describes the experiential or felt effect of the study findings on the reader (De Witt & Ploeg, 2006). In describing my setting, research process, and findings, I tried to write in a way that would bring readers into the setting. I hoped that my writing would help them 'see', 'feel', and 'hear' what I did in this setting, as well as the stories told to me by the participants and through the recreation programs I observed. I will continue to consider resonance as I begin to share the results of this work more broadly in more relevant and creative ways for different audiences. The fifth expression, actualization, describes the future interpretation and influence of the research findings (De Witt & Ploeg, 2006). This implies that the work findings created in this study will continue to be interpreted by readers in the future (De Witt & Ploeg, 2006). Although no formal mechanism exists within the research community for recording actualization (De Witt and Ploeg, 2006), I kept in mind this potential for my research to advocate for social, relational, and narrative approaches to recreation and leisure in long-term care for people living with dementia. I believe that just my involvement within my research setting opened up a space for critical reflection about the staff's commitment to person-centred care and new possibilities for expanding their practice to better support relational citizenship within the home. My hope is that when other professionals engage with my findings they might also be inspired to think about how they might also support the relational citizenship of the people living with dementia they work with.

Chapter 4: Stories of Social Relational Citizenship, Leisure and Long-Term Care

Introduction to Stories

This chapter presents four interwoven stories that illustrate how social and relational citizenship emerged – or, at times, were constrained – within leisure spaces of Evergreen Manor. Each of the four stories explores a different aspect of residents’ engagement in leisure, highlighting how these spaces both support and undermine autonomy, relationships, self-expression, purposeful roles, and well-being. The four stories include: *Holding onto Selfhood: Expression, Roles, and Purpose in Long-Term Care*; *The Right to Choose: Supporting Agency in Long-Term Care*; *Beyond Isolation: Building Connections, Belonging, and Meaningful Relationships*; and *Negotiating Freedom and Care: Autonomy, Safety, and Institutional Barriers in LTC*.

These are not isolated narratives. They do not unfold in a strict beginning-middle-end sequence. Instead, they reflect the fluid, relational, and non-linear nature of lived experience, shaped by interactions, institutional structures, and personal agency. This approach to storytelling is influenced by Indigenous epistemologies, which understand knowledge as relational, dynamic, and embedded within lived experience rather than as fixed, objective truths (Kovach, 2009; Wilson, 2008). In many Indigenous traditions, for example, stories are not meant to be read in a singular way or interpreted through a rigid structure; rather they are meant to be returned to, engaged with, and understood in relation to the listener’s own experiences (Archibald, 2008). Similarly, the stories in this chapter are not just accounts of leisure in LTC – they reflect the ways social citizenship unfolds through residents’ voices and interactions.

While these stories aim to reflect residents’ experiences in context, my presence, interactions, and positionality inevitably shaped what was shared with me and what I observed. Grounded in a

social constructionist epistemology, I recognize that multiple truths exist and that meaning is co-constructed through relationships, conversations, and shared experiences. The stories described in this chapter were developed through thematic analysis of research conversations with residents and staff, observations of leisure programs, and informal interactions throughout the data collection process. They also reflect my interpretation of the stories that were shared with me and although I tried my best to be true to the stories people felt comfortable sharing with me and that I witnessed, they represent my telling of the stories and only a piece of a much larger, complex story of social citizenship in the context of LTC institutions. Each story is divided up into different parts, presented with direct quotes from residents, alongside observational data to capture lived experiences in context. Staff perspectives are also included, specifically when discussing supports and barriers that shape residents' leisure opportunities. Furthermore, these stories intertwine the supports that enable meaningful engagement and social relational citizenship with the barriers that hinder participation and threaten social relational citizenship, recognizing that access to fulfilling leisure is shaped by the complex intersections of institutional structures, staff facilitation, and resident's individual experiences.

Holding Onto Selfhood: Expression, Roles, and Purpose in Long-Term-Care

In long-term care, identity does not disappear. It shifts, it adapts, it finds new forms of expression. It lingers in the objects that residents choose to display, in the stories they tell, in the roles they continue to embody despite the constraints of institutional life. It is in the paintings created, the flowers arranged, the animals cared for. It is in the hands that help, the voices that guide, the wisdom that is shared. It is in the small, everyday moments where selfhood is affirmed. This is a story of how selfhood is expressed and reaffirmed.

Part 1: Objects, Memories, and the Stories They Tell

Helen's room at Evergreen Manor told her story before she ever spoke. A digital frame on her nightstand cycled through photographs - each one capturing moments of family, laughter, and love. As the images changed, one caught her attention during our research conversation, prompting a reflection: "They're part of the family group... yeah, she's my granddaughter I guess you would say." Memories were woven into the fabric of her space. On her wall, there is a painting of a red barn and a woman carrying a bucket with Helen's name on it: "This picture is the funny farm, I called it," she explained. Helen grew up working on her family farm and described it as a place of joy for her family, so much so that they gave it the affectionate nickname. On her door, a picture of a cardinal – her favourite bird – served as a familiar landmark. Every time we entered her room, she pointed it out, reaffirming its significance. Near her bed, a photograph of her father as a Shriner hung on the wall. She gestured toward it, explaining: "My dad would care about the Shriner's, like the Shriner's care... he was a good Shriner... that's why I put that up." These objects were not just decorations. They were anchors – reminders of who she was before LTC, and who she remained.

For Daniel, it was music that tethered him to his past. His room was lined with jazz posters, a silent testament to a lifelong love of music. It had shaped his marriage, giving him and his wife shared joy. Even now, in LTC, he held onto that part of himself. When I asked if they still enjoyed listening to music together, he nodded: "Yes, we do... and that's what we did in Toronto, quite a lot... we drove and went once a week or so." The music programs at Evergreen Manor did not always feature jazz, but I watched as he and his wife found connection anyway. During a rock music program, they sat together, holding hands, chatting to one another between songs.

Music was more than entertainment, it was a space where their relationship could continue through a shared valued activity.

Frank's room also reflected his selfhood. He had photographs of each of his three children on his wall, which he frequently pointed to throughout our conversation. His care for his children was evident when I asked about his hopes for the future:

I guess my hopes would be to, to see my kids settle into something that they can hold on to.

And it doesn't have to be, you know, here, go off to school and become a doctor or something like that. It doesn't have to be that... you know, just go and do something that I can tell drives you... and that's what I tell them. That's the thing that always brought me more energy. If it was something that drove me.

Even in LTC, Frank continued to see himself as an active father – someone who still had wisdom to offer his children. His selfhood was not defined by where he lived, but by the relationships he maintained and the values he passed down. These examples demonstrate how objects serve as more than memory aids – they become prompts for storytelling, allowing residents to share their values, social roles, and relational ties with others.

Yet, selfhood in LTC was not always easily expressed; institutional routines, cognitive changes, the loss of personal spaces could create barriers to self expression. Some residents found a new way to assert themselves. For Frank, creativity became that outlet: "If you see here, with the tree. I'm just gonna use the tree for ideas... you see how it's got tape all over it?" For Frank, creativity was a process, an act of making something meaningful out of what was there. In the OMA (Opening Minds through Art) program, residents painted, each stroke more than just colour on canvas. Frank explained his approach, revealing something deeper about the way he saw the world:

They say, ‘what does this picture mean?’... and I said ‘okay, now here, you might laugh, but I’m just gonna tell you, when I drew this, this is what it meant to me.’ And I had a bunch of circles in the stick, so in a way, it looked like a hockey game, but it wasn’t that... it was the pieces that built that house, okay, in this little artwork of mine... The people I then tell that to and look at it, then they see it, and it becomes more important to them that, I can build that too... I can build that house... You know, like, just little pieces. Just try. You know, that was the biggest thing. Just try... I’m not necessarily an artist by any means.

Art, for Frank, was not just about expression. It was about being seen, about others recognizing the meaning in his work. It was proof that he still had something to say.

Recognizing the importance of these forms of expression, recreation staff played a critical role in counteracting these barriers to selfhood. Samantha, a recreation staff member, described an activity where she selected objects from residents’ memory boxes to encourage storytelling in a group setting: “Now he’s telling us the story about the picture because he’s so proud of it... he’s so happy about it. And he could share it... it makes them feel important.” By incorporating personal items into leisure programming, staff created opportunities for residents to actively shape their own narratives, reinforcing their sense of self within the LTC community. Ethan, another recreation professional, reinforced this approach, emphasizing that building relationships over time was just as important as gathering information from family members:

To kind of get some background information as much as we can from the residents’ families is definitely a key... but also sitting down and talking with the residents and the family... I think over time is the biggest thing... because when you share time with people and you get to know them a little bit better, you learn more than just asking a question right away.

These moments of recognizing, storytelling, and engagement helped ensure that residents' selfhood remained visible – that they were not just defined by their diagnoses or institutional setting, but by the lives they had lived and the selfhood they continued to shape. Selfhood in Evergreen Manor was not static. It was nurtured, rediscovered, and, at times, fought for. Whether through the objects in their rooms, the music they listened to, the art they created, or the stories that they told, residents continued to express who they were. And in the moments when barriers threatened to silence them, staff who truly listened helped to ensure their voices remained heard.

Part 2: Familiar Work, New Purpose: How Roles Evolve in LTC

Elaine, a resident at Evergreen Manor, had always been a gardener. When a flower-arranging program was introduced, something shifted in her. In other programs, she often remained passive. During the Roman Catholic Mass, for example, she neither sang nor actively participated. But here, surrounded by flowers, she instinctively began plucking excess leaves from the stems without any prompting. The movement was precise, deliberate. It was not simply a task; it was embodied knowledge, ingrained through years of experience. This technique of removing leaves to prevent rotting was something she has not been taught in the program, but something she already knew. It was muscle memory, a reflection of a life spent tending to plants, caring for something that would grow and thrive under her hands. Unlike other activities where she followed along, here, she led. In this moment, she was not just a participant in a program, she was a gardener again.

For Evergreen Manor resident Daniel, his role was never about tasks – it was about relationships. He had always been a caring husband and father and Daniel's daughter knew this and through her relational support, Daniel was able to find ways to continue that role: "My one daughter comes over right away. She says, 'okay let's go now, pick flowers.' She likes to pick

flowers and give them to her mother... or give them to the nurses' station." Daniel's actions, supported by his daughter, were not about the flowers themselves, but about care – about making sure the people he loved were thought of, appreciated, and given something beautiful. His identity as a husband and father did not vanish when he moved into LTC. It continued in small, everyday acts of kindness. Roles don't simply disappear. They evolve. They find new ways to exist when support is in place.

Some residents held onto old roles. Others discovered new ones. Frank, for example, became a guide to his peers. Despite using a wheelchair himself, he actively helped porter other residents to and from programs. He saw himself not as passive, but as someone with something to give: "If I was to describe myself, it would be as an active leader... But I don't need to be the leader. I don't need to treat it like that. Like an active participant in all group settings." Frank understood that participation was not about ability – it was about support: "We'll sometimes see that, like, the person's not, not trying... and it's not because they don't want to. They just don't know how. So we're gonna show them how." By helping others engage, Frank demonstrated his relational capacity and reclaimed a sense of leadership and purpose. He was not simply there to be helped, but saw an important role he could play in helping others and took it.

For Helen, animals brought back a sense of responsibility, of care. When a rabbit was placed in her lap during the farm visit, she held it, stroked it, and smiled, as though a familiar instinct had returned. During our research conversation, Helen told me: "You feel like you're accomplishing something when you've got... you have the animals... you're looking after them." Helen did not describe this moment in terms of entertainment or comfort. She described it as an accomplishment. Staff like Martha saw the power of human-animal relationships and

facilitated them. She brought her own dog, Finn, into the home weekly, where a former dog trainer found a new role:

There's a gentleman who used to live here, and he used to raise dogs, and when he came here, all his dogs already passed away, but he really, really missed having a dog. So I told him, he was in charge of Finn and was the dog sitter... I would bring Finn into his room and I would bring him a brush so he would brush Finn, and then he would like, he didn't really teach him tricks, like he would say "Sit. Oh look what I've taught Finn" and then I would give him some liver bites that Finn likes to eat. Like he felt like he was actually taking care of Finn on like a daily basis... I would close the door give them like 15 minutes, and he would brush him, and play with him, and talk to him, and then I'd come back, "oh Finn had his brush for the day, he had his treats, he's done" like he actually thought, which he was, taking care of animals again.

This was not just a visit from a therapy dog, this was a job, a responsibility, a renewed sense of self. The resident was not just engaging with the dog; he was taking care of him. Even in LTC, there was still a chance to be responsible, to contribute, to have a purpose.

Part 3: Growth Does Not Stop: Learning and Thriving in LTC

Growth does not stop in LTC. Some residents found ways to keep learning, exploring, and contributing, even within the constraints of institutional life. Frank put it simply: "Yeah, I always learn something new." For Samantha, a recreation professional, supporting growth and learning was critical to changing the way people view LTC. Too often, she explained, LTC was seen as a final stop, rather than a place where life could continue:

It was always like, this is the place you come. This is it. This is the place you're gonna die... But it doesn't have to be that sad... People end up learning new things, different things, when

they do come into LTC...So, there's a lot of things that people haven't done that they wish they could have done or never thought they would have done when they come in here.

Samantha recognized that LTC did place limits, but within those limits, new possibilities could still emerge. She emphasized that once residents no longer had to navigate the exhausting demands of daily personal care on their own, they could redirect their energy toward engaging in meaningful activities:

So that's kind of. I look at it that way...Because you got to remember, out in the community, they came here for a reason...So they come here now, they have more or less, like a set schedule, but things are a little bit easier. So they start thriving... The ease and the burden of caring for themselves is lessened...And we take that role... [so they can focus on] being who they are, being human again... I think it's important to be human.

Although, I did not necessarily witness what I would fully describe as growth firsthand, I do believe this could partly be due to the time constraints of this project and the particular social demographics of the LTC institution at that particular time. Despite not witnessing opportunities for growth, I did hear stories of growth that demonstrate to me that when staff take the initiative, residents can learn new things and grow. For example, Martha described the growth she witnessed in her own grandmother, who was once a resident at Evergreen Manor: “She came in very quiet, but by the end she was like the bingo queen, she was very sociable.” Samantha, similarly tells a story of one woman who actually moved from hospice into LTC, was still able to grow “I got her to dye wool, got her to do knitting... we did so many different things together... She said “I never thought I could do this.””

The shift – from struggling to manage daily needs to being able to engage in meaningful activities – was an important part of selfhood and thriving in LTC. Residents are not just passive

recipients of care; they still have interests, roles, and potential to contribute. Martha, another recreation professional, reinforced this perspective, explaining how staff actively worked to ensure residents still had opportunities to contribute in ways that aligned with their interests:

They can still pursue their own interests, we will help them pursue their interests, they still have a role here. Like if somebody was still wanting a job, like we can give them a job at Residents' Council for this unit, we can have them, you know they were, ... if they love plants, they could be in charge of watering the plants on the balcony. You can still give them jobs to make them feel like they have a purpose, like this doesn't have to be the end all be all, lay in bed everyday, watch TV, and pass away.

For some residents, this was true and they found new ways to be involved, to shape their environment, to learn. But not all residents felt this possibility. When I asked June if she has had the opportunity to learn new things, she responded with humour, but her words carried weight: "How to sneak out the window (laughs)... No, I haven't really." For some, LTC created possibilities. For others, it placed limits. And that is why selfhood must be intentionally fought for, protected, recognized, and nurtured in every way possible.

Final Thoughts: Selfhood as a Continuing Story

Selfhood in LTC is not something that disappears – it shifts, adapts, and finds new forms of expression. It is in the stories residents tell, the art they create, the roles they continue to embody despite institutional constraints. Yet, selfhood is not always recognized. The structures of care can either reinforce identity or diminish it. When staff listen, adapt, and advocate, they do more than provide care – they ensure that residents are seen for who they are, not just who they were.

The Right to Choose: Supporting Agency in LTC

This is a story about choice. Choice, in LTC settings, is not always straightforward. It is not just about what residents want—it is about who listens, how choices are recognized, and the ways people express their agency every day. Choice is spoken, written, embodied, and sometimes advocated for by others. It is in the decisions residents make every day. It is in the ways they express themselves when words are not enough. It is in the resistance against structures that try to take it away. But not all choices are recognized. Not all choices are honoured. And not all residents have the same power to insist on their autonomy.

Part 1: Everyday Autonomy: How Residents Navigate and Assert Choice

Frank, a resident of Evergreen Manor felt strongly about one thing: he would always say what he wanted:

Oh yes, I don't think I get things pushed on me... All you got to do is be willing to open your voice and speak it and bring things up and they might say you know, 'that'll be fantastic' and 'we'll get you some help with that. We'll get you some equipment for that.

For Frank, choice was an active process—something you had to claim for yourself. June, a fellow resident, agreed, though she acknowledged that choice had limits:

They do listen to your questions and give you the answers even if you don't agree with them... of course, they have to stick with their own rules. But all in all, I wouldn't choose another place other than [Evergreen Manor].

And when asked if she is listened to? Through laughter she responds: "Well, they do, or I give them a kick in the ass." June made her voice known. When I first approached her about this research project, she made it clear: she would not say anything bad about Evergreen Manor. She repeated this often, yet, at times, she also spoke of feeling trapped - of Evergreen Manor

sometimes feeling like jail. In the story *Negotiating Freedom and Care*, she described wishing for more freedom to go outside when she chooses, rather than having to ask and be escorted. Choice, having choice, and having choices respected were not givens, dependent on the situation, and compromised resident autonomy at times.

Frank and June's ability to assert choice was shaped by their personalities and confidence in self-advocacy. But not all residents had the same ability to insist on their autonomy. For residents with advanced dementia or communication challenges, expressing choice became more vulnerable to institutional routines and assumptions. This became evident in moments where non-verbal preferences were overlooked or dismissed, raising critical questions: Who ensures that choice is acknowledged?

Not all choices were about big decisions. Sometimes, they were about small moments of autonomy—choosing whether to participate, deciding how to spend the day, asserting a preference in the moment. At the Roman Catholic Mass Service, participation was based on real-time resident decisions. A list of Catholic residents guided the invitations, but attendance was not mandatory. One resident, who normally attended, declined to join. Volunteers were surprised, asking her again just to be sure. "No." She said firmly. Volunteers exchanged glances "Well that was a pretty clear no." One volunteer noted while the other brought her back to the TV room. Her choice was respected. No pressure. No insistence. Just choice.

Ethan, a recreation staff member, ensured programming remained flexible, shaped by resident input rather than rigid schedules:

I never say no... If people come to me and say, "Hey, why don't we try to do this?" or "Why don't we try to do that?" "I try to add that to the program list. Or even within those programs, I'll make adjustments if a resident makes a suggestion.

Decisions didn't just happen in formal settings, such as Resident Council meetings, they happened in the moment, in the willingness to listen and adapt. But even when residents expressed choice in nonverbal ways, it was not always honoured; a tension that will be returned to in *Advocacy in Action* below.

Part 2: Beyond Words: Creative Expression as a Form of Agency

Not all decisions were made with words. Some choices were felt, seen, and created. Rebecca, a recreation staff member, knew this well: "I use a lot of physical gestures. If I get somebody who either can't speak or doesn't speak my language, I get down on their level. You've got to read body language at all times." Choice was not just spoken – it was expressed through movement, through the smallest gestures, through the act of creating something personal. During the flower arranging program, facilitated by Rebecca and a horticultural staff member, choice was woven into colours, textures, and touch. A variety of vases and flowers were set out, and residents selected their own materials. Some pointed, others reached, some simply lingered over a particular flower, signalling their preference without a word.

Elaine, a resident who rarely spoke during programming, was unable to verbalize her choice when asked what colours she liked. Instead, different flowers were brought closer to her, allowing her to choose for herself. Once within reach, her hands moved instinctively, selecting, arranging, creating. Every movement was a choice. Every selection, an assertion of agency.

The Opening Minds through the Arts (OMA) program operated on the same principle: Residents controlled the creative process. If assistance was needed, residents directed the students. Colours, brushstrokes, materials— each decision was theirs. For Frank, participation in OMA was more than just making art- it was a process of claiming confidence, embracing choice, and finding joy in creation. Although I did not officially observe Frank in this program, he was a

participant. In a casual conversation, he shared with me how he had been nervous at first, unsure of his artistic ability. But in an environment where, as he described it, everyone was treated as equals, his hesitation faded. Over time, he stopped worrying about the final product and started embracing the process, the choices, the time spent with others. Through art, Frank – like Elaine – expressed his autonomy. Choice isn't just spoken, it is felt in the hands, seen in the colours, and made real in the act of creation.

Part 3: Advocacy in Action: Who Ensures That Choice is Recognized?

Choice does not exist in isolation. It is shaped by relationships, support, and advocacy. In LTC settings, residents do not always have the ability to insist on their choices, especially those with advanced dementia or communication challenges. When residents cannot assert their preferences verbally, staff play a crucial role in ensuring that choice remains central. Recreation staff saw firsthand how assumptions about dementia could lead to choice being overlooked or denied. Martha, a recreation staff member, described how non-verbal residents were often excluded from activities without consideration of their interests:

This person can't speak for themselves so the PSWs will just take them and put them to bed...
“oh they can't speak they don't enjoy TV, they don't enjoy Lawrence Welk” and they'll put them to bed... they don't give them an opportunity to pursue their own interests.

For Martha, this was not just about participation – it was about choice. A resident's silence was often interpreted as a lack of interest. Martha made it her responsibility to challenge these assumptions:

If we're doing something outside like entertainment, they say “Oh, they can't speak for themselves, they're not going to enjoy the music.” Well, how do you know? So they put them to bed... But one time, I was so angry. We have a monthly birthday party for each unit, and it

was somebody's birthday, and she could not speak for herself, and they put her to bed. And I said, "But it's the monthly birthday party." "Well, she's not going to know it's her birthday." I said, "It doesn't matter."

For Martha, choice was not just about what residents could say – it was about what staff made possible. If residents were not given opportunities to engage, their autonomy was diminished, not by cognitive decline, but by the assumptions of those around them. These examples illustrate how the assumptions and experiences of other staff members in the LTC setting, and the nature of others' jobs, can conflict with the opportunities provided by the recreation staff to ensure residents at least have the possibility to be included and make choices about their inclusion. These examples also point to the critical role recreation staff play in advocating for resident choice.

The ability of recreation staff to advocate meaningfully for resident choice was also shaped by the supportive leadership culture at Evergreen manor. Several staff described how management consistently prioritized recreation and provided access to high-quality resources, from sensory tools to adaptive technology. As recreation staff member Martha explained:

She [the recreation manager] provides us with very good, stimulating activities... she's always keeping up with good resources to give us, equipment too... very good top of the line iPads to do our attendance, and our calendars, like she keeps us very well stocked with excellent activities and resources.

Another recreation member, Rebecca, emphasized that this support extended beyond material resources to a broader organizational culture that valued leisure: "If you see something, or you want something... I'd be pretty surprised if it's a no... our CEO started in rec... and I think she values it, 100%." The presence of this kind of leadership enabled a greater range of

programming and flexibility in responding to residents' unique needs. As Rebecca shared, even larger items like sensory tools, technology, and a dedicated bus were available for recreation use:

We all have our Mobii sensory... we all have our own Snoezelen carts... the fact that we raised money and have a bus... the government doesn't give you money to have a bus... so to me, that says a lot.

These examples highlight that supporting resident choice is not only a matter of individual staff effort, but also requires organizational support. When leadership values and invests in leisure, it enables recreation staff to create inclusive, flexible, and personalized programming. This is especially important for residents who may not always be able to express their preferences clearly.

Family involvement and collaboration was also critical to supporting resident choices, especially when verbal communication became difficult. Luke described how gathering biographical information from family members was essential to ensuring that residents' selfhood, values, and past choices continued to shape their lives:

I send a letter to the family as well and ask them to give me a little bit more information. So [Rebecca] started it... and I thought it was a great idea... because sometimes the residents can't fill us in with all the information but the kids or POAs [Power of Attorneys] know more than sometimes the resident remembers.

These efforts ensured that even when residents could no longer verbalize their preferences, staff could still honour their past choices – whether that meant playing their favourite music, engaging them in familiar activities, or structuring their day in ways that felt comfortable and familiar.

However, family input was just a starting point, not the full picture. Ethan, another recreation

staff member, emphasized that ensuring choice was not just about gathering past history – it was about building relationships over time:

To kind of get some background information as much as we can from the residents' families is definitely a key... but also sitting down and talking with the residents and the family... I think over time is the biggest thing... because when you share time with people and you get to know them a little bit better, you learn more than just asking a question right away.

Luke reinforced this, acknowledging that not every resident wants to do what they did before:

Again, not every resident wants to do what they did before, but those residents who seek out programs, or ideas, or tell us what they like to do, you know, I think we do our best to incorporate that into our programming.

But what about those who do not actively seek out programs or express their preferences?

Luke's statement raises an important critique: choice in LTC should not only be recognized when residents self-advocated for themselves. Many residents, such as people living with dementia, cannot easily assert their interests. Without intentional effort from staff, these residents risk having their choices overlooked. Choice is often treated as something that must be requested, yet many residents lack the confidence, verbal ability, or cognitive clarity to assert their desires outright. This underscores the responsibility of staff not just to listen when choices are spoken, but to recognize and validate them in all forms – verbal and nonverbal, direct and subtle. As Luke put it: "At the end of the day, people just want to be treated with respect."

Final Thoughts: Choice as Relational Practice

Choice in long-term care is not always about big decisions. Often, it is in the smallest acts of agency. It is in a resident selecting a flower, choosing where to sit, saying no to an activity, or trusting a staff member enough to know that you will be included or to try something new.

Autonomy is not an individual act but a relational one, shaped by who listens, who advocates, and who ensures that choice remains central to care. True dignity comes not from simply allowing choices but actively recognizing, honouring, and supporting them in all forms – spoken and unspoken.

Beyond Isolation: Building Connection, Belonging, and Meaningful Relationships

This is a story about connection. In long-term care, belonging is more than just being in a space—it is about being seen, being known, and being part of something beyond oneself. It is in the conversations shared at a bingo table, the familiar faces at a music program, the trusted voices of staff who remember your favourite songs. It is in the moments when residents are not just cared for, but truly feel connected.

Part 1: Finding Each Other: Peer Relationships Through Leisure

June always sat with the same three women at bingo. Every time. No one assigned their seats. No one told them where to go. And yet, week after week, they found each other – drawn together by familiarity, shared stories, and the quiet comfort of simply being together. Luke, the bingo caller, moved through the room, cracking jokes as he called out numbers. When he stopped by June's table, it was never just to check cards, it was to tease them, to share a moment, to make them laugh. These were more than just games; they were rituals of connection, moments of belonging. June understood this: "If there is something that's being done for the group, let's say, a get-together, I always join that... whenever I can." She spoke of the deep sense of community these programs fostered:

Oh all the time... we all get together. All of us. And we have different group sessions, which is nice... (everybody's) likeable and wants to help you out with whatever you're doing, and, oh, yeah, it's a really great place.

But belonging was not just about participation – it was about connection, responsibility, and care for one another. June reflected on how these relationships had personally affected her, describing a shift in perspective since moving into LTC. While she sometimes wished for more personal freedom in her daily routine, she prioritized the well-being of her peers, demonstrating a deep sense of empathy for others in the LTC community:

I don't want anything shortened. Do you know what I mean? ... Like in looking after people because of me. No, I don't want that at all... I want it so they have something that everybody can participate in and feel happy... after you live in a long-term care, you change your ways.

For June, belonging was not just about receiving care, it was about ensuring that everyone had a place, a purpose, a way to be included, and were cared for. Frank knew this too. During an unstructured music program on the patio, he chose to sit with the same married couple with whom he regularly ate lunch. The warm summer breeze carried the sound of soft music, creating an easy, open atmosphere where residents could choose to listen, to relax, or to engage. Frank chose where to sit, who to be with. With his wheelchair, he could move freely and he used that movement to seek out familiar faces. When I joined their table, he welcomed me in, launching into a story about his past harness racing, then shifting the conversation to the upcoming U.S election. This was not a program designed for conversation, yet, it became a space for exactly that; as Frank put it, "I guess my biggest thing for activities is, is likely just getting around and talking with people. And they can shoot whatever they want at me." After programs, people often told him, "You need to come by here more." He reflected, "Here I am thinking I'm just a guy who walked in." Yet he left feeling as though he belonged.

Belonging doesn't always happen on its own. Sometimes it has to be made possible. Martha, a recreation staff member, understood this deeply:

You try to make the unit a family-type thing as much as you can... If somebody new is here, or there, we have a new resident move in and they're at a program at our table, I'll introduce them to everybody... And then I'll go introduce each single person and include them in that, and they really feel like they're part of... making this person feel welcome.

She knew that belonging isn't just about being present – it's about being included. And so, she made sure that no one felt like a person who just walked in.

Part 2: Community Bonds: Expanding Social Worlds in LTC

Belonging was not just about peers—it was about the wider community. It was found in shared moments, familiar faces, and connections that stretched beyond the care home walls. One event that exemplified this was the dog show. Residents, staff, family members, and community members from the on-site retirement home all gathered, bringing their dogs and their presence. It was more than an event; it was a moment of coming together. As we lined the path in no particular order, I watched connections unfold. Family members introduced themselves to nearby residents. Retirement home residents reunited with old friends now living at Evergreen Manor. Some residents reconnected with pets they had once left behind, running their hands through familiar fur, their faces lighting up. Others simply took in the outdoors, the warmth of the sun, the feeling of being together.

Although I did not 'officially' observe Elaine for this program, I noticed her there, in her favourite place – the gated backyard – her smile stretching ear to ear. When I asked her if she was enjoying the outdoors, she nodded slowly but enthusiastically. Even after the show ended, residents lingered, talking, laughing, staying in the shared warmth of the afternoon. The event itself was planned, but the connections it nurtured carried on after it was over.

Similarly, the Opening Minds through the Arts (OMA) program fostered a different kind of belonging – intergenerational relationships between residents and local students. Rebecca, a recreation staff member, saw firsthand how connection could transform participation. Helen, who sometimes declined activities, did not miss an OMA session. Rebecca explained to me that Helen did not want to disappoint her student partner by not attending. The bond she formed with her student partner made it meaningful. At the final art showcase, these relationships were deeply felt. I sat at the table with Helen, whose student partner was unfortunately absent for personal reasons. In her place, Helen and I read quotes printed out on the table. These quotes were quotes from residents that were written down during the weeks that the program took place. One quote stood out to Helen: “I am so glad to be here with you today.” She lingered on the words, rereading them. Family members were invited to attend and students read personal letters directed to their resident partner out loud for their family members to hear as well. Many family and staff members were visibly emotional, some brought to tears, embracing the students in gratitude. Since Helen’s student and family were not present, we did not open her letter as I did not feel it was mine to read. After the event, I brought her letter up to her floor and ensured it would get to the family to read to Helen the next time they are in. Though I was not able to read one of the letters, Helen and I chatted and observed others in the room. I could feel the emotion throughout this event and also found myself brought to tears from witnessing the beautiful bonds that had been formed.

Belonging was not just built through organized events. Luke, a recreation staff member, emphasized this:

I can tell ya, there are a number of relationships at the tables that form, not because of rec, not because of staff, it’s because they just want to have someone to talk to, and as you talk and get

to know another resident...they become friends... We, you know, have group, small and medium programs where we all sit around and talk... but that's not really going to accomplish any social connection, they're here as part of a larger group. I think in the dining room is the best place where they can make social connection with other residents.

Belonging was found in the rhythms of daily life, in the moments of recognition, in the simple act of conversation. A townhome owner – a priest whose late wife had lived at Evergreen Manor – visited the café in the front entrance almost daily. After eating his lunch, the priest would regularly visit with residents, providing them with conversations. Frank explained to me in a casual interaction that he found these visits grounding and familiar and that their conversations became something he looked forward to. I saw this in my own conversations with residents. Many individuals simply thanked me for sitting with them, for listening, for sharing a moment. “Oh, I’m glad you dropped in. And I hope you come back,” June told me one afternoon. When I told Frank I had no more questions for him in our research conversation, I asked if he had any for me, he simply smiled: “Well, no. I’ve been glad to see you again.” These exchanges were small, yet they held weight. Some residents, like Daniel, wanted these connections to extend beyond the conversation itself: “You should leave me your name and number, well, if you want to.” Others, like Elizabeth, made it clear that being with people mattered most. “What are some things that make you happy?” I asked her during our conversation. “People,” she responded. “You like being around people?” “Yeah.” After a pause she smiled and added, “I like you.” Even June, towards the end of our conversation, showed how much connection meant to her: “Oh, no. You’re going already?” She said sadly. I responded: “I can stay if I’m not bugging you.” She responded with a chuckle “You’re not bugging me! Let’s make up some stories!” Belonging was

not just about grand events or structured programs. It was in recognition, in conversation, in the quiet assurance that someone was there and listening. It was in the invitation to come back.

Part 3. The Emotional Bonds Between Residents and Staff

Belonging was not only peer-to-peer or resident-to-community. It was also found in the relationships between residents and staff, relationships built on trust, familiarity, and genuine care. Throughout my time at Evergreen Manor, residents consistently spoke about the recreation staff with warmth and appreciation. Even when residents could not recall staff names, their interactions displayed comfort and emotional connection. I observed several instances where a BSO (Behavioural Supports Ontario⁶) staff member brought a resident with dementia to a specific recreation staff member – the only person the resident trusted enough to share personal concerns with. For many residents, recreation staff weren't just facilitators of leisure, they were friends.

Leisure activities often provided the shared moments of joy, laughter, and connection that strengthened these bonds. The Elvis show, for example, created an atmosphere of lightheartedness and warmth, as residents and staff laughed together, sang along, and actively engaged. The event featured an Elvis and Marilyn Monroe impersonator, who performed familiar songs and playfully interacted with staff and residents. When Marylin sat on Frank's lap, joking about his bald head, she asked him "what should I wish for?" He laughed and played along, responding: "Me." The room erupted in laughter and staff noticed that even residents who were typically more passive were visibly engaged, smiling and interacting. Elizabeth stood up to sing and dance, encouraging staff members to join her by dancing near them and making eye contact. Staff members danced and sang, with some laughing and smiling to the point of tears,

⁶ BSO is a provincial initiative that provides specialized support for older adults in LTC who experience responsive behaviours related to dementia, mental health, or other neurological conditions.

demonstrating how leisure activities created shared experiences that transcended resident-staff roles. These moments of shared joy reinforced the emotional closeness between residents and staff, helping to build trust, familiarity, and companionship beyond structured care interactions. They were important to continued nurturance of these relationships. June, a resident of Evergreen Manor, for example, described her great affection for Luke, the recreation staff member assigned to her floor:

Oh god yes, he's my friend... he makes everyone feel included... when you're down, he'll come and tell you 'get up!'... He is a jokester... he's really good-hearted... If they ever changed him to go to a different place, I think I would change also... he does care. We know that.

June's words reflect not just appreciation, but a sense of loyalty and emotional connection. Luke was more than staff, he was a steady presence, a source of joy and encouragement.

These relationships extended beyond organized activities, into everyday moments of familiarity and care. Rebecca, a recreation staff member, described how her bond with one resident went beyond structured programs:

So [resident name] was in bed, and I knocked and "Oh! Hey! C'mon in!" And she remembers anything I tell her, like she knows when my daughter is visiting, how she's doing, how she like, I told her when she was writing her drivers test like "did she pass?" Like, she remembers... so yeah, it's a friendship.

This illustrates how even brief informal conversations nurtured meaningful connections.

Residents and staff were not just interacting, they were sharing in each other's lives. Luke, a recreation staff member, described the depth of these relationships: "I wanna see them as more than not just a resident, but part of the family, right like at the end of the day, we spend, I spend

more time at this place than I do with my own family.” For staff like Luke, residents weren’t just part of their job – they were part of their family life, part of a shared community of care and companionship.

These relationships also played a crucial role in residents’ continued participation in leisure programs, which, in turn, deepened their sense of belonging. Ethan, a recreation staff member, shared a powerful example of how rapport and trust helped one resident re-engage in social life:

There was a lady that never came to anything... One day we had a Blue Jays game that we took residents down to the Blue Jays game in Toronto, and she wanted to go... she came and she came to everything after that... if you continue to ask people “hey, we’ve got this going on and we’ve got that going on” sometimes you’ll be able to get that rapport with people and they might not even want to come to the program, but they know me... and they know what I’m doing and they see my face and they’re like well, I want to be around people. I want to be apart of what you’re doing... I have a lot of residents down here that come to almost everything we do because of that. Because I think the rapport you get with them and that they get to know who you are and what’s going on.

This highlights how belonging is built through relationships, encouragement, and recognition. Staff were creating a culture of belonging, one that fostered social participation and emotional connection. Having opportunities to share in these types of experiences was essential for building strong, trusting relationships and sense of community.

Final Thoughts: Belonging as an Everyday Practice

Belonging in LTC is not just about simply being present – it is about being seen, remembered, and included. It is in the laughter at the bingo table, the quiet companionship of a shared conversation, and the trust between residents and staff. It is found in the smallest of gestures, a

familiar greeting, a remembered name, an invitation to return. Belonging is not incidental; it is nurtured. It is the difference between simply existing in a place and truly feeling at home.

Negotiating Freedom and Care: Autonomy, Safety, and Institutional Barriers in LTC

Living and working in a LTC setting is complex. Maintaining selfhood, agency, belonging and a sense of community become challenging when negotiating barriers that threaten these important aspects of life. There are three kinds of barriers in long-term care. Some are broader systemic barriers, rooted in how society perceives aging, dementia, and care. These barriers influence funding decisions, policy priorities, and cultural assumptions that shape the entire system. Some are structural – the deep-seated social and economic and labour-related forces that dictate staffing levels and workloads. Understaffing, time constraints, and the prioritization of efficiency over relationships all emerge from these broader structural conditions. Finally, some are institutional – embedded in the day-to-day rules and structures of a specific facility. These barriers determine schedules, permissions, privacy policies, and routines within the setting. This is the story of the barriers that come together to shape life inside long-term care, limiting autonomy, relationships, and identity for residents and the work environment for the staff.

Part 1: Halfway Free: The Contradictions of Choice in Long-Term-Care

June described the restrictive nature of long-term care:

Well, before I came here, I was always an outside girl, so to speak. We had a home in the country, and I valued that. Here, I figure I'm in jail... because you're locked up. You can't go here, you can't go there. But on the other hand, it's the only place that I can go to live halfway to what I like to be... I guess if you ask them to go out, they have to have somebody with you... and it's almost like a prisoner, I think.

Halfway. That's the word that lingers. In the story *The Right to Choose: Supporting Agency in LTC*, June spoke about not wanting to live anywhere else. But choice in LTC is complex. Even when LTC is the best option available, it still comes with limits and compromises. Elizabeth, too, expressed frustration with the limits placed on her movements: "If I could wish for something? ... I'd wish to get out of here." Elizabeth enjoyed walking outdoors, but living in the secured unit meant she could not simply go outside; she had to ask permission and be escorted. Institutional policies restrict movement. Systemic ideas about safety and risk aversion justify it. And between those two forces, residents like June and Elizabeth learn the boundaries of their world, affecting their agency and sense of self.

Yet, it wasn't just where residents could go that was limited. It was also when, how, and with whom. Martha, a recreation staff member, critiqued the way institutional routines often dismissed residents' preferences:

They [other staff] feel like they're on a time management so, those people have to go to bed... we used to have pub night every Tuesday and by 6:00, half the people would be in bed, like what gives you the right to put them to bed?

Luke, another recreation staff member, reflected on the broader impact of institutionalization on residents' autonomy. While he believed Evergreen Manor supported some aspects of social citizenship, he acknowledged that institutional norms still imposed rigid routines: "It's not a home, it's their home but it's not really a home... because they are not able to do a lot of the things they want to do." Luke recognized that his role as a recreation staff allowed him more flexibility, but that other staff were often conditioned to follow strict schedules. As he put it, recreation staff can "turn on a dime," but not everybody else can.

Residents had formal spaces to voice concerns, such as Resident Council, but staff themselves questioned their effectiveness. While recreation staff member Rebecca acknowledged that these meetings provided some input, she noted that cognitive decline limited engagement: “as dementia increases you get a lot of blank faces when you say you know ‘what can we do?’... at least you’re trying.” Luke was more skeptical, describing these meetings as a bureaucratic requirement rather than a tool for real change

We, you know, have to do them [Resident Council meetings] by legislation. Sometimes I question how useful they are... other than checking off a box that the ministry says we have to do this... I get it looks good on paper, but at the end of the day, are we actually accomplishing anything?

Only a small number of residents participated in Resident Council, most of whom did not have dementia. This raised questions: are traditional consultation structures designed in a way that truly includes those with the greatest barriers to self-advocacy? Without intentional efforts to adapt engagement strategies, many residents were left navigating an environment where their voices were rarely considered in institutional decision-making.

Part 2: Loneliness in a Crowd: Barriers to Social Connection in Long-Term-Care

While some residents found friendship and community in shared leisure spaces, others struggled with disconnection. Being surrounded by people did not automatically foster relationships, and for some, LTC felt isolating despite its communal setting. When asked if she had formed relationships, Elizabeth’s response was blunt: “I don’t really bother with too many people here.” Her relationship with her roommate was also strained: “She’s okay... she can be really rude though at times”. Social life in LTC was not simply a matter of proximity; it was shaped by the environment, institutional structures, and the level of support available to facilitate

meaningful interaction. Leisure programs provided opportunities for engagement, but participation alone did not always lead to connection. Luke, a recreation staff member, reflected on this challenge: “I don’t think we... emphasize too much on that, I think its up to the residents to form those bonds or those relationships”. While structured activities created spaces where residents could meet, there was no guarantee that these encounters would develop into meaningful social ties. Some residents naturally gravitated towards familiar faces, while others remained on the periphery, participating but not necessarily forming connections.

Elaine, a resident of Evergreen Manor, made this distinction clear. When asked if she has friends in LTC, her response was simple: “No.” But she did not dwell on this. Instead she offered a quiet self-assessment: “I was just kind of a loner anyways.” When asked if that was how she preferred it, she shrugged and responded: “I guess.” Yet, Elaine was not completely disengaged. Recreation staff member Rebecca described her as “A big smiley girl,” noting that while she enjoyed participating, she also had limits: “She’s good for a little while and then she goes ‘okay, that’s enough.’” I witnessed this firsthand during our research conversation. When I first approached Elaine for the conversation, we had already built a rapport. She greeted me with a large smile and a hello. When I asked if she had time for a visit, she was enthusiastic about spending time together. At first, Elaine was highly engaged in our conversation but as the questions continued, she eventually responded “Oh, for heavens sake.” Indicating that she was done with the questions and ready for some alone time.

Elaine participated in many group activities, including bingo, and her family told me they appreciate seeing her included, even if she required some assistance. As Rebecca noted: “She’s actually got high participation.” Elaine’s experience highlights an important nuance: choosing solitude is not the same as experiencing loneliness. She enjoyed social activities but also knew

when she needed space. She did not necessarily seek deep friendships in LTC, but she also wasn't socially isolated. This distinction is crucial in understanding the emotional landscape of LTC. Some residents, like Elaine, self-regulated their engagement, comfortably balancing solitude with participation. Others, however, wanted connection but found barriers in their way, whether cognitive, structural, or institutional. Samantha, a recreation professional, echoed this sentiment, emphasizing that being alone does not always mean being lonely. She described how she reframed questions when speaking to residents. Rather than asking residents if they felt lonely, she asked: "How do you like to spend your alone time?" She shared how residents responded in different ways:

One person said, "reading books about people." Another said, "you're never alone, you have your thoughts." Someone else told me, "I like to walk in the woods, it relaxes me." Others said they didn't like being alone at all. Another resident told me, "I like to be involved."

Samantha's approach highlighted an important oversight in how loneliness is sometimes discussed in LTC: "So when you keep asking that question about loneliness, are people truly lonely? Or is it just that they're alone? Is it a feeling of lonely? Or is it physically being alone?" At Evergreen Manor, residents were often encouraged to be socially engaged at all times, but this did not always align with individual preferences. Samantha noted:

Sometimes we're trying to keep people occupied all the time... and then you actually lose context. But if you ask, "How do you like to spend your alone time?" You get a different perspective. Because some people do prefer to be alone. And there's nothing wrong with that. Elaine's own words – "I was just kind of a loner anyways" – reflected this reality. She was not necessarily experiencing social isolation but rather maintaining a familiar pattern of engagement

and withdrawal. This was not a problem to be fixed but rather a personal preference that needed to be understood. For some residents, solitude was a choice. For others, loneliness was imposed.

For residents living with dementia, the barriers to social connection were even more pronounced. Rebecca, a recreation professional, described the challenges of fostering engagement among residents with cognitive or sensory impairments: “I would say we struggle at [Evergreen Manor], just probably like any LTC institution, to get them to engage more with each other... the dementia, the hearing loss.” Even when group programs encouraged interaction, residents who had difficulty following conversations or recognizing familiar faces often withdrew. Without intentional facilitation, they risked becoming isolated within the very spaces meant to foster connection.

Institutional policies also shaped the social environment in ways that reinforced isolation. When a resident passed away or was hospitalized, privacy regulations prevented staff from sharing updates with other residents, leaving them uncertain about what had happened. Rebecca reflected on how this lack of communication deeply affected residents:

When somebody’s been in the hospital... they do pick up on that... and I don’t think we do a great job always recognizing that. That they have feelings too when they lose a table mate... They get no closure... and you try and drop hints and hope they can read between the lines... without getting in trouble... it breaks my heart.

While I did not directly observe residents reacting to these absences, staff members expressed concern about how privacy rules limited opportunities for acknowledgement. Some noted that residents would ask about missing peers, but with no formal way to provide updates, responses were often vague. Rebecca described trying to navigate these moments carefully, offering quiet hints in the hope that residents would understand without staff violating confidentiality policies.

This uncertainty, shaped by institutional rules, created an environment where loss was present but rarely spoken about openly.

Even when residents wanted to engage socially, staffing constraints sometimes restricted their opportunities to do so. Rebecca described how the demands on the staff left little time for fostering relationships:

I think I treat it like, hopefully, most people here, that if this was my mother, or my father, or my grandparents, what would I want for them? ... Like you'll always feel like, I think even on a great day, you can still go to the 'but I could've done more'... [there are] too many needs.

Rebecca further emphasized that these constraints extend beyond Evergreen Manor, pointing to structural issues across the LTC system:

It's not necessarily [Evergreen Manor] per se, but in LTC, staffing... Staffing Ratios ... so that's not necessarily [Evergreen Manor] per se, but we're at the, because we're a not for profit, you are at the mercy of government funding.

Luke echoed these concerns, providing a historical perspective on how the organization and culture of Evergreen Manor have changed over time. He described how when the home first opened, it has fewer resources but stronger interpersonal connection:

I think a lot of people found that the staffing made the place. Because the building wasn't great, it was falling apart... The staffing was a close-knit group. And now kind of as time has gone on, it's changed. You know, we've had a lot of different things happen, whether it's COVID or different things that come down through the ministry guidelines and just changes the business itself.

Luke also described how the home had evolved under new leadership, with the CEO introducing innovations such as AI and robots to support staff. Still, he explained, staff retention remains a significant challenge in the aftermath of the COVID-19 pandemic:

I would say COVID really knocked us for a loop in terms of staffing issues... We had a really tough time. People didn't want to be in the business. I still think that's the case... We lost some staff to hospitals because they were hiring more people. So, the PSWs went there for more money, maybe benefits, maybe full-time lines that they didn't have here. So, we're still trying to recover from the COVID years. And that is one of the things I think that um, I don't know how long it's going to take.

He further reflected on how these staffing issues affect care and staff morale:

I think they care... the staff here really, really are trying to do the best they can. But I think sometimes they, they're short and there's only so much they can do and they get frustrated at that because they want to give the best they can... I think that's one of those things that, COVID, we're still trying to work through those things... but I think they're getting better for sure... since COVID... it's just been tougher to keep people on um, because they are looking for full time jobs and different things like that.

Even when residents actively sought opportunities to claim meaningful roles, systemic and institutional barriers often prevented them from fully engaging in these activities. Staffing constraints, rigid policies, and assumptions about capacity meant that residents were often limited to passive participation rather than being given opportunities to contribute meaningfully. Rebecca went on to describe how staffing shortages limited one-on-one engagement: "I always struggle with the balance of trying to fit in my 1:1's... it's very challenging. Even though it's

only 30 residents, it might as well be 100... plus your paperwork.” Luke shared an example of how environmental support was critical for maintaining purposeful activities:

I ran knitting groups with people before because there are ladies who like to knit or crochet... that’s what they liked to do before. They still want to do it... sometimes they just need a little bit more... a place to be set up to succeed.

Luke mentioned this program in the past tense because he saw a decrease in interest in this program, though he is thinking about bringing it back now that some new knitters have moved in. With staff stretched thin, medical and physical care often took priority over emotional and relational needs, leaving some residents to navigate loneliness and boredom largely on their own.

The time constraints and lack of staffing also had an impact on recreation staff who saw it as their purpose to ensure that residents continued to thrive in the LTC environment, fostering joy and engagement through leisure. The dedication and the passion of the recreationists was evident throughout my time at the facility, from their long history of employment at the home to the consistently positive feedback from residents and family members. A number of recreationists I spoke with described how creating a sense of joy is a relational experience:

But the thing is I really feel like I'm so lucky because I feel like I have, yeah I'm definitely doing what I was meant, it sounds, sounds cheesy but, I was put on this earth to be a recreationist. (Martha)

Until I actually got here and realized how uh rewarding it is and the differences that you can make in people's lives, just one day at a time... One smile at a time. I don't think I realized how rewarding it would be. That's probably why I've stayed so long...working with people doesn't always reward you financially... But it does in a lot of other ways, that’s for sure.

(Ethan)

It gives me the ability to (brief pause) um enhance the last days of our residents' lives, whether its years, or months, or days (Luke).

Their enthusiasm, creativity, and ability to connect with residents on a personal level helped ensure that leisure remained meaningful and emotionally fulfilling, at least for some residents and at least some of the time. Martha emphasized the importance of staff personality and engagement, stating:

You have to enjoy, you have to let the residents enjoy your programs. You want them to come to you, you don't want to drag them... I call myself the 'fun girl'—I just get to be the fun person who says, 'Come on over, let's have fun!'

Luke similarly highlighted the role of fun and playfulness in supporting resident well-being: "My way of, of working with our residents, depending on who it is... is having fun, and joking with them". However, this emotional labour required significant energy and effort from recreation staff. Rebecca described the mental and emotional demands of creating an engaging environment:

I will say, I'm actually exhausted when I get home because emotionally, I've had to be the cheerleader all day. There are days you might come into work and not feel like that, but you know that's what they need.

This demonstrates how staff's ability to create a lively, fun environment directly impacted not only residents but the recreation staffs' emotional well-being. Their work extended beyond running programs; they worked hard to build relationships and ensure that leisure was an uplifting, enriching experience, rather than just an activity. This was emotionally and physically exhausting work.

For many residents, moving into LTC also meant leaving behind previous social networks – family, lifelong friends, and familiar community spaces were no longer a part of daily life. Adjusting to this shift could be particularly difficult, especially for those who had strong ties to their past communities. Rebecca, reflected on the emotional weight of this transition:

That goes back to “how do I fit in here?” And “how does everyone else have me fit in here?”
“... cause there’s nothing worse than going someplace and you feel like you’re over here... especially when you’ve been taken out of your own community. Now I don’t have my community... so I’ve got to be brought into a new community. How am I fitting in? ... How are we gonna have this person fit in?”

While some residents eventually found companionship through structured leisure programs, shared meals, or developing relationships with staff, others remained disconnected. Without intentional efforts to create meaningful social opportunities, some residents found themselves physically surrounded by people but emotionally alone. For example, during my time at Evergreen Manor, I often observed a common practice that I believe is typical in many LTC settings: When residents were not engaged in leisure or care, they were brought to shared spaces, such as the TV room, with the intention of encouraging passive engagement or ensuring they were not alone. However, being near others did not necessarily result in connection or interaction. For instance, when I went to find Elaine and Helen for our research conversations, I found them sitting in silence in the TV room, positioned close to other residents, but not speaking or engaging with anyone. This was not an isolated instance. I frequently observed residents seated quietly in common areas, often watching TV passively or attempting to get the attention of busy staff who were unable to stop in that moment. This lack of engagement was especially pronounced for residents in wheelchairs who could not self-propel and were therefore

dependent on staff assistance to move elsewhere. It also appeared to be more common among residents with advanced dementia, who were less able to initiate conversations or sustain relationships without external support. In contrast, residents without cognitive impairments or in the earlier stages of dementia, were often better able to navigate these spaces independently and build connections through spontaneous conversation or shared activities. Without intentional support, residents living with dementia can remain isolated even in shared spaces. Loneliness, in these cases, is not from being alone, but from being unseen.

Part 3: Stigma and Silence: When Assumptions Shape Care

Despite the power of personal storytelling and creative expression, stigmatizing attitudes sometimes limited residents' ability to fully assert their selfhood within the LTC setting. This stigma was not always explicit, but shaped how people living with dementia were perceived, often as passive recipients of care rather than individuals with rich histories, ongoing relational capacities, and meaningful contributions to make. I witnessed this firsthand in moments that revealed how assumptions about dementia shaped interactions within the home. One afternoon, I noticed a resident, alone in the dining room, quietly crying while rearranging chairs and place settings. She was visibly distressed, moving objects as if trying to establish order in her environment. When a personal support worker (PSW) witnessed me trying to speak with her the PSW said "Just leave her be. That's just what she does." There was no attempt to engage with her emotional state or understand her actions. Instead, her distress was framed as a meaningless, repetitive behaviour, something to be observed but not responded to. Similarly, while assisting a recreation professional during bingo, I sat with a resident living with dementia, repeating the numbers to ensure she could hear and participate. She listened carefully, following along and circling the correct numbers herself. Yet, at one point, I was told to just do it for her and that she

does not really know what is going on. But she did know. She was actively engaged, just going at her own pace.

These moments illustrate how stigma operates in practice, reinforcing the assumption that people living with dementia are disconnected from reality, incapable of meaningful participation, or not worth engaging beyond surface-level care. Rather than being seen as individuals experiencing distress, confusion, or requiring minor accommodations, they were often treated as if their actions lacked meaning. These assumptions – whether intentional or not – directly shaped how staff engaged with residents, the level of effort made to include them, and the opportunities available for self-expression. Martha, a recreation staff member, reflected on these deeply ingrained societal beliefs that shape LTC: “At what point in time did society have to say people with dementia can’t do things? You know? ... The stigma. So, does that occur in long-term care? Absolutely... How do we change that?” These systemic assumptions, embedded in cultural narratives about aging, cognitive decline, and dependence, directly shaped institutional practices that overlooked residents’ capabilities. The result was an environment where some residents were excluded from opportunities for engagement, not because they lacked the ability, but because the system had already decided for them that they lacked capacity.

Stigma was not the only barrier to self-expression. The very act of moving into LTC meant leaving behind deeply personal spaces, filled with objects, routines, and histories that defined residents’ selfhood. Martha reflected on how this transition stripped residents of important aspects of their former lives:

It’s not a doll you’re just getting dressed for the day, like this is a person with feelings, and I think we forget everybody who came here had a life before they came here... and we forget that... some of them moved here from this huge house full of their stuff to this little 12x12

room where you're allowed one chair and some pictures and a couple ornaments... like, think about it.

The reduction of personal space limited opportunities for self-expression through objects, making it even more crucial for recreation programming to provide alternative avenues for residents to assert their identity. Yet, changes in staff training over time also impacted how selfhood was recognized in LTC. Samantha, who had worked as a PSW for 25 years before transitioning to recreation, noted that shifting educational standards have prioritized task-oriented care over relational engagement:

That was a whole year of schooling, okay. They said, and you had to work in LTC in order to take the program... so now it's just like everybody's being pushed through the program... But I was, you know, four different placements, six weeks at a time... there was a set of standards and you went through it. And some things that I learned aren't even applied today... but it's still a part of my ethics.

For Samantha, selfhood was more than just about basic care – it was about creating a sense of home:

For me, it's their home, you know, is there room clean? I should hope so... Do they have a bedspread on their bed... Do they have, you know, room that looks like home to them? Pictures, articles, you know, comfortable chair? Is it all clean, settled?... If it's not, you know, I can't, I wouldn't sleep... that's just me... that's my makeup... I can't teach people that... I'd like to but I can't... like we always say, empathy can't be taught... you have to learn it. And how do you learn empathy? It takes years, it takes years.

She also questioned past teachings that emphasized reality orientation over personal storytelling:

I love to hear the stories... we were always taught years ago “reality orientation, time, day, and place. You got to snap them out of it. You got to bring them back to reality”... but I love the story of him working on the farm and he needs to go to the farm and all that. Let him tell me that story... he’s being heard... and that’s how you build the relationship.

Institutional infection control policies, designed to ensure safety, often undermined residents’ ability to participate in meaningful activities. Rebecca, a recreation staff member, described how these rules became barriers to create a home-like environment:

The rules... COVID, the isolation, the bureaucracy, the ministry sitting in their glass houses making the rules that don’t... they don’t make sense and stop you from being like... like wouldn’t it be great if we had a washer and dryer and they can load and fold it? ... But then, I can’t have a dryer... Like IPAC, the infection control rules are **over the top...** like that you can’t even fold the linens because then they’re going to touch, they’ve touched everybody’s linens? **Who cares...** But I can’t break any of those rules... the government wants it to be a home but... it’s just impossible to meet those needs... and it **just won’t work...** it’s so frustrating to, ‘cause I want it to be more home like... I understand there’s rules in place, at **some point** it becomes (brief pause) all the rules they create make it **worse** for the environment.

Rather than flexible, relational care, institutional rigidity led to standardization, reducing opportunities for residents to make choices about how they spent their time, what they ate, and how they participated in daily life. Institutional policies also shaped how and when residents could experience joy and spontaneity. Policies, including infection control, can lead to standardized approaches that do not always align with residents’ individual needs and

preferences, further contributing to passive participation or disengagement. Rebecca further explained how these formal structures impact day-to-day experiences:

There's another thing that drives me insane, the dietitian says "[resident's name] likes grapes" well that means [resident's name] is going to have, she'll have grape juice everyday for the rest of her life, because that's what it says and you have to follow the care plan.

Institutional routines were not neutral; they shaped the extent to which residents could assert autonomy. While some staff worked to create flexibility within programs, others were bound by rules that prioritized efficiency over individualized care. During our research conversation, when I asked a resident, Elizabeth, how she liked living at Evergreen Manor, she spoke bluntly about how this structure left her feeling disengaged: "I'm bored." Elaine, another resident, too, shared similar feelings when asked "Do you feel like you have fun while you're here?" She stated "no." To clarify, I asked if she gets bored sometimes, to which she responded: "yeah." This was observed in programs where Elaine did not seem to be actively participating. Elaine appeared disengaged during the church service, as she did not sing or follow along with the hymn book. Similarly, Elizabeth, despite being highly engaged in the Elvis performance, seemed disinterested during Bingo, marking random numbers, and showed little concern for the outcome of the game. This highlights how not all leisure activities evoke joy or emotional connection for all residents, particularly when they are not meaningful to residents, emphasizing the importance of personalization and variety in programming. Yet, within the constraints of institutional care, the ability to create truly resident-driven experiences remained limited. Some residents found ways to assert their agency, but for others, systemic, structural, and institutional barriers dictated not just their daily routines, but the extent to which they could express themselves at all.

Final Thoughts: Autonomy and Dignity in Tension

Autonomy in LTC is never absolute – it exists within constraints. Residents navigate freedom within safety policies, choice within institutional routines, and voice within systems that do not always listen. But autonomy is not just about what residents are allowed to do; it is about what they are supported to do. Dignity is upheld when autonomy is not an afterthought but a guiding principle – when residents’ choices are not just acknowledged but actively protected and prioritized. This negotiation of freedom and care shaped the experiences of both residents and recreation staff, who often had to balance institutional demands with their commitment to supporting autonomy and meaningful engagement.

Chapter 5 – Discussion and Moving Forward

Introduction

When I set out to embark on this research, I aimed to use narrative citizenship and ethnographic tools as a means to capture the stories of social and relational citizenship for people living with dementia in LTC settings, and the role of leisure in supporting or limiting social and relational citizenship for residents living in these settings. Stories told to me orally in the research conversations conducted with people living with dementia and the recreation staff and in embodied ways as witnessed during my time spent at the home suggest that social citizenship at Evergreen Manor is complicated.

Evergreen Manor stands out as a unique LTC institution, a distinction recognized not only through my research but also by the recreation staff and residents themselves. When I worked in LTC, as described in Chapter 1, residents living with dementia told consistently negative stories of living in LTC with few, if any positive reflections. While I was working during the height of the COVID-19 pandemic when strict protocols were in place, I recognized that many of the challenges I witnessed were not exclusive to the pandemic, but rather amplified and made more visible by it. As a result, I anticipated hearing similarly difficult stories marked by loneliness, boredom, and hopelessness. Although such narratives are present at Evergreen Manor and must not be overlooked, I was genuinely surprised by the number of positive stories shared by residents. While most, if not all, acknowledged certain aspects of LTC life they disliked, many also expressed appreciation for the staff and the overall atmosphere at Evergreen Manor.

Unlike many LTC environments where leisure is undervalued or constrained by limited resources, Evergreen Manor prioritizes leisure as an essential aspect of residents' well-being. This commitment is evident in the home's strong leadership, dedicated recreation team, and the

physical environment, all of which, for the most part, contribute to fostering meaningful engagement and joy. As a standalone institution with expansive grounds, including gardens, multiple outdoor spaces, a retirement home, and townhomes, Evergreen Manor provides residents with opportunities that extend beyond the traditional confines of LTC institutions. The leadership actively supports leisure initiatives, embracing innovation and ensuring that recreation remains a dynamic and evolving component of care. Recreation staff noted that this culture of support allows them to implement new programs, access resources, and adapt to the changing needs of residents more effectively than in many other LTC settings. Despite broader structural challenges within LTC institutions, staff at Evergreen Manor see themselves as playing a critical role in ensuring that leisure is not just an activity but an emotionally fulfilling and relational experience, something that residents themselves highlighted in their conversations with me. The staff's enthusiasm, creativity, and ability to connect with residents on a personal level help sustain a vibrant recreational culture within the home. With five full-time recreationists, more recreation staff than many LTC settings have, there is more opportunity for personalized engagement, diverse programming, and stronger relationships between staff and residents. Additionally, the presence of large, dedicated recreation rooms in each home area ensures that leisure activities are not disrupted by the distractions and noise of communal spaces, allowing for a more immersive and engaging experience.

Residents often spoke positively about the variety of activities available, the creativity of staff, and the relationships formed through shared experiences. However, the experiences of people living with dementia at Evergreen Manor also revealed the ongoing tension between institutional structures and resident autonomy. In research conversations, some residents communicated frustration with constraints on their freedom while others expressed a strong

sense of purpose and agency, particularly when given opportunities to engage in leisure activities that reflected their interests, histories, or values. Even in moments when roles were not formally recognized, residents found ways to support one another, share stories, and assert their citizenship through creative and relational acts. While recreation staff did not intentionally frame their work through the lens of social and relational citizenship, aspects of this approach were present in practice. However, these moments are often incidental rather than embedded within broader organizational practices. Much more is needed to fully realize the potential of social and relational citizenship for all residents, particularly for residents living with dementia. This includes ongoing efforts to shift institutional cultures, address systemic barriers, and reimagine leisure as not just an activity, but as a meaningful space for agency, connection, and contribution. To move in this direction, much more research is needed to examine the institutional conditions that either enable or restrict social and relational citizenship in LTC for different groups of people, and to explore how leisure can more intentionally serve as a site for the recognition of citizenship.

I begin this chapter with a critical discussion on how each component of social citizenship is being supported or undermined in each story presented in Chapter 4: *Holding onto Selfhood, The Right to Choose, Beyond Isolation, and Negotiating Freedom and Care*. Woven into this discussion, I will also examine how components of relational citizenship were supported or constrained. Next, I discuss the implications of this research. This includes personal, practical, theoretical, and methodological implications. Finally, I conclude this chapter by discussing directions for future research.

Leisure and Social Citizenship at Evergreen Manor

From Comfort to Growth: Identity Maintenance vs. Growth in LTC

Within LTC settings, the prioritization of disease prevention and medicalized control tends to emphasize safety and stability, inadvertently constraining residents' opportunities for personal growth, autonomy, and relational engagement (LeVasseur, 2021; Bartlett & O'Connor, 2010). A social citizenship lens advocates for moving from simply maintaining comfort to promoting opportunities for growth. In the first story *Holding onto Selfhood*, meaningful personal objects such as family photos and posters were important to residents for communicating important aspects of themselves and their life histories. As important as these were, they served primarily as tools for reminiscence rather than as gateways to supporting new social roles or evolving selfhood. While preserving past social roles can be comforting, such approaches often restrict residents' capacity to engage dynamically within their social worlds. Even well-intentioned activities can inadvertently rely on static or retrospective conceptions of the self rather than fostering dynamic, embodied engagement. Staff attempts to facilitate self-expression at Evergreen Manor typically reinforced this pattern. For example, recreation staff provided activities anchored primarily in memory and past experiences. While valuable, these activities seldom offered residents opportunities to reshape or expand their current identity. This reflects existing research suggesting that person-centred approaches, while supportive, risk maintaining a narrow view of selfhood if individuals do not account for ongoing social/relational citizenship (Bartlett & O'Connor, 2010). Kontos and Martin (2013) argue for recognizing the pre-reflective, expressive capacities of the body as meaningful forms of selfhood and agency that persist despite cognitive decline.

There were glimpses within Evergreen Manor where growth was being supported, such as in Frank's participation in Opening Minds Through Art (OMA) described in *Holding onto Selfhood*. Initially uncertain about his artistic abilities, Frank embraced a new creative process, discovering a form of expression that moved beyond familiar identity markers. While OMA provided space for self-exploration, its structure, like many LTC programs, remained primarily staff/facilitator-driven, shaping the ways residents engaged in artistic expression. While OMA intentionally follows person-centred approaches, the Bitove Method, in contrast, is intentionally grounded in a relational caring philosophy (Mitchell et al., 2020). While the person-centred paradigm represents a welcome shift from the biomedical focus on deficits to an emphasis on the person living with dementia, research has critiqued its tendency to reinforce an individualized rather than a relational understanding of personhood (Bartlett & O'Connor, 2010). Mitchell et al. (2020) emphasize the importance of initiatives focusing on honouring embodied selfhood, lifelong learning, and relationships, where everyone thrives. Although I do believe OMA unintentionally supports aspects of relational citizenship- such as the emphasis on inclusivity regardless of skill level and providing opportunities to learn new things - without intentionally engaging with relational and social citizenship, this program may be limited in providing opportunities for growth. As Basting (2018) notes, most arts-based projects are a one-time event or short term, which can impede opportunities for growth and learning. OMA typically runs for 8 weeks with one session occurring a week. There is then a final showcase and the event is over, this model is not integrated into the day to day lives of residents, which is what is likely needed for more robust opportunities for growth to be available for residents living in the home.

In the story *Holding onto Selfhood*, staff themselves acknowledged the tension between structure and growth. Samantha, a recreation staff member, recognized the potential for residents

to thrive when freed from the pressures of daily care management. She observed that some residents discovered new interests and engaged more fully in life once their basic needs were met, yet she also acknowledged that LTC's rigid structures often prevented this kind of flourishing from becoming the norm. Institutional constraints such as understaffing, task-oriented care, and risk-averse policies frequently left staff with little time or flexibility to support residents' evolving selfhood. June's humorous comment about "sneaking out the window" underscores how some residents perceived LTC as more restrictive than expansive. Beyond structural barriers, staff perspectives on resident growth varied.

Some staff members actively encouraged residents to explore new roles and social positions, while others, constrained by both time and ingrained institutional norms, defaulted to viewing residents as passive care recipients rather than evolving social actors. Research suggests that dominant care practices often reflect and reinforce stigmatizing views of dementia, leading to dismissed expectations for resident agency and a tendency to treat selfhood as static or lost (Kontos & Martin, 2013; Kontos & Grigorovich, 2018a). This does not reflect a lack of care but rather deeply embedded systemic barriers and an institutional culture that prioritizes risk management and routine over relational engagement (Bartlett & O'Connor, 2010; Mitchell et al., 2020).

Overall, the story *Holding onto Selfhood*, shows how Evergreen Manor demonstrates *some* movement towards supporting resident growth and evolving selfhood, particularly through personalized engagement and occasional opportunities for creative expression. However, these instances remain the exception rather than the norm. The home's leisure offerings, while more robust than many LTC settings that I have experienced, tend to reinforce static understanding of selfhood unless staff actively and intentionally challenge these norms.

Despite these challenges, some staff members actively worked to create moments of personal growth within these constraints. Samantha's perspective highlights that even within a highly structured environment, opportunities for residents to take on new roles and experiences do exist, but they are often dependent on the creativity, advocacy, and available time of individual staff members rather than being ingrained into the system itself. Ultimately, the potential for resident growth in LTC is not an inherent feature of the system but an outcome of individual staff efforts that push against structural limitations. To more fully support the shift from comfort to growth, leisure practices need to evolve from short-term, structured interventions to sustained, resident-led opportunities for creative exploration and relationship building. Embedding creative, relationally grounded leisure into daily life, rather than isolating it to short-term programs may help shift the culture of care from one of maintenance to one of growth and social recognition.

From Identity to Social Positions: Making Social Roles Visible in LTC

In LTC, selfhood is often acknowledged through passive validation rather than active recognition of residents' evolving social roles and positions. Bartlett and O'Connor (2010) argue that social positions provide a more dynamic understanding of selfhood than static identity markers, as they account for how individuals negotiate roles within their communities rather than being defined solely by their past. However, LTC settings primarily position residents as care recipients rather than active social participants, limiting opportunities for meaningful contribution and recognition. This passive framing of selfhood is particularly evident for residents with more advanced dementia, whose ability to enact a social position depends on whether the institution creates space for their agency to be recognized and supported.

Institutional routines in LTC settings prioritize efficiency, risk management, and consistency, often leaving little room for residents to adopt or negotiate evolving social positions. As

demonstrated in *Holding onto Selfhood*, the selfhood of residents at Evergreen Manor is often acknowledged through individual history or recognition of past roles, however, there is limited recognition of residents evolving social roles and limited institutional support for residents to take up new or ongoing roles within the home. Different social positions, when they emerge, tend to do so informally and are often sustained by the resident alone rather than facilitated or reinforced by the structure or culture of the institution. Frank's experience in *Holding onto Selfhood* demonstrates this: he regularly describes himself as an "active leader," offering informal support to his peers in social settings. Yet, this leadership exists because Frank has claimed it for himself, not because the LTC institution has provided structured support or formal recognition. These informal roles may be less likely to be taken up by individuals living with more advanced dementia who require more relational support.

Daniel's nurturing role in *Holding onto Selfhood* further exemplifies how social positions are maintained through relational engagement rather than institutional recognition. His role and social position as a caring husband and father and member of his community remain contingent on personal connections, such as Daniel's relationship with his daughter, rather than structural acknowledgment. Kontos and Grigorovich's (2018a, 2018b) concept of relational citizenship highlights that selfhood is enacted through social interaction, affective connection, and embodied participation rather than solely through verbal or cognitive expressions. However, in LTC settings, these relational roles often remain dependent on personal relationships rather than being structurally embedded into care practices and social positions are primarily acknowledged retrospectively rather than as relational and evolving.

In contrast, community settings have demonstrated how people living with dementia actively engage in social citizenship, taking on roles such as advocacy (Bartlett, 2014; Knauss & Moyer,

2006) or participating in research, education, and public awareness campaigns (Innes et al., 2021; Russell, 2020). When the continued capacity of people living with dementia is recognized, it can be nurtured. In LTC institutions, structured forums such as Resident Council meetings allow for limited participation for some residents, but broader opportunities to extend leadership beyond these designated spaces remain rare. This reflects broader critiques that LTC institutions often fail to incorporate resident-initiated contributions into formal structures, leaving active citizenship largely unsupported (Bartlett & O'Connor, 2010; Kontos et al., 2017).

Autonomy in LTC is also socially structured through institutional norms that determine who is positioned as an active decision-maker. Bartlett and O'Connor (2010) argue that agency is relational, meaning that a resident's ability to act with autonomy depends not just on their cognitive or verbal abilities but on whether the institution and relationships within the setting create meaningful opportunities for participation and power-sharing. However, LTC institutions often reinforce hierarchies of competence, shaping whose voices are recognized and whose are dismissed. At Evergreen Manor, residents may find themselves socially positioned with respect to their cognitive abilities. In the story *The Right to Choose*, Frank and June illustrate how verbal self-advocacy plays a crucial role in navigating LTC environments. Frank expresses confidence in his ability to make choices, explaining that if residents speak up, staff are often willing to listen and provide support. June similarly asserts her influence through humour, making it clear that she expects to be heard. Yet, both acknowledge that institutional policies ultimately define the limits of choice; staff may listen, but decision-making authority still rests within pre-established rules and procedures.

For residents who cannot advocate verbally, their social position in the decision-making hierarchy is even more restricted. In *The Right to Choose*, Martha, a recreation staff member,

described how non-verbal residents are often denied opportunities based on staff assumptions rather than explicit preferences. While recreation staff at Evergreen Manor pay close attention to non-verbal residents' body language to gauge enjoyment, this typically influences attendance but not the structure or content of activities. Staff are far more likely to act on explicitly verbal suggestions from residents when planning or modifying programming. Thus, residents who cannot express preferences verbally risk exclusion from influencing activities, reflecting broader institutional governance patterns prioritizing efficiency over relational, individualized approaches (Kontos et al., 2010). Leisure has the potential to flatten this hierarchy of agency not only by responding to embodied communication in the moment, but by also involving non-verbal residents in shaping and co-designing programs. In doing so leisure can help make the social roles of all residents more visible and valued,

Few opportunities to take on new social positions within LTC settings exist, though thinking intentionally about this provides opportunities to better support this aspect of social citizenship in the future. Leisure holds significant potential for creating and affirming resident roles in more intentional and visible ways. Residents who support or guide others, such as Frank, may be well-positioned to take on recognizable roles such as co-leading programs or welcoming new residents. For example, in the Java Mentorship program, resident mentors living with dementia were paired up with community members providing people living with dementia the opportunity to help others, themselves, build a larger social world and learn with others (Theurer et al., 2022). Social positions can also be expressed through more subtle, embodied and relational forms of communication, particularly for residents with advanced dementia. Recognizing these forms of participation requires expanding institutional understandings of communication and contribution, acknowledging people living with dementia, including individuals who cannot

communicate verbally, as active contributors. Thinking intentionally about providing and supporting these opportunities can enhance social citizenship by embedding diverse forms of participation into everyday LTC practices.

From Inclusion to Participation: Beyond Tokenism in Resident Engagement

Social citizenship requires active engagement in shaping one's environment, yet participation in LTC settings is often structured within institutional limits rather than being genuinely resident-driven (Bartlett & O'Connor, 2010). Resident councils are presented as mechanisms for participation, yet they rarely translate into meaningful influence over institutional policies. Seetharaman and Chaudhury (2020) critique tokenistic consultation practices in dementia-friendly community initiatives, where people living with dementia are often invited to provide input but are not granted genuine power in decision-making processes. Similarly, Robertson and McCall (2020) highlight how participation in formalized institutional settings can limit authentic, resident-led dialogue, noting that overly structured formats may restrict the expression of personal meaning and identity.

The story of *The Right to Choose* demonstrates how participation is not just about structured meetings or formalized input—it happens in everyday moments. Ethan, a recreation staff member, keeps programming flexible, allowing residents to influence activities in real time. Residents also shape leisure through subtle, creative acts of self-expression. At the Elvis Show, Frank jokingly plays to the crowd using humour to spark laughter and connection. June, never shy about speaking up, teases that she will give staff “a kick” if they ignore her input. These small but powerful acts reflect what Bellass et al. (2019) call ‘little-c’ creativity – the everyday ways people living with dementia adapt, improvise, and assert themselves within structured environments. Unlike ‘big-C’ creativity, which is associated with exceptional artistic

achievement, ‘little-c’ creativity refers to subtle, relational acts of meaning-making that arise within ordinary interactions and constrained environments. Recognizing these small, everyday expressions of preference and resistance is essential for supporting authentic participation in LTC.

Bellass et al. (2019) emphasize that these forms of creativity are shaped through power relations and often go unrecognized within institutional systems that prioritize efficiency and control. Leisure when approached flexibly and relationally, can become a space where residents express agency not only by choosing activities but by shaping how these activities unfold. However, to move beyond tokenistic participation, LTC institutions must replace rigid, staff-led engagement with resident-driven models. The Authentic Partnership model (Dupuis et al., 2012d) provides an alternative by embedding co-creation into governance structures, ensuring that participation is not just symbolic but actively shapes institutional decisions. This will require the elimination of the stigma associated with dementia and recognition of the contributions people living with dementia can make to their communities. Further, if institutions do not truly commit to changing how decisions are made, participation will stay limited to surface level activities instead of giving residents real influence over their lives. I suspect, however, that residents living with dementia will continue to find creative ways in everyday moments and interactions to assert their agency. Due to its relational nature, leisure programming may be uniquely positioned to recognize and acknowledge these ‘small-c’ moments of creativity and expressions of agency. These everyday acts of resistance and co-creation also speak to broader issues raised in the next section: how residents pursue not just activity, but meaningful purpose and connection through leisure.

From Occupation to Purpose: Honouring Individual Meaning in Leisure

While traditional models of engagement for people living with dementia often emphasize occupation, research suggests that this focus may overlook a deeper and more fundamental human need: purpose (Dupuis et al., 2024). The distinction is crucial. As Bartlett and O'Connor (2010) argue, occupation is primarily about doing, whereas purpose is about meaning. This shift in focus calls for a re-evaluation of how leisure and recreation programs are structured in LTC settings, ensuring they do not simply fill time but instead cultivate experiences that hold personal significance for each resident.

Meaning is not universal but deeply personal. What provides a sense of purpose for one resident may not resonate with another. As shown in the story *Negotiating Freedom and Care*, Elaine, who has always described herself as a “loner,” does not derive meaning from social interaction in the same way that Frank does. In *Beyond Isolation*, it is seen that Frank values conversation as his primary motivation for engaging in activities, finding fulfillment in social participation. Similarly, June experiences purpose not from the activities themselves but through the relationships they foster. She speaks of the deep sense of community that leisure programs create for her, not just among fellow residents, such as her bingo companions, but also through her connections with recreation staff. This aligns with relational citizenship, which underscores the importance of everyday relationships in shaping the experiences of people living with dementia (Kontos et al., 2016). The first tenet of relational citizenship, relationality, emphasizes mutual, reciprocal, and interdependent connections, recognizing that people with dementia retain the capacity for meaningful social engagement.

The importance of these relationships is evident in how leisure programs at Evergreen Manor shape social belonging. For example, in *Beyond Isolation* June describes how interactions with a recreation staff member on her floor bring her joy and encouragement, making these programs

personally meaningful. Rather than passively participating or merely being occupied, she thrives when surrounded by friends, illustrating that leisure is most impactful when it fosters relational connections. Staff also recognize the centrality of relationships in sustaining purposeful participation. Even Helen, who often refused to attend programs, was consistently motivated to join OMA due to the bond she formed with her student partner. This suggests that participation in leisure programs is not driven solely by activity preference but by the relationships and emotional connections that emerge through them. Other research demonstrates the importance of relationships for people living with dementia and the role that leisure can play in building and nurturing relationships and meaningful leisure experiences (Dupuis et al., 2012c; Fortune & McKeown, 2016).

The second tenet of relational citizenship, embodied selfhood, challenges the assumption that meaning making and communication are solely cognitive or verbal processes. Instead, it acknowledges the pre-reflective ways in which the body itself can express identity and purpose (Kontos & Grigorovich, 2018b). This perspective is crucial when considering how meaning manifests differently for Elaine. When engaged in activities that seem to merely occupy her, such as sitting through a church service without singing or interacting with the hymn book, she appears disengaged, looking down and withdrawn. However, when participating in something meaningful to her, such as the flower arranging program described in *The Right to Choose*, her entire bodily presence shifts. Her hands move with familiarity and purpose, revealing a deep connection to her past as a gardener. This shift underscores how the body carries and expresses personal history, skills, and socio-cultural dispositions—the ingrained habits and knowledge accumulated over a lifetime. For Elaine, engagement is not about following structured programming but about accessing activities that align with her embodied memories and

expertise. In this way, meaning is not simply an internal cognitive process, but something lived and enacted through the body.

To fully support relational citizenship, LTC settings must move beyond rigid, standardized programming and instead create resident-led, flexible engagement opportunities that honour diverse ways of finding meaning. Kontos et al. (2017) illustrate this potential through their study on red-nosed elder clowns in dementia care. One clown was able to interpret a resident's bodily movements as an artistic expression and responded in a way that fostered a creative exchange. This example highlights how relational citizenship can be supported at a micro-level of care, recognizing and validating non-verbal forms of communication and engagement. Supporting a sense of purpose also requires knowing the people living with dementia we work with at a deeper, more relational level, which means capturing each resident's evolving story. What is meaningful to a person can shift over time and cannot be assumed.

Expanding opportunities for embodied, relational, and resident-driven participation in LTC institutions is essential not only for inclusivity but for fostering experiences that hold deep personal meaning. Rather than structuring engagement around predetermined activities, care partners must attune themselves to the diverse ways residents express selfhood, whether through social interactions, movement, or creative expression. By shifting the focus from occupation to purpose, LTC environments can move beyond simply keeping residents busy and instead cultivate experiences that genuinely resonate with their selfhood and capacities for connection. Ali et al. (2023) and Dixon et al. (2022) reinforce this argument, highlighting that residents actively shape their social environments even within restrictive settings. While staff at Evergreen Manor may incorporate resident input when structuring programs, truly moving beyond a model where participation is equated with structured activity requires a shift toward more relational and

flexible approaches. The examples of June and Helen illustrate that purpose does not necessarily emerge from the activity itself, but from the relationships formed within it.

While leisure can serve as a platform for relational connection, fostering these moments often requires intense emotional labour from staff. In *Negotiating Freedom and Care*, Rebecca, a recreation staff member, described how maintaining a cheerful and engaging presence throughout the day could be emotionally exhausting, especially on days when she was not feeling upbeat personally. This emotional labour is often invisible but crucial to sustaining residents' participation and sense of community. However, when resident engagement depends on individual staff effort rather than institutional structures of support, the risk of burnout increases (White et al., 2020). Supporting social citizenship then, requires not only valuing residents' agency but recognizing the labour that enables it and ensuring that staff are given the time, resources and relational support needed to continue work. Leisure becomes most meaningful when it creates space for shared presence, trust, and emotional connection; these elements cannot always be scheduled or standardized. Supporting relational citizenship means fostering environments where these connections can grow, even in small unscripted ways. These examples also remind us that meaningful engagement is not only individual but shaped by the emotional labour of staff and the relational conditions in which leisure unfolds, issues returned to in the final two sections.

From Attachment to Solidarity: Questioning the Depth of Social Bonds in LTC

Solidarity in social citizenship encompasses mutual support, shared experiences, and collective recognition and action (Bartlett & O'Connor, 2010). In the story *Beyond Isolation*, some strong peer relationships at Evergreen Manor are described. However, these connections appear primarily activity-based rather than deeply reciprocal forms of support. Unlike

community-led dementia networks, which facilitate long-term collective advocacy (Innes et al., 2021), social bonds in LTC settings tend to be shaped by structured programming rather than emerging organically from resident-led initiatives. As a result, while attachment and companionship consistent with person-centred approaches is present at Evergreen Manor, the conditions for sustained, collaborative solidarity remain limited. June's experience at bingo illustrates this dynamic. She finds familiarity and enjoyment in participating alongside a consistent peer group, yet these relationships appear reinforced by routine rather than by active, reciprocal support. While she values group participation, she does not describe an ongoing role in supporting or advocating for others, raising questions about whether these connections extend beyond social enjoyment. Similarly, Frank's peer relationships emerge in both structured and unstructured spaces, he engages socially, seeks out familiar faces, and enjoys conversation. Yet his reflections suggest that these interactions remain momentary rather than sustained. He recalls hearing, "You need to come by here more," yet this does not necessarily indicate an ongoing social commitment. His experiences highlight how social ties in LTC institutions are often episodic rather than embedded in a larger culture of mutual care and advocacy. This episodic nature may be shaped not only by program structures, but also by staff limitations, cognitive differences, and the opportunities for residents to sustain relationships outside of formal programming. Without dedicated time, facilitation, or continuity, bonds that begin within leisure settings may struggle to deepen into the kind of mutual support that solidarity requires.

While attachment and companionship were evident in the *Beyond Isolation* story, particularly through activity-based connections like June's bingo group and Helen's mentoring experience in OMA, there was limited evidence of collective solidarity or ongoing mutual support among residents. Relationships for people living with dementia remained largely framed by the structure

of scheduled programs or mealtimes. However, leisure holds significant potential to foster deeper forms of solidarity if intentionally approached as a space not only for connection, but for contribution. Dupuis et al. (2012d) found that making a difference was a deeply valued aspect of leisure for people living with dementia. Many wanted to help others, feel needed, and be a part of something larger than themselves. Yet, these desires were often overlooked in care settings focused on symptom management or entertainment. Similarly, Fortune and McKeown's (2016) study of peer-led community programs illustrates how people living with dementia and their care partners can foster mutual support, shared leadership, and a strong sense of belonging when given opportunities to shape their own social environments. These programs helped participants feel valued, empowered and connected through activities like gardening, dancing, and group discussion, demonstrating how leisure can foster collective well-being. If recreation staff were to intentionally co-create leisure spaces where residents work together – whether mentoring, sharing knowledge, or collaborating on meaningful projects – leisure could begin to move beyond companionship toward solidarity. However, as Bartlett and O'Connor (2010) remind us, solidarity is not only about interpersonal support but is concerned with the shape of society as a whole. In the LTC context, where structural constraints limit resident connection, this broader vision of solidarity remains difficult to achieve within the current structure of LTC. Still, leisure may offer a foundation for such possibilities by creating small-scale opportunities for shared leadership, collective voice, and participation in shaping the community's everyday life.

From Love to Freedom from Discrimination: Shifting from Protective Care to Relational Autonomy

In LTC, resident autonomy is often constrained by institutional structures prioritizing risk management and efficiency over relational and self-directed care. Rather than viewing autonomy as an isolated, individual trait, a relational autonomy perspective emphasizes that autonomy is

shaped by social relationships, support structures, and the broader institutional environment (Mackenzie & Stoljar, 2000; Nedelsky, 2011). From this perspective, genuine autonomy in LTC requires not only individual choice, but also relational supports that enable residents to meaningfully exercise agency within their social and institutional contexts. While policies framed as protective may appear well intentioned, they frequently limit residents' ability to make meaningful choices about movement, relationships, and participation. Bartlett and O'Connor (2010) argue that true social citizenship requires more than just safety and care—it demands relational engagement, personal agency, and the freedom to experience life beyond medicalized control. The story *Negotiating Freedom and Care* highlights how institutional policies, rigid routines, and staff constraints shape residents' experiences of autonomy, often reinforcing structural discrimination rather than addressing it. June's description of feeling halfway free encapsulates this tension. Her humour, such as joking about sneaking out the window, was more than just lightheartedness, it became a tool and subtle form of advocacy. She acknowledges Evergreen Manor as her best available option but describes it as feeling “almost like a prisoner” due to restrictions on movement. Similarly, Elizabeth expresses frustration at being denied the simple act of walking outdoors, a decision based not on her preferences but on institutional concerns about risk and supervision.

Beyond movement, autonomy is further shaped by institutional routines that prioritize operational efficiency over personal choice. In *Negotiating Freedom and Care*, Martha critiques how residents are routinely put to bed early, not because they choose to, but because staffing constraints require rigid schedules. Luke similarly reflects on how, despite the LTC setting being presented as “home,” it remains an environment where residents must adapt to institutional structures rather than the other way around. Kontos and Martin (2013) critique how institutional

routines and surveillance practices in LTC settings can limit residents' opportunities to actively express preferences. These structured routines grant residents conditional agency within predefined boundaries.

Social engagement is similarly constrained by institutional assumptions. As described in *Negotiating Freedom and Care*, while some residents, like June, express a desire for greater freedom, others, like Elaine, highlight the complexity of social engagement in LTC settings. Elaine's preference for time on her own rather than continuously fostering social bonds challenges institutional assumptions that all residents should be continuously engaged. Samantha, a recreation professional, critiques how LTC settings often conflate social withdrawal with loneliness, failing to recognize that solitude can be a valid preference rather than a problem to be solved. For residents who do seek connection, institutional barriers often make it difficult to form and sustain relationships. Privacy policies prevent staff from sharing updates about resident hospitalizations or deaths, denying resident opportunities for closure and collective mourning. In *Negotiating Freedom and Care*, recreation staff member Rebecca highlights the emotional toll of these policies, reflecting broader critiques that LTC governance often overlooks residents' relational and emotional needs (Kontos & Grigorovich, 2018a). These policies create a culture of silence around death that undermines relational citizenship. Residents are often aware when someone is missing, particularly a table mate or familiar figure, but without acknowledgement or ritual, they are left to guess and grieve privately. Rebecca described trying to drop hints so residents and family members could understand without violating policies, highlighting the ethical tension staff experience between institutional compliance and relational care.

Kontos et al. (2010) critique how institutional systems in LTC prioritize standardized care routines over individualized decision-making, often marginalizing residents who cannot participate in formal care planning processes. For example, in *Negotiating Freedom and Care*, Rebecca critiques how dietary plans become overly prescriptive, reducing meal choices to repetitive options rather than adapting to residents' evolving preferences. Similarly, infection control policies prevent residents from engaging in familiar, everyday tasks such as folding linens or doing laundry, activities that could reinforce social positions and a sense of purpose. Grigorovich and Kontos (2018b) emphasize how LTC structures often overlook the embodied and relational aspects of selfhood, prioritizing cognition when measuring the success of creative programs, limiting opportunities for meaningful engagement and self-expression. Residents like Elizabeth and Elaine express boredom with structured activities, highlighting how participation alone does not guarantee meaningful engagement. Kontos et al. (2017) argue that without institutional commitment to relational, embodied forms of care, leisure programming risks becoming routine-based, limiting authentic social connection.

Bartlett and O'Connor (2010) argue that social citizenship requires freedom from discriminatory care practices that assume incapacity rather than supporting autonomy. Armstrong and Lowndes (2018) argue that even in well-intentioned LTC settings, a culture of protective paternalism often prevails where institutional priorities like risk management and liability frequently override resident autonomy and self-determination. Dementia-led advocacy organizations, such as Dementia Alliance International and Dementia Advocacy Canada, challenge these restrictions by positioning people with dementia as political actors rather than passive care recipients (Bartlett, 2014; Keyes et al., 2019). However, these movements largely operate outside of LTC institutions, suggesting that systemic reform within care homes remains

limited. To ensure freedom from discrimination, LTC institutions must move beyond protective paternalism toward models that centre resident decision-making as a right, not a privilege. As mentioned in the discussion on *From Inclusion to Participation*, The Authentic Partnership model (Dupuis et al., 2012d) seeks to integrate resident co-leadership within governance structures, redistributing power among staff, residents, and families. Without institutional commitment to shared power, autonomy remains precarious, granted only to those who fit within staff expectations rather than universally protected.

Despite these limitations, some staff recognize the importance of supporting resident agency, but their ability to do so is constrained by staffing shortages and task-oriented care models. Samantha reflects on how LTC training has shifted away from relational approaches toward efficiency-driven care, making it harder to create a home-like environment where residents feel seen as individuals. This shift reflects broader neoliberal trends in LTC, where relational caring is often deprioritized in favour of cost-efficiency and risk management (Polivka & Luo, 2019). Without structural change, staff advocacy alone cannot counteract the institutionalized constraints that limit residents' choices, daily autonomy, and social connections. Ultimately, *Negotiating Freedom and Care* illustrates how freedom and social citizenship in Evergreen Manor is shaped by the structures, policies, and routines that govern daily life. While staff work within these constraints to provide meaningful engagement where possible, systemic issues such as rigid institutional policies, staffing shortages, and risk-averse care models continue to limit the full realization of social citizenship for residents. Without a shift in institutional priorities toward supporting relational autonomy, relational caring, and resident-led decision-making, LTC settings will continue to offer a conditional and limited form of freedom.

Leisure practices, though constrained by institutional routines, offer meaningful opportunities to address these limitations. By creating everyday opportunities for residents to make choices and take initiative, leisure activities can support autonomy and become meaningful spaces for resisting institutional constraints. When staff attune to residents' embodied expressions and relational needs, even structured programs can become sites of genuine agency, emotional expression, and connection. For residents like Elisabeth, access to more self-directed or flexible leisure activities can meaningfully acknowledge choices. However, leisure alone cannot fully counteract discriminatory institutional practices. True autonomy and freedom from discrimination require broader structural forms, shifting from protective paternalism toward relational, resident-led models of care.

Final Thoughts

The four stories presented in Chapter 4 reflect the nature of social and relational citizenship in this particular LTC setting, illustrating how growth, participation, freedom from discrimination, social positions, solidarity, and purpose are shaped—and often constrained—within these settings. While some residents find opportunities for growth through creative expression and social engagement, others face institutional structures that limit self-expansion beyond their past identities. Participation in decision-making remains largely symbolic, with resident councils and structured programs offering input but rarely shifting institutional power. The freedom from discrimination promised in LTC is frequently compromised by protective paternalism, where safety concerns justify restrictions on movement, autonomy, and personal decision-making. Social positions within LTC settings tend to reinforce hierarchies of agency, where those who can self-advocate are granted more control over their experiences, while others rely on staff discretion to have their preferences acknowledged. Solidarity, in contrast, was less developed,

with peer connections often emerging around structured programs rather than through ongoing mutual support or collective advocacy. Finally, purpose is often framed as occupation rather than meaningful contribution, with structured activities filling time but not always supporting personally significant roles and relationships.

These findings reinforce the need for structural shifts in LTC that move beyond passive inclusion toward models of care that actively and intentionally embed social citizenship, ensuring all residents—not just those who fit institutional expectations—have the right to agency, connection, and growth. These efforts are often sustained not only by institutional initiatives but by the everyday emotional labour and advocacy of staff who work to create space for resident agency and relational connection despite structural constraints. These stories demonstrate that leisure is far more than a recreational outlet, it is a political and relational space where agency, connection, and resistance take shape. When residents are given the opportunity to participate meaningfully in their communities, leisure becomes a site not just of inclusion, but of citizenship in action. However, achieving this requires both immediate, practical changes within LTC institutions and broader systemic transformations in policy, funding, and staff training. The following section explores these implications, considering both small-scale improvements that can be implemented now and larger-scale reforms that challenge the institutional foundations of LTC settings.

Implications of Research

This research highlights the structural, institutional, and social barriers that shape residents' ability to experience social citizenship in LTC. While LTC institutions provide necessary support, they also impose constraints that limit autonomy, participation, and meaningful engagement. This study demonstrates that social citizenship in LTC is not solely an individual

capability but relational and structurally enabled and restricted. The findings have practical, social, theoretical, and methodological implications. Practically, it identifies both barriers and opportunities for fostering relational and social citizenship in LTC, highlighting where small-scale improvements can be made and where broader structural shifts are necessary.

Theoretically, it contributes to social citizenship literature by reinforcing the importance of institutional structures and non-verbal agency in LTC settings. Methodologically, it supports the need for ethnographic and participatory approaches to better capture complexities of agency in these settings. The following sections explore these implications in greater depth, considering both immediate strategies for improving resident agency within LTC and long-term systemic transformations needed to fully embed social citizenship in care structures.

Practical Implications

As described in Chapter 2, little research on social citizenship focuses on people living with dementia, and of that research, most takes place in a community setting. Although there is evidence that leisure may support the citizenship of people living with dementia, how leisure supports or otherwise undermines the citizenship of people living with dementia in LTC settings has not been examined. With systematic and structural concerns being exacerbated by the COVID-19 pandemic, my practical justifications come from trying to understand the experiences of people living with dementia to make visible how current leisure practices are supporting or undermining the social citizenship and personhood of people living with dementia. While full social citizenship may be difficult to achieve under current conditions, my research highlights ways that LTC institutions can move toward a social/relational citizenship approach. These practical implications stem from what was working well at Evergreen Manor that could be applied to other LTC institutions, what was getting in the way of supporting social/relational

citizenship at Evergreen Manor, and from discussions with staff and residents about what might be needed moving forward.

Perhaps it was not surprising to me that the lens of social and relational citizenship within the LTC context was not being intentionally engaged with at Evergreen Manor. Although researchers and professionals have been advocating for a move away from medical and person-centred models in LTC settings, culture change is hard to achieve and most, if not all, LTC settings continue to be guided by aspects of both medical and person-centred models (Kontos et al., 2017; Bowers et al., 2000; Garratt et al., 2021; Rahman & Schnelle., 2008). This was evident at Evergreen Manor, where few recreation staff demonstrated familiarity with the concept of social citizenship, and where institutional structures appeared to reinforce more traditional models of care. Part of the disconnect between culture change initiatives and what actually plays out in practice may stem from underlying stigma about dementia that persists. As Grigorovich et al. (2024) found, recreation and leisure students and professionals held stigma in relation to beliefs about incapability and loss, endorsing negative stereotypes about the capabilities of people living with dementia. These assumptions, even when paired with generally positive intentions, may contribute to practices that underestimate the abilities and agency of people living with dementia. To address this, the authors recommend several strategies including embedding dementia-related content into post secondary recreation and leisure curricula, providing structured opportunities for direct interaction with people living with dementia, and utilizing arts- and narrative-based approaches to disrupt stigma and promote more relational, rights-based understandings (Grigorovich et al., 2024). Without shifts in education and professional development, the potential of leisure to support social and relational citizenship may remain unrealized in practice.

During research conversations, I asked each recreation staff member whether they had encountered the term *social citizenship* before. Four out of five participants had never heard of it. One person thought it sounded familiar but was unsure of the source, though I suspect this recognition may have come from my own introductory presentation to the recreation team that I gave when first starting my research. When I offered a definition of social citizenship, staff often attempted to connect it to more familiar frameworks such as the Eden Alternative or person-centred care. While these frameworks share some similarities with social citizenship, it became clear that staff had difficulty envisioning how a social and relational citizenship might extend beyond or transform current care models. This uncertainty may stem in part from a lack of exposure to critical or alternative theoretical frameworks in LTC, but it also likely reflects the structural and systemic constraints recreation professionals face in practice such as infection control procedures, chronic staffing shortages, and time pressures. While many recreation staff intuitively supported aspects of social citizenship through their actions – particularly when engaging residents in meaningful and reciprocal ways – these practices were not framed or recognized within a broader model that emphasizes a social citizenship approach.

Truly supporting the social and relational citizenship of people living with dementia and other residents in LTC settings requires intentionally and thoughtfully reflecting on how each of the components of social citizenship could be supported and how leisure might play a role in that. Recent research demonstrates how intentionality is critical to ensuring practices align with the philosophies guiding those practices (Dupuis et al., 2025). It is my hope that this research provides a first step in raising awareness of the components of social citizenship and the importance of leisure in realizing social and relational citizenship. Going forward, recreation and leisure students need opportunities to learn about social and relational citizenship and the role of

leisure in supporting the components of citizenship; embedding social and relational citizenship in curricula is a first step to ensuring it is intentionally engaged with in practice.

A significant finding of this research is that LTC institutions often focus on preserving past identities rather than creating opportunities for self-exploration, growth, and evolving social roles. This reinforces findings that leisure programs in LTC often rely on reminiscence-based approaches rather than fostering new social roles or skill development (Dupuis et al., 2016). LTC institutions should shift toward programs that support lifelong learning and evolving selfhood, allowing residents to develop new social positions and talents rather than being confined to past roles (Kontos & Martin, 2013). This could be achieved through co-created leisure programs where residents have a more active role in shaping activities, ensuring that programs reflect not only past interests but also current and future aspirations. Additionally, staff training could emphasize supporting growth rather than maintaining static conceptions of selfhood.

Although some residents influence leisure programs to a certain extent, their ability to shape decisions is often dependent on their verbal ability and the discretion of staff. Programs tend to be staff-led rather than truly resident-led, meaning that many residents, particularly people living with dementia, have fewer opportunities to shape their leisure experiences (Seetharaman & Chaudhury, 2020). Addressing this requires embedding resident decision-making into governance structures rather than relying solely on informal advocacy from staff. LTC institutions could implement feedback mechanisms that move beyond verbal input, such as creative engagement tools that capture non-verbal preferences – for example, the use of objects, images, or multi-sensory materials to support expression and choice (Gerbaudo-González et al., 2024). These kinds of tools align with Baldwin's (2008) concept of narrative citizenship by enabling residents to express themselves in ways that reflect their selfhood and agency, even

when traditional verbal narration may not be possible. Recognizing peer mentorship and informal leadership roles among residents would also be a step toward ensuring that agency is not only acknowledged but actively supported in leisure programming. In addition, supporting in-the-moment decision-making of residents, going where they want and need to go in the moment, could also better support the embodied agency and choices of people living with dementia, which requires flexibility in both programming and approach (Dupuis et al., 2025).

Another crucial consideration is the role of risk management in shaping residents' autonomy. Many LTC policies prioritize safety over self-determination, leading to restrictive measures that limit residents' ability to make decisions about their daily lives. For instance, residents who require staff assistance to go outside may be denied this opportunity due to staffing shortages rather than personal preference. This reflects broader structural and organizational constraints, where operational efficiency takes precedence over individualized care (Armstrong & Lowndes, 2018). Shifting toward a risk-enablement framework and universal design principles would allow residents to make informed choices about their activities, movements, and relationships while balancing safety considerations (Bartlett & O'Connor, 2010; Carr et al., 2013). Rather than implementing blanket restrictions, personalized risk assessments could provide a more nuanced approach, ensuring that autonomy is supported within safe and flexible boundaries. These strategies could serve as models for moving beyond protective paternalism toward an approach that respects resident agency while addressing legitimate safety concerns.

Beyond the LTC institution itself, residents' access to social citizenship is also shaped by the extent to which they remain connected to broader community life. Many LTC institutions operate as isolated institutions, limiting opportunities for engagement beyond their walls (Boamah et al., 2021). Maintaining ties to the outside world is essential for fostering social citizenship, as it

allows residents to participate in civic life and maintain meaningful relationships beyond the care environment. Strengthening partnerships with local organizations, schools, and community groups could create more opportunities for intergenerational connections, advocacy efforts, and volunteer-based social programs that help residents sustain relationships and a sense of belonging within the wider community. Some LTC institutions have integrated shared community spaces, such as cafés, libraries, or community centres, where residents and non-residents interact regularly. Resident-led mentorship programs for younger volunteers could also provide opportunities for older adults to share knowledge, build relationships, and contribute to social initiatives. The small home movement may provide another option for ensuring that people living with dementia remain connected to their communities and the leisure opportunities and relationships present within those communities. This model prioritizes home-like environments, empowered staff, and smaller resident groupings, which together support more relational care (Sinha et al., 2025). For example, the Green House model in the U.S and its adaptations in Canada demonstrate how smaller-scale, relationship focused care can foster improved resident quality of life, staff satisfaction, and health outcomes, while also mitigating risks during public health crises like COVID-19 (Sinha et al., 2025). In Canada, provinces such as Nova Scotia, Alberta, and Quebec have taken steps to integrate these principles into design and policy. However, widespread adoption remains limited, and implementation is often hampered by cost concerns and infrastructure priorities that favour institutional models (Sinha et al., 2025). Meanwhile, Chum et al. (2022) highlight the importance of expanding diverse community-based housing options that foster autonomy, inclusion, and interdependence for adults, arguing that supportive housing models should be more than just medicalized spaces –

they must be places where people can live with dignity and connection. Together, these reports call for a paradigm shift that reframes LTC as community-integrated and relational.

Ensuring inclusion in decision-making also requires recognizing non-verbal agency as a legitimate form of participation. Current participation frameworks in LTC settings often privilege verbal communication, leading to the exclusion of residents who express preferences through movement, facial expressions, or relational interactions (Kontos & Grigorovich, 2018a). As discussed in Chapter 1, narrative citizenship is not solely held by the individual but is co-constructed through interpretive and ethical engagement of others (Baldwin, 2008). This means that enabling participation depends on the relational literacies of staff. Staff training should emphasize interpretive approaches to engagement, ensuring that non-verbal forms of self-expression are not overlooked in decision-making processes. Building the relational literacies (e.g., slowing down, embracing silence, being attuned to body and facial expressions, etc.) of recreation staff and intentionally drawing on these will be important in supporting the agency of all people living with dementia in LTC settings (Dupuis et al., 2025). Staff must be supported in recognizing everyday embodied actions as meaningful forms of communication, rather than dismissing them as irrelevant or unintelligible. Participatory approaches that centre embodied engagement can create more inclusive spaces for decision-making. However, these approaches will only be effective when grounded in relational practices that honour the diverse and non-verbal ways residents communicate preferences, express selfhood, and assert agency.

While these practical changes would improve everyday resident experiences, they must be accompanied by larger systemic and structural shifts at the policy level. Current funding models often prioritize medical care over social and relational well-being, meaning that leisure and social engagement programs remain underfunded and undervalued (Mitchell et al., 2020; Dupuis

et al., 2012b). Without policy changes that mandate and fund relational approaches and recognize and value the role of recreation professionals in supporting life quality and social citizenship, these improvements will remain contingent on individual staff initiative rather than being embedded into LTC frameworks. Policy reforms could include dedicated funding for social citizenship initiatives, required training in relational and risk-enablement approaches, and revised accreditation standards that assess LTC institutions based on resident autonomy and inclusion rather than just medical outcomes.

Ultimately, fostering social and relational citizenship in LTC requires both immediate, practical changes, such as expanding resident-led leisure programming and shifting risk-management practices, and long-term systemic reform. Without addressing institutional hierarchies, staffing constraints, and funding priorities, efforts to support social citizenship will remain partial rather than transformative. By embedding these principles into policy, governance, and daily practice, LTC institutions can begin to create environments where residents are not just cared for but recognized as active, contributing members of their social world.

Social and Theoretical Implications

This research deepens and extends existing theories of social and relational citizenship by exploring how everyday life in LTC shapes – and often constrains – the enactment of citizenship for people living with dementia. While Bartlett and O’Connor’s (2010) framework conceptualize social citizenship as an active, relational process emphasizing growth, social positions, purpose, participation, solidarity, and freedom from discrimination, it pays limited attention to the institutional structures and routines through which these ideals are practiced. Similarly, Kontos et al.’s (2017) model of relational citizenship challenges cognitive hierarchies by emphasizing the importance of embodied, affective, and relational forms of agency. By bringing these two

frameworks into conversation with ethnographic data, this study offers a more grounded, practice oriented account of citizenship that attends to both systemic barriers and everyday acts of resistance, expression, and care.

For example, while growth is ideally a universal right, this study reveals that institutional policies, staffing constraints, and risk management often limit residents' opportunities for meaningful engagement. Drawing on relational citizenship (Kontos et al., 2017), the study emphasizes that growth is not solely cognitive or individual, but relational and embodied, emerging through everyday social interactions, gestures, and affective connections.

The concept of social positions, as described by Bartlett and O'Connor, emphasizes the recognition of multiple and fluid roles as opposed to fixed identities. However, this research shows that institutional norms often legitimize the agency of some residents while marginalizing others. Relational citizenship offers a more inclusive perspective by illuminating how people living with dementia can continue to enact meaningful selfhood through relational and embodied practices (Kontos et al., 2017).

In relation to participation, this study supports Kontos et al.'s (2017) call to recognize embodied and relational forms of engagement. Residents assert agency not only by voicing preferences, but through humour, improvisation, and subtle forms of resistance – what Bella's et al. (2019) refer to as 'little-c' creativity. These moments of participation often unfold outside formal decision-making processes, highlighting the need for more flexible and inclusive models of resident involvement.

The shift from occupation to purpose further illustrates how leisure becomes meaningful not simply through activity, but through its capacity to foster relationships, recognize selfhood, and offer opportunities to contribute. While existing literature emphasizes the need for purposeful

engagement (Bartlett & O'Connor, 2010; Dupuis et al., 2024), this study expands this view by highlighting that purpose can also be expressed through embodied, affective, and relational interactions, such as humour, gestures, and informal roles, that institutional definitions of participation may overlook. These findings suggest the need for social citizenship theory to more fully embrace multimodal, non-traditional expressions of purpose and engagement.

Solidarity, as theorized by Bartlett and O'Connor, involves moving beyond emotional connection toward shared responsibility and collective action. However, this research reveals the challenges of achieving solidarity in large institutional LTC settings, where structural limitations make it difficult for true solidarity to be realized in these conditions. Acknowledging these barriers, this study suggests that alternative forms of solidarity, relational, embodied acts of mutual recognition and affective support, can also constitute meaningful collective agency.

Finally, the shift from love toward freedom from discrimination emphasizes that genuine care must not be paternalistic or controlling but must actively uphold residents' rights and autonomy (Bartlett & O'Connor, 2010). This study shows how discrimination often takes structural form. Through risk policies, surveillance, and standardized routines that suppress choice. Expanding the scope of social citizenship requires greater critical attention to these systemic conditions and how they undermine the very rights that relational and social citizenship aim to uphold.

Narrative citizenship significantly enriched the theoretical insights of this study by demonstrating how residents construct and communicate their social positions and agency through diverse forms of communication, both verbal and embodied. Building on concepts of embodied selfhood (Kontos & Grigorovich, 2018), and everyday creativity (Bellass et al., 2018), these findings emphasize that agency is enacted through small, co-created movements of connection. Hydén (2013) highlights embodiment as an interactive resource, where gestures,

rhythms, and shared actions become relational expressions of meaning and presence. In LTC settings, recognizing these everyday embodied practices, including co-constructed narratives, challenges assumptions of passivity and affirms that agency and citizenship are relationally produced, not individually isolated. Storytelling in this context is not a solitary act, but a collaborative and relational process shaped through interactions with others. These co-constructed stories support agency by enabling residents to participate in meaning-making, even when verbal communication is limited. This emphasis on relational storytelling also highlights how others play a vital role in affirming residents' experiences, selfhood and contributions, reinforcing a view of citizenship that is socially situated and dynamically expressed through everyday encounters.

People living with dementia in LTC settings have a right to active citizenship, supported through relational practices. However, if a resident chooses more passive forms of participation, this choice must be equally respected. Citizenship should not be conditional on visible activity or engagement, and assumptions should not be made based on a person's cognitive status. Instead, what constitutes meaningful citizenship is highly individual, highlighting the essential role of relational approaches in recognizing and honouring each resident's preferences.

Methodological Implications

This research highlights critical methodological implications for exploring social citizenship within LTC settings, particularly regarding residents living with dementia. Sole reliance on verbal interviews or research conversations significantly limits the depth of understanding, as these methods do not adequately capture the complexity of institutional structures, relational dynamics, and nuanced non-verbal expressions of agency. Ethnographic approaches, including participant observation, offer valuable insights into daily interactions within LTC environments,

revealing how agency and social citizenship are shaped, enabled, or restricted in real-time. Such methods allow researchers to document subtle embodied communication, informal roles, moments of resistance, humour, and sensory engagements, thereby providing a more comprehensive and nuanced understanding of social citizenship and life in LTC settings. This research also drew on narrative citizenship to explore how residents express their selfhood and agency through both verbal and non-verbal narratives, highlighting the diverse ways citizenship is enacted in daily LTC life. Narrative citizenship guided the methodological and analytical approach, emphasizing the importance of residents' stories and storytelling practices. Traditional linear, text-based storytelling approaches prominent in the Global North have marginalized and excluded people living with dementia (Hydén, 2018; Baldwin, 2015). Future research should adopt more flexible, creative, and inclusive approaches to storytelling, honouring the diverse ways residents communicate and make meaning of their lives. Employing narrative ethnographic methods in this study emphasized the necessity for methodological flexibility in LTC research. A broader conceptualization of what is perceived as 'valid' data, inclusive of embodied and relational narratives, enhances the depth of research with people living with dementia. Recognizing and interpreting non-verbal narratives enriches our understanding of residents' citizenship experiences, ensuring that all forms of expression and agency are authentically represented. I hope this research highlights the importance of including people living with dementia and their stories in research and inspires others to think about how they might do this in their research.

This research also underscores for me the importance of actively involving residents as co-researchers rather than simply studying their experiences. Due to a number of limitations and constraints, I was unable to do this. Engaging residents in shaping research questions, methods,

analysis, and dissemination enriches the authenticity and relevance of findings, and is a further way to support the social and relational citizenship of people living with dementia. Participatory and co-research methodologies, including peer-led storytelling, arts-based methods, and embodied narrative practices, offer inclusive avenues for resident engagement.

Limitations and Future Research

One of the limitations (and strengths) of this study is its highly contextualized nature. The findings are specific to a particular LTC environment and are shaped by the institutional culture, staffing structures, and demographic composition of this setting as well as my presence and previous knowledge/experiences. While this level of specificity provides depth, the results may look different if this study was completed at different LTC institutions with different organizational frameworks, funding models, staffing resources, or cultural demographics. Future research could explore how social and relational citizenship manifests across diverse LTC settings, including those with varying levels of funding, different staffing ratios, and alternative models of care such as small-scale, household-based settings. Many LTC settings do not have the resources to support leisure in the way that Evergreen Manor does.

This study primarily centres on the perspectives of residents living with dementia who participate in leisure programming and recreation staff members. However, the perspectives of fully non-verbal residents, family members, PSWs, nurses, and other staff members involved in leisure provision such as music therapists or horticultural therapists, were not fully represented. Expanding research to include these perspectives would provide a more comprehensive understanding of how social and relational citizenship is facilitated, challenged, or overlooked within LTC settings. The exclusion of non-verbal residents, in particular, is a notable gap, as their experiences of agency and participation may differ significantly from individuals who can

verbally express their preferences. Additionally, there are many residents in LTC settings who do not engage in leisure programming at all. Understanding whether their disengagement is a matter of personal choice or the result of institutional barriers, such as lack of personally meaningful, flexible, or accessible programming, would be an important area for future research.

Additionally, residents who are unable to attend programs due to physical limitations, such as those who are primarily bed bound, were not included in this study. While recreation staff provide one-on-one visits for residents who do not attend group programming, these interactions were not explored in this research. Future research should examine how social and relational citizenship is supported for residents who experience greater physical restrictions or social isolation.

All participating staff and residents in this study were white, reflecting the demographic of the specific LTC institution where the research was conducted. However, LTC institutions serve increasingly diverse populations, and cultural background plays a significant role in shaping experiences of social citizenship. Future research should explore how residents and staff from different cultural, linguistic, and religious backgrounds experience social and relational citizenship, specifically in LTC institutions, particularly homes where the residents are predominantly white. Important questions include whether citizenship is respected in ways that honour residents' cultural and religious identities, whether culturally appropriate leisure programming and food options are available, and whether staff from diverse backgrounds feel supported in advocating for inclusive care practices. Further, people who identify as LGBTQ2S+ fear a move to LTC largely due to concerns about their citizen rights not being recognized and supported (Fasullo et al., 2021). To build a more comprehensive understanding of relational and social citizenship in the context of dementia, future research is needed that explores the

intersections of gender identity and/or sexual identity, and other social categories on experiences of social citizenship and leisure in various care settings. Studies that incorporate intersectional perspectives would deepen understanding of how different forms of marginalization influence agency and social citizenship within institutional care settings.

As with any qualitative research, there is an inherent tension between observation and interpretation. My presence as a researcher inevitably influenced what I observed, and the process of narrative construction (such as the stories presented in Chapter 4) involved researcher interpretation. These narratives were shaped by my epistemological and ontological perspective, my research questions, and the overall purpose of this project. With the data I collected, multiple stories could have been told in multiple different ways. I chose to present the narratives in this particular manner due the research objectives and my positionality as a researcher advocating for social and relational citizenship.

While this research highlights the role of recreation staff in fostering social and relational citizenship, it does not fully explore the broader institutional constraints that get in the way of staff supporting/upholding social and relational citizenship. Many LTC staff members face systemic barriers, such as understaffing, high workloads, and restrictive labour policies. Staff burnout is a significant issue in LTC, affecting the consistency and depth of relational caring. Future research should examine how labour conditions, union policies, and institutional expectations influence the ability of staff to advocate for residents and implement social citizenship principles in their daily practice.

Related to the above, this study focuses on the everyday lived experiences of residents and staff within LTC but does not fully explore the broader policy structures that shape institutional decision-making. Government policies, funding allocations, regulatory requirements, and

accreditation standards all play a significant role in determining how LTC institutions operate, including their capacity to support social and relational citizenship. Future research could conduct a policy level analysis to examine how external forces such as government oversight, funding models, and healthcare regulations and policies, shape the possibilities and constraints for social citizenship in LTC settings. A clearer understanding of these systemic forces would provide a stronger foundation for advocating for policy changes that better support resident agency, relational engagement, and meaningful leisure participation.

Conclusion

This research aimed to support the narrative agency of people living with dementia, advocate for more narrative approaches by providing a space for them to contribute to the telling of their own stories in their own ways, to gain a better understanding of the role leisure plays in supporting or undermining the social and relational citizenship of people living within dementia in the context of LTC institutions, and to raise awareness of the importance of social relational citizenship and narrative approaches to the culture change process in LTC. Through narrative ethnographic methods, this research demonstrates the complexity of institutional life in LTC settings, highlighting the subtle ways that residents living with dementia exert their selfhood and agency and the significant impact of organizational policies, staff practices, and dominant cultural narratives on residents' social citizenship. This study represents an initial step in addressing the study aims, highlighting the substantial need for ongoing research to comprehensively understand and enhance social citizenship in dementia care.

Clandinin (2012) argues that without an understanding of what brings researchers to the inquiry, they run the risk of entering into relationships without a sense of what stories researchers are living and telling in the research relationship. What brought me to this research were stories

like the one I told you in Chapter 1 about Mabel. After beginning to work as a recreation professional in LTC, I formed many meaningful relationships with residents and staff, however, deeply struggled to work within a system that is not structured to support residents in the ways I felt necessary. I struggled to continue to work in this environment and began looking into ways individuals were already working towards culture change within LTC settings. I learned about more relational approaches to care that were concerned with recognizing and supporting the well-being of all of those involved in a caring relationship. I chose to do my master's because I wanted to learn more about the work that is being done already, and how I might be able to contribute. As an activist academic (Can & DeMeulenaere, 2020), I see this work as part of a larger movement to working towards a social and relational citizenship approach in LTC.

Through this research, I have deepened my understanding of the structural and systemic barriers that make it difficult to fully support the social citizenship of all residents. These findings do not suggest that social citizenship is impossible in LTC settings, as some aspects were present, although unintentionally supported. Within the current funding structures, staffing limitations, and institutional policies, it is challenging to ensure that all residents experience full agency, participation, and recognition as citizens. This is a reflection of broader systemic and structural constraints that limit what is possible within LTC environments. At the same time, I remain committed to identifying and advocating for ways to enhance social citizenship within existing LTC structures while also recognizing the need for a more radical approach. Working within the system while also challenging its foundations is essential for both immediate improvements and long-term transformation. It might also mean advocating for alternative approaches to LTC institutions, such as the small home movement emerging in Canada and internationally.

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Appendix A: Narrative Research Conversation Guide for Residents

Introduction: Hi, my name is Erica MacTavish and I'm a Master's student in the Department of Recreation and Leisure Studies at the University of Waterloo. We met earlier when I was telling you about the project I am working on. I am interested in learning more about the leisure and recreation programs here and your experiences in those programs.

1. Could you tell me a bit about yourself? How would you describe yourself?
 - a. What are some moments or times in your life that are important to you?
 - b. What makes you happy?
 - c. How do other people here get to know you and what is important to you?
2. How would you describe this place?
 - a. What do you like about this place?
 - b. What might you change about this place and life here?
3. What types of things do you enjoy doing here?
 - a. Do you participate in any of the activities?
 - i. If yes, what types of activities do you participate in? What do you like about this/these activities? Is there anything you don't like about this/these activities?
 - ii. If no, can you tell me why you don't participate in the activities or programs offered here? What would make programs more meaningful to you?
4. Do you feel like you have a sense of purpose here? If so, when do you feel that you have purpose here?
5. Do you feel you can make your own decisions about what you participate in here?
 - a. Do you feel supported in making your own choices when it comes to what you participate in?
 - i. If yes, how are you supported in making your own decisions?
 - ii. If no, what prevents you from making your own decisions about what you participate in?
 - b. Do you have the opportunity to contribute to decisions about the types of activities that are offered here?
 - i. If yes, how so? What does this mean to you?
 - ii. If no, what would it mean for you to have this opportunity?
6. What hopes do you have? Do the things you do here help you to achieve your hopes and desires?
 - a. If yes, how so?
 - b. If no, how might your hopes be supported here?
7. Do you have opportunities here to learn new things? How so? If not, would that be important for you?

8. Can you tell me about the friends you have here?
 - a. How do activities you participate in help you connect with others? How do they help you make new friends?
 - b. What does being with others mean to you?
 - c. Do you help out others here? How? How do other people who live here support or help you?
 - d. Do you feel that you belong here? What helps you feel a sense of belonging here?

9. What, if anything, would you like to change about your life here? About the activities here?
 - a. How might you be better supported here?

10. Is there anything else you would like to mention in regards to the activities provided here? Do you have any questions for me?

Conclusion: Thank you for your time and for sharing your stories with me. If after this conversation you come up with any follow up questions about this research project, you are welcome to work with the staff here to get in contact with me or my supervisor, Dr. Sherry Dupuis. Take care and have a great day!

Appendix B: Narrative Research Conversation Guide for Staff

Introduction: Hi, my name is Erica MacTavish and I'm a Master's student in the Department of Recreation and Leisure Studies at the University of Waterloo. I am interested in learning more about the leisure programs in your long-term care home and how they may support the personhood/social citizenship of people living with dementia.

1. Could you tell me a bit about yourself and what's important to you? How would you describe yourself or how would others describe you?
 - a. What aspects of your identity are important to you (i.e., culture, race, ethnicity, leisure interests, geographical location, birthplace, religion, etc.)?
 - b. Can you describe your experiences working in recreation?
 - i. How long have you worked in recreation in long-term care? How long have you worked in this home?
 - ii. What does it mean to you to work in recreation in long-term care?
2. How would you describe this long-term care home?
 - a. What do you like about this home?
 - b. What might you change about this home?
 - c. Is there a particular care model that guides practices, including recreation practices, within this home. If so, can you describe the care model used in this home?
 - d. How do you decide what programs to offer/facilitate? What is the purpose of the recreation programs you facilitate?
3. Have you ever heard of the concept 'social citizenship' in the context of dementia care?
 - a. If yes, where did you hear this concept and what does it mean to you?
 - b. Share definition:

Bartlett and O'Connor describe social citizenship in the context of dementia as "a relationship, practice or status in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level (p. 37).

- What do you think of this description?

4. Thinking about this understanding of social citizenship in the context of dementia,
 - a. Where do you think the social citizenship of residents is best supported? In what places in the home is it most supported?
 - b. Who is in the best position to support the social citizenship of residents living with dementia? Who is involved in supporting the social citizenship of residents in this home?

- c. When is social citizenship best supported in this home? Is there a particular time when social citizenship might be better supported in the daily life of residents?
5. How do you support the inner hopes and aspirations of residents, particularly residents living with dementia, through your recreation programming?
 - a. Could you provide me with a specific example?
 - b. How do you support residents in continuing to grow and develop?
6. How do you and members of the recreation team get to know the residents and what is important to them?
 - a. How, if at all, do you support residents living with dementia in taking on different social roles in this home?
 - b. If residents are unable to communicate verbally, what are some strategies you use to ensure their preferences are understood and being met? What does this look like?
7. How do you use leisure and recreation to provide purpose and meaning in life for the residents, particularly those living with dementia? Can you give an example?
8. How do you support the continued participation in life of the residents here?
 - a. Are people living with dementia actively involved in decision-making about programs? If yes, how so? What does this look like?
 - b. If no, what stands in the way of including people living with dementia in decision-making and creation of recreation programs?
9. How do you use leisure to support a sense of community and belonging here in the home?
 - a. How, if at all, is leisure and recreation used to build and nurture different relationships in the home? Can you provide an example?
 - b. How, if at all, are residents supported in sharing ideas and opinions with the larger group? Can you provide an example?
 - c. What are some ways that residents support each other in the recreation programs? How are these actions acknowledged?
10. An important aspect of supporting the social citizenship of people living with dementia is ensuring freedom from discrimination. How do you and the recreation team ensure that the leisure programs provided do not discriminate residents in any way?
11. What might help you to support the personhood/social citizenship of people living with dementia in the future?
 - a. What might make it difficult to support the personhood/social citizenship of people living with dementia? (e.g., institutional practices, policies, etc.)
 - b. What would you need to better support the personhood and social citizenship of people living with dementia?

Conclusion: That's all the questions I have for you today. Do you have any questions for me?

Thank you for your time and for sharing your stories with me. If after this conversation you come up with any follow up questions about this research project, you are welcome to contact me or my supervisor, Dr. Sherry Dupuis. Take care and have a great day.

Appendix C: Guiding Framework for Participant Observation

I will be attending to the following during my observations of the recreation programs:

- **Setting (Place)**
 - Physical environment
- **Social environment (Sociality)**
 - Social interactions
 - Relationality and relational processes (Who is there? How are individuals interacting? How is the relational capacity and narrative agency supported? How am I interacting with participants?)
- **Temporality**
 - Time of experiences and experiences of time (How are past, present, and future aspects of residents and their lives integrated into recreation programming?)
- Affect (emotional expressions, facial expressions)
- Body language and gestures
- The shift from comfort to growth
 - Are the inner hopes, desires and an individual's capacity to grow and contribute to life supported and recognized? How?
- The shift from identity to social positions
 - How are the multiple identities of individuals being supported?
 - How are individuals' social locations in the world reflected in terms of rights and responses (consider gender, age, race etc.) and how these identities are positioned within the home. (E.g., gender bias?)
 - What is the social position of residents in the home/activity?
- The shift from occupation to purpose
 - Doing VS. Meaning → are residents simply being occupied or do activities seem meaningful to residents? How?
- The shift from inclusion to participation
 - How are residents supported in actively participating throughout the program?
 - Are residents/people living with dementia actively involved in decision-making throughout the program? How?
- The shift from attachment to solidarity
 - Are their opportunities for residents to work together to make a difference/contribute to a larger cause inside or outside of the home?
 - How are residents supported in contributing to the program?
 - How do residents support each other during the program?

- The shift from love to freedom from discrimination
 - Is love being manifested as protectionism, paternalism and control or are residents free from discrimination? How?
 - How are residents referred to? What language is used?
 - Are there examples of discrimination evident? In what ways?
 - Who is present? Who is not? Why?
 - How, if at all, do residents resist actions/interactions they do not like?

- Involvement in the planned activity
 - What is being done
 - Who is involved
 - How the activity occurs
 - How are decisions made
 - When things happen
 - Beginning the activity
 - Middle of the activity
 - Concluding the activity

- Involvement in any unplanned activity
 - Before the planned activity
 - After the planned activity
 - Interruptions/distractions during the planned activity

Adapted from Patton (2002)

Appendix D: Verbal Script – Meetings with Potential Residents

Hello, my name is Erica MacTavish. I am a Master's student at the University of Waterloo in the Department of Recreation and Leisure Studies.

I am meeting with you today to see if you might be interested and willing to participate in my research project. I am working with [Evergreen Manor]⁷ to explore leisure and recreation in long-term care. Leisure can be an important space for recognizing and supporting the personhood of people like you living here. However, very little research has explored this from the perspectives of older adults living in these settings.

I am looking for people like you who are willing to talk about their experiences participating in leisure programs at [Evergreen Manor]. As part of this project, I hope to participate in and observe 6-8 recreation programs offered at this home, including programs you might participate in. Observations are important because they will help me understand more about the types of leisure activities offered, the experiences in those programs, and how the leisure programs might support people like you in different ways. I will be participating in these leisure activities as a researcher volunteer and will be supporting the activities in any way I can. All observations will be restricted to where these leisure programs take place. If you agree to participate, I would also like to meet with you in a one-on-one research conversation to talk about your experiences in the leisure programs. This conversation should take no more than one to one and a half hours depending on how much you would like to talk about.

You should know, this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board. If you think you might be interested in participating, I have a copy of the information letter and consent form here. Would you like to go over the information letter and consent form together?

If yes, work through the information and consent form with the resident.

If no, this is not a good time: When might be a better time for me to come by to go through the information letter with you?

If no, not interested: Thank you for your time today. I wish you all the best.

⁷ Real name replaced with pseudonym to protect confidentiality of participants

Appendix E: Verbal Script – Meeting with Recreation Staff

Hello everyone, thank you for taking time out of your day to learn about my research project.

My name is Erica MacTavish. I am a Masters student at the University of Waterloo in the Department of Recreation and Leisure Studies. After working in long-term care as a recreation professional myself, I was inspired to pursue a Masters degree and explore the role leisure plays in supporting the social and relational citizenship of people living with dementia in long-term care homes.

In the context of dementia, social citizenship can be defined as practice in which a person living with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. Relational citizenship is a model premised on the importance of interdependence, reciprocity, and the support of persons with dementia as active partners in their own care. This model emphasizes the significance of day-to-day relationships for people living with dementia, highlighting the continued relational capacities of people living with dementia.

Leisure can be an important space for recognizing and supporting the social and relational citizenship of people living with dementia. However, very little research has explored this particularly from the perspectives of people living with dementia. As a student researcher, I am hoping this study provides individuals with the opportunity to listen to the opinions and experiences of individuals who often go unheard and identifies specific ways that leisure might be used to support the social and relational citizenship of residents living in residential care settings.

I am looking for recreation professionals to participate in this study. To participate you must: have worked at [Evergreen Manor]⁸ for at least 3 months and facilitate recreation programs at [Evergreen Manor].

If you agree to participate, you will be asked to participate in observations of leisure programming in the home and a one-on-one research conversation. This research conversation will take approximately 1 to 1.5 hours of your time. More specifically, I hope to participate in and observe 6-8 recreation programs offered at this home, including programs you might facilitate.

Observations are important because they will help me to understand more about resident's leisure experiences at [Evergreen Manor]. I will be noting the ways recreation programs support the social citizenship of residents (e.g., are residents able to make choices?) and how residents express their social citizenship (e.g., how are individuals interacting?). I will be participating in the leisure activities as a researcher volunteer and all observations will be restricted to public, communal spaces within the facility. Only those who provide consent will be observed during these programs.

⁸ Real name replaced with pseudonym to protect confidentiality of participants

If you think you might be interested in participating, I have copies of the information letter and consent form here that provide more detailed information about the study. Please take as much time as you need to go through this form before you make a decision. If you have any questions about the study, my contact information can be found on the first page of the consent form. Please feel free to reach out to me should you have any questions. If you agree to participate, please sign the attached consent form and drop it off in the secure box at the front desk or scan it and email a copy directly to me.

You should know, this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board.

Does anyone have any questions?

Thank you for considering participating in this research project surrounding leisure in long-term care.

Appendix F: Resident Information and Consent Form

INFORMATION AND CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY FOR RESIDENTS IN LONG-TERM CARE HOMES

Study Title: Exploring Social Citizenship in the Context of Leisure in Residential Care Settings.

Student Investigator: Erica MacTavish
University of Waterloo
(705-795-9378; em2mactavish@uwaterloo.ca)

Student Advisor: Dr. Sherry Dupuis
University of Waterloo
(519-888-4567, ext 46188; sldupuis@uwaterloo.ca)

Why am I meeting with you?

I would like to tell you about a project that involves people living in long-term care settings. I am a master's student at the University of Waterloo conducting a research project. I am working with [Evergreen Manor]⁹ to explore leisure in long-term care. I am talking to you now to see if you might be interested and willing to participate in this project.

What is the purpose of this project?

Leisure can be an important space for recognizing and supporting the personhood of residents in long-term care. Leisure activities can support important aspects of residents' personhood. I am hoping this study can help advance leisure in long-term care settings.

What will you be asked to do if you are in the project?

I am looking for residents like you who are willing to talk about their experiences participating in leisure programs at [Evergreen Manor]. I would like to start with observations of the leisure programs you participate in.

I hope to participate in and observe 6-8 recreation programs offered at this home, including programs you might participate in. Observations are important because they will help me to understand more about the types of leisure activities offered, the experiences in those programs, and how the programs might support residents in different ways. For example, are residents able to make choices? I will be participating in the leisure activities as a researcher volunteer and all observations will be restricted

⁹ Real name replaced with pseudonym to protect confidentiality of participants

to public, communal spaces within the facility where these leisure programs take place. Only individuals who consent will be observed.

If you agree to participate, you will also be asked to participate in a one-on-one research conversation following the observations where we will explore your perspectives and experiences. You will be asked questions such as:

- What types of things do you enjoy doing here?
- Do you feel like you have a sense of purpose here?
- Do you feel you can make your own decisions about what you participate in here?
- What hopes do you have?
- Do you have opportunities to learn new things here?

This conversation will be held here at your home and should last between one and one and a half hours in length. With your permission, I will be recording our conversation, so I do not miss any important information that you share.

Do you have to be in the project?

You do not have to be in this project. The decision is completely up to you. If you decide to participate now but later you change your mind, then you can tell me or your family members you do not want to be in the study anymore. If you choose to leave the study, any information you shared will be removed from the research unless you give me permission to use what you had already shared. Once the research findings are shared in reports, articles, or presentations, it will not be possible to remove your information. You may decline to answer any question you prefer not to answer, and you may decline to contribute to the study in other ways if you so wish.

What risks might be involved?

There are no anticipated risks involved with participating in this research project.

What are the benefits of participating in the project?

In research, I am hoping this study provides individuals with the opportunity to listen to the opinions and experiences of residents and identifies ways that leisure can support residents in long-term care moving forward.

You may or may not receive any direct benefit from being in this project. Some research participants find it helpful to talk about their experiences during research sessions. They may also find it helpful to know that they may be providing important information to advance leisure in long-term care.

Will you have to answer all questions and do everything you are asked to do?

You do not have to answer any questions that you prefer not to answer. You can end the conversation at any time by letting me know that you would prefer to end the conversation. You can also stop participating in observations at any time by letting Erica know or by leaving the recreation program.

How will information you share be protected?

The list of participants and their assigned code as well as other documents with identifying information (e.g., consent forms, audio-recordings) will be stored separately from the rest of the data in a password-protected file on a TEAMS site set up for this project. Only my supervisor and I have access to this file and to the study materials that contain identifying information.

All audio recordings of the research conversations will be saved in a password-protected file to my local computer (i.e. in the computer hard drive), and then up-loaded to the TEAMS site at the University of Waterloo and deleted once transcribed and verified for accuracy. Any paper copies of documents such as signed consent forms from residents will be scanned and saved as an electronic copy on the Teams research site, and then immediately shredded. All electronic documents (list of participants and codes, transcripts of research conversations, observation notes, signed consent forms) will be stored on the University of Waterloo servers (the project TEAM site). All of these documents will be kept for a minimum of 2 years.

The information transcribed from the audio recordings that are collected for the study will have all names and identifying information removed. Observation notes will include no names or identifying information.

Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46121). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

What if you have questions about the project?

You can ask questions at any time. You can ask now, or you can ask later. You can talk to me now or I can be reached by telephone at (705)-795-9378. You may also contact the student advisor, *Sherry Dupuis* (sldupuis@uwaterloo.ca)

You should take as much time as you need to make your decision. Before you make your decision, feel free to talk about this study with anyone you wish including your friends or a family member.

If you are willing to participate in this study, you will need to provide written consent by signing the consent form on the next page or provide verbal consent by letting me know

that you wish to participate, and I will complete the consent form with you. Should you choose to participate, you will be given a copy of the signed consent form.

Thank you for considering participating in this project on leisure in long-term care settings.

Consent

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my information as described in this form.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46121). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

I consent to the following:

I understand that quotations from the research sessions will be used in written materials (e.g., reports, articles, teaching materials), as well as in presentations or other speaking engagements and give permission for the use of my quotations with the understanding that a different name will be used in place of my real name (e.g., Jane Doe).

YES NO

I agree to my interview being audio recorded for accurate transcription and analysis.

YES NO

I agree to participate in observations of recreation programs as described in the information letter.

YES NO

Signatures:

I understand the nature of this project and wish to participate. My signature below indicates my consent.

Print Study Participant's Name

Signature

Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person
Obtaining Consent

Signature

Date

For verbal consent:

For verbal consent:

Participant's name: _____

[] Verbal consent was obtained by:

Researcher's name: _____

Researcher's signature: _____

Date verbal consent obtained: _____

Appendix G: Substitute Decision Maker Information and Consent Form

INFORMATION AND CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY FOR SUBSTITUTE DECISION-MAKERS IN LONG-TERM CARE

Study Title: Exploring Social Citizenship in the Context of Leisure in Residential Care Settings

Student Investigator: Erica MacTavish
University of Waterloo
(705-795-9378; em2mactavish@uwaterloo.ca)

Student Advisor: Dr. Sherry Dupuis
University of Waterloo
(519-888-4567, ext 46188; sldupuis@uwaterloo.ca)

Introduction:

You are being asked, as your family member's substitute decision maker, to consent to their participation in a research study. Please read the information about the study presented in this form. The form includes details on what your family member will be asked to do that you should know before you decide if you would like to consent for your family member to take part. You and your family member should take as much time as you need to make your decision. You should ask the study researcher to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision along with your family member who lives with dementia, feel free to talk about this study with anyone you wish including your friends, family, or a member of your family member's healthcare team.

What is the purpose of this project?

In the context of dementia, social citizenship can be defined as practice in which a person living with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. Relational citizenship is a model premised on the importance of interdependence, reciprocity, and the support of persons with dementia as active partners in their own care. This model emphasizes the significance of day-to-day relationships for people living with dementia, highlighting the continued relational capacities of people living with dementia.

I want to understand what role leisure plays in supporting the social and relational citizenship of people living with dementia in long-term care homes. Leisure can be an important space for recognizing and supporting the social and relational citizenship of people living with dementia. However, very little research has explored this from the perspectives of people living with dementia particularly within long-term care settings. I

am hoping this study provides individuals with the opportunity to listen to the opinions and experiences of individuals who often go unheard. I am hoping this study will work to challenge the stigma surrounding dementia and the loss of self and raises awareness of the importance of a social citizenship approach to the culture change process in long-term care homes.

Who can participate in this project?

We are looking for approximately 5-6 residents with dementia living at [Evergreen Manor]¹⁰ to participate in our research. To participate your family member must:

- Have lived at [Evergreen Manor] for at least 3 months.
- Have a diagnosis of dementia.
- Be able to communicate verbally and English to some degree.

In order for your family member to participate, you will need to provide written or verbal consent as the substitute decision-maker. We will also be obtaining consent from all resident participants prior to beginning each research conversation session. Residents will be told that they are being asked to participate in a project that seeks to understand how leisure within the home might support their personhood and social citizenship; no references will be made of dementia.

What will your family member's participation involve?

Your family member's participation in this study is voluntary. You and your family member may decide not to participate in this study, or to participate in the study now, and then change your minds later.

If you and your family member agree to participate agree to participate, your family member will be asked to participate in observations of their leisure programming and a one-on-one research conversation.

Observations involve myself being present on the unit to take notes about what I see and hears in interactions between all participating staff and residents at your institution. Observations are important because they will help me to understand more about your family member's leisure experiences at [Evergreen Manor]. I will be noting the ways recreation programs support the social citizenship of residents (e.g., are residents able to make choices?) and how residents express their social citizenship (e.g., how are individuals interacting?). I will be participating in the leisure activities as a researcher volunteer and all observations will be restricted to public, communal spaces within the facility. Only those who provide consent will be observed during these programs.

¹⁰ Real name replaced with pseudonym to protect confidentiality of participants

If you and your family member agree to participate, your family member will be asked to participate in a one-on-one research conversation with myself about their experiences participating in leisure within [Evergreen Manor]. They will be asked questions such as:

- What types of things do you enjoy doing here?
- Do you feel like you have a sense of purpose here?
- Do you feel you can make your own decisions about what you participate in here?
- What hopes do you have?
- Do you have opportunities to learn new things here?
- What, if anything, would you like to change about your life here?

These conversations should last between 1 and 1.5 hours in length and with permission, will be audio-recorded so we do not miss any important information that your family member shares. Your family member will be asked periodically if they are wishing to continue to participate in the conversation.

Withdrawal from the Study:

If you and your family member agree to participate in this project, you should know that your family member may leave the study at any time by you or them notifying a member of the research team. The data we collected from your family member will be removed from our research unless you and your family member give us permission to use what they had already contributed. You may withdraw your consent and request for your family member's data to be deleted by contacting us up until study findings are submitted for publication, anticipated sometime in 2024. It is not possible to remove data once findings have been published.

Conflict of Interest:

The researchers are interested in seeing the study to completion. The researchers' interests should not influence your consent for your family member to participate in the study.

What risks might be involved?

There are no anticipated risks involved with participating in this study.

What are the benefits of participation?

In research, a model of social citizenship is still under-theorized, particularly within the context of long-term care. My hope is that this research will help to advocate for the importance of a social citizenship lens in the context of long-term care and identify the ways that leisure can support this for people living with dementia moving forward.

You and your family member may or may not receive any direct benefits from being in this study. Some research participants find it helpful to share their meanings and experiences during research conversations. They may find it helpful to know that they may be providing important information to advance leisure in long-term care.

How will information shared be protected?

The list of participants and their assigned code as well as other documents with identifying information (e.g., consent forms, audio-recordings) will be stored separately from the rest of the data in a password-protected file on a TEAMS site set up for this project. Only my supervisor and I have access to this file and to the study materials that contain identifying information.

All audio recordings of the research conversations will be saved in a password-protected file to my local computer (i.e. in the computer hard drive), and then up-loaded to the TEAMS site at the University of Waterloo and deleted once transcribed and verified for accuracy. Any paper copies of documents such as signed consent forms from residents will be scanned and saved as an electronic copy on the Teams research site, and then immediately shredded. All electronic documents (list of participants and codes, transcripts of research conversations, observation notes, signed consent forms) will be stored on the University of Waterloo servers (the project TEAM site). All of these documents will be kept for a minimum of 2 years.

The information transcribed from the audio recordings that are collected for the study will have all names and identifying information removed. Observation notes will include no names or identifying information.

Voluntary Participation:

Your family members participation in this study is voluntary. You may decide for your family member not to be in this study, or to be in the study now, and then change your mind later. Your family member may decline to answer any question they prefer not to answer, and they may decline contributing to the study in other ways if you/they wish.

What is you have questions about the project?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46121). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

If you have any questions, concerns or would like to speak to the study team for any reason, you can email *Erica MacTavish* (em2mactavish@uwaterloo.ca). If you would rather a telephone conversation you can reach Erica at (705)-795-9378. You may also contact the student advisor, *Sherry Dupuis* (sldupuis@uwaterloo.ca)

If you are willing to provide consent for your family member to participate in this study, please complete the attached consent form and email it to Erica at em2mactavish@uwaterloo.ca once completed. If you would prefer to go over this information letter with Erica and provide verbal consent, please contact Erica and she will arrange a time to meet with you on Zoom or over the telephone at your convenience. Should you provide consent, you will be given a copy of the signed consent form (see next page).

Thank you for considering supporting your family member's involvement in this project on leisure in long-term care.

Consent

This study has been explained to me and any questions I and my family member had have been answered. I know that my family member may leave the study at any time.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46121). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

As my family member's substitute decision-maker, I consent to the following:

I understand that quotations from the research conversations will be used in written materials (e.g., publications, teaching-learning resource materials, PowerPoint presentations, policy briefs), as well as at conferences or other speaking engagements and give permission for the use of my family member's quotations with the understanding that a pseudonym will be used in place of their real name (e.g., Jane Doe).

YES NO

I agree to my family members interview being audio recorded for accurate transcription and analysis.

YES NO

I agree to my family members participation in observations of recreation programs as described in the information letter.

YES NO

Signatures:

I understand the nature of this project and wish for my family member to participate. I am not waiving any of my legal rights by signing this form or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities. My signature below indicates my consent.

Participant's Name: _____

Substitute Decision-Maker's Name: _____

Substitute Decision-Maker's Signature: _____

Date: _____

My signature means that I have explained the study to the substitute decision-maker named above. I have answered all questions.

Print Name of Person
Obtaining Consent

Signature

Date

For verbal consent:

Participant's name: _____

Substitute decision-maker's name: _____

[] Verbal consent was obtained by:

Researcher's name: _____

Researcher's signature: _____

Date verbal consent obtained: _____

Appendix H: Professional Information and Consent Form

INFORMATION AND CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY FOR RECREATION PROFESSIONALS

Study Title: Exploring Social Citizenship in the Context of Leisure in Residential Care Settings

Student Investigator: Erica MacTavish
University of Waterloo
(705-7959378; em2mactavish@uwaterloo.ca)

Student advisor: Dr. Sherry Dupuis
University of Waterloo
(519-888-4567, ext 46188; sldupuis@uwaterloo.ca)

Introduction:

I am writing to ask you to take part in a research study I am conducting for my MA thesis in the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Dr. Sherry Dupuis. Please read the information about the study presented in this form. The form includes details about what your participation will involve before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask me, Erica, to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form.

Background/Purpose:

In the context of dementia, social citizenship can be defined as practice in which a person living with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. Relational citizenship is a model premised on the importance of interdependence, reciprocity, and the support of persons with dementia as active partners in their own care. This model emphasizes the significance of day-to-day relationships for people living with dementia, highlighting the continued relational capacities of people living with dementia.

Leisure can be an important space for recognizing and supporting the social and relational citizenship of people living with dementia. However, very little research has explored this from the perspectives of people living with dementia particularly within residential care settings. The purpose of my research is to fill this gap by exploring how leisure might support the social and relational citizenship of people living with dementia in residential care homes, and what might get in the way of this. I am hoping this study provides an opportunity to hear the opinions and experiences of individuals who often

go unheard and identifies specific ways that leisure might be used to support the social and relational citizenship of residents.

Study Design:

I am looking for recreation professionals who currently work at [Evergreen Manor]¹¹ to participate in my study. To participate you must:

- have worked at [Evergreen Manor] for at least 3 months as part of the recreation team.
- facilitate recreation program at [Evergreen Manor].

Study Procedures:

If you agree to participate, you will be asked to participate in observations of leisure programming in the home and a one-on-one research conversation.

I hope to participate in and observe 6-8 recreation programs offered at this home, including programs you might facilitate. Observations are important because they will help me to understand more about resident's leisure experiences at [Evergreen Manor]. I will be noting the ways recreation programs support the social citizenship of residents (e.g., are residents able to make choices?) and how residents express their social citizenship (e.g., how are individuals interacting?). I will be participating in the leisure activities as a researcher volunteer and all observations will be restricted to public, communal spaces within the facility. Only those who provide consent will be observed during these programs.

The one-on-one research conversation will be facilitated by me and focus on your experiences facilitating leisure within [Evergreen Manor]. You will be asked questions such as:

- How would you describe this long-term care home?
- How do you support the inner hopes and aspirations of residents, particularly living with dementia, through your recreation programming?
- How do you support the continued participation in life of the residents here?
- How do you use leisure to support a sense of community and belonging here in the home?

These conversations should last between 1 and 1.5 hours in length and with your permission, will be audio-recorded so we do not miss any important information that you share.

Risks:

There are no anticipated risks in participating in this research study.

¹¹ Real name replaced with pseudonym to protect confidentiality of participants

Benefits:

In research, a model of social citizenship is still under-theorized, particularly within the context of long-term care. My hope is that this research will help to advocate for the importance of a social citizenship lens in the context of long-term care and identify the ways that leisure can support this for people living with dementia moving forward.

You may or may not receive any direct benefit from being in this study. Some research participants find it helpful to share their meanings and experiences during research conversations. Others may find it helpful to know that they may be providing important information to advance leisure in residential care settings.

Confidentiality:

The list of participants and their assigned code as well as other documents with identifying information (e.g., consent forms, audio-recordings) will be stored separately from the rest of the data in a password-protected file on a TEAMS site set up for this project. Only my supervisor and I have access to this file and to the study materials that contain identifying information.

All audio recordings of the research conversations will be saved in a password-protected file to my local computer (i.e. in the computer hard drive), and then up-loaded to the TEAMS site at the University of Waterloo and deleted once transcribed and verified for accuracy. Any paper copies of documents such as signed consent forms from residents will be scanned and saved as an electronic copy on the Teams research site, and then immediately shredded. All electronic documents (list of participants and codes, transcripts of research conversations, observation notes, signed consent forms) will be stored on the University of Waterloo servers (the project TEAM site). All of these documents will be kept for a minimum of 2 years.

The information transcribed from the audio recordings that are collected for the study will have all names and identifying information removed. Observation notes will include no names or identifying information.

Voluntary Participation:

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. You may decline to answer any question you prefer not to answer, and you may decline contributing to the study in other ways if you wish.

Withdrawal from the Study:

You may leave the study at any time by notifying me. The data collected from you will be removed from the research unless you give permission to use what you had already

contributed. You may withdraw your consent and request for your data to be deleted by contacting me up until study findings are submitted for publication, anticipated sometime in late 2024. It is not possible to remove data once findings have been published.

Questions about the Study:

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46121). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

If you have any questions, concerns or would like to speak to me for any reason, you can email *Erica MacTavish* at em2mactavish@uwaterloo.ca. If you would rather a telephone conversation you can reach me at (705)-795-9378. You may also contact the student advisor, *Sherry Dupuis* (sldupuis@uwaterloo.ca).

If you are willing to participate in this study, please go to the next page and complete the consent form and email it to me at em2mactavish@uwaterloo.ca once completed. If you would prefer to go over this information letter with me and provide verbal consent, please contact me and I will arrange a time to meet with you in person or over the telephone. Should you choose to participate, you will be given a copy of the signed consent form (see next page).

Thank you for considering participating in this project on leisure in long-term care.

Consent

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46121). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), or 1-519-888-4440, or reb@uwaterloo.ca.

I consent to the following:

I understand that quotations from the research conversations will be used in written materials (e.g., publications, teaching-learning resource materials, PowerPoint presentations, policy briefs), as well as at conferences or other speaking engagements and give permission for the use of my quotations with the understanding that a pseudonym will be used in place of my real name (e.g., Jane Doe).

YES NO

I agree to my interview being audio recorded for accurate transcription and analysis.

YES NO

I agree to participate in observations of recreation programs as described in the information letter.

YES NO

Signatures:

I understand the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities. My signature below indicates my consent.

Print Study Participant's Name

Signature

Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person
Obtaining Consent

Signature

Date

For verbal consent:

Participant's name: _____

[] Verbal consent was obtained by:

Researcher's name: _____

Researcher's signature: _____

Date verbal consent obtained: _____

Appendix I: Verbal Assent Prior to Audio Recording of In-Person Research Conversations
Exploring Social Citizenship in the Context of Leisure in Residential Care Settings

Verbal Assent Prior to Audio Recording of In-Person Research Conversations

Researcher (R): Hello, thank you for making the time to be here today. My name is Erica, and I am a Master's student at the University of Waterloo completing a thesis titled, 'Exploring Social Citizenship in the Context of Leisure in Residential Care Settings'. This research aims to explore the role that leisure plays in supporting individuals living in long-term care settings. Ultimately, I hope this research will provide the opportunity for others to hear the opinions and experiences of individuals who often go unheard and will provide tools to make leisure experiences even better in long-term care settings.

Today we are going to participate in a research conversation where we will be collectively exploring some questions around your perspectives and experiences of leisure at [Evergreen Manor]¹².

With your permission, you will be audio-recorded so that I can accurately capture everything you have shared with me. Recordings will be deleted after I have created a transcription of our conversation. All names and identifying information will be removed in the process of creating the transcription.

A few reminders before we begin:

- Your participation in this project and in this conversation is completely voluntary.
- You may decline to answer any questions that you prefer not to answer. If you feel you need to take a pause during our discussion, please feel free to ask for a break and we can continue when you are ready.
- Your name will not appear in any publication or presentation resulting from this research, however, with your permission quotations may be used with a pseudonym (a made-up name) used in place of your real name.
- You may leave the study at any time by letting me know that you no longer want to participate. The data I collected from you will be removed from the research unless you give me permission to use what you had already contributed. Once I have submitted the research for publication it will not be possible to remove your data.

¹² Real name replaced with pseudonym to protect confidentiality of participants

- I want to remind you that this study has received ethics clearance through a University of Waterloo Research Ethics Board. Should you have any questions or concerns resulting from your involvement in this study, you are encouraged to contact this office using the contact information in the Information and Consent Form.

R: Do you have any questions?

Participants (P): No

OR:

P: Yes

R: Okay, what is your question?

P: Question(s)

R: Answer(s). Any other questions?

P: No

R: Please indicate yes or no that you agree to share your views about leisure in this recorded research conversation.

P: Yes

OR

P: No

R: (If participant says 'No') Okay, no problem I will be in touch within the next couple of days to discuss whether or not you still wish to participate in this research. Thank you for your time today and I will talk to you soon.

?

R: [Once participant has agreed to this] Okay let's begin. I will now turn on the audio- recording and we will begin our discussion.

Appendix J: Verbal Script Prior to Observations

Hello everyone,

My name is Erica MacTavish. I am a Master's student at the University of Waterloo in the Department of Recreation and Leisure studies. I am doing a project here exploring recreation and leisure in these settings. As a part of that project, I will be observing and participating in your leisure program as a researcher volunteer to gain a better understanding of leisure experiences here at [Evergreen Manor]¹³. Only individuals who have previously consented to participate in observations will be observed. I am mostly interested in understanding what happens during the program and how it might support you in different ways. I am looking forward to today's program!

Does anyone have any questions for me?

¹³ Real name replaced with pseudonym to protect confidentiality of participants

Appendix K: Appreciation Letter

[Insert date]

Dear [Insert Name of Research Participant],

I would like to thank you for your participation in the research project entitled, “Exploring Social Citizenship in the Context of Leisure in Residential Care Settings.” As a reminder, the purpose of this project is to explore experiences of leisure programs in long-term care settings. The data collected during this research project may help improve leisure opportunities and experiences in long-term care settings.

Please remember that your identity will be kept confidential in study findings. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through written materials (e.g., publications, teaching-learning resource materials, PowerPoint presentations, policy briefs), as well as at conferences or other speaking engagements. If you are interested in receiving more information about the findings of this study, or would like a summary of the results, please contact Erica MacTavish at 705-795-9378, or em2mactavish@uwaterloo.ca and when the study is completed, anticipated by November 2024, I will send you the information. In the meantime, if you have any questions about the study, please contact me by email or telephone.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #46121). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

Again, I want to thank you for all the time you have given to this project. Your insights will be invaluable as we move forward with improving leisure in long-term care settings.

Sincerely,
Erica MacTavish
Erica MacTavish
Faculty of Health
University of Waterloo
Em2mactavish@uwaterloo.ca