"We are doing it all wrong": A Narrative Inquiry Journey Co-Directed by Persons Living with Young Onset Dementia to Illuminate Inequities and Advocate for Change

by

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AUTHOR'S 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

In recent years more attention and concerns are being drawn to the noticeable increase in diagnoses of young onset dementia (YOD), that is individuals who are diagnosed with dementia and are under the age of 65 years. This increase is partially attributed to the high density of the Canadian population that are between the ages of 25 and 64. Despite the growing numbers, there remains a lack of awareness about, and support services for younger persons with dementia and their families, potentially contributing to early institutionalization. A time of crisis, such as with the onset of the COVID-19 pandemic, is particularly harmful for persons with YOD and their families, as not only are there not enough support services available, but persons who are admitted to long-term care (LTC) facilities are at a higher risk of experiencing inhumane treatment or exposure to the illness. This research aimed to gain a deeper understanding of the experiences of persons living with YOD, with hope that the impactful stories shared will create awareness around what it is like to live with young onset, and the steps that need to be taken to better support individuals and their families. As there is little research to-date that privileges the voices of younger persons with dementia, bringing their stories to the forefront of this research was of the utmost importance.

This critical narrative inquiry (CNI) project, informed by Critical Gerontology (CG), Critical Disability Studies (CDS), and other critical theoretical frameworks, had three main purposes, which were to: illuminate how younger persons with dementia story their experiences of YOD and with the LTC system; 2) open spaces for persons living with YOD to collectively reflect on their experiences and engage in dialogic processes; and 3) develop a collaborative and synergistic narrative representation that illuminates experiences and paths for positive change in dementia care. To achieve these aims, this project had two guiding questions, which included: 1) What stories do persons with YOD share about their experiences of YOD and with the LTC system? and 2) What do persons with YOD need to live well that needs to be considered in a re-imagination of caring for persons with YOD?

Using participatory methods and a series of storytelling workshops with six individuals living with YOD, four overarching narratives were created and comprised a total of 11 embedded narrative dialogues that reflect the experiences and viewpoints of the co-researchers.

These narratives were presented in the form of podcast scripts, which will be integrated into an interactive multimodal e-flipbook that is continuing to take shape beyond this dissertation.

Overarching narratives included: *Shifting to New Realities, Recognizing and Resisting Ostracism, Learning from Past and Present,* and *Looking to the Future.* The 11 embedded storylines included: ***Podcast 1A:*** *"You better hope it's not dementia" - Diverse Journeys to Diagnosis,* **Podcast 1B:** *"You can't drive anymore" - Experiences of Losing a Driver's License,* ***Podcast 1C:*** *"They weren't downsizing, I just got the boot" - Forced Transitions Out of Employment,* ***Podcast 1D:*** *"How you have to give up things is ridiculously hard" - Navigating Financial Challenges,* ***Podcast 2A:*** *"Stigma follows us wherever we go" - Stories of Stigma and Challenging Stigma,* ***Podcast 2B:*** *"They don't want to be part of your life" - The Impact of Stigma on Relationships,* ***Podcast 3A:*** *"Oh no sorry, it's only for people 65 and older" - Current Realities of Community-Based Supports,* ***Podcast 3B:*** *"You hear the lock behind us" - Perceptions of Long-Term Care,* ***Podcast 3C:*** *"It's a complicated topic" – Palliative and End of Life Care Options and Considerations,* ***Podcast 4A:*** *"Dementia's given me something to get excited about" – Hopes and Aspirations for Living Well with Young Onset Now and in the Future,* and ***Podcast 4B:*** *"It's like the hamster on the wheel" - Hopes and Aspirations Related to Care and Support.*

From the perspectives of persons with YOD, findings inform the steps that need to be taken to better support persons with young onset in living well with dementia. The stories and dialogues shared send powerful messages about the inequities experienced by persons with young onset, how individuals resist and challenge stigmatization and discriminatory practices, and the changes that need to be made to protect human rights and to make our society and the healthcare system more inclusive.

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Thank you all

DEDICATION

In loving memory of Marjorie Munn – A Nana like no other

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Foreword – Finding and Re-Finding My Direction

When I was completing my undergraduate degree at Wilfrid Laurier University, I never envisioned myself pursuing further education as I did not identify myself as being academic in nature. It was only about a year or so into my degree when my Nana was diagnosed with Alzheimer's dementia, a disease I knew very little about at the time but became immediately eager to learn more. What I did know was that my Nana wanted to continue living her life to the fullest, yet the societal and systemic limitations of this quickly became apparent. It was from this experience that I developed a passion for working with persons living with dementia, as well as gained an intense desire to contribute to the reformation of the dementia care system. From here, and following the completion of my undergraduate degree in psychology, I started volunteering as a friendly visitor in a long-term care[1] (LTC) home, and later applied and was accepted into the Master of Science in Health Studies and Gerontology program at the University of Waterloo.

Through this experience I was provided a number of opportunities to work on dementia related initiatives, and while I am grateful to have been a part of those, there is one particular situation that led me to pursue the project at hand. Our research group was approached by a couple of organizations in Southern Ontario that had developed two day programs for younger persons living with dementia – two of few known to exist in Canada. Knowing that the programs had been developed with little input from persons with young onset dementia (YOD) or their care partners, the organizations sought to evaluate the programs using participatory methods so

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[1] It is important to clarify how I will be defining long-term care (LTC) in the context of this research, as it can be defined in several ways. For the purposes of this research, 'LTC home(s)' will specifically refer to "residential facilities, such as nursing homes or homes for the aged, that provide care for people who are no longer able to fully care for themselves" whereas 'LTC' or 'LTC system' will refer to "a continuum of care, including services received at home such as home care and meal and day programs, hospital-based care, retirement homes, small group homes, supportive housing and assisted-living facilities, and nursing homes" (Dupuis et al., 2012, p. 218).

that the programs would better reflect the needs and interests of these groups. At the time I was also exploring potential opportunities for my thesis and so to me, this seemed like fate. At the time, I was uneducated to the fact that dementia can impact younger adults, as I and many others in society assume that it is a disease that only impacts the elderly. I was immediately intrigued by the project and was quickly enlightened about the extent to which the young onset population is very much overlooked by the system and by society; something of which I was guilty of up until that moment. It was this injustice that started the fire in my belly and that continues to drive me to this day.

After graduating from the Master's program in the summer of 2016, I was struggling to decide whether to pursue a career beyond the academic world or to proceed with my studies. I struggled with this debate for a while, but I remember exactly why I decided to take the latter path. In the decision-making process I continued to ask myself questions about where and how I could make the greatest impact and influence positive change in dementia care. From the experiences with my Nana, I had a particular passion for improving the LTC system and so figuring that I would start my mission there, I went to see my now supervisor Dr. Sherry Dupuis to pick her brain. In our discussions about creating positive change in LTC, I felt encouraged that no matter which path I chose, I would be able to challenge current practices and policies within the system. However, upon further reflection, and perhaps a small nudge from Dr. Dupuis, I decided that pursing a PhD would best support me in making the impact I deeply desired.

Working with younger persons with dementia and their care partners was an eye-opening experience. An inadvertent finding from my research on the day programs was the amount of concern regarding the lack of appropriate support services, and the fear and anxiety associated with the impending transition into a LTC home. I knew when I decided to pursue a PhD that I wanted to further explore the experiences of persons with YOD and their care partners within the LTC context, the specifics of which I still needed to work through. This was later solidified when my family received news that my uncle had been diagnosed with YOD, which only deepened my passion for this area of research.

Prior to and throughout the comprehensive exam process, my supervisor Dr. Dupuis and committee members Dr. Carrie McAiney and Dr. Kim Lopez, supported me in articulating my positionality as a critical researcher, developing an understanding of relevant theories, contexts and concepts, and exploring potential methodologies. From this process and through further reflection and discussion the idea for my dissertation proposal was solidified… or so we thought. That brings us to the summer of 2020, when the world was in the midst of a global pandemic. In short, the initial plan was to use narrative inquiry with ethnographic methods to bring to light the stories and experiences of persons living with YOD in LTC homes (as well as those of care partners and staff), while creating space for processes of self-reflection, the awakening of critical consciousness, and the act of resistance through counter-narratives. In addition to forming a plan for the research, we had also met with and secured a research site for this project. Although whispers of a pandemic technically dated back to December, COVID-19 was declared a pandemic by the World Health Organization (WHO) on March 11th, 2020, after which the Canadian government began enforcing a number of emergency protocols.

As it was anticipated that the pandemic would continue to impact Canadians for the foreseeable future with no clear end in sight, I came to two realizations with regards to this research project. First, there was little to no chance that I would be able to conduct my research within a LTC home, as it had been one of the hardest hit areas of our society. That begs the question, why is it one of the hardest hit areas of our society? The answer, while likely long and complicated, boils down to the realization that the LTC system is broken and requires change. I would like to take this moment to acknowledge the bravery and hard work of the individuals working in LTC who continue to support and brighten the days of residents despite homes which are often “too big; inadequately staffed; and financially insecure” (Phillipson, 2020, p. 2). I would also like to take this moment to raise awareness about the harmful repercussions being experienced by residents and care partners due to the systemic inadequacies of the LTC sector to effectively manage the pandemic. Beyond the separation of residents from friends and family, there have been a number of allegations coming to light regarding multiple care homes across Ontario and Quebec, allegations that were confirmed in a report prepared by Military personnel who were working in LTC homes in Ontario (Canadian Division Joint Task Force, 2020). This report indicated realities of “bug infestations, incidents of force feeding leading to “audible choking,” and patients who were heard “crying for help with staff not responding”” (CTV News, 2020). I do not want to lump all LTC homes into one picture, and recognize that there are many homes that are going above and beyond to support residents, care partners and staff through this challenging time. However, with 69% of COVID-19 deaths in Canada being connected to LTC (CBC News, 2021), and Canada having the largest number of deaths in LTC than other countries, it is undeniable that the system has failed to keep individuals protected and safe, a reality contradictory to that which the system claims to do. A more in-depth discussion of the harmful discourses and practices that are emerging from the COVID-19 pandemic and mainstream media discourses will be provided in Chapter 2.

This first realization is what led to the second – there is a clear need to re-think the current model of care and envision new possibilities. Despite my initial disappointment from the realization that research within LTC homes would not be possible, at least for now, discussions with my supervisor uplifted my spirits, and ignited excitement and a new level of determination to use the current circumstances as an opportunity to imagine what the future of dementia care could look like. What made me particularly excited about this project is that it shifted from one which aimed to illuminate the various experiences of persons with YOD within LTC homes, ultimately unveiling areas of the system that need to be improved to better support these individuals, to one which does not bear the preconceived notion that LTC homes is the way forward. This is not to rule out LTC homes as a model of care entirely, but instead will give people living with YOD the opportunity to not only describe what life has been like for them living as a younger person with dementia but also to re-think the ways the system currently exists and to imagine and describe what their ideal care situation would look like, *or*, perhaps co-researchers will envision a different path entirely.

As will unfold throughout the remainder of this dissertation, there is a clear lack of support services for persons with YOD and their care partners, a factor likely leading to early institutionalization into LTC homes. With it being estimated that more than half of residents in LTC homes are over the age of 85 (Oyebode, 2015), it is not overly surprising that the needs and desires of the YOD population are often overlooked, leading to a number of harmful repercussions that will be unpacked in Chapters 1 and 2. Given what has surfaced during the COVID-19 pandemic, I am more convinced than ever that LTC homes are particularly detrimental to the health and well-being of younger adults with dementia and should not be the only option for care and support. Working closely with persons living with YOD, it is my hope that this research will provide new possibilities for the care of persons with YOD and inform future opportunities for change in dementia care more broadly. Next, I share a story that will provide a glimpse into a series of experiences that are common amongst persons with YOD and their families.

Chapter 1: Introduction

Setting the Stage

Imagine you are 54 years old. You are married to your partner, have two children who are in university, and you live half-an-hour away from your parents, one of whom has kidney failure and requires dialysis three times a week, and both of whom need your support with care. At this time, you have a full-time job and use your days off to go visit your parents to help with the maintenance of their five-acre property, as well as with other things like bookkeeping. For the last four years you have started to notice changes in your memory and speech that don't make sense to you and that prompt you to go to the doctors, leading you to be sent from specialist to specialist and put through test after test with only guesses being offered at what you are experiencing. Finally, one test shows neurological changes, and you are given a diagnosis of YOD. What now?

This is what happened to my uncle and is one representation of what the beginning journey of YOD can look like. There is such a lack of awareness in society that YOD exists, and for a variety of possible reasons physicians are reluctant to provide younger adults with this diagnosis. As this story demonstrates, people who are diagnosed with YOD often have intricate lives, which in the case of my uncle included contributing to the financial support of his family, helping with the care of his aging parents who live in a rural area, all the while trying to figure out why he was experiencing changes in memory and speech.

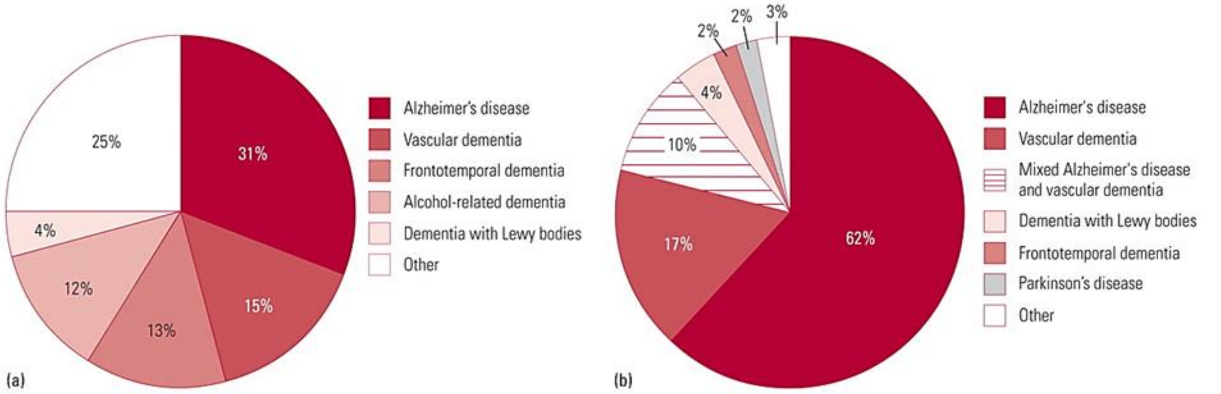
As will be discussed in the paragraphs below, and further in Chapter 2, the current system of dementia care is largely structured for the older adult population, creating complications in the referral process and accessibility of support services for persons with YOD and their care partners (van Vliet et al., 2010). Services that are available are often neither relevant nor meaningful for younger adults, which has been identified as a key issue for persons with YOD and their care partners while they live at home and need support (Oyebode, 2015). Without the necessary support systems in place there is only so long that persons with YOD and their care partners can adjust their everyday lives to accommodate for the changes the individual and family are experiencing. This situation is further exacerbated by the fact that many care partners of persons with YOD are often still working (or must seek employment) as they become the sole financial provider post-diagnosis, and so are unable to stay at home as the primary care partner (Bayly et al., 2021). With few options to turn to, it is often the inevitable path that the move to a LTC home becomes a prominent discussion in these situations (Carter et al., 2016; van Vliet et al., 2010.

Returning to my uncle's story, it is mystifying thinking about him in the context of a LTC home. While my uncle is no longer employed, there are very few other things he has allowed his diagnosis to change. With the support of his amazing partner, my uncle continues to train for and race in marathons and triathlons multiple times a year. Beyond this my uncle and aunt have come up with innovative and creative ideas (Kontos et al., 2020) and tools that they use to practice speech and recall memories and have sourced a local social group of individuals with a similar diagnosis (which organically developed from a gap in service provision). Despite my uncle's high level of physical activity, cognitive awareness, and ability to communicate, the family has been advised to start thinking about a transition into a LTC home. While it is better to be prepared than not, I believe the system has failed by allowing this to be essentially the only option available for persons with YOD, the reasons for which will be explained in the following paragraphs. Through this research project, I will bring the experiences of persons with YOD to the forefront to resist and challenge existing models of care, and explore opportunities for change.

Background: Differentiating YOD in the Dementia Context

In recent years more attention and concern are being drawn to the noticeable increase in diagnoses of YOD, partially attributed to the high density of the Canadian population that are between the ages of 25 and 64 (Statistics Canada, 2018). The WHO (2012) defined YOD as the onset of a dementia that occurs before the age of 65 years, representing a demographic who are likely still employed, physically fit, and have dependent children or parents (Jefferies & Agrawal, 2009; Shnall, 2009). To date, most studies that explore the prevalence of dementia focus on individuals who are over the age of 65, making it difficult to gauge the number of people impacted by YOD (Canadian Study of Health and Aging (CSHA), 2000; Lambert et al., 2014). That being said, it is estimated that between 2-8% of all cases of dementia occur before the age of 65, and thus it can be inferred that of the 564,000 Canadians living with dementia, between 11,000 and 45,000 have a diagnosis of YOD (Alzheimer's Society of Canada (ASC), 2016). It should be noted that the prevalence of individuals with YOD may be further underestimated due to a number of factors including the often difficult and lengthy diagnostic process, lack of awareness among healthcare providers to look for dementia in younger populations (Alzheimer's Association, 2006; ASC, 2016; Ducharme et al., 2014; O'Malley et al., 2021; Vieira et al., 2013), as well as the fear and stigma associated with dementia resulting in some individuals choosing not to seek out a medical diagnosis (Mitchell et al., 2013). This underestimation of prevalence is also likely in part responsible for undermining the need to develop appropriate support services specifically for persons with YOD and their care partners.

Beyond the distinction of age between late onset dementia (LOD) and YOD, the latter is also more likely to have a genetic component or be a secondary dementia (Rogers & Lippa, 2012; Draper & Withall, 2015), resulting in a much more heterogenous etiology (see ***Figure 1)*** (Jefferies & Agrawal, 2009). For instance, Alzheimer's Disease (AD) is 50% less prevalent in individuals under the age of 65, yet 'other' rarer forms of dementia are 20% more prevalent (Jefferies & Agrawal, 2009). Differences in dementia diagnoses have important implications for the development of support services, as each dementia is known to present differently, and to varying degrees. For example, individuals with fronto-temporal dementia may experience alterations in their personality and social behaviour, yet their memory and perception may remain intact (Jefferies & Agrawal, 2009). Individuals with Alzheimer's disease, on the other hand, will likely experience progressive memory loss and visuospatial and perceptual changes, yet their language and social functioning may remain intact (Jefferies & Agrawal, 2009). Overall, differences in age, physical ability, and diagnoses (in addition to other experienced stratifications) often result in practical and emotional needs that are unique for persons with YOD and their families, yet these differences are often overlooked within healthcare and society.



(a) Distribution of diagnoses in young-onset dementia (data from Sampson et al 2004); (b) distribution of diagnoses of dementia occurring in later life (redrawn from Knapp & Prince 2007, with kind permission of the Alzheimer's Society).

Figure 1: *Distribution of Diagnoses in YOD and LOD (from Jefferies & Agrawal, 2009)*

A systematic review unveiled that studies exploring service provision for persons with YOD and their care partners nearly doubled between 2010 and 2016 compared to what was seen between 1990 and 2008. Despite the full 26-year period that this review examined, only 20 studies were able to be included, 10 of which were non peer reviewed descriptive accounts, and all of which spanned five countries (Mayrhofer, et al., 2018). Unfortunately, the scant research that does exist continues to tell the same story, yet there has been little discernable action taken to improve service provision. Repeatedly these studies tell us that more support services are needed for persons with YOD and their care partners, yet questions remain regarding the referral process, effectiveness of such programs, what they should look like, and how to find and access such services (Mayrhofer et al., 2018).

A lack of appropriate support services can create an abundance of negative repercussions, with one being the institutionalization of persons with YOD into LTC homes; this is a system that has evolutionized into one that focuses on supporting individuals who are deemed to require around-the-clock extensive assistance, and palliative care for the ill and older adult populations. As will be discussed further in Chapter 2, the LTC system has a lengthy history that is rooted in the separation of the ‘other’ in an effort to hide individuals in the population who differ from idealized societal norms (Burghardt, 2015; Forbes et al., 1987; Rinaldi, 2021). Throughout the years, the system has continued to shift alongside the relevant demographic and socio-cultural trends of the time. One of the most recent recognizable shifts occurred in 2011, as the oldest of the baby-boomer generation turned 65. Coincidingly an initiative known as ‘aging in place’ was gaining in popularity as a more humanistic alternative to LTC home placement, shifting the focus to the institutionalization of individuals deemed to require high levels of care and constant ‘surveillance’, with almost two-thirds being over the age of 65 (as cited by the Family Caregiver Alliance (FCA), 2015).

While strong efforts have been made to revitalize an outdated system through initiatives such as culture change (Dupuis et al., 2016a), there is a long road ahead in terms of dismantling harmful ideologies and practices related to dementia, illness, and LTC that have sedimented over the years. Beyond the critiques of the system as a whole, LTC environments create a particularly troubling existence for persons with YOD. To date, no research that I was able to find has been done to explore the *experiences* of persons with YOD in the LTC home context, and so to speak directly to what these experiences are would be uniformed. Sadly, even beyond the LTC home context, few studies have worked with persons with YOD to gain a better understanding of their lived experiences, however, some do exist. In a meta-ethnographic review of the qualitative literature exploring the experiences of people with YOD, Greenwood and Smith (2016) identified eight studies, all of which were from Western countries and included the experiences of 87 people with YOD. What was highlighted in this review, and which corroborates what I have found in my own work, is that younger persons with dementia often experience: difficulties through the diagnostic process, changes and tensions with one’s self-identity, changes in relationships, social exclusion, and loss of meaningful activity (Greenwood & Smith, 2016). To adapt to these changes, this review also indicated that persons with YOD often seek connections with others who have the same diagnosis in an effort to regain control over their lives and to create a network of support (Greenwood & Smith, 2016). In my earlier work exploring day programs for younger persons with dementia, this last finding was of the utmost importance to the group, particularly for forming feelings of social connectedness (Main, 2016).

What research with persons with YOD has demonstrated – and what will be discussed further in Chapter 2 - are the unique physical and social challenges associated with YOD, and the stigmatizations that come along with it. In the LTC context, practices perpetuated by a biomedical model of care, as well as other sociocultural factors such as ageism, leave persons with YOD especially marginalized, threatening their physical, emotional and social well-being (Appelhof et al., 2017; Millenaar et al., 2016). These harmful stigmatizations and care practices have been further perpetuated by media discourses regarding the COVID-19 pandemic, the contribution of which will be unpacked in Chapter 2.

One example of the marginalization and discriminatory treatment that exists in LTC is reflected in a study that explored the neuro-psychiatric symptoms (NPS) of 382 residents with YOD that were considered ‘burdensome’ for nurses within LTC homes in the Netherlands; behaviours most commonly claimed as the most predominant were agitation/aggression and apathy (Van Duinen-van den Ijssel et al., 2018). It was also assumed that this ‘difficult behaviour’ was in large part due to high levels of physical and verbal functioning, and from which nurses were urged to “manage (extreme) aggressive behaviour” (Van Duinen-van den Ijssel et al., 2018, p. 628) often resulting in the excessive use of psychotropic drugs. This pathologizing approach to behaviour is problematic, as many assumptions about the person and their diagnosis are made without consideration for alternative meanings behind behaviour or other possible contributing factors (e.g., social and environmental factors) (Dupuis et al., 2012a). This narrative of persons with YOD, along with many other stereotypical narratives, are shallow and uniformed, and can cause unnecessary harm to persons with YOD.

The COVID-19 pandemic has exacerbated the already predominant challenges of the LTC system, further shifting the focus away from persons with YOD, a population that has continuously been overlooked. Instead, the system has reverted back to a heavy reliance on biomedically driven modes of ‘managing’ to try and minimize the ‘damage’ (the deaths of older adults and people living with dementia), which is largely attributable to a failed system (Estabrooks et al., 2020). Phillipson (2020) spoke strongly about the ways through which the system has failed to protect the individuals it promises to keep safe. In recognition of the horrible injustices that are occurring throughout LTC homes, Phillipson (2020) has called upon the research community to dismantle the system and to re-imagine what the future of care will look like. In recognition of this urgent need, particularly for the YOD population who have very little access to support services, this research addresses Phillipson’s (2020) call by bringing the perspectives of younger persons with dementia to the forefront of the discussions that are taking place regarding major care reform.

Purpose

This study has three central purposes to: 1) illuminate how younger persons with dementia story their experiences of YOD and with the LTC system; 2) open spaces for persons living with YOD to collectively reflect on their experiences and engage in dialogic processes; and 3) develop a collaborative and synergistic narrative representation that illuminates experiences and paths for positive change in dementia care. By attending to these purposes, this project aims to achieve two key objectives: 1) to expose and deepen societal understandings of the inequities experienced by persons with YOD, particularly in the LTC system; and 2) to collaboratively find innovative ways to share the collective narratives derived from this study in a way that resists current care practices, calls for change, and envisions a new way forward. I will now move on to a discussion about my positionality, as the positions, theories and concepts discussed are important for shaping the research questions that will be outlined at the end of this chapter.

Positionality Statement

Berbary and Boles (2014) outlined a fluid eight-point scaffold for researchers to reflect on and utilize in the development of a solid research strategy that not only satisfies traditional expectations of qualitative rigour, but also allows for flexibility and innovation. In this chapter, I will explore three components of this scaffold, which include ontology, epistemology, and theory. Within each of these sections I will describe my positionality and how it shaped this research.

Relational Ontology

"Having a relational view inevitably means not giving up sovereignty but rather admitting that it has always been an illusion." – Roberto Marchesini, 2016

I consider ontology (how things are) and epistemology (how we know what we know) to be separate but in relation. Some believe that epistemology and ontology cannot be separated, such that *how things are* and *how we come to know* are not distinct but are rather one in the same

– Roy Bhaskar labelled this concept the ‘epistemic fallacy’ (Alvesson & Skoldberg, 2018). I view ontology and epistemology as being fluid and interacting, such that *how we are* can shape the ways through which we come to know, and *how we come to know* can shape our perceptions of how things are. If one experiences a tension between the two, I believe it can create possibilities for self reflection and personal shifts in one’s positionality.

When exploring what ontology means beyond *“how things are,”* Crotty (1998) explained it to mean, “the claims or assumptions that a particular approach to social inquiry makes about the nature of social reality” (p. 11). In thinking about this research project and reflecting on how I perceive existence I have uncovered my belief in relational ontology, which after going down the proverbial rabbit hole, I learned to be a broadly defined concept with diverse historical roots. That being said, one article was able to capture what I believe to be the common underlying components of a relational ontology that can be applied across countless disciplines and contexts. According to Santos (2015), in a truly relational ontological perspective, “the basic categories are not relations and objects, but relations and relata. Objects are just one kind of entities (among others) that are able to assume the role of being in relatum” (p. 439). What I derive this to mean is that regardless of what the object of being is (an individual, an animal, an inanimate object, etc.), one does not get ontological priority over the other, as all ontological categories are in relation and contribute to the understandings of the other. Paraphrased from Santos’s (2015) work, all entities must be viewed as both:

1) A relatum that continuously interacts with other entities/groups of entities (extrinsic relations)
2) A collective of local relations that frequently interact between its component parts (intrinsic relations)

To me, these two components demonstrate the belief that relations are everywhere. As will be discussed further below, the relations that were explored in this research are reflected in Habermas's theory of communicative action. In the systems world we have the LTC system, which is comprised of an entanglement of relations between external structures and processes (such as economics, politics, government regulation, etc.) that influence the way the system is constructed, behaves, and is understood by others. In the lifeworld are the relations that persons with YOD, their care partners, and paid care providers have both individually, as well as collectively as a group. For instance, an individual with YOD lives in relation to other relational entities such as culture, family, community, education, employment, and so on, all which influence who the person has become (identity) and how they will continue to adapt and evolve as they continue to interact with, and in the world of relations around them. Beyond this we can also see a collective group of relations between persons with YOD, their care partners, and paid care providers that will influence the trajectory of one's care journey. Beyond this even further are the extrinsic relations between the systems world and the lifeworld that will both work together and in friction, in processes of care and also in systemic transformation.

Lastly, the other component of Santos's (2015) relational ontology that I find appealing is its recognition that "in the course of such networks of ongoing relational processes, new types of relations, relata, and relational systems are continuously generated, destroyed and transformed, while different levels of composition and organization are formed" (p. 440). The notion that relational processes can contribute to the construction, deconstruction, and transformation of various entities and being aligns nicely with the following section, which discusses my positionality as a social constructionist researcher.

Social Constructionist Epistemology

Complementary to a relational ontology, I position myself within a social constructionist epistemology where it is believed that “meanings are constructed by human beings as they engage with the world they are interpreting” (Crotty 1998, p. 43). *How we know what we know*, then, is created in a relational process between individuals and the world around them, resulting in the existence of multiple realities and multiple truths. In this case, the limiting factor is the culture surrounding the interaction between subject and object. What I mean by this is that when we are born into the world, we are born into a culture that has been engrained in the localized history of our society. This cultural influence shapes our existence and character as individuals in a community, and to an extent influences a number of aspects of our lives including but not limited to our values, beliefs, and behaviours (Mallon, 2007). While it is assumed that we are born into a world with pre-existing cultural meanings that give context to our being, the critical nature of social constructionism considers cultural identity to be fluid and transformable as tensions between traditional and new ways of thinking, being, and relating emerge. When resistance to traditional ways of thinking, being, and relating occur, it is possible to see that culture is not just a limiting factor, but also can be a liberating factor through its ability to foster experiences, thought, and interaction in a way that creates space for cultural shifts.

Working in relation to culture, historical relativity is also important in this epistemological perspective as ways of understanding “are dependent upon the particular social and economic arrangements prevailing in the culture at that time” (Burr, 2003, p. 4). As will be demonstrated in Chapter 2, the LTC system in Canada has a long history of transformations that have been perpetuated by the cultural beliefs of the time. For example, the initial development of houses of refuge in the mid-1800s (what we now know as LTC homes) were used as a place to house a range of socially excluded groups deemed ‘burdensome’ to society such as the elderly and the disabled, while individuals who were deemed ‘senile’ were sent to the ‘insane asylum’ (Forbes et al., 1987). However, because of demographic shifts, the deinstitutionalization of ‘insane asylums’, and the Second World War, houses of refuge transformed into LTC facilities for the elderly. The continued expansion of institutional facilities continued to take precedence over the development of community support services up until a growing emphasis was placed on “rehabilitation and monitoring” (Forbes et al., 1987, p. 47) and the belief that a shift to community care would be less expensive. This shift later became established as the ‘aging in place’ movement, which will be further discussed in Chapter 2. Understanding the historical roots of different understandings, practices and ways of relating, and reflecting and questioning historical and cultural shifts are critical in social constructionist research, as it helps us understand and critique how things have come to be and why, as well as demonstrate that societal transformation is possible.

In the pursuit of emancipation and liberation, social constructionism seeks to understand and illuminate multiple realities and multiple truths to transform or change dominant ways of knowing. Alvesson and Skoldberg (2018) outlined four key tenets of social constructionist research, which align with the objectives I outlined in the Purpose section. Abbreviated from the original text, these assumptions are:

1) Identifying and being critical of a taken-for-granted truth
2) Exposing this truth as not concrete and as susceptible to change
3) Revealing the harmful nature of this truth
4) Demonstrating that society would be better off if this truth was radically transformed or all together non-existent (p. 49)

Through its critical nature, social constructionism urges us to constantly reflect and be suspicious of our assumptions about how the world appears to be. For example, families may feel that caring for people in LTC homes is the only way to care for people with complex health needs. Certainly, the capitalist complex of aged care has worked hard to convince us that this is true. However, if one begins to reflect on how the system developed (i.e., its history), the model of care driving the industry (e.g., biomedical model of care), and the structures that produce and reproduce harmful discourses, ideologies and practices (e.g., economic/capitalist, political/governmental, etc.) then we begin to question the harmful nature of this assumption for individuals who live and work in these settings and advocate for change.

The main tension I hold within this epistemological position is in its assumption of hierarchical structures of power, such that power is seen as ‘have’ or ‘have not’. This interpretation can limit emancipatory efforts, as it is assumed that individuals must be given the power to free themselves. By employing a Foucauldian understanding of power as relational, possessive notions of power are replaced by the idea that power is already always present (Foucault, 1980). This opens up possibilities for liberation/emancipation, as where there is power, there is power to resist (Hall, 1992).

Critical Theories

I view theory as the engine of the research process as it is connected to ones ontological and epistemological position and provides a lens from which to think about the content, research questions, methodology and methods, analysis, and representation (Berbary and Boles, 2014; Creswell, 2014). Complementary and connected to relational ontology and social constructionism, my positionality is rooted in critical theory. This theoretical perspective is concerned with challenging dominant ways of knowing by working with marginalized groups to resist, dismantle, and transform harmful ideologies and practices that are produced and reproduced throughout various facets of societal structure (Creswell, 2014).

Critical theory is a macro-level theory within which many meso and micro theories reside. In the paragraphs below I will begin by providing a brief history and understanding of critical theory as an overall approach, from which I will delve into meso theories of critical gerontology (CG) and critical disability studies (CDS), as well as relevant micro theories informing my study.

Critical Theory

The term ‘critical theory’ describes a group of philosophical perspectives that bring into question “the existence of taken-for-granted assumptions, established ideologies, various kinds of power relationships and institutions [that] may at least sometimes obstruct or restrict people’s thoughts and freedoms” (Alvesson & Skoldberg, 2018, p. 243). As such, critical theorists strive to dismantle dominant ideologies through the exploration and exposure of different ways of knowing that consider social, historical and cultural contexts, as well as through action-oriented processes that aim to change the practices of oppressive structures; the end goal being the emancipation and liberation of marginalized and oppressed individuals or groups (Chriss, 1995; Freeman & Vasconcelos, 2010).

Despite the differing angles and interpretations of CT, Crotty (1998) usefully summarizes the unifying tenet that distinguishes CT as an overarching theoretical perspective from other approaches to inquiry:

> It is a contrast between a research that seeks merely to understand and a research that challenges… between a research that reads the situation in terms of interaction and community to a research that reads it in terms of conflict and oppression… between a research that accepts the status quo and a research that seeks to bring about change. (p. 113)

Critical theorists embrace a number of tenets. When I was beginning this research, I gravitated especially to four of these tenets because of their importance to my research. I describe these next. In brackets beside these tenets I have indicated the theorists who have contributed most to (but are not solely responsible for) my understanding of each of these tenets.

1) **Context** *(Habermas)***:** Acknowledging that the research being undertaken must be explored within a contextual framework. Consideration must be made of historical, cultural and social factors.

As part of the second generation of the Frankfurt school, Habermas extended Marx's focus on oppression stemming from political power and economics to not only look at structural factors, but also to include an exploration of factors at the level of the individual. In this regard, Habermas developed a theory of communicative action through which two worlds are described as co-existing and interacting – the systems world and the lifeworld (Chriss, 1995; Edgar, 2006; Habermas, 1984, 1987). In brief, the systems world refers to various societal structures largely emanating from the capitalist economy and political system, but also inclusive of organizations and institutions (Baars & Phillipson, 2013; Kemmis, 2011). The systems world is perceived to view individuals as meaningless, and the focus is placed on functionality and instrumental rationality (Edgar, 2006; Kemmis, 2011). In the context of this research, I would argue that the instrumental rationality of the LTC system is socially skewed and immorally motivated, such that instead of focusing on the well-being of individuals, the system is instead focused on utilizing biomedical approaches to care to drive efficiency, lower costs, and generate economic profitability (Diamond, 2009; Beattie et al., 2005). In contrast, Habermas theorized that in the lifeworld people interact and communicate with each other to establish a shared understanding of the world (Baars and Phillipson, 2013; Edgar, 2006; Habermas, 1984, 1987). Habermas (1984, 1987) posited that the ongoing interactions and tensions between the two worlds determine the extent to which freedom and liberation are possible.

Habermas's theory of communicative action creates a framework from which I can explore systemic and individual factors as both separate entities, as well as interacting relational entities. In this research, the LTC sector can be seen as the systems world that is comprised of an entanglement between socio-political and economic factors that are constantly changing alongside historical and cultural developments. For instance, persons with dementia used to be referred to as 'senile' and 'insane', and thus it was socially acceptable at that time to admit these individuals into an 'insane asylum' governed by municipal councils. Over time, and as more knowledge was gained about dementia, this previous trend became socially unacceptable and thus the development of LTC homes began. As this system began growing rapidly, government at the provincial and federal levels started taking more control over these homes through the allocation of funding that in turn allowed these bodies to impose a number of rules and regulations (Forbes et al., 1987).

What has remained fairly constant over time are the economic motivations driven by capitalist greed. The institutionalization of others has turned into an opportunity for economic gain, and has generated a thirst among capitalist giants in both private and public sectors to take, package, and market this care product to individuals in need, all the while being able to quash the development of alternative options (Diamond, 2009). Together, these socio-political and economic factors are responsible for producing and reproducing harmful ways of thinking about dementia, leading to the dehumanization of an individual into a dollar bill.

I believe it is important here to speak to how in times of crisis, such as we are experiencing now in the midst of a global pandemic, economic objectives are threatening the lives of the older adult population; a population that has helped build our countries through years of contribution. For example, it has been documented that a for-profit status of LTC homes was associated with the extent of an outbreak and the number of resident deaths compared with non-profit homes (Stall et al., 2020). The explanation of these findings attributed the poor management of COVID-19 to older design standards and chain ownership (Stall et al., 2020). This raises questions about the motives of these homes, as a focus on profit and quantity over quality has clearly limited the ability of these homes to truly provide the best quality of care and life.

Beyond LTC facilities, the disregard for our aging population is reflected in broader society, as is reflected in the media. For example, one article entitled, *Politicians who consider sacrificing the old for the sake of economy face backlash,* illuminates the reality that “human life does, indeed, have a price” (para. 3). In this article, Don Pittis (2020), specifically draws attention to a statement made by Texas Lt.-Gov. Dan Patrick, who suggested that ‘senior citizens’ should risk their chances of survival during the pandemic in *exchange* for keeping the economy strong for future generations - if this is not ageism, I don’t know what is. Also, while Patrick is one government official to be directly called out, there is no mistaking that he is not the only politician or citizen who agrees with such a proposition.

To continue with Habermas' (1984, 1987) theory, on the other side of the system world we look at the dynamics of the lifeworld, which is comprised of three components: culture, society, and personality. The relation of these components in the process of communicative action was described by Habermas (1987) as the following:

> Under the functional aspect of *mutual understanding*, communicative action serves to transmit and renew cultural knowledge; under the aspect of *coordinating action*, it serves social integration and the establishment of solidarity; finally, under the aspect of *socialization*, communicative action serves the formation of personal identities…. Corresponding to these processes of *cultural reproduction, social integration*, and *socialization* are the structural components of the lifeworld: culture, society, person. (p. 137).

It is these components that are at risk of being jeopardized by the systems world. The relationship between the systems world and the lifeworld is one of unequal proportions of power, and there is an ongoing concern about the colonisation of the lifeworld by the systems world (Edgar, 2006). With the systems world being governed by specific rules, there is a "high degree of consistency, which is to say that they will be largely coherent with each other and will generate relatively few conflicting instructions to the people who are following them" (Edgar, 2006, p. 39). As such, various systems in our society (such as economic or political systems) have developed their own logic and follow a set of principles that have been developed and become systemically engrained over time; the longer these systems have been established, the more difficult they become to change. For example, and in line with the context of this research, let's look at the possible influences that the LTC system may have on the three components of the lifeworld as described in the quote above:

1) "Under the functional aspect of *mutual understanding*, communicative action serves to transmit and renew cultural knowledge" → The LTC system, rooted in a biomedical perspective, has produced and reproduced stigmas (cultural knowledge) around a number of relevant concepts including dementia and age. For example, due to the perpetuation of dominant healthcare narratives, dementia is seen as a disease of the elderly where personhood slowly deteriorates until only symptoms of the disease remain (Dupuis et al., 2012a; Mitchell et al., 2013, 2020). With regards to age, there is a cultural narrative around "successful aging" from which the economic contribution of an individual is a central factor (Martinson & Berridge, 2014; Martinson & Minkler, 2006; Rowe & Kuhn, 1997). Persons with YOD are subject to the negative repercussions of both cultural understandings.
2) "[U]nder the aspect of *coordinating action*, it serves social integration and the establishment of solidarity" → The LTC system determines the ways through which individuals are socially integrated post-diagnosis. For example, the system directs persons with YOD to utilize support services that have been designed for people with LOD, assuming that all persons with dementia (despite significant age differences) should be able to benefit from the same services (Beattie et el., 2005; Oyebode, 2015; Shnall, 2009; van Vliet et al., 2010). For persons with YOD, being socially integrated likely means something much different, and the establishment of solidarity would likely reflect support from the community and community services in helping persons with YOD continue living their everyday lives.
3) "[F]inally, under the aspect of *socialization*, communicative action serves the formation of personal identities" → For persons with YOD, the LTC system currently limits the extent to which individuals can continue to live and grow their personal identities. These limitations are caused by factors such as inadequate service provision, leaving only options that often

place individuals in a position that conflicts with their self-identity (Clemerson et al., 2014). In other words, the system dictates part of one's personal identity post-diagnosis. The predominance of the biomedical model in the LTC system and society more broadly, makes it difficult for younger persons with dementia to access life experiences that support living well with dementia, such as having meaningful activities, purpose, and compassionate relationships, due to the many stigmatizations and misunderstandings about YOD.

The LTC system is obviously one that is long-standing and thus remains very much engrained in its biomedical model roots and driven by socio-political and economic motivations. However, creating communicative spaces brings groups together to challenge the pressures imposed by the systems world to conform to their 'rules', 'principles', and 'values'. This research, for example, engaged persons with YOD in a narrative inquiry project that used the power of discourse and story to challenge dominant narratives by establishing counter-narratives to help to imagine new possibilities for the future of dementia care for persons with YOD. Processes of reflection and dialogue contributed to the awakening of a critical consciousness amongst co-researchers, whereby questions were raised about why things are the way they are in various facets of the system and how they came to be that way. Through such processes, tensions between the systems and the lifeworld became apparent, and the group envisioned desired transformations, as well as actions to get there.

2) **Critique and Expose** *(Habermas, Foucault, Freire)***:** Questioning and challenging dominant ways of knowing and the ways in which they are produced and reproduced.

Common among all critical researchers is the "commitment to expose and critique the forms of inequality and discrimination that operate in daily life" (Denzin & Flick, 2017, p. 9). With its emancipatory interest, critical inquiry aims to expose the forces and dominant ideologies that influence individuals and groups perceptions of knowledge and life, to the extent where they are no longer able to decipher between how they construct meaning, and how they are *influenced* to construct meaning; otherwise known as a process of sedimentation that leads one to develop a false consciousness (Crotty, 1998). To further explain, sedimentation occurs when individuals are repeatedly exposed to oppressive ideologies in such a way that these dominant ways of knowing continue to layer and solidify before individuals have a chance to become aware of this harmful process (Crotty, 1998). Such a process forces individuals into a state of false consciousness, whereby one can no longer decipher their beliefs from those that are imposed on them (Crotty, 1998; Freire, 1970). The goal to critique and expose promotes the awakening of a critical consciousness where self-reflexive processes begin to peel away the layers of sedimentation that have accumulated. From this perspective, it is believed that exposing and questioning dominant truths is important for individuals and groups to achieve emancipation from taken-for-granted truths.

3) **Power and Power Relations** *(Foucault)***:** Understanding various ways of interpreting power and power relations through a critical lens.

Critical theory emerged as a critique and extension of interpretivist forms of inquiry, by moving beyond a research that seeks to understand, to one which also seeks to uncover the underlying historical, cultural, social, political, and economic factors that have contributed to these understandings. In doing so, it "looks critically at social structures and social institutions from the point of view of their dominating effects on individual human subjects" (Haugaard & Cooke, 2010, p. 1). By bringing into question why things are the way they are, and how we have come to know what we know, critical theoretical approaches do not simply examine and identify such institutions, but also act to correct social injustices and push for social change. In this sense, critical theory is very much engaged with the idea of *theory in practice* or *praxis*, which Crotty (1998) defined as "a search for knowledge, to be sure, but always emancipatory knowledge, knowledge in the context of action and the search for freedom" (p.159).

However, in emancipatory processes, there is a divide amongst critical theorists regarding the way with which the notion of power should be perceived. In more traditional approaches stemming from the Frankfurt School, it is believed that forms of domination are rooted in "agent-centred relations" (Haugaard & Cooke, 2010), or in other words the power of some individuals or group *over* others. While in some instances these conceptions of *power over* consider the systemic forces at play, they ultimately revert to an "agent-centred, episodic view of power" (Haugaard & Cooke, 2010, p.2). I hold tension with this notion, as I believe it takes a narrow and pessimistic view of power by ignoring the potential of positive power, or the *power to* (Haugaard & Cooke, 2010). To address this tension, I began to explore the ways with which other critical and post* theorists took up notions of power. More specifically, I looked to the work of Foucault, who moved away from agent-centred notions of power to those that explored processes of systemic domination and the role of social forces and social practices. As will be further discussed below, Foucault's perception views individuals as "social agents" with "certain powers and dispositions" (Haugaard & Cooke, 2010, p. 2), diminishing the idea of 'power over' and instating the idea of productive power through the utilization of power relations, knowledge production, and resistance.

Foucault (1975), who is widely known for engaging with both social constructionist and post* ways of thinking, provided insight into the limitations of viewing power as a stable hierarchical structure that is imposed upon individuals to varying degrees. Counter to this viewpoint, post* theorists believe that power is relational, and thus is something with which all individuals always already obtain (Foucault, 1980; Hall, 1992); power is not seen as a ‘have’ or ‘have not’. Foucault (1980) illuminates this post* perspective by explaining that both the oppressors and the oppressed are caught up in a circulation of power, whereby power is not a unidirectional process. Instead, he posits, it is infused throughout every aspect of social life (Foucault, 1980; Hall, 1992). This reflects the notion that power can be as productive as it is negative. By removing possessive notions of power, power becomes an unstable construct from which opportunities for resistance and change can be grasped by those who seek them. Foucault’s perception of power and its impact on efforts of liberation/emancipation will be discussed in the next section.

4) **Liberation/Emancipation** *(Habermas, Foucault, Freire)***:** Engaging with action-oriented processes that will transform oppressive structures and liberate those who are oppressed by them.

One of the goals of critical theoretical perspectives is to *liberate* and *emancipate* marginalized groups. These two terms are used liberally in the literature and are frequently equivocated. This may be the result of a lack of precision with which the terms are employed, or it may be the result of an insufficiently deep understanding of their meanings. However, the terms can be distinguished. In particular, I find myself drawn to a critical feminist distinction between the two terms, that “emancipation means working from within existing systems and trying to change them, whereas liberation implies a complete overthrow of the *status quo*” (Pojmann, 2005, p. 74).

For me, emancipation can be interpreted as the transformations that occur *within structural systems* in pursuit of equitable and inclusive opportunities. Liberation, in contrast, seems to be tied to more grandiose transformations that move beyond working within these systems to challenging the ideological foundations of the systems themselves (Box & Hale, 1984). Achieving equality within structural systems reflects the Habermasian notion that "constitutions [are] the main device for uniting citizens and regulating power in a pluralist society" (Flyvbjerg, 2000, p. 4). Habermas can be interpreted as seeking the emancipation of oppressed groups through transformations in constitutional discourse and institutional reform (Flyvbjerg, 2000). From this we can derive that Habermas is more aligned with goals of emancipation, where Foucault is more aligned with goals of liberation. For example, the acceptance of 'working within existing systems', denotes Habermas's belief in "constitutions as the main device for uniting citizens and regulating power in a pluralist society" (Flyvbjerg, 2000, p. 4); this reflects a top-down process of emancipation. Whereas 'overthrow of the status quo' implies Foucault's belief in liberation through "resistance, struggle, and conflict, in contrast to consensus" (Flyvbjerg, 2000, p. 11); this reflects a bottom-up process of liberation.

Critical pedagogy, and more specifically the work of Paulo Freire, has contributed to my understanding of *praxis* as a means of reflexive empowerment and a tool for change. In his book, *Pedagogy of the Oppressed*, Freire (1970) discusses the role of critical pedagogy in driving the oppressed to challenge and struggle against the oppression imposed upon them by the oppressors. To Freire (1970), education is used by dominant groups to enforce dominant narratives, legitimise inequities, and to promote their objective reality as one to aspire to. While education can be used as a tool for oppression, Freire (1970) also believes in its use for emancipation. According to Freire (1970), critical pedagogy is centred around the idea of *praxis,* which he defines as "the action and reflection of men and women upon their world in order to transform it" (p. 51).

The process of praxis is thought to help individuals develop what Freire (1970) referred to as *critical consciousness* - or conscientização – which is “learning to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality” (p. 35). As discussed above, false consciousness develops through the sedimentation of oppressive ideologies. To begin peeling the layers of sedimentation away, it is believed that self-reflexive processes will support individuals in developing a critical consciousness, whereby the imposed ideologies and taken-for-granted truths will be challenged and brought into question – a step that must come *a priori* to meaningful action. Dialogue is a key component to facilitating these self-reflexive processes.

In the final sections of this chapter, I will be discussing each of the meso level theories and the micro theories and concepts within them that are relevant to this research.

Critical Gerontology (CG)

Critical gerontology developed out of a need to identify and challenge dominant ideologies of aging that views the aging generation as a burden to society, and that promotes and engages discourses and practices deeply rooted in a biomedical perspective (Baars et al., 2006; Minkler, 1996). Critiques of dominant ideologies in this space have become particularly relevant with the ongoing demographic shift towards an increasingly aged population in many Western countries. Contributing to the production and reproduction of such dialogue are scientific research paradigms that frame aging as a normative process of deficit and decline, and ‘mainstream’ gerontological approaches that have tried to replace the deficit and decline models with positive frameworks of aging (van Dyk, 2014). However, these approaches to aging research often lack a critical perspective. They largely rely on the images and assumptions of aging that are present in popular culture and ignore the fact that *age* is a social construct that is largely influenced by social processes, structures, and history (Baars, 1991; Baars et al., 2006).

To identify and address these gaps in knowledge, a critical gerontological approach works to provide “a more value committed approach to social gerontology – a commitment not just to understand the social construction of ageing but to change it” (Phillipson & Walker, 1987, p. 12). The long-standing and deeply engrained structures within our society have produced and continue to reproduce a number of harmful ideologies with respect to the aging population. As a researcher, I believe taking a value committed approach is a necessary step in moving beyond just talking about the change we wish to see happen, to vowing to actively do my part in helping to dismantle these dominant and misled ways of thinking about aging. As it is beyond the scope of this dissertation to address the vast array of approaches to critical gerontology, I have chosen to highlight two highly cited and interconnected approaches to critical gerontology: the political economy of aging, and the humanistic perspective. These approaches to critical gerontology consist of “a collection of questions, problems and analyses that have been excluded by the established mainstream” (Baars, 1991, p. 220), and both of which were utilized in this research.

Critical gerontology brings into question the power dynamics that exist between individuals and society. The Political Economy of Aging perspective, which is an approach inspired by the works of Marx, is cited as one of the earliest forms of critical gerontology (Polivka, 1998; van Dyk, 2014). As opposed to mainstream gerontology that promotes the individualization of aging, the political economy approach focuses more on aging in structural terms. It explores how political and economic factors shape the aging experience with a focus on social class, but also considers varying contexts such as race and gender (Minkler, 1996). Hendricks and Leedham (1992) describe the political economy approach as involving two components: “investigation of how social location affects patterns of aging, and analysis of the dynamic, ever-changing relationship between the distribution of power and forms of economic organization as various groups strive to attain and maintain measure and control” (p. 127). When applying such an approach to this research, it was the latter component that was of particular importance for examining the socio-political and economic forces that contribute to the segregation of the third and fourth age, which I will describe more in the next section. and the impact of these categories on systems of care and the institutionalization of persons with YOD into LTC homes.

Where the political economy approach critiques the structural and social forces that marginalize and oppress the older population, the humanistic perspective seeks to cultivate an understanding of the ways in which people experience aging within these contexts (Baars & Phillipson, 2013). These approaches reflect Habermas’s notions of the systems and lifeworld discussed earlier. Thus, the goals of the humanistic path to critical gerontology are to understand the experiences of older adults in later life - and the social, political and economic forces that have shaped these experiences - as well as to articulate these understandings in ways that provide alternative discourses to common (mis)conceptions of aging. The humanistic perspective was also pertinent to this research, since as I have mentioned, there is very little research to date that explores the experiences of persons with YOD particularly in relation to the LTC system. Thus, to effectively engage a critical approach, I first had to create a foundation of understanding of the current context.

Together, the humanistic perspective of aging alongside the political economy approach can expose the ways through which macro-system level developments impact social constructions of aging (and identity), as well as how they influence experiences of aging and the care trajectory. In Western industrialized countries in the 1990s, economic concerns pertaining to the aging populations and the cost of pensions and care services resulted in a rise of flexible employment, including the adoption of short-term contracts (Phillipson, 2015). In turn, retirement became a point in life full of risk and insecurity, signaling the demise of the welfare state through a notable shift in the perception of aging from a collective responsibility to an individual responsibility (Martinson & Minkler, 2006; Mitchell et al., 2020; Phillipson, 2015). The emphasis now placed on individual responsibility reinforces modern society's concept of an 'independent and autonomous self'. However, this view has increased inequities among the aging population by creating new divides amongst the aging population into *third age* and *fourth age* categories (Grenier & Phillipson, 2013).

The Development of Third and Fourth Age Categories.

The segregation of the aging population into two distinct categories – the third age and the fourth age – was intended to be a harmless way to distinguish between older adults who are between 65 and 79 (third age) and older adults who are 80+ years of age (fourth age); this was done for purposes such as distinguishing research participant groups, as well as outlining eligibility criteria for support services (Grenier & Phillipson, 2013). However, these sociocultural constructs also signify a distinction between members of society who share similar lifestyles to that of middle-aged individuals (a reinforcement of normative ideals), and individuals who are experiencing chronic impairment (a reinforcement of deficit and decline models of aging) (Grenier & Phillipson, 2013). Both of these constructs are harmful in their own way.

While the development of the third age was intended to be a positive counter-narrative through its focus on the "active, healthy and productive aspects of aging" (Grenier & Phillipson, 2013, p. 57), it has put pressure on individuals to conform with normative ideals, such as those presented in activity theory, as well as in constructs of successful aging and civic engagement. Concepts of activity theory, successful aging, and civic engagement promote slightly different adaptations of normative ideals, which, from my perspective, appear to be driven by the political and economic structures of society. Activity theory denotes that “it is better to be active than to be inactive; to maintain the pattern characteristic of middle age rather than to move to new patterns of old age” (Havighurst et al., 1968, p. 127). This reflects ‘successful aging’ discourses, which promote the engagement of older adults in active, healthy and social lifestyles, while avoiding disease and disability, and maintaining cognitive and physical function (Martinson & Minkler, 2006; Rowe & Kuhn, 1997); a clear reflection of a biomedical model of aging and the assumption that individuals are in control of their physical and cognitive well-being. These positive paradigms of aging may appear innocent, but they pay insufficient regard to the political, economic, and social factors that may impede certain individuals/groups from aging as ‘successfully’ as others (Martinson & Berridge, 2014).

Holstein and Minkler (2003) explained that “normative terms such as successful aging are not neutral; they are laden with comparative, either-or, hierarchically ordered dimensions” (p. 791), either you age successfully by avoiding it or you do not. From a humanistic perspective, the focus placed on active and successful aging raises questions about how value and meaning are shaped by the structural and social systems of society. In addition to the harmful promotion of normative desirable states, the construction of these ideals is driven by political and economic forces that actively seek to exploit the aging population for productive means, often guised in terms of civic engagement. In addition to pressures of ‘contribution’, there are also pressures to consume. Mitchell and colleagues (2020) draw attention to the ever-growing connection between health and the marketplace, a large part of which targets the older adult population with pressures to purchase products and lifestyles that are going to help them look younger, and “ward off the prospect of succumbing to dementia and other chronic diseases” (p. 5).

In addition to the pressure placed on older adults in the third age to conform to the normative standards of the middle-aged generation, there have been a number of negative implications for individuals in the fourth age. For example, Grenier and Phillipson (2013) explained that the distinction between these two age categories has been “criticized for overstating the potential of the ‘third age’, defining illness and impairment as negative, and for pushing the stigmatising aspects of ageing into the ‘fourth age’” (p. 57). The construction of these age categories and paradigms of positive aging have resulted in the binaries that shape the way society comparatively views the third and fourth age: successful aging/bad aging; independent/dependent; active/inactive; healthy/unhealthy; productive/unproductive; agentic/unagenetic; and so on.

As identified above, categories of the third and fourth age have been driven by socio-political and economic desires that have created harmful stigmatizations and expectations relating to one’s age category. For persons with YOD this is even more detrimental, as their identity does not fit yet has been forced into a confusing mixture of these two categories, and also lies in tension with their own notions of self-identity. The system has been clear in letting persons with YOD know that they do not meet the idealized norms of society through the portrayal of ageism. By not meeting the standards of ‘successful aging’, persons with YOD are generalized as belonging to the fourth age of disease and decline because of their diagnosis of dementia. Yet, persons with YOD are diagnosed before the even reach what is chronologically defined as ‘old age’. With service provision also being based on segregations of these categories, persons with YOD are left with no choice but to integrate into the care options largely developed for 'fourth age' populations. These harmful implications were explored throughout this project, and will be discussed and reflected on in Chapter 8 of this dissertation.

Critical Disability Studies (CDS)

CDS emerged in the 1970s through the activist efforts of disabled people[2] (Reaume, 2014). This approach both complements and extends many of the ideas and theories of critical gerontology. At its core - similar to other critical theories - is a focus on societal power relations and the social and political contexts that shape human experience. However, where critical gerontology challenges the social constructions and inequities associated with aging, CDS, "challenges approaches that pathologize physical, mental, cognitive, and sensory difference as being in need of correction, and instead, advocates for both accommodation and equality for disabled people in all areas of life" (Reaume, 2014, p. 1248). In recent years, and as will be discussed in depth in Chapter 2, CDS has become an even more relevant approach in research with persons living with dementia, as dementia is now recognized as a disability in Canada (Dementia Alliance International [DAI], 2016).

A number of non-critical models of disability have emerged, some of which reproduce and reinforce harmful social constructions around disability, and others that aim to dismantle them. For example, the charity model of disability often results in individuals being viewed as "pitiable, tragic victims who should adjust to the world around them" (Reaume, 2014, p. 1248). There is also the biomedical model approach, which contributes to the dehumanization of an

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[2] Critical disability scholars prefer language of 'disabled people' rather than 'people with disabilities' to highlight how people with disabilities do not 'have' disabilities, they are disabled by structural and systemic factors (McColl, 2019).

individual into a condition that requires treatment (Llewellyn & Hogan, 2000). Both of these models of disability tend to view the individual as the entity which needs to be changed, with no question of the alterability of society.

Biomedical and social models of disability have dominated disability discourse over the last 20 years (Aitchison, 2003). Informed by critical theories, the social model of disability, largely rooted in Marxist materialist thought, seeks to explore and change the socio-economic forces that contribute to the social construction of disability, and the exclusion of disabled people in everyday society (Goodley, 2013). Through this foundational work, activists and scholars, led by individuals who identify as disabled people, were able to begin dismantling the structural underpinnings of oppression that excluded disabled persons from mainstream life, and that manipulated biomedical opportunities for profit.

The social model of disability was transformational in shifting biomedical discourses that “placed the disabled person in the role of victim and defined such individuals in terms of their functional limitations” (Gilliard et al., 2005, p. 572), to discourses around the societal and structural limitations that discriminate and exclude. From this perspective, disability is:

> all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. (Oliver, 1996, p. 33).

This shift in responsibility highlights disability as a social creation and has been successful in spurring political activism and the (re)claiming of civil and human rights by disabled people. However, while the social model has been successful in “shifting debates about disability from biomedically dominated agendas to discourses about politics and citizenship” (Hughes &

Paterson, 1997, p. 325), it has created a new challenge through its separation of impairment and disability; a similar outcome to the emancipatory efforts that resulted in the divide between the third and fourth age.

The divide between impairment and disability reflects a divide between the self and the body, providing an opportunity for the biomedical model of disability to obtain the power to define, control and treat disabled people (Aitchison, 2003; Hughes & Paterson, 1997). The Union of the Physically Impaired Against Segregation (UPIAS) defined this distinction as the following:

> Impairment: Lacking part or all of a limb, or having a defective limb, organism or mechanism of the body; Disability: The disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (as cited in Hughes & Paterson, 1997, p. 328)

Thus, while the social model has contributed to the emancipation of disabled people from biomedical discourses, it has ignored the implications of this for discourses of impairment, which remain rooted in biomedical perspectives that view the body as an object devoid of history (Hughes & Paterson, 1997).

Some CDS scholars have recognized this gap and begun to re-focus attention on impairment and the body, by building on the social model in a way that re-socializes impairment, rather than ignores it (Goodley, 2001). To do so, CDS scholars draw on anti-foundationalist perspectives, such as those found in other critical, as well as post* theoretical perspectives, to better articulate the cultural, discursive and relational aspects of impairment (see the section on the social relational model of disability below). More specifically, post-structuralist thought can help explain the role of language in discursively constructing impairment, such that impairment should be viewed as an outcome of cultural and social processes rather than biological deficit (Hughes & Paterson, 1997). Foucault’s work does well to illuminate this through the identification of language and knowledge as means of power that becomes inscribed on the body, and reflected in “their actions and attitudes, their discourses, learning processes, and everyday lives” (Foucault, 1980, p. 39).

The development of disability studies (while by no means a smooth and linear evolution) has become more critical over time, starting in medical model interpretations of disability, to Marxist influenced social models, to now more frequently being recognized as a transdisciplinary space. In relation to CDS, a transdisciplinary space is seen as, “breaking boundaries between disciplines, deconstructing professional/lay distinctions and decolonizing traditional medicalized views of disability with socio-cultural conceptions of disablism” (Goodley, 2013, p. 632). CDS in particular, is viewed as a space through which a range of political, theoretical and practical issues can be thought through, and dominant ableist hegemonies challenged. This theoretical position is viewed as such because the construct of disability is one that “absorbs the fetishized and projected insecurities of the precariously ‘able-bodied’” (Goodley, 2013, p. 634), to the extent that disabled people become *the other*, and *the other* becomes a site through which other marginalized groups converge around tensions with ableist normativity (Goodley, 2013). CDS not only provides a means through which academics and activists can expose and challenge ableist systems of oppression as they pertain to disabled people, it has the potential to shed light on ways through which these systems promote certain values and justify the oppression of other marginalized groups. I will now discuss the social relational model of disability, followed by an explanation about the implications of CDS for this research, and how I fused both of these meso theories to create a comprehensive framework.

The Social Relational Model of Disability.

One such example that seeks to rejuvenate the social model of disability is the social relational perspective, where disability is viewed as a “social relational phenomenon” (Thomas, 2004, p. 23). Thomas (2004) acknowledges that the social model of disability from its roots has always perceived disability in this way, but that over time it has become second thought to the focuses placed on dichotomy between impairment/disability and the affiliated critiques. By reinvigorating the social relational aspects of the social model of disability, the focus can be shifted towards the unequal power dynamics at play between individuals with and without impairment, as well as the systemic and social relationships that generate and fuel these inequities on both a macro and micro societal levels (Thomas, 2004). Thomas (2004) suggested that by understanding disability as the limitations created from the “exercise of the power to exclude” it becomes “possible to avoid being trapped in arguments about whether or not impairment and chronic illness cause restrictions of activity” since the term becomes representative of oppressive social action upon individuals who are constructed as “problematically different” (p. 29). By recognizing the systemic and social relationships that perpetuate inequities, there is also the acknowledgement of the ways through which these factors shape the experiences of disabled people – in the context of this research, persons living with YOD. For example, we once again return to notions of ‘productivity’ and ‘economic contribution’, as individuals with a disability or impairment are labeled as being ‘inferior’ in terms of “labour-power” (Thomas, 2004, p. 30). This perception of disabled people has persisted since the establishment of capitalist industrialization in the 19th century, as even today, people with YOD are either let go from their place of employment due to confusion around changes in performance, or are forced out of employment after diagnosis as the workplace is not able to adapt or support the individual (Draper & Withall, 2015; Greenwood & Smith, 2016). This is only one of many examples that could be provided as to the ways with which the system can shape the experiences of disabled individuals, often unjustly.

CDS embraces a politics of difference that destabilizes idealized norms - or 'sameness' - and instead legitimizes human variation (Jones, 2006). In doing so, differences in communicative ability are recognized and respected, which is of particular importance when engaging with persons living with a dementia.

Fusing Critical Disability Studies with Critical Gerontology

I do not believe I could have approached this research project by using one of these meso theories over the other, and instead find strength in fusing the two. While CDS provided a framework to challenge systems of oppression that impact individuals with various marginalized identities, it did not have the capacity to delve into the interrogation that needed to take place regarding the marginalization and discrimination of persons living with YOD based on their age. The critical gerontological approach created an opportunity to specifically focus on problematizing the ageism experienced by persons with YOD, by exploring the influence of third and fourth age constructions on the perpetuation of harmful discourses, and the discriminatory practices of the LTC system.

Conversely, CDS offers a space through which the social and political nature of disability/aging can be attended to, by drawing on the relational aspects of the social model of disability as highlighted by Thomas (2004). As mentioned earlier, Thomas (2004) broadened the notion of *disability* from the exclusion of disabled people in everyday society, to also using the term to represent *all individuals* who are constructed as “problematically different” (p. 29). In doing so, the focus is placed on the ways through which societal and structural oppression impacts the daily lives of individuals who differ from the idealized norms of society. When conducting research with persons with YOD, this is particularly important as often there is no ‘visible’ sign of disability and so this opens the avenue to explore the ‘invisible’ aspects of disability. Also, with dementia now being recognized as a disability in Canada (as will be discussed in Chapter 2), this research used CDS and relational models to call attention to civil and human rights concerns experienced by persons living with YOD by addressing the ways these rights have been violated.

In addition to the ways through which each of these theoretical approaches ‘fill the gaps’ of the other, the critical nature of such perspectives converges in a number of areas as well. Particularly important to this project are the ways through which these approaches seek to understand and challenge systems of oppression at all levels of society, as well as the socio-political and economic drivers that fuel such injustices. For this research, that meant bringing into question the current values and practices of the LTC system and its affiliate institutions, gaining an understanding of the factors that have contributed to the neglect of younger persons with dementia within this system, and generating knowledge and knew ways of knowing that will resist current practices and call for change and justice. Together CG and CDS can expose and challenge the extrinsic and intrinsic workings of systemic relations, allowing room for new possibilities to be imagined.

A Discussion About Citizenship and Narrative Citizenship

While the theoretical frameworks above have been used to guide this research and inform the analysis process, I felt it was also important to include a discussion on the consideration of the concept of citizenship and it’s unstable nature for ‘others’. This discussion is offered to illuminate the inequities experienced by marginalized groups, such as younger persons with dementia, and to provide insight into how to reconstruct this concept in a more inclusionary way.

Social and structural forces shape macro-level inequities, such as is seen in the lack of social and economic opportunities for persons with dementia, and poor access to appropriate health services (Bartlett & O’Connor, 2007). Such inequities demonstrate the impact of power dynamics on the preferential support and inclusion of particular groups over others. A citizenship lens has been adopted by researchers in CG and CDS to expose the harmful discourses and unfair treatment of marginalized groups, and advocate for the recognition of these individuals as equal, valued, and contributing members of society (Bartlett & O’Connor, 2007). While existing conceptualizations of citizenship provide insight into the interrelationships between the personal and the political, I highlight the ways with which I perceive these approaches as limited, and posit that these conceptualizations can be strengthened by a critical evaluation of what *citizen* really means. In the following paragraphs I unpack a few existing approaches to citizenship, providing some critiques along the way, and then suggest a way to reconstruct citizenship as a more inclusionary construct.

Perceptions of persons with dementia as unagentic has often resulted in dehumanizing treatment and care of this group, leaving these individuals feeling undervalued and stigmatized on the basis of a label (Bartlett & O’Connor, 2007). Since the 1980s, and through the well-known work of Tom Kitwood (1997), the concept of personhood has been highly influential in challenging the marginalization of persons with dementia (Bartlett & O’Connor, 2007). The personhood approach introduced a counter-narrative to the dominant biomedical narrative of deficit and decline, by moving the perception of a person with dementia beyond just their diagnosis to also include historical, interactional and contextual factors that may influence their being. This approach provided a starting point for the development of new discourses, recognition of the importance of the voices of people with dementia being heard, and a foundation on which various models of care have been built (e.g., person-centred and relational caring models). However, the personhood approach has been criticized for lacking a political dimension, and so a move towards a citizenship model of dementia was used to bring to light the unequal status of discriminated groups of people and push for the redistribution of power and opportunity. As such, Bartlett and O’Connor (2007, 2010) proposed the utilization of citizenship to ‘fill the gaps’ in the theorization of personhood in dementia, which beyond being apolitical included: a narrow and individualized lens for understanding the dementia experience, resulting in a lack of research focusing on macro level inequities; and its failure to “explicitly recognize a person with dementia as a social actor, capable of exerting power and influence” (p. 110). To address such gaps, Bartlett and O’Connor (2010) provided the following working definition of social citizenship:

> Social citizenship can be defined 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)

Baldwin (2008) also acknowledged the power a citizenship lens has in fusing the personal and the political in the dementia context, however, his interpretation differed slightly to that put forth by Bartlett and O’Connor (2007). Where Bartlett and O’Connor (2007) perceived personhood and citizenship as separate constructs, Baldwin (2008) believed that the “personal, inter-personal and the institutional/structural are inter-related through the stories we tell and are told about us, whether by individuals or collectivities (such as the Law, businesses and government" (p. 224).

Baldwin (2008) views narrative citizenship as an entanglement of relationships between the personal, inter-personal, and the institutional/structural. These relationships are central to citizenship as they contribute to our understandings of ourselves and the world around us, the level to which we feel we belong and can practice our legal, political, and social rights, and to the formation of collective narratives that either create or limit space to exercise citizenship rights (Baldwin, 2008). Assumptions about persons with dementia being unagentic and lacking personhood inhibits the ability of this group to exercise their narrative agency, particularly within the context of policy making. Baldwin's (2008) perspective is that narrative citizenship can be used as a concept to maximize opportunities for the narrative expression of persons with dementia, thus restoring narrative agency. In institutional and organizational settings this would include "enhanced communication between people living with dementia and staff" and "for the stories of people living with dementia to be heard within the professional hierarchy, contributing to the monitoring, evaluation and development of practice" (Baldwin, 2008, p. 226). Using this perspective, persons with dementia can reposition themselves away from the imposed identity of deficit and decline towards one of citizenship, and exercise power by resisting oppressive practices and seeking out opportunities for community engagement (e.g., joining advocacy and self-help groups or participating in research; see Bartlett, 2014, 2015). The idea of providing opportunities for persons with dementia to enhance their narrative agency, particularly within institutional and organizational settings, is what I connect with most in regard to the concept of narrative citizenship.

In the context of this research, not only are the experiences of persons with YOD largely overlooked in the LTC sector, but there has also been little effort made to include persons with YOD in the evaluation of policies and practices (Beattie et al., 2004; Mayrhofer et al., 2018; Seetharaman & Chaudhury, 2020; Van Rickstal et al., 2019) in a system that is largely focused on the needs of the elderly population, and individuals who are deemed severely impaired or palliative. Therefore, within the LTC system, policy and social rights associated with citizenship are virtually non-existent, leaving the identity and everyday lives of persons with YOD to be surveilled and dictated by the institutional powers that be. To challenge the existing dominant narratives of deficit and decline around dementia, Baldwin (2008) noted the importance of developing counter meta-narratives that show the ways through which persons with dementia make unique contributions to society. For example, Baldwin (2008) suggested that "policy could be based on focusing on the strengths and retained abilities of persons living with dementia" (p. 226). Enhancing the narrative agency of persons with dementia to establish counter-narratives would shift the perception of persons with dementia as 'patients', to the acceptance of persons with dementia as contributing citizens, therefore also shifting policy narratives from exclusionary to inclusionary. This is not as straightforward as it may sound. The battle between the personal and political goes beyond having to advocate for change within institutional and organizational settings. As described earlier, the provision of appropriate services and resources for persons with YOD is lacking and so, in a broader societal sense, opportunities need to be created for persons with dementia to exercise their citizenship rights.

While I value the premises underlying narrative citizenship and see how instrumental this concept could be in changing societal views in a way that values persons with dementia as agentic and contributing members of a community, I have struggled to come to terms with the use of the word citizenship for three principal reasons of which I will summarize here and unpack in the following paragraphs. First, citizenship is founded in hegemonic ideologies that began with the denial of women's rights and their recognition as citizens (Lister, 1997, 1998), and continue to discriminate against marginalized groups through a lack of recognition of these individuals as equal members in society (Bartlett & O'Connor, 2007). Second, citizenship is a product of, and is connected to, the structures that oppress marginalized groups (i.e., socio-cultural; politic-economic). For example, in the aging context, emphasis on 'productive' and 'successful aging' denotes individuals that do not meet these standards as less than, and thus their right to be treated equally in society is stripped away by the societal embrace of ageism (Holstein & Minkler, 2003). Third, citizenship propagates a binary perspective (citizen vs. non-citizen). It seems counterintuitive to try and use a concept to include persons with dementia, when not all persons with dementia in our society are Canadian citizens. Also, despite the provision of the label of 'citizen', many marginalized groups in our society, whether Canadian citizens or not, are denied their rights, perceived as unequal members, and treated as non- or partial- citizens (Bartlett & O'Connor, 2010; Lister, 1997).

These concerns relate to current understandings and connotations associated with the word *citizen.* Where I once believed that it would be impossible to use this concept to create a space for inclusion, I now see opportunities to reconstruct it in a way that strips it of its hegemonic roots and revises it within a foundation of differentiated universalism, whereby a politics of difference is embraced and the status of discriminated groups of people as equal is reinstated. Thus, my critique of Baldwin (2008) is his lack of focus on unpacking the notion of *citizenship* within *narrative citizenship,* resulting in the depiction of citizenship as idealistic when in reality it entails exclusionary connotations through its glorification of embodied and enacted idealized norms. To strengthen narrative citizenship and the premises underpinning it, I look to the feminist literature for guidance with how to reframe this concept within differentiated universalism.

Feminist theory has extensively unpacked the notion of citizenship and evaluated its exclusionary powers (see, for example, Dale & Foster, 1986; Lewis, 1994; Lister, 1997; Mouffe, 1991; Sarvasy, 1992). Similar to the issues I described above, feminist theory explores the ways through which citizenship – both as a status and a practice - has excluded women and other marginalised groups by denying them full citizenship. While there are many different perspectives and theorized meanings of citizenship, there are often tensions between inclusionary and exclusionary components driven by varying social, political, and economic factors. Ruth Lister's (1997) solution to ease these tensions was to re-establish citizenship within the notion of *differentiated universalism,* which is based on belief in the "universality of moral commitment to the equal worth and participation of *all*" (p. 39, italics added). Differentiated universalism is a complex yet comprehensive approach to citizenship. In the following paragraphs I will outline how Ruth Lister (1997, 1998) synthesized a variety of approaches to citizenship to form this framework for inclusion.

The establishment of the concept of citizenship is culturally and historically specific to the place in question; however, in the Western world, this concept was born in the revolutionary overthrow of the feudal system[3], from which the idea of "political order established through social contract" (Glenn, 2000, p. 2) was emplaced. This shift not only represented the birth of citizenship but also of capitalism, and although this shift claimed, "free and equal status", it still very much fostered social and economic divide. Historically, there have been two main

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[3] Feudal system meaning a "society organized as a hierarchy of status, expressed by differential legal and customary rights" (Glenn, 2000, p. 2).

approaches to citizenship since its establishment in the eighteenth century: liberalism, which focuses on citizenship rights (status), and civic republicanism, which focuses on political obligation (practice) (Lister, 1997). Within the feminist literature, both approaches are seen as having advantages and disadvantages as theories of citizenship. The former is thought to support the autonomy of individuals, while also recognizing the social dimension of autonomy, and is valued for its role in protecting human needs and mitigating economic and social inequities. On the other hand, feminist theories have also exposed liberalism as an expression of male values and power, and have highlighted "the failure of citizenship rights vested in liberal democratic institutions to meet the needs of women and racialized groups and the socially and economically marginalised" (Taylor, 1989, p. 29 *as cited in* Lister, 1997, p. 30). The perspective of 'liberal citizenship' largely stems from the work of Karl Marx, who brought to light that democratic rights were not equal, and were used as a means through which to deepen economic and class division in favour of the bourgeois (i.e., 'upper class' citizens). Recognizing this Marx worked to expose that "democratic citizenship was a bourgeois concept that obscured economic and class division beneath a veneer of equality" (Glenn, 2000, p. 2).

I see civic republicanism as highly connected to what was discussed in the above section on CG, where there is a clear emphasis placed on "the market-oriented conceptualization of social citizenship rights" (Lister, 1997, p. 31), demonstrated by a focus on citizenship obligations, particularly engagement in paid employment (Lister, 1997). The support for this perspective comes from the value placed on civic duty and "the submission of individual interest to that of the common good and the elevation of the public sphere in which the citizen is constituted as a political actor" (Lister, 1997, p. 32). The aspect of this approach that is supported by some feminist writers is the belief in the active and participatory engagement of citizens in the public world, as a means through which action can be taken to create an inclusionary space for political participation (Lister, 1997). However, feminist writers have noted that the demanding nature of republican citizenship produces implications such as the unfair and clearly gendered division of labour and time, a distinct separation of public and private spheres (marginalized groups being particularly suppressed in the former), and uncritical acceptance of notions of universality, impartiality and the common good (Lister, 1997). This perspective argues that citizenship originated in opposition to women and was heavily connected to masculinity, since the public-private divide in society represents on one hand the “public realm of politics, rights, and generality” (Glenn, 2000, p. 2) where men were predominantly ‘visible’, and on the other hand the private sphere which represented “activities of daily maintenance, emotion, and specificity” (Glenn, 2000, p. 2) from within which women were confined.

In addition to the use of citizenship to perpetuate the societal status of wealthy men, race was also an important factor, and as such citizenship was more specifically a means through which to perpetuate the class divide and bourgeois status of *white, wealthy, men.* Glenn (2000) explained that “since the early republic, the idea of *whiteness* has been closely tied to notions of independence and self-control necessary to republican government” (p. 2, emphasis added), a perception that only continued to grow over the colonization and takeovers of many non-western societies. Similar to what is sadly still present today, citizenship represented the normative ideals of society, and perceived ‘others’ as dependent and lacking the capacity for self-governance (Glenn, 2000). What I feel is an important observation by Glenn (2000) is that “despite the bourgeois, masculinist, and white trappings of American citizenship, the very groups that have been excluded have often been among the most eloquent proponents of the *ideal* of citizenship” p. 2), which is demonstrated through various social justice movements that demand equal rights for all (i.e., the disability rights movement; Black Lives Matter movement). Despite the injustices experienced by so many groups, it is the push for equality by collectives of ‘others’ who demand change and create hope. It is within this space that Lister (1997) has highlighted the “emancipatory potential” (p. 39) of universal citizenship that does not just recognize, but also values difference.

Despite these different perspectives on citizenship, Lister (1998) highlighted an important underlying commonality; while citizenship poses universalist claims, “its denial of difference has served to exclude those who do not fit its universalist template, most notably women” (p. 71), otherwise known as false universalism(s). Recognizing this as a key limitation of the two main citizenship traditions, feminist writers suggested a shift in the conceptualization of citizenship that focuses on building on the respective strengths of each by pushing towards free and equal rights from the liberal left, and integrating reconceptualized notions of active political participation, civic engagement and the ‘common good’ (Mouffe, 1991; Lister, 1997; Sarvasy, 1992). This shifts the underlying commonality of exclusion and false universalism, to one that embraces the notion of human agency; citizenship as rights enables people to act as agents where rights are seen as fluid not fixed, and citizenship as participation reflects an expression of human agency in reconceptualized political space (a now dialectical relational space between public and private spheres).

In the context of this research working with younger persons with dementia, this meant bringing attention to the notions of agency discussed earlier, as well as engaging methods that encouraged co-researchers’ self-expression, in turn supporting the reclamation of their citizenship. One example that was used to inform this process was provided by Dupuis and colleagues (2016b), who utilized Baldwin’s (2008) notions of narrative citizenship and narrative agency by working with persons with dementia (and other participant groups) to challenge the tragedy discourse of dementia through the use of critical arts-based approaches. Through processes of coming together and critical reflection, the group was able to collaboratively produce a number of visual and poetic representations that challenged the dominant assumptions of the tragedy discourse. I see this as a strong representation of what can happen when the power of difference is embraced. In this case, Dupuis et al. (2016b) used the arts as a means through which to unite oppressed individuals in a dialectical relational space that ignited the power of agentic realization and denied the imposition of the societal pressures for persons with dementia to accept their ‘status’ as ‘passive victims’.

There are three attributes of differentiated universalism that I feel are important to citizenship in the context of this research. Firstly, citizenship is perceived as a dynamic construct, where process and outcome are in an ongoing dialectical relationship driven by human agency. Within this dialectic, there is a commitment to dialogue and the opening of communicative spaces from which different viewpoints can be raised, and deliberation between citizens can occur (Lister, 1998). For this project, this meant a commitment to supporting all communicative capacities to the extent possible to create a more comprehensive understanding of the stories and experiences shared. Secondly, differentiated universalism strives for a politics of difference that recognizes and embraces the importance of difference in democratic political processes, and views rights as “dialectical and relational in respect of opening debate and discussion about how to positively alter relationships of oppression” (Lister, 1997, p. 40). For this research, such a statement highlights the importance of the responsibility to not only generate an understanding of the systemic oppression experienced by persons living with YOD, but to also demonstrate the ways through which the knowledge produced is able to link and support the interest of other movements. Lastly, human rights can be perceived as a tiered and interacting relationship between the universal and the particular, such that paying attention to difference and the needs of varying groups embraces universalistic values of equity and justice[4]. In this sense, the tensions between universalism and diversity are viewed as an opportunity to address the exclusionary tendencies of citizenship, by integrating the universal and particular in a way that allows the prior to become contingent upon attention to difference (Lister, 1998). I perceive this to mean that although it is important to understand and contribute to the dismantling of oppression impacting various marginalized groups on a broader level, it is equally as important to pay attention to the different experiences of said groups in order to better attend to the unique ways with which systemic oppression is imposed. In the context of this research this meant exploring the specific ways through which persons living with YOD are marginalized and discriminated against in life and the LTC system, while also acknowledging the unique individual experience of each co-researcher.

Although perhaps a long-winded argument, I feel it was important to illustrate why citizenship has been a contested construct, and to demonstrate the ways through which it can be reconstructed as an inclusionary and emancipatory concept. The rights of persons with dementia have long been overlooked, their citizenship denied, and their voices unheard. When exploring Bartlett and O'Connor's (2007) conceptualization of citizenship, I agree with Baldwin's (2008) critique that it lacks a relational understanding of power dynamics. Also, while I understand the contributions that the notion of personhood has on challenging harmful discourses and informing more humane care practices, it still remains a concept that undermines the agentic ability of the

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[4] For example: The disability rights movement and the recognition of disability as a different social and political category, bringing awareness to the needs of a group that was previously overlooked in a system that catered to the masses.

individual. So, where Bartlett and O'Connor still very much embrace the recognition of personhood, I prefer to engage notions of embodied selfhood[5] to highlight that agency does not just exist in assumed ways, but that it also manifests and acts corporeally. I also align with the idea of relational subjectivity and relational citizenship that are described by Baldwin (2008), and Dupuis et al. (2016b), as the inclusion of a relational component speaks to the ways through which all aspects of being in the world are connected (i.e., the personal, inter-personal and the institutional/structural), as well as the importance of relationships in accessing shared experiences and mutual support.

As described in the paragraphs above, there are many aspects of Baldwin's (2008) conceptualization of narrative citizenship that I align with, and that informed and supported the processes in this research. As discussed, the one concern I had was not with the premises behind his ideas, but with the lack of critical reflection on citizenship itself. So, where Baldwin (2008) recognized the marginalization and oppression of persons with dementia in various structures and systems, and recognized their exclusion as valued members of the community and broader society, he did not speak to the historically rooted hegemonic traditions of citizenship, which in my opinion, ignores the false universalisms of this construct. Also, by not operationalizing what he perceives 'citizenship' to mean, how is one to understand what the reclaiming of citizenship means? What are we reclaiming? That is why I turned to differentiated universalism and the feminist literature, to shed light on the historical roots of citizenship, but also to develop a more hopeful perception of what the reconstruction and future of citizenship looks like – the embracement of difference. As such, I argue that restoring citizenship is not enough, and that

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[5] Embodied selfhood is a concept used to describe the notion that "fundamental aspects of selfhood are manifested in the way the body moves and behaves" (Kontos, 2005, p. 556)

prior to doing so it must first be redefined within a framework of inclusion (differentiated universalism).

Returning to the Purpose and Research Questions

To reiterate, the purposes of this study were to: 1) illuminate how younger persons with dementia story their experiences of YOD and with the LTC system; 2) open spaces for persons living with YOD to collectively reflect on their experiences and engage in dialogic processes; and 3) develop a collaborative and synergistic narrative representation that illuminates paths for positive change in dementia care. By attending to these purposes, this project aimed to achieve two key objectives: 1) to expose and deepen societal understandings of the inequities experienced by persons with YOD, particularly in the LTC system; and 2) to collaboratively find innovative ways to share the collective narratives derived from this study in a way that resists current care practices, calls for change, and envisions a new way forward.

To address these purposes and objectives, the research questions provided below depict the guideline that was used to initiate discussions with persons living with YOD that provide an understanding of the current experiences of persons living with YOD, as well as their hopes and aspirations for the future. However, as this research is very much focused on creating an opportunity for persons with YOD to share their stories in the ways they desired to share them, including what they wanted to focus on, it must be noted that these questions were always in flux so as to prioritize what was most meaningful to the people living with YOD who agreed to participate in this research.

This research set out to explore the following questions:

1) What stories do persons with YOD share about their experiences of YOD and with the LTC system?
    a. How do they envision their care changing over time?
    b. What place, if any, do LTC homes play in their stories of care?
    c. What do these stories tell us about how stigma (stereotypes, prejudice, discriminatory practices) is experienced by persons with YOD in life and in LTC and contribute to the normalisation of inequitable and unjust treatment of persons with YOD?
2) What do persons with YOD need to live well that needs to be considered in a re-imagination of caring for persons with YOD?
    a. What does a re-imagined approach to caring for people with YOD look like from the perspectives of people with YOD?
    b. What do the stories shared tell us about the action that needs to be taken to re-design the system?
    c. What ways can policy makers, healthcare professionals, organizations, and researchers contribute to putting the changes suggested into motion?

In Chapter 2, the literature review, I delve more deeply into some of the key concepts of this research as a first step towards illuminating, challenging, and informing the systemic and societal transformations that are needed to better support persons living with YOD. I begin by providing a brief historical overview of the LTC system and the perpetuation of the biomedical model, and then delve into understanding YOD and YOD support services within the Canadian context. I close the chapter with a discussion about the ways the current system fails to recognize and embrace the unique differences of younger persons with dementia, thus contributing to the marginalization and exclusion of individuals in LTC.

Chapter 2: Literature Review

This section will begin by providing an historical overview of the LTC system from its initial roots until present day, including a discussion on the biomedical model and how it has influenced the practices and discourses within the institutions of healthcare and society more broadly. From here I will explore what we know about YOD specifically within the Canadian context and unpack the longstanding debate regarding the classification of dementia as a disability. In the remaining sections of this chapter, I fuse existing knowledge about the LTC sector and the impact of stigma and dominant discourses on persons with dementia and YOD, to provide insight into the ways through which the LTC system may unintentionally perpetuate the marginalization of persons with YOD. These discussions are intended to: demonstrate the development of LTC into a facility that currently reflects a focus on the provision of care to *older* persons with dementia, who are labelled as having high levels of cognitive impairment; demonstrate the unique differences that persons with YOD often experience; and illuminate that little research has been conducted to explore YOD (and the experiences of persons with YOD) within the LTC context.

A Brief History[6] of the LTC System in Canada

During British rule, institutionalization within Canada had two distinctive trajectories based on geographic location. In Lower Canada, the initial connection between the Canadian government and institutionalization occurred in 1801, when provincial legislature allocated a fixed amount of money per year to the philanthropic groups that had been caring for persons in

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[6] The language used in the history portion of this chapter reflects that which was used at the time, and thus does not reflect what is currently viewed as appropriate terminology (e.g., aged/elderly as opposed to older adults). Additionally, 'long-term care home' is used interchangeably with 'homes for the aged' and 'institutionalization'.

need (Forbes et al., 1987). Despite this new allocation of resources, the government did not try to impose any regulations or standards at that time. It was not until 1823 when a group of commissioners were appointed to document the expenditure of the funding provided, which introduced a limited but present influence of the government over these philanthropic groups.

Whereas in Upper Canada, it was not philanthropic groups but rather municipal councils that held primary responsibility over individuals in need (Forbes et al., 1987). As there was little tolerance for people who - at the time – were deemed destitute, it was difficult to obtain welfare, and required a thorough evaluation by the municipal council on the individual’s current and potential worth. Individuals who qualified for welfare were auctioned off to families who were looking for extra help in their home; whereas individuals who were deemed as sick or not physically/mentally able were often placed in the local jail. This continued until 1830 when the growth of urban areas led to a higher number of individuals who were in need of welfare support. In an effort to acknowledge this need, “the government of Upper Canada passed legislation which permitted the building and maintenance of a house of industry in the province at public expense” (Forbes et al., 1987, p. 6). Admission to the house of industry was socially looked down upon, and was largely comprised of individuals who were considered elderly, disabled, poor or unemployed.

Despite the segregated beginnings of Upper and Lower Canada, the histories of both converged as the need for support systems increased nationwide. The following years between 1867 and 1870 saw a vast increase in unemployment and poverty, forcing government and legislation to develop more “houses of refuge” (Forbes et al., 1987, p. 8). However, this need was met with reluctance from the public. Consequently, in 1980, provincial legislation began providing grants to counties to assist in land purchase and construction for these homes.

Additionally, these grants covered the inspections of these houses by the “provincial Inspector of Prisons and Public Charities” (Forbes et al., 1987, p. 7). At this point within the history of institutionalization in Canada, the elderly shared these spaces with other excluded groups, such as the disabled; however, elderly individuals who were deemed ‘senile’, the common term for people with cognitive or mental challenges at the time, were sent to the ‘insane asylum’ (Forbes et al., 1987).

In the early 1900’s, LTC facilities for the elderly slowly began to develop (Forbes et al., 1987). Some of the earliest established facilities were built in the 1920s in Saskatchewan, which included a combination of both independent living and, on a smaller scale, nursing care. As the number of LTC facilities grew, the Ontario Association of Managers of Homes for the Aged and Infirm was established in the mid-1920s, with the intention to share information between facilities since uniform regulations were not yet established. However, little effort was made to access and use this information.

Expansion of LTC facilities increased greatly at the end of the Second World War in 1945, which led to the development of provincial insurance plans, and subsequently the establishment of the Hospital Insurance and Diagnostic Services Act by the federal government to assist provinces in the funding of said insurance programs (Forbes et al., 1987). By 1964 each province had homes for the aged, with Ontario requiring (through legislation) that each municipality had government assistance to subsidize half of the construction and operating costs (Forbes et al., 1987). The continued rapid expansion of these facilities through the mid-to-late 1900s was further perpetuated by the deinstitutionalization of ‘insane asylums’, which resulted in an increase in the number of elderly persons entering nursing homes. As such, the provincial and federal governments began to build more structure into the LTC system, including the expansion of financial assistance to further support programs and facilities for the aged. This also included provincial-specific Acts that established rules, regulations, and adjustments to terminology (e.g., ‘inmate’ became ‘resident’; Forbes et al., 1987). It was also in this time period that the Ontario Hospital Association (1980) provided a definition of institutional care, which was defined as care:

> … provided on a sustained and prolonged basis to meet the physical, social and personal needs of individuals whose functional capacities are chronically impaired to at risk of impairment. It implies a team approach which utilizes the skills of physicians, nurses, social workers, behavioural scientists, physical therapists, nutritionists and others in an effort to treat social-psychological as well as physical disabilities.” (as cited in Forbes et al., 1987, p. 1)

Within this brief historical overview of institutionalization in Canada from the early 1800s to late 1900s, a couple of key trends can be noted. First, in its early history, institutionalization was seen as a place with which society could admit individuals with whom it did not wish to ‘deal with’, including people who were poor, sick, elderly, and impaired. Individuals who were deemed not mentally well were further segregated into ‘insane asylums’. However, throughout the years, and with the deinstitutionalization of mental hospitals, the focus of LTC facilities shifted to caring for elderly both with and without nursing needs. The second major trend to note is the gradually increasing control of the government over these facilities, which was facilitated by increased funding and reflected through the establishment of rules and regulations.

These trends have continued into the 21st century. Up until 2010, a large proportion of residents had varying needs ranging from low to high (Ontario Long-Term Care Association

(OLTCA), 2014). However, in 2011, major changes occurred as the oldest of the baby-boomer generation turned 65, triggering a shift in LTC home demographics to elderly individuals who often required 24-hour support (OLTCA, 2014; Statistics Canada, 2018). At this time the 2011 "Census of Population counted nearly 5 million (4,945,000) seniors aged 65 and over in Canada" from which it was estimated that 8% lived in "collective dwellings" (Statistics Canada, 2012, p. 1). Of this eight percent, it was estimated that 4.5%, or 224,280 people over the age of 65 resided within LTC homes, chronic care, and hospitals.

As the concept of 'aging in place' also began to grow in popularity, LTC homes were deemed a place for the older adults who required around-the-clock extensive assistance (ASC, 2016; OLTCA, 2018). Thus, the level of care required by residents has increased significantly over the years. According to OLTCA (2018), "85% of long-term care residents need extensive or complete help with daily activities, compared to 77% just five years ago" (p. 2). While the age demographics of the LTC population within Canada were hard to find, a report based out of the United States (published by Georgetown University Press, 2003) estimated that 63% of residents were 65 or older, with the remaining 37% being under the age of 65 (as cited by the FCA, 2015). To put this in perspective, with regards to increased government control, all LTC facilities within Canada are now governed by provincial and federal regulations, yet there remain discrepancies in the standards of care within and between various publicly and privately run homes (Ontario Health Coalition, 2012).

Over the years more, 'recent' definitions/descriptions of LTC homes were offered, and include:

> In general, long-term care facilities provide living accommodation for people who require on-site delivery of 24 hour, 7 days a week supervised care, including professional health services, personal care and services such as meals, laundry and housekeeping. (Government of Canada, 2004)

> Provid[ing] care and services for people who no longer are able to live independently or who require onsite nursing care, 24-hour supervision or personal support. LTC Homes are governed under the Long Term Care Homes Act (LTCHA) and Ontario Regulation 79/10, the single legislative authority for safeguarding resident rights, improving the quality of care and improving the accountability of LTC Homes for the care, treatment and well-being of residents. (Ontario Ministry of Health and Long-Term Care, 2008)

> Nursing homes [long-term care homes] serve seniors and others who do not need to be in a hospital but who do need access to 24-hour nursing care not generally available in home care programs or retirement homes. (Canadian Institute for Health Information (CIHI), 2014)

Despite changes in LTC, particularly over the last 20 years, these definitions of LTC homes have not changed much since 1987, with the exception of a new emphasis on government regulation of these facilities. There are four primary concerns I have with the definitions provided above. To begin, I would like to point out that the first two definitions are provided on official government websites yet have not been updated in 16 years and 12 years respectively. I find this troubling as the definitions portray LTC homes as a consumer product where the emphasis is placed on the system and services provided rather than the person. This is despite the extensive research conducted since the time that these definitions were established, which has pushed for culture change through the development of new discourses and understandings of the LTC system, dementia, and dementia care settings (Dupuis et al., 2016a; Kitwood, 1995; Kontos et al., 2020; Mitchell et al., 2013).

Secondly, these definitions denote notions of dependence, lack of autonomy, and *power over*, through the use of language such as “requiring supervision” and “no longer able to live independently” This language is problematic as it perceives residents as unagentic, dependent beings, ideas which perpetuate dehumanizing discourses and practices in the dementia context. Again, it is puzzling that definitions of LTC in the Canadian context, and more specifically within Ontario, do not align with or reflect current movements that are pushing for social and systemic reform.

Thirdly, and connected to the perpetuation of dehumanizing discourses and practices, is the focus of these definitions on the medical aspects of care (i.e., ‘nursing care’ or ‘supervised care’), and activities of daily living. This reflects the systemic priority of ‘managing the body’ and ‘improving functionality’, instead of focusing on supporting individuals in living their life to the fullest or enhancing the social, spiritual, and emotional aspects of well-being – supporting people to thrive (Dupuis et al., 2012, 2012c; Mitchell et al., 2020).

Lastly, despite my concerns with the definitions themselves, this research will demonstrate that persons living with YOD often do not align with what LTC homes portray they are for, which is 24/7 care and supervision for individuals with extensive needs, more than half of whom are over the age of 85 (Oyebode, 2015). With many of the residents in LTC homes being older in age, recreation and leisure activities are tailored to suit the majority’s interests and needs, contributing to social disengagement and isolation of persons with YOD (Mulders et al., 2014).

As the oldest of the baby-boomer generation was turning 65, the ‘ageing in place’ movement was gaining in popularity as a more humanistic alternative to LTC placement, through its focus on supporting older adults to remain in their homes and communities for as long as possible by improving access to community-based support services. For many groups such as older adults, care partners, families, and policy makers, it was not just the humanistic aspect of this movement that was appealing, it was also motivated by the belief that community care is less expensive to use (as a consumer) and to facilitate (as a policy maker) (Forbes et al., 1987; Vasunilashorn et al., 2012).

Initially, ‘ageing in place’ primarily explored the use of “community housing, congregate housing, and boarding homes” and later evolved to include “services and technology as important contributors to an older adult’s ability to remain in [their] home” (Vasunilashorn et al., 2012, p. 2). Despite the good intentions driving the ‘ageing in place’ movement, there still remains many barriers for individuals who are seeking alternatives to institutional care, including factors such as “limited funding for programs that provide home modifications, service delivery issues, consumer awareness and training issues, and poor communication among government agencies that address health, housing, and services for older adults and people with disabilities” (Vasunilashorn et al., 2012, p. 5). So, what has been derived from this movement is that LTC homes are now in large part “an option of last resort” (Vasunilashorn et al., 2012, p. 1) for individuals who require extensive support, and ‘aging in place’ and community-based care although initiated around 2011, are still very much in their infancy with many ‘kinks’ left to sort out. This leaves the LTC system as a whole leaving many individuals inadequately supported, indicating a serious need for systemic reform. Reports throughout the pandemic have made it all too clear the consequences of a LTC system ill-equipped to protect and care for societies' oldest and most vulnerable citizens.

Biomedical Dogmatism

Developing adjunctly to the growing LTC sector has been the model of care predominantly used to guide it – the biomedical model. Prior to delving into the history and limitations of such a model, I would like to recognize that this field has made contributions and advancements in knowledge, medicine and technology that have been beneficial within healthcare and society more broadly. However, the place and dominance of this model in LTC homes has been critiqued for decades (see, for example, Ducak et al., 2018; Dupuis et al., 2012a; Kitwood, 1997; Mitchell et al., 2020; Nolan et al., 2008).

The early beginnings of biomedicine dates back to 16th century Europe, a time where the process of rationalization was on the rise (Hewa & Hetherington, 1995). Major tenets of rational thought include calculability, predictability, and control, all of which were swiftly adopted by Western medicine and the perception of the human body as 'mechanistic'. Prior to a shift towards a process of rationalization, knowledge was very much rooted in traditional, spiritual and moral values that stemmed from the teachings of the Roman Catholic Church (Hewa & Hetherington, 1995). This continued until the 16th century Reformation when the authority of the Church and concerns about its corruption were met with resistance by reformers across Europe (Hewa & Hetherington, 1995). From this, "[n]ew ways of thinking promulgated by the new religious movement encouraged the individual to seek rational and logical interpretations of the world" (Hewa & Hetherington, 1995, p. 130), or what Max Weber (1958) identified as the beginning of instrumental rational thought (also known as a form of technological rationality).

Such a paradigm shift meant the departure of knowledge as solely rooted in religious, moral and spiritual beliefs, to the domination of rationalization of which empirical observations, predictability and calculability were the cornerstones. Max Weber (1958) held a fatalistic perspective of rationalization for humankind, as he believed that this process "undermined the traditional moral and spiritual values in society" leading to the "alienation of the human spirit from the scientific and rational world" (Hewa & Hetherington, 1995, p. 131). The rise of this new scientific and rational way of thinking was only further perpetuated by the social and economic benefits that accompanied it, jeopardizing the survival of humanity across a range of disciplines that were adopting this line of thought.

It was throughout the 17th century when a number of medical discoveries contributed to the sedimentation of rational thought in medicine, and the birth of the biomedical model. Cartesian dualism – the belief in the separation of the mind from the body, the subject from the object (Crotty, 1998) – became a prominent way of viewing the human body and making it analogous to a machine. Illness then became seen as "a result of the failure of mechanical functions of various parts of the human body" and that the body "can be manipulated and cured either by introducing chemical compounds into the mechanical system of the body, or by replacing and repairing parts" (Hewa & Hetherington, 1995, p. 133). Such a perspective provided a way to mask the psychological, cultural, and social dimensions of human existence, which became not only dehumanizing for the 'patient' but also for healthcare provider. Guided by the biomedical model, throughout their medical training, students were often taught that they must remain emotionally detached from their 'patients' and should not engage with any social or emotional aspects of care, removing the humanness of care from the practice of caring (Hewa & Hetherington, 1995).

As the biomedical model became more and more engrained in medical practice, a number of concerns surfaced, of which I have selected three that I find particularly problematic. Firstly, the biomedical approach is heavily reductionistic by only allowing for illness and disease to be diagnosed and treated based on biological criteria, therefore neglecting the subjective experiences of the individual, as well as the possibility of other contributing factors (e.g., psychosocial, economic, and cultural factors) (Beard et al., 2009; Dupuis et al., 2012a; Grigorovich & Kontos, 2016; Mitchell et al., 2020). Secondly, and as mentioned above, are the dehumanizing practices associated with medical treatment, both for the healthcare provider and 'patient' (Brannelly, 2011; Mitchell et al., 2020); interaction between the two was solely used for the purpose of obtaining technical information to contribute to diagnosis and treatment. Lastly, the biomedical model has become prevalent within all facets of the healthcare system and its institutions, leading to "unnecessary hospitalization, overuse of drugs, excessive surgery, and inappropriate utilization of diagnostic tests" (Engel, 1977, p. 134). Particularly in the dementia context, the inappropriate use of 'diagnostic tests' or merely connecting behaviours with psychiatric disorders, leads to an often 'quick and easy' reliance on psychotropic medications, when really 'behaviours' are likely individuals' responses to social or environmental factors or trying to communicate unmet needs (Dupuis et al., 2012a; Volicer & Hurley, 2003). In LTC homes specifically, the biomedical model has perpetuated a 'therapy culture' whereby persons with dementia are "subjected to multiple assessments by various professionals who populate a list of needs and functional deficits and assign interventions, therapies and modifications to meet them" (Mitchell et al., 2020, p. 3). This inhibits persons from dementia in participating in decisions around their care or being able to engage in meaningful activities, as even leisure activities are morphed into ‘therapeutic interventions’ to achieve “medicalised outcomes” (Mitchell et al., 2020, p. 3).

Despite these concerns, the biomedical model persisted and continues to persist in present day, a blind faithfulness from society which Engel (1977) has deemed as biomedical dogmatism. So how has the biomedical model continued to dominate despite the apparent downfalls of such an approach? While there are many possible factors, there are three key areas that I would like to discuss. To begin, the legitimation of the medical profession occurred alongside the prevalence of the biomedical model, which was established and reinforced by ongoing discoveries that proved the mechanistic model of the human body to be effective (Hewa & Hetherington, 1995). Unfortunately, with a lack of attention given to the possible role of other contributing factors (e.g., psychological, social, and economic factors), society was reluctant to see these components as viable sources of information because at the time there was no proven method to predict, calculate and measure them (Hewa & Hetherington, 1995). As such, the biomedical model has remained central to the professional dominance of the field, and alternative approaches that could improve healthcare have been overlooked and overshadowed in an effort to protect the social and economic power of medical institutions and the status of those who govern them (Engel, 1977).

Despite introductions to alternative approaches to care, such as the personhood and relational approaches, biomedical discourses continue to perpetuate assumptions of persons with dementia as lacking the capacity to actively participate in decisions about their care (Dupuis et al., 2012b). In response to alternative models of care struggling to break through the bounds of the biomedical model, for example, Dupuis and colleagues (2012b) developed the authentic partnerships approach, which views “persons with dementia as equal partners in dementia care, support and formal services” (p. 429). Such an approach is important in equally valuing the perspectives and expertise of all parties involved in the caring process, including persons with dementia. However, while this approach has begun the process of penetrating through biomedical model discourses of practitioner as ‘expert’ by engaging culture change processes, the biomedical model is so deeply sedimented that any major shifts in thinking or changes in practice will take time. So, although new approaches are igniting culture change processes, once something has become so deeply engrained in society to the point it has achieved a status of dogma, it is difficult to achieve a shift towards other approaches as will be touched on in the paragraphs below.

The last aspect I want to touch on is the power of social, political, and economic influence on the maintenance of the biomedical model. The delivery of health care is a major industry, totalling 11.6% of Canada’s gross domestic product (CIHI, 2019). Engel (1977) noted the “enormous existing and planned investment in diagnostic and therapeutic technology alone strongly favors approaches to clinical study and care of patients that emphasis the impersonal and mechanical” (p. 328), making it difficult for alternative approaches to be adopted let alone acknowledged. As such, the perseverance of social power was of paramount importance and so the industry curbed reform efforts that explored alternative approaches. With reference to the politics of health in the 18th century, Foucault (1980) echoed the use of the industry for economic gain and social control but stating that the “biological traits of a population become relevant factors for economic management, and it becomes necessary to organise around them an apparatus which will ensure not only their subjection but the constant increase of their utility” (p. 172). This reflects the power associated with dehumanizing the body into a mechanistic device, as it then becomes possible for the industry to gain governance and control over the body, and determine its fate based off of systematic calculations of its utilization for profit.

Along with Weber's (1958) fatalistic perspective of the biomedical model, I have also highlighted a number of 'doom and gloom' opinions. That being said, while the biomedical model and its assumptions are still very much prevalent in the healthcare system today, there have been some shifts most notably beginning around the mid-20th century. Weber (1958) placed a focus on technical rationality, yet in doing so he overlooked practical rationality which includes "moral, ethical, and cultural progress (value rational) of society that often competes with technical rationality in economic and political spheres" (Hewa & Hetherington, 1995, p. 132). It is thought that in order to address the limitations of the biomedical model, that both these approaches to rationality must work in tandem and be incorporated with cultural progress (Hewa & Hetherington, 1995). Others, like Thomas Kuhn (1962, 1970), believed that "revolutionary social changes occur when the dominant social paradigms can no longer provide satisfactory solutions to emerging problems" (Hewa & Hetherington, 1995, p. 135), causing a paradigm shift. Engel (1977, 1981) was one of the first individuals to introduce an alternative model of care – the biopsychosocial model – which was an approach that moved beyond a person's biological attributes to also look at the integration of other possible factors such as psychological and social attributes (Guillemin & Barnard, 2015). I believe it was the introduction of this model that begun to trigger the further critique of the biomedical model and created an opportunity for alternative approaches to be acknowledged and explored. Hewa and Hetherington (1995) noted this as a beginning moment of a paradigm shift, which they believed would occur not as a singular event but instead would reflect ongoing changes in society more broadly. These changes continued to occur, as in addition to Engel's (1981) biopsychosocial model of care, there were a number of other approaches that were beginning to pick up momentum in the mid-late 20th century, including person-centred care, relational approaches, and the social model of disability (touched upon in Chapter 1).

This history and explanation on the development of the biomedical model and the dogma status it has obtained has highlighted a number of ways from which this approach is harmful and still present today. From the acceptance of Cartesian dualism, the body became a dehumanized entity that the medical industry and those who practiced within could ‘manipulate’, ‘control’, and ‘fix’ to bring it back to ‘normal functioning condition’ in an effort to maximize political, social and economic gain. As discussed, these harmful practices and the associated biomedical discourses have become a central component in Western healthcare and provide a clear indication of the ageism that exists within our society. I feel this is a timely place to share the WHO’s definition of ageism to set the stage for the following discussions on the unequal treatment of older adults. The WHO (2020) defined ageism as “the stereotyping, prejudice, and discrimination against people on the basis of their age”, which is reflected in older adults being “overlooked for employment, restricted from social services and stereotyped in the media”. For persons with dementia, the stigma associated with biomedical ideologies and discourses has perpetuated a number of ageist assumptions around disease and disability, deficit and decline, that have become manifested within institutions such as LTC homes and hospitals, but also in society more broadly.

The biomedical model is heavily called upon in the LTC context, perpetuating stigmas and harmful consequences for persons with dementia. As discussed in Chapter 1, the biomedical model is one that favours Cartesian Dualism – the separation of the mind from the body and “position[ing] the former as superior to the latter” (Kontos, 2004, p. 829). Such a perspective views the body as passive and unagentic, claiming it as a machine that can be controlled and manipulated by medical intervention. This is particularly problematic for persons with dementia, as through the assumption that personhood exists solely within cognition is the associated belief that a diagnosis of dementia inevitably leads to a loss of self (Kitwood, 1995; Kontos, 2004). In the LTC context, such perceptions are reflected in pathologizing ‘behaviours’ as symptomatic, ignoring the possibility that individuals are using bodily expression to respond/resist some aspect(s) of their surrounding context (i.e., the built environment, social interaction, internal need, etc.) (Dupuis et al., 2012a). Attributing ‘behaviour’ as being simply a part of one’s diagnosis influences the response to such ‘behaviours’. For example, and as will be discussed below, one study explored the NPS of persons with YOD in LTC facilities that were considered ‘burdensome’ to nursing staff (Van Duinen-van den Ijssel et al., 2018). The study by Van Duinen-van den Ijssel and colleagues (2018) highlighted “extreme aggressive behaviour” (p. 628) as one such symptom, from which it was indicated that the excessive use of psychotropic drugs was used as a solution. Only within a bio-medically driven context, such as LTC, would this be considered an acceptable response. In resorting to such responses, the system is literally sedating self expression in order to control the body in a way that supports the smooth operation of systemic functioning.

The harmful realities associated with a biomedical model of care have been exacerbated during the COVID-19 pandemic. Prior to delving into this more deeply, I would like to reiterate that it is (to a very large extent) the system which is to blame for the unequal treatment of residents within LTC, and is not at the hands of the staff who are working hard to keep homes running and residents safe despite inadequate pay, inadequate staffing, and the overwhelming responsibility of large capacity facilities (Phillipson, 2020).

As I mentioned in the introduction, 69% of COVID-19 deaths in Canada are attributed to LTC homes (CBC News, 2021), which I believe speaks volumes to ageism that exists within our society through the blatant lack of value placed on the lives of older adults, who comprise a large proportion of the LTC population. Delving into mainstream media news articles was eye-opening to say the least. Headlines such as: *For-profit nursing homes have four times as many COVID-19 deaths as city run homes, Star analysis finds* (The Star)*; One-third of region's long-term care homes built to 1972 design standards* (The Guardian); *Long-term care reform apparent amid COVID-19, but crisis needs solving first* (Global News)*; Where the tragedy really lies': The crisis in Canada's long-term care homes* (CTV News), really speak to the systemic failures that have resulted in the disproportionately experienced consequences of the pandemic for residents, families/care partners, and staff. In its grimmest form, one such consequence is the high number of resident deaths, triggering a series of class action lawsuits: *$20M class-action lawsuit filed against Scarborough long-term care home that was part of military report* (CP24); *Class action proposed at long term care home where 53 died from COVID-19* (Halifax Today).

In addition to ageism, in asking why LTC homes have been the source of such injustices, I circle back to the biomedical model, which through the mechanisation of the body has devalued the lives of residents by perceiving individuals not as social, emotional and relational beings, but rather as 'shells' of human beings who are a 'burden' to society. It is also important to note the economic drivers behind the way LTC is currently structured (i.e., large institutions that can 'hold' more residents and thus generate greater profit). Such economic motivations have resulted in the creation of homes that are too big, where efficiency is valued, and where the lives of staff and residents are devalued and reflected in practices such as task-based care, underpaid staff, and large resident to staff ratios (Diamond, 2009; Phillipson, 2020).

Stigmas Relating to Age, Dementia, and LTC

The concept of ‘stigma’ is used to describe “a process whereby certain individuals and groups are unjustifiably rendered shameful, excluded, and discriminated against” (Graham et al., 2003, p. 672), and is comprised of three elements – stereotypes, prejudice, and discrimination (Blay & Peluso, 2009). Such stigmatizing processes create what Erving Goffman (2006) described as a “discrepancy between virtual and actual social identity” (p. 132), where I interpret ‘virtual identity’ to be the embodiment of how society perceives one’s role or place in the world, and ‘actual identity’ as the awakening of critical consciousness that leads to the recognition of the attributes, power, and agency that one possesses, by both the self and society. Within the context of aging and dementia, there are two types of stigma that Erving Goffman (2006) described that are of particular relevance, which are “abominations of the body – the various physical deformities” and “blemishes of individual character” (p. 132) such as having a mental illness.

When looking at the older adult population (i.e., individuals over 65 years of age) one or both of these types of stigmas are often present, which contribute to the sedimentation of ageism in our society. First, older persons may appear to deviate from normative ideals of ‘successful aging’ with regards to their physical appearance and/or their physical ability, in addition to experiencing stereotypes associated with cognitive decline. By the standards of society, to age ‘successfully’ means to live a long and healthy life, remaining independent and free from disability and illness, and continuing to contribute to society (Rowe & Kahn, 1987). Other terms used to describe successful aging include “vital aging or active aging or productive aging” which denotes that “later life can be a time of sustained health and vitality where older people contribute to society rather than merely a time of health and dependency” (Martin et al., 2015, p.

15). Along with this notion of successful aging came the further division of older adults into two groups: the third age (65-79 years of age), denoting active, healthy and productive aging; and the fourth age (80+ years of age), denoting deficit and decline models of aging (Gilleard & Higgs, 2010; Grenier & Phillipson, 2013). Ideal aging then, contributes to the perpetuation of ageism, and the notion that older adults are “weak, ill, peculiar, inflexible, unproductive, etc.” (Graham et al., 2003, p. 673). Additionally, the discourse of an ‘apocalyptic demography’ is created, which casts the aging population (including persons living with dementia), as a great economic burden to society (Robertson, 1990). Ageist beliefs not only have the power to influence reactions towards older people, but also negatively impact the way in which these individuals perceive themselves. The process by which individuals begin to believe these ageist notions is known as the internalization hypothesis, whereby individuals eventually apply stereotypes to themselves, and unknowingly begin contributing to a self-fulfilling prophecy (Bennett & Gaines, 2010); thus, individuals will turn public-stigma into self-stigma (Corrigan & Watson, 2002).

Specific to older persons living with dementia, there exists the burden of a double stigma. For instance, in addition to changes in physical appearance and physical ability (as perceived by society), they are also judged as having a mental illness, which is associated with a number of harmful discourses that perpetuate the stigmatization of persons with dementia, and result in discriminatory practices (Mitchell et al., 2013; 2020). Mitchell and colleagues (2013, 2020) outline two dominant discourses that I feel are particularly relevant within the context of dementia and LTC, which are the *biomedical* and *dementia as tragedy* discourses.

As I have already highlighted, discourses stemming from a biomedical perspective reduce an individual to their impairment, through which a decline in cognitive function is equated with a loss of personhood. As a result, the individual’s ‘behaviour’ becomes largely attributed to their diagnosis, from which it is assumed that therapeutic intervention can be used to ‘manage’, ‘manipulate’ and ‘control’ such ‘problematic’ expressions (Dupuis et al., 2012a; Mitchell et al., 2020). Pathologizing behaviour as an aspect of the diagnosis rather than evaluating other contextual factors (such as the environment), has led to persons with dementia to be perceived as ‘infantile, violent objects’ that need to be managed, leading to the blind acceptance of a therapy culture within LTC (Dupuis et al., 2012a; Mitchell et al., 2013, 2020). Consequently, at the heart of treatment and care plans lies the dehumanizing practices of therapeutic intervention, which resorts to “mechanical, environmental and/or pharmacological/chemical restraints” (Mitchell et al., 2020, p. 3), completely denying the rights of persons living with dementia to “meaningful participation” and to “living life in ‘normalized’ ways” (p. 3).

Reinforcing these harmful practices is the associated discourse of dementia as tragedy, which also contributes to the dehumanization of persons with dementia through the assumption of ‘loss of personhood’. Mitchell and colleagues (2020) highlighted such discourses as being evident in “the metaphors and images in policy and popular culture that represent dementia as ‘the funeral without end’, ‘the loss of self’, ‘the zombie’, and ‘a living death’ (p. 4). In the LTC context, such perceptions of persons living with dementia are particularly harmful as they relate to assumptions of persons with dementia as ‘unagentic’ and ‘dependent’, often times stripping individuals of their recognition as a citizen. Consequences of discourses of dementia as tragedy are similar to those perpetuated by biomedical understandings of deficit and decline, in that they create a fear and anxiety around the diagnosis of dementia, and impact how healthcare professionals and members of society treat and interact with these individuals (Mitchell et al., 2013, 2020). Fear and anxiety towards dementia further perpetuate fear and anxiety towards LTC through negative association, which is largely a result of what is known as stigma consciousness.

This phenomenon occurs in individuals who are not yet stigmatized whereby they “fear that they may acquire a stigmatizing condition” (Dobbs et al., 2008, p. 518). In the case of aging and dementia, people not only fear that they will experience physical and cognitive decline, but also that they will have to succumb to institutionalization and become one of the ‘dependent’ and ‘helpless’ people who they believe reside there.

The stigmatization of persons with dementia as incompetent impacts the health and the well-being of that individual, which if internalized may cause them to “become depressed, experience poorer function and self-confidence, have decreased social interaction, and lowered self-esteem” (Dobbs et al., 2008, p. 518). Swaffer (2015) termed such defeat and fear as *Prescribed Dis-engagement*™, as the inception of such thought begins following a diagnosis of dementia wherein “most health care professionals, including neurologists, geriatricians, physicians, general practitioners, and dementia service providers prescribe giving up a pre-diagnosis life and put all the planning in place for the demise of the person newly diagnosed…” (p. 3). The dehumanization and objectification of persons with dementia into ‘perishable goods’ tells persons with dementia that society does not care about or value their lives, which if internalized “disempowers, devalues and demeans the person and lowers self-esteem; it increases isolation, loss of identity, lost employment, and therefore, reduced income” (Swaffer, 2015, p. 4). I think the concept of *Prescribed Dis-engagement*™ does well to demonstrate how deeply embedded biomedical and dementia as tragedy discourses have become in the LTC system, and how from the outset of diagnosis, persons with dementia are often told to give up. There is no denying that the lives of persons with dementia are extremely undervalued; we are witness to it right now in the clear neglect of and lack of protection for persons living with dementia and residents living in many LTC homes.

Within the segregated constructed realities of LTC, beliefs in such discourses are reflected in policies and regulations governing rigid and structured routines (Wiersma, 2010), near constant surveillance (Hall et al., 2017; Landau et al., 2010; Niemeijer et al., 2014), and (as mentioned above) the exclusion and silencing of the individuals in creating and carrying out their own care plan (Dupuis et al., 2012b). Other impacts of these discourses were described by Dobbs et al. (2008) who noted that “attention is often paid to dependent behaviours rather than to independent behaviours; that “elder speak” or baby talk within the [nursing home] lowers self-esteem; and that the negative attitudes of staff toward older persons result in lower quality of care” (Dobbs, et al., 2008, p. 518). Such actions and practices are both a result of such discourses, and further perpetuate the stigma and loss of autonomy that drive their existence.

Recreation and leisure practices in the LTC context are very much influenced by the biomedical discourses of illness and disease. Emphasis of recreation and leisure activities is placed on therapy through which the functioning of persons with dementia can be improved, rather than engaging with activities that the individual perceives as meaningful (Dupuis, et al., 2012; Dupuis et al., 2012c). Consequently, while recreation and leisure should be experienced as something that one enjoys, hegemonic discourses pertaining to how the body should look and be able to perform, has set a standard from which any deviance is seen as a deficit that needs to be fixed. Unfortunately, in the LTC context, the individualization of recreation and leisure activities is viewed as an impossibility due to time and resource limitations. For example, and as discussed earlier, OLTCA (2018) described that LTC homes in Ontario currently cater to “providing 24-hour personal and nursing care for a population with advanced physical and cognitive decline” (p. 14). With this being viewed as the target population, LTC homes and their operations and practices will cater to what they feel is appropriate for older persons experiencing physical and cognitive decline in the general sense. Particularly with regards to recreation and leisure, this results in activity programming mostly being used as a way to "keep people with dementia busy with their hands or their minds" (Chung, 2004, p. 23), without considering individual wants and needs.

I will now move into a section that unpacks the ways through which the experiences of persons with YOD differ from persons with LOD, and offer a contextualization of service provision to highlight the gaps in and limited access to appropriate supports for younger persons with dementia. Following this, I will circle back and provide a discussion about how the unique experiences of persons with YOD are not supported in the current system of care, leading to an (often) involuntary transition into LTC homes; a place where the exclusion and marginalization of younger persons living with dementia is amplified.

An Overview of Young Onset Dementia

In the previous Chapter a number of aspects of YOD were discussed including a definition, the estimated prevalence in the Canadian population, the characteristics that differentiate it from LOD, as well as current challenges and experiences of persons with YOD and their care partner(s) in the system and in everyday life. This section then, will be used to focus in on what we know about YOD and service provision, particularly within the Canadian context. As mentioned previously, research in this area is limited and so this section also draws on the available grey literature to try and find some answers. One reason for why literature is limited in this area is because while there is a growing body of research that explores the experiences of individuals living with dementia more broadly – some of which do include individuals living with YOD – little of the existing research has separated out the experiences of individuals with YOD from the experiences of individuals living with LOD. Research that explores the experiences of individuals with dementia as a homogenous group have contributed extensively to our knowledge base today, however, there is something different to be gained from exploring YOD and LOD separately. As has been outlined previously, the experiences of individuals living with YOD, and their care partners, have a journey that can look quite different due to the life stage differences that exist. It is also important to explore this journey within the Canadian context, as although inspiration for change can be sought from work in other countries, we need to understand the ways through which such frameworks and ideas can be applied and sustained throughout our healthcare systems.

I would like to use this section to bring together what I could find regarding the availability of support services and resources that relate to YOD. Just as I provided a history of the LTC sector, I feel that it is equally as important to outline what has been done in Canada to date for the YOD population, as it not only speaks to the gaps in service provision, but also the ways through which these gaps likely contribute to the institutionalization of persons living with YOD into LTC homes. As there is scant research that specifically focuses on YOD within Canada, this information is particularly important for contextualizing this research, and providing the reader with an understanding of the unequal treatment of persons with YOD in the LTC system. Such contextualization is also important for making sense of the stories and experiences that were shared with me by persons living with YOD, as will be unpacked in the findings and discussion sections.

Setting the Context: From Hospital to Where?

CIHI collected data from three different pillars of the healthcare system that are commonly used by persons with YOD including from hospitals, home care[7], and LTC[8]. From this data it was determined that persons with YOD have longer hospital stays, with a high proportion of individuals having extremely long stays. In large part this has been attributed to difficulties in finding age-appropriate services or home supports that can accommodate high levels of physical fitness (CIHI, 2016).

The hospital data showed that 24% of individuals with YOD would be discharged to home care compared to 31% of persons with LOD, and 26% of individuals with YOD would be discharged to LTC compared to 31% of persons with LOD (CIHI, 2016). There is a clear disconnect between need and service provision available, as neither of these options are constructed to meet the needs of persons with YOD. On the same CIHI page, it clearly indicates that "people with young-onset dementia tend to be physically fit, so finding appropriate home supports may take time" (CIHI, 2016, para. 3). Therefore, discharging persons with YOD back to their homes essentially leaves the individual and their care partner to fend for themselves and to search for appropriate and helpful support services that may or may not exist in their area.

Similarly, the Alzheimer's Association (2006) in the U.S. analyzed data from the Health and Retirement Survey (HRS) and put out a report highlighting the unavailability of appropriate support services. As mentioned in Chapter 1, home care (among other situations) is further complicated by financial matters as a diagnosis of dementia will "inevitably lead to loss of employment, for the person themselves, and also at some point, the spouse or partner may need

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[7] Data represented five provinces: Newfoundland and Labrador, Ontario, Alberta, B.C. and Yukon

[8] Data represented six provinces: Newfoundland and Labrador, Ontario, Saskatchewan, Alberta, B.C. and Yukon

to reduce their working hours to provide sufficient support" (Oyebode, 2015, para. 11). With few support services in place for younger persons with dementia and their care partners, I now turn first to an exploration of what community-based services for people with YOD look like in Canada, followed by a discussion on the use of LTC homes in supporting persons with YOD, that included feedback from persons with YOD and their care partners. Two of the key findings from my review of this literature was that most of the services available for persons living with dementia are designed for the older population, and individuals with YOD report that they "do not fit in and feel uncomfortable with these services" (Alzheimer's Association, 2006, p. 9).

Community-Based Service Provision, Issues, and Gaps

After reviewing the literature, it became clear to me that Canada seems to be behind in terms of the level of focus placed on the YOD population, and many qualitative studies that do exist tend to focus on the information provided from family and/or care partners (e.g., Arai et al., 2007; Ducharme et al., 2014b; Johannessen et al., 2017; Svanberg et al., 2010; van Vliet et al., 2010b, 2011). That being said, the three most recent reviews of the literature I could find pertaining to the experiences of persons living with YOD were by O'Malley and colleagues (2021), Mayrhofer and colleagues (2018), and Greenwood and Smith (2016).

O'Malley and colleagues (2021) conducted a scoping review that looked at the experiences around receiving a diagnosis of YOD. There was a total of eight articles included in the review, with the earliest studies taking place in 2004 reflecting the relative recency of this area of research, as well as how little research has been done over the past 18-years. The themes identified in this review included: 'The journey to diagnosis – delay in accessing help', 'Misattribution of symptoms – delay to diagnosis', 'Communicating diagnosis – impact of diagnosis', and 'The reaction to the diagnosis – reassuring, destabilising and shock'. To be included in this review, the studies had to have at least a qualitative component and include persons living with YOD.

Greenwood and Smith (2016) discussed only eight studies that purely focused on YOD, of which cumulatively included the experiences of 87 persons with YOD. Similar to the review by O’Malley and colleagues (2021), within this review the earliest study identified was conducted in 2004, and all studies must have had a qualitative component. The articles explored in this review covered a range of topics, including but not limited to participants’ subjective experiences of living with YOD, assessment of the implications of living with YOD for practice and service development, examining the experiences of transition and health expectations in YOD, and the experiences of individuals with YOD who live at home.

Lastly, Mayrhofer and colleagues’ (2018) review specifically focused on exploring existing age-appropriate service provision, with many of the studies including persons living with YOD in the research process. The studies included quantitative, qualitative, and mixed methods studies, with all studies taking place from 2002 onwards except for one study that was conducted in 1990. Twenty articles were included in this review, which provided an overview of different support services for persons living with YOD and/or their care partners, such as day centres, gardening programs, volunteer programs, and telehealth online support. The entire search located age-appropriate support services in five countries, an overwhelming amount of which resided in the United Kingdom. While drawing on the work of scholars in other countries can be helpful and inspirational, more research is needed in Canada to understand the experiences of individuals with YOD, the strengths and limitations of our healthcare system, and paths and strategies for moving forward that apply within our national, provincial, regional, and local contexts.

Also, in terms of the grey literature, since 2016 the ASC and other organizations have made significant progress in developing resources for individuals living with YOD and their care partners, such as booklets and factsheets, many of which are presented on the ASC website (see also ASC, 2016) – I have summarized the information provided on the website in ***Table 1*** below.

Table 1*: Summary of ASC (2019) Information and Resources Pertaining to YOD and YOD Support Services*

Heading	**Summary of information provided**
Young onset dementia	• Provides an overview about what YOD is, who is impacted, and common experiences
Get a diagnosis	• A short description on the challenges of obtaining a diagnosis, as well as a link that connects to information about how to prepare for a doctor's visit
Plan ahead	• Suggests contacting a financial advisor and a lawyer early on and selecting a power of attorney
Reassure your children	• Describes common challenges for children and teenagers and how to support them throughout the dementia journey • Provides two links – *helping children* and *helping teens*
If you're still working	• Provides suggestions for those who have already been diagnosed, as well as options that could be explored for both employed and self-employed individuals
Be safe	• Prompts individuals to start thinking about factors such as driving, adapting one's home, and suggests helpful contacts
Share your story	• A short description about the ways that sharing one's story can help reduce stigma
Live well	• A short description that lists healthy lifestyle choices • Provides a link to *Make healthy lifestyle choices* which further discusses brain health
Webinars	• Two webinar videos are provided: 1) *Living with Young Onset Dementia: Let's have a conversation!* → Two individuals with YOD discuss their experiences with the health care system 2) *The importance of Social Programs for People Living with Young Onset Dementia* → A Community Partnerships Manager

	discusses ways to support the unique needs of persons with YOD and the importance of programs that are specifically designed for this population. Provides an example a social program for persons with YOD in Toronto.
Fact sheets	Links to the following fact sheets were provided: • "Early Onset Dementia: Advice for Caregivers" provided by: National Initiative for the Care of the Elderly • "Early Onset Dementia: Advice for Couples" provided by: National Initiative for the Care of the Elderly • "When Dementia is in the House: Advice for Parents" provided by: National Initiative for the Care of the Elderly • "I have younger onset dementia: Information and ideas for you to consider, and types of support" provided by: Dementia Australia" • "Young-onset dementia" provided by: Alzheimer's Society UK
Booklets	Links to the following booklets were provided: • "What is young onset dementia?" provided by: Alzheimer Society UK • "Younger people with dementia: Living well with your diagnosis" provided by: NHS health Scotland
Other links	Other links that were provided are: • Young Onset Dementia: Facilitators Resource Manual • "Young onset dementia: An inspirational guide for people like us with early-stage memory loss" • "Resources for young carers" • "Young Onset Dementia Information Gap Analysis: Executive Summary" • "Young Onset Dementia Information Gap Analysis: Report" • "Frontotemporal dementia"

This is significantly more information than was provided in 2016 by the Alzheimer's Society of Canada, a time when I was wrapping up my master's thesis research on social programs for younger persons with dementia. Information about common experiences, resources, next steps, and groups/organizations that persons living with YOD and their care partners can reach out to are now all accessible from the Alzheimer Society of Canada's website. From the table provided above, I would like to focus in on the Young Onset Dementia Gap Analysis Report that was initiated in 2016, as while more information has been provided, action and accessibility to helpful services is still extremely limited. Of the recommendations provided in this report, ASC and affiliates have begun to make progress in some areas, while others remain essentially untouched. I reiterate my point made in Chapter 1 – the scant research continues to tell the same story, yet there has been little action taken to improve service provision.

Young Onset Dementia Information Gap Analysis Report

In early 2016, the National Information Support and Education Committee (NISE) alongside ASC initiated a Young Onset Gap Analysis Project in an effort to identify aspects of learning and support resources that needed to be improved, and obtain advice and feedback from persons with YOD and their care partners on these ideas (ASC, 2016). In line with what I mentioned previously, NISE and ASC also recognized that a number of International Alzheimer's Societies and other organizations had "developed YOD information materials and programs" and that "some of the information offered is generic which can be adapted for use by ASC while other information is specific to a country or organization" (ASC, 2016, p. 4) In recognition of this, NISE and ASC set out to specifically identify areas where Canadian content and service provision need to be re-vamped or newly created.

The gap analysis compiled information collected from a literature review, online surveys and focus groups (which included persons living with YOD, care partners, and healthcare professionals), and a scan of available national and international resources to produce a list of recommendations. After reviewing the information collected in this gap analysis it became clear that there is an overwhelming number of areas of improvement that need to be attended to for persons living with YOD, their care partners and families, as well as healthcare professionals, all of which cannot be covered by the scope of this literature review.

There are a few findings in this gap analysis that I believe are particularly important in the context of my study. Firstly, while programs exist both nationally and internationally, very few have been 'evaluated' through research and so it is difficult to discern the effectiveness to which these programs support the needs of persons living with YOD and/or their care partners (ASC, 2016). Another concern is that there are a very limited number of YOD specific support services known to exist in Canada, largely attributable to a combination of both underdevelopment, as well as a lack of recognition and documentation of programs and services created through grassroots and community efforts. The literature review of peer-reviewed articles noted only one program for persons with YOD in Vancouver Canada (ASC, 2016; Phinney et al., 2016), and the gray literature identified only seven other YOD specific programs within Canada, with the majority being located in Ontario (Alzheimer's Society Toronto, 2022; Crawford, 2020; Memory Lane Home Living; 2021; Region of Waterloo, 2021; St. Joseph's Health Centre Guelph, 2018; Toronto Central Healthline, 2022; YouQuest, 2021). Some of these programs have indicated on their website that they are temporarily (and in some cases permanently) no longer offering services due to COVID-19, while others have switched their services to virtual programming. The apparent lack of specific programming in Canada may play a role in the early institutionalization of persons with YOD into LTC homes. There is no doubt about the clear lack of appropriate support services for persons with YOD and their care partners. Beyond the few that have been directly developed for people with YOD, remaining support services are often not designed to meet the needs of younger adults (Alzheimer's Association, 2006; ASC, 2016; Oyebode, 2015), with some even being age specific and going as far as excluding individuals who are under the age of 65 (Shnall, 2009; van Vliet, 2012).

This report has drawn attention to a number of issues and gaps that are now considered more relevant than ever given the crisis in LTC that has generated out of the COVID-19 pandemic (reflected in the headlines provided earlier). In terms of community-based support services, there is a clear need to work with persons with YOD and care partners to develop programs and services the reflect and support their needs and desires (in turn reducing forced dependency on the use of LTC homes). The YOD gap analysis report also speaks to a number of concerns and questions regarding the transition of persons with YOD into LTC homes, as well as the lack of education and training materials available about YOD, particularly for health care providers. I will now move into a discussion about these concerns and questions beginning with the LTC home context.

Persons with YOD within the LTC Home Context

Without sufficient support services in the community, persons living with YOD are often forced to move to a LTC home before they are ready. For the 4000 Canadians with YOD who reside in LTC homes, there are additional concerns beyond appropriate programming and financial matters. With more than half of residents in LTC homes being over the age of 85 the system is largely structured to cater to the needs of older residents and older persons with dementia who are often physically frail (Oyebode, 2015). There are a number of reasons this is problematic. Firstly, differences in age between YOD and LOD results in life stage differences that often make it difficult for persons with YOD to feel a sense of belonging and socially connected, which is further exacerbated by a disconnect between generational interests and activity programming. Oyebode (2015) noted that “most people in their middle age have grown up and lived with different experiences from those who are in their old age, and so they may have differing generational attitudes, likes and dislikes” and that “many people with LOD who are living in care home settings are quite physically frail, whereas people with YOD may be fit and wish to be active” (para.13).

Secondly, persons with YOD are more often labeled as displaying ‘difficult behaviour’ in LTC settings because of their high level of physical and verbal ability. Since this is seen as posing danger to the staff and other residents, persons living with YOD are more likely to be victims to misuse of antipsychotic drug use. CIHI reported in 2016 that the rate of potentially inappropriate antipsychotic drug use for persons living with YOD was 42%, compared to 27% for individuals with LOD. Restraint use was similar between the two groups with 10% for persons with YOD, and 9% for persons with LOD. These inhumane practices stem from a lack of understanding about the disease and how to work with persons living with dementia, as well as pathologizing behaviour and creating misconceptions about YOD (Dupuis et al., 2012a).

The literature pertaining to persons with YOD within the LTC home context is extremely limited. The majority of these studies are rooted in a biomedical framework, such that the primary focus of these studies were to determine: predictors for the institutionalization of persons with YOD (e.g., Bakker et al., 2013); the course of NPS of persons with YOD in LTC (e.g., Bauhuis et al., 2020); and the impact of the NPS of persons with YOD on nurses within LTC (e.g., Van Duinen-van den Ijssel, et al., 2018). One study even highlighted the difficulties that care partners can experience when trying to find a placement for the person they care for in a LTC facility, one of which was the hesitance of the home to accept a younger “patient” who exhibits “social and personal misconduct” (Merrilees & Ketelle, 2010, p. 247).

In addition to these concerns, the YOD gap analysis report identified that care partners wanted more information on LTC and nursing home ‘issues’ although specific examples were not provided beyond the indication of a correlated concern, which pertained to the lack of information around financial assistance (ASC, 2016). The analysis also showed that 60.6% of English speaking and 55.6% of French speaking healthcare professionals experienced challenges in supporting persons with YOD in LTC and nursing homes, although only one quote was used to demonstrate what those challenges might be. The healthcare professional who was quoted stated that one of the challenges is having staff within these facilities who are knowledgeable and experienced in providing care ‘for’ people with YOD and meeting their unique needs.

With no specialized support services and a reluctance from some LTC homes to accept persons with YOD (and persons with YOD being reluctant to resort to LTC), individuals and their care partners continue to face ongoing challenges pertaining to the existing care options available. I also feel like it is important to note that LTC homes were not mentioned by persons with YOD in the ASC (2016) gap analysis survey responses, nor within the focus groups. This gap demonstrates the already existing issues regarding persons with YOD transitioning into LTC, as well as the lack of service provision that often time forces this transition. The current pandemic and the emerging discourses around LTC homes, will only further make LTC homes an unappealing option for persons living with YOD. Unfortunately, the perpetuation of such discourses is only likely to further the marginalization of younger persons with dementia in these settings.

The Marginalization of Persons Living with YOD in LTC Homes

I view processes of stigmatization and discourse to be intertwined through their ability to perpetuate one another in the production and reproduction of harmful conceptualizations of aging and dementia. Earlier I identified a number of stereotypes, prejudices, and discriminatory practices, as well as a few over arching discourses that contribute to the generation of such assumptions. Stemming from this overview, I would like to explore ways through which discourses of successful aging, biomedicine, and dementia as tragedy contribute to the marginalization and exclusion of persons living with YOD in LTC homes.

As I was reading and thinking about stigmas and discourses relating to aging and dementia, it became apparent that the persons living with YOD are a living contradiction to normalized standards of aging, more so than their LOD counterparts. In addition to persons with YOD experiencing stigmas associated with dementia, these individuals also experience ageism, such that when they inform people of their diagnosis, the common reaction is *'you're too young to have dementia'* (Novek & Menec, 2020; Rabanal et al., 2018). Through the discussion of successful aging above, it can be seen that most deviations from normalized ideals are depicted as occurring in individuals who are 65+ years of age. So where do persons with YOD fit within constructions of the third and fourth age? As a refresher from Chapter 1, these age categories were created to distinguish research participant groups, as well as to outline the eligibility criteria for support services (Grenier & Phillipson, 2013). It is the latter of these two that is important to discuss; as we have seen there are few services in Canada specifically developed for persons with YOD. As a result, the healthcare system has integrated these individuals into the fourth age category. The consequences of this are two-fold: first, persons living with YOD will have to utilize support services that were initially developed for older persons with dementia; secondly, some of the services for individuals with LOD cannot be accessed by persons with YOD due to the age requirements in their eligibility criteria (often influenced by government policies and funding). As a result, persons living with YOD and their families have access to limited support services, which do not fully target their specific needs and can contribute to early institutionalization into LTC (Carter et al., 2016).

From the overview of YOD provided in Chapter 1, it was noted that diagnoses of YOD are much more heterogenous than is seen with persons with LOD (see ***Figure 1***). While Alzheimer's disease and Vascular dementia are the two most prevalent forms of dementia in both YOD and LOD, the distribution of the remaining diagnoses vary drastically. One important distinction to note is the difference in prevalence of fronto-temporal dementia (FTD), which is the third most common form of dementia in YOD at 13%, but in LOD it only accounts for 2% of all dementia cases (Jefferies & Agrawal, 2009). Rather than symptoms of cognitive impairment and memory loss, this form of dementia is typically known for changes in personality and behaviour, such as "disinhibition, apathy, reduced empathy, [and] poor self-care" (Ratnavalli et al., 2002, p. 1618). Although based out of the Netherlands, and thus potentially not reflective of dementia numbers in Canada, Van Duinen-van Den Ijssel and colleagues (2018), determined that following Alzheimer's disease, fronto-temporal dementia was the second most common form of YOD in LTC facilities, at almost 25%. Due to this high prevalence, the same study made the inference that the FTD population may be in large part responsible for the 'disinhibiting behaviours' (e.g., rude and offensive) that contribute to nurse stress. While this study made specific reference to FTD, the majority of the study discussed YOD as an overarching diagnosis, and so before discussing the implications of these findings, I want to delve into other factors that contribute to the marginalization of this population in LTC homes.

The overall purpose of the study by Van Duinen-van Den Ijssel and colleagues (2018) was to explore the NPS of persons with YOD that are considered ‘burdensome’ for nurses within LTC facilities. The authors concluded that nearly 90% of persons with YOD displayed associated behaviours, most predominantly agitation/aggression, and apathy. This study also made the assumption that men are more aggressive than women through their statement that, “for YOD, half of the residents are male, compared with a quarter in LOD [and] it is therefore likely that nurses caring for YOD residents must manage (extreme) aggressive behaviour more often than nurses caring for residents with LOD” (Van Duinen-van Den Ijssel et al., 2018, p. 628). The specific reference to the male/female distinction makes the inference that men are more aggressive. They attribute this ‘difficult behaviour’ as being in large part due to high levels of physical and verbal functioning which exist in YOD relative to LOD. This is where I would like to begin to draw attention to some of the implications and discriminatory practices that persons living with YOD experience in LTC.

The findings from this Netherlands based study and the framework in which they are discussed, are clearly rooted in (and further contribute to) the biomedical and tragedy discourses that perpetuate the stigmatization of individuals with YOD. Firstly, the description that “nurses caring for YOD residents must manage (extreme) aggressive behaviour” (Van Duinen-van Den Ijssel et al., 2018, p. 628), results in the excessive use of psychotropic drugs, most of which are antipsychotics and antidepressants (Mulders et al., 2016). A follow-up study[9] explored the prevalence and correlates of NPS in persons with YOD in LTC facilities, which included 225 persons with YOD with a mean age of 60.1 years of age (Mulders et al., 2016). Of these individuals it was determined that 87.6% had been prescribed a psychotropic drug. The provision

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[9] These two studies were part of a larger study known as the BEYOnD study – Behaviour and Evolution in Young Onset Dementia

of psychotropic drugs to persons with YOD is in large part due to the problem-based and pathologizing approaches to behaviour, whereby staff in LTC homes, as well as in LTC more broadly, connect the behaviours of persons with YOD to their diagnosis, label these behaviours as problematic, and resort to reactive strategies. As I have emphasised previously, viewing behaviour solely within the context of disease is problematic, as alternative meanings and understandings behind these behaviours are not sought, and thus other possible contributing factors (e.g., social and environmental) are overlooked (Dupuis et al., 2012a).

In addition to the use of psychotropic medication, recreation and leisure programming provide another avenue through which healthcare professionals in LTC use to control behaviour. Dupuis and colleagues (2012c) provided an overview of how leisure is often used as a treatment method in dementia contexts, including LTC homes, particularly with its use for managing the 'difficult behaviours' of persons with dementia through recreation therapy and clinical intervention. This is not the only concern regarding recreation and leisure for persons with YOD. As discussed above, one of the repercussions of persons living with dementia being viewed as deviant from idealized norms of the body and body functionality, is that they are viewed as *less than* to the status quo. In an effort to bring those who are '*less than'* up to the standards of the 'norm', especially in LTC homes, a portion of the recreation and leisure activities are dedicated to improving body functionality (Yang et al., 2020).

As has been highlighted, persons living with YOD differ quite drastically from persons with LOD when it comes to levels of physical ability. This leads to a whole other discussion on the social construction of disability, as technically there should be a way to make recreation and leisure activities inclusive to all parties who wish to participate. However, given the structural limitations of current LTC practices, persons with YOD often overlooked as most programming has been designed primarily to cater to older persons with dementia (e.g., Buettner & Fitzsimmons, 2003; Backman et al., 2021; Chung, 2016; Lem et al., 2021). This is also reflected in the lack of literature describing recreation and leisure for younger persons with dementia in LTC homes, with a focus instead on the use of pharmacological and nonpharmacological interventions for the management of NPS and ‘difficult behaviours’ (Appelhof et al., 2017, 2018). Thus, where persons with YOD may prefer leisure activities requiring higher levels of physical mobility (e.g., going for a walk), they are limited to exercises that limit mobility (e.g., chair exercises).

Just as important to discuss as the physical aspects of recreation leisure, are the leisure programs that are aimed at reflecting individuals’ interests. While enjoyable activities, such as listening to music, have also been morphed by recreation and leisure discourses (e.g., enjoying listening to music into music as therapy), that is not what I want to focus on in my next point. It has already been highlighted that there is a lack of programs that provide meaningful activity for persons with dementia, however, if it’s possible, this is even more true for persons with YOD. For example, programs (within and beyond LTC homes) that are not specifically designed for younger adults will use activities such as listening to music and singing songs, however, the music selected often reflects songs that were popular to those who are now in their mid-to-late 70s and 80s. That is not to say that persons with YOD do not necessarily know or like these songs, but their favourite songs that have associated memories and emotional connections to may not be played. Now, given the realities of COVID-19, even fewer opportunities for engagement in leisure, recreation, and life enrichment activities will be available to people with YOD; within LTC homes this is attributable to the shortage of staff and the prioritization on reducing case numbers and protecting residents, and community-based programs have been intermittently either shut down or running at a reduced capacity (depending on the stage of reopening).

Also important is the social component of recreation and leisure activities. Activities that are designed to provide opportunities for social engagement often cater to older residents and often do not take into consideration the age and life stage differences between persons with YOD and LOD, meaning that the preferences of the former may be overlooked. For example, in LTC homes, Van Duinen-van Den Ijssel and colleagues (2018) determined the youngest person with YOD to be 39 years of age, and the youngest person with LOD being 70 years of age, which means that in some cases persons with YOD will be closer in age to the staff than they are with the other residents. While it is in no way acceptable to discriminate based on age, it is understandable that a person with YOD being admitted into LTC (often against their wishes), may have a hard time making this transition, particularly because they do not feel like they belong based on their age, physical appearance, and diagnosis. This transition may be especially difficult because of *stigma consciousness* and the fear of becoming subsumed by the stigmas of LOD; such experiences hold true to community-based contexts as well (Dobbs et al., 2008). Again, dominant discourses of LTC have now only been further exacerbated by the stigma and fear associated with the pandemic, which has ignited many media stories and research articles that have shed light on the limitations and called for the reformation of the LTC model (e.g., Estabrooks et al., 2020; Flanagan, 2020; Ireton, 2021; Phillipson, 2020). In recognition of a failed system, it is likely that more and more people living with YOD will no longer consider LTC homes a possible option.

Social isolation is very highly cited outcome of a YOD diagnosis (van Vliet, 2012), and while at this time there is not much empirical support, this trend carries over into the context of

LTC facilities. This experience of isolation could be one of the unexamined underlying factors for the ‘deviant behaviour’ discussed earlier - and also more generally a contributor to a poor quality of living - as these behaviours may be enacted as a reaction to a lack of social connectedness, amongst other factors. The pandemic has only made matters worse. With much of the recreation and leisure programming cancelled, and families/care partners not allowed to visit the homes, residents are at risk of social isolation and its harmful implications now more than ever. Media headlines such as: *‘Are you coming tonight?’: Yarmouth daughter says separation from mom by COVID and Alzheimer’s is devastating* (The Chronical Herald, 2020), and *Senior pictured behind window of long-term care centre near death* (Toronto Sun, 2020), are only two examples of the harsh realities the pandemic has created in the deepening of social isolation in LTC homes.

This chapter has highlighted a multitude of ways through which the LTC system, both in the community and in LTC homes, has marginalized, excluded, and discriminated against persons with YOD. These include: the production and reproduction of biomedical practices and discourses; a lack of provision for appropriate support services; pathologizing and problematizing behaviour; attempting to control these behaviours through the use of psychotropic medication and structured recreation and leisure programs; a lack of provision for appropriate recreation and leisure programming; and the perpetuation of social isolation through a disconnect in resident/program participants similarities and interests. It is also clear that to date, little has been done to engage persons living with YOD in research, particularly within the LTC context.

Addressing Training, Education, and Resources in YOD Service Provision

Another important issue raised in the literature has to do with the lack of training on YOD provided in both community-based and LTC home settings. For example, the report put out by the Alzheimer's Association (2006) noted complaints from persons with YOD and their care partners regarding a lack of training, and thus a lack of understanding of how to treat or provide care for persons with YOD, particularly referencing medical, residential care, and community service providers. The report also acknowledged that "much of the information that government agencies and private organizations need to plan for appropriate services for people with early onset dementia[10] does not exist" (Alzheimer's Association, 2006, p. 10). This gap in education leaves healthcare providers feeling unsure and unconfident about how to provide care and programming for these individuals, and contributes to the unintentional mistreatment of persons living with YOD (including the overuse of antipsychotic medications and physical restraints). A lack of awareness and education pertaining to YOD is problematic in many phases before healthcare and programming including during employment, where changes in job performance or behaviour are misunderstood, as well as in the diagnostic process. With particular reference to the latter, the report from the Alzheimer's Association (2006) highlighted that dementia is not something expected in younger populations and that doctors often do not consider it as a possibility or feel confident diagnosing it as such. Beyond age, another contributing factor in the complicated diagnostic process is the atypical presentation of symptoms in even the most common forms of dementia such as Alzheimer's disease. For example, for individuals with

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[10] Early onset dementia is another term used for young onset dementia, however, dementia language guidelines have determined that the prior should not be used as it is often confused as a term that describes the first symptoms that occur with dementia at any age (Dementia Australia, 2018). There have also been concerns that early onset dementia is associated with a negative connotation, as it infers that the individual was diagnosed earlier than the 'norm'.

LOD, the typical presentation of Alzheimer’s disease is memory challenges, however, “in the third of cases where a person with YOD has Alzheimer’s disease, one-in-three will have visual difficulties associated with posterior cortical atrophy (PCA) rather than early memory problems” (Oyebode, 2015, para. 7). Improving education and training about YOD both throughout the healthcare system, as well as society more broadly, is a pertinent step in creating more awareness and a stronger understanding about the unique experiences of persons with YOD.

Lastly, the ASC (2016) noted that a lack of training and available resources was identified by persons living with YOD, care partners, healthcare professionals, as well as in the literature review they conducted as part of their YOD gap analysis report. This was a heavily mentioned theme which covered a lot of different aspects of training, education, and general knowledge, including but not limited to education for healthcare professionals, information on financial assistance, navigating stigma, maintaining relationships, employment and driving issues, as well as accessible support tools for children of the families affected. Healthcare professionals who responded to the ASC (2016) survey recognized that further learning and support about YOD was important for their roles. When asked about what further support they might need, some of the responses included “literature specific to this population; information sheets”, “more training for staff on how to support the children of pwd[11]”, “webinars: e.g., specific challenges faced by YOD”, “recreation resources specific to this population” and “advocacy for appropriate programs, care facilities etc.” (ASC, 2016, p. 16). There is no doubt that training and resources for healthcare professionals throughout various facets of the LTC system is of extreme importance, particularly for raising awareness and gaining a better understanding about the unique experiences and needs of persons living with YOD and their care

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[11] Abbreviation for persons with dementia

partners. The development of support services will not be enough if the individuals who are running such services are not educated to the unique experiences of persons living with YOD. Concerns have already been identified within the LTC context with respect to the lack of training of staff about YOD, which the research suggests results in staff feeling uncomfortable with the level of physical ability and certain ‘behaviours’, and resorting to the (over)use of antipsychotic drug and restraint use. Through their conceptualizations of the future, persons living with YOD may use this research as space with which to speak about their experiences and relationships or (non-relationships) with health care providers, and well as how they envision them to exist in the future. Another important consideration, which will be discussed now, is the importance of recognizing YOD as a disability. Despite the ongoing debates, this recognition has a number of relevant and important implications for people with dementia throughout the entire care journey.

Dementia as a Disability in Canada

There has long been a debate regarding whether or not dementia should be considered a disability. In Chapter 1, I explored a number of models of disability and unpacked the social relational model as one through which the systemic and social worlds that generate inequities can be challenged (Thomas, 2004). Therefore, the debate regarding the recognition of dementia as a disability has important implications for shifting assumptions that perceive persons living with dementia in terms of their ‘functional limitations’ and ‘dependency’ on others, to discourses around the societal and structural limitations that discriminate and exclude. I would like to use this section to first provide a brief history on this debate and its current status, and then present potential issues that persons living with YOD may experience throughout the process of claiming disability. Within these discussions, attention will be drawn to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which has important implications for this research in its use as a social justice framework.

DAI was established in early 2014 as an internationally recognized non-profit association that was created by and is comprised of persons living with dementia at all ages. The organization was formed to “represent, support, and educate people living with all forms of dementia” and to provide a “unified voice of advocacy, empowerment and support to their individual autonomy and an improved quality of life” (DAI, 2016, p. 4). Persons living with dementia have long experienced social inequalities including the denial of basic human rights and so the formation of this organization was really a catalyst to the promotion and adoption of various human rights-based approaches (HRBA). One of the areas that this organization placed its focus was in pushing for dementia to be seen through the lens of disability and human rights, so that society as a collective could move beyond viewing dementia care strictly as a concept and practice and towards that of “empowerment, enablement and social change” (Rushford & Harvey, 2016, p. 47). In their attendance at the WHO’s First Ministerial Conference on Dementia in 2015, DAI outlined three demands:

- “We have human right to a more ethical pathway of care, including our pre and post diagnostic care, including rehabilitation.
- Being treated with the same human rights as everyone else, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities.
- That research focuses on care as much as a cure.” (DAI, 2016, p. 4).

Based on what I have read, this pinpoints the shift in thinking about dementia as care and practice to that of a social justice and human rights issue, and in setting precedence for dementia to be considered a disability. Following the conference, Alzheimer’s Disease

International (ADI) decided to partner with DAI on their push for a rights-based approach, which included having access to the CRPD (DAI, 2016). As a brief aside, ADI is a globally recognized organization that collaborates with the WHO, as well as a number of Alzheimer's Associations, Societies, and working groups worldwide to make changes on both global and localized levels of society. In reference to this organization, DAI (2016) noted that "just as DAI is the voice *of* people with dementia, ADI is the voice *for* people with dementia" (p. 5).

Although the UN CRPD was adopted in 2006 it was about 10 years later that the dementia community began to advocate for the recognition of persons living with dementia by this convention, particularly given that dementia is technically included in its definition. The definition of persons with disabilities by the Article 1 of the convention is the following:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (United Nations, n.d.)

There are 163 countries who have committed to this convention (including Canada) that DAI and ADI continue to urge, support, and work with at all levels of governments and organizations to push for the integration of the convention's principles and articles in dementia strategies and other support efforts. DAI (2016) specifically mentioned their communication with the Alzheimer Society of Canada and hoped to support them in 2017 – coinciding with the beginning of data collection for the Canadian dementia strategy.

There is little mention about disability in Canada's 2019 dementia strategy beyond a statement recognizing that dementia is a major cause of disability worldwide, as well as the indication in Appendix A of the report of four disability financial support initiatives that persons living with dementia can apply for. Although there is little discussion about the connection between dementia and disability, nor the UN’s CRPD, there is clear influence from DAI and ADI in terms of emphasizing the importance of upholding human rights and taking a rights-based approach.

One gap that I foresee as problematic for persons living with YOD is the lack of connection made between dementia, disability and CRPD, as when provincial, territorial, regional and local strategies and initiatives continue to grow and develop based off of the national strategy, the commitment Canada made to the articles and principles of CRPD may be underrepresented or overlooked. As will be further discussed below, persons with YOD experience stigmatization not only because of their diagnosis of dementia, but also because of their age and appearance. For example, imagine seeing an elderly individual walking around the streets of a community looking lost – it would not be surprising if a fellow civilian stopped to see if the individual was lost as they may wonder if the individual has dementia due to their age. Now imagine on the other hand the elderly individual in this scenario was replaced by an individual in their 40s or 50s – do you think this individual would be stopped by a fellow civilian to see if they were lost? It could happen, although the chance is not as likely as in scenario one. So, where a common stigma for elderly individuals is ‘you’re old, you probably have dementia’, for younger individuals it is ‘you’re too young to have dementia’.

I believe that Canada’s acknowledgement of dementia as a disability, while a positive step in the right direction, is not enough. Common stigmatizations and stereotypes relating to dementia are heavily rooted in societal beliefs and this translates into the way persons living with dementia are treated in everyday life. The debate about whether dementia should be considered a disability has persisted for years, and so if major reports, such as Canada’s official dementia strategy, do not emphasize the acceptance of dementia as a disability, then how will awareness be raised and how will the beliefs of society be reshaped? For example, one of the most prominent concerns for persons living with YOD that comes to mind is in the discrimination that these individuals will experience in the workplace and in applying for government and organizational disability benefits. ASC’s (2016) gap analysis clearly identified a number of concerns around employment such as a lack of understanding from employers (this could be from unknown changes in work performance and behaviour prior to an accurate diagnosis, or not understanding what YOD is and the implications post-diagnosis), a lack of workplace accommodations by employers, and a lack of employment options overall for persons living with YOD who are often still very much willing and able to fulfill some roles. I would imagine it is extremely frustrating to be pushed out of or having to exit one’s employment role due to a lack of understanding about changes in job performance (both with and without diagnosis), and the impact that this premature termination would have on persons with YOD and their care partners for exploring and understanding financial support options such as the Canadian Pension Plan Disability (CPPD). Even with a diagnosis, it is hard to know if employers, persons with YOD or their care partners know that dementia is considered a disability and that persons with dementia are protected by CRPD and have access to a number of disability-related financial support options.

Beyond any discrimination persons living with YOD undergo in the workplace and transitioning out of the workplace, I anticipate that there are further complications for receiving disability related financial supports as a younger adult who appears ‘normal’ to the assuming eye and who may not meet eligibility requirements as the level of ‘decline’ experienced may not be considered sufficient. For example, the Government of Canada's (2020) eligibility criteria for the disability tax credit is documented as follows (individuals must meet at least one of the criteria):

- be blind
- be markedly restricted in at least one of the basic activities of daily living
- be significantly restricted in two or more of the basic activities of daily living (can include a vision impairment)
- need life-sustaining therapy

Every individual has a different journey with YOD and so while some may qualify and not have difficulty successfully applying for the disability tax credit, in other instances persons with YOD continue to live a fairly similar life to that pre-diagnosis despite small disruptions in daily functioning. For these individuals, financial matters can become extremely complicated as in addition to not having access to a pension plan, they would also likely not qualify for other disability related financial supports until later in their journey.

While dementia is considered a disability in Canada, it can be seen from the discussion above that it is not as simple as recognizing it as such, and that more action needs to be taken to raise awareness across all facets of society so that persons living with YOD are better supported societally and systemically. Organizations including workplaces need to be educated about YOD, what to look for, and ways that they can adapt to and support individuals through changes in performance. Governments need to recognize dementia more solidly as a disability so that it is widely recognized as such and incorporated into existing and future strategies and initiatives. Although human rights are supposed to exist for everyone, the UN's CRPD represents the recognition that the rights of disabled people, including persons living with dementia, are too frequently denied or overlooked, resulting in discrimination and unfair treatment. The principles and articles of this convention should be more explicitly addressed in all dementia strategies, something that DAI and ADI have recognized as lacking. As dementia becomes more widely recognized as a disability, I believe that persons with YOD and their care partners will feel more encouraged to resist inequitable treatment by better understanding their rights and that they are supported by CRPD. I also believe that through this awareness societal beliefs will begin to shift towards an understanding that many limitations experienced by persons with dementia are societally not biomedically rooted.

I do feel it is important to recognize that disability is a social construction, and that disabled people are one of the many groups of people who have been negatively impacted by the biomedical model. However, as discussed in Chapter 1, the social relational model has been successful in “shifting debates about disability from biomedically dominated agendas to discourses about politics and citizenship” (Hughes & Paterson, 1997, p. 325), thus emancipating disabled people from biomedical discourses and placing the responsibility on societal limitations. Recognizing dementia as a disability and not just an illness creates an opportunity to include learnings from the disability movement in discussions and the future development of support services for persons with YOD.

Looking to the Future: Canada’s National Dementia Strategy

The Public Health Agency of Canada (PHAC) (2019) pulled together information from various stakeholder groups to create an initial report that would inform Canada’s first national dementia strategy. At the beginning of the report, it was noted that the strategy was developed with an “emphasis on those groups who are at a higher risk of dementia as well as those who face barriers to equitable care" (PHAC, 2019, p. XI), of which the list following included persons living with YOD. What I found to be particularly promising about Canada's national dementia strategy was in its guiding principles, of which some of the important aspects recognized included: "prioritizing quality of life" which spoke to improving quality of and access to support services, shifting the focus to living well with dementia, and creating supportive communities; "respect and value diversity" which spoke to the importance of inclusive initiatives in supporting diverse communities, as well as individuals who are most at risk; and lastly, "respect human rights" where the importance of recognizing and respecting the human rights of people living with dementia was recognized, specifically bringing attention to the need to identify persons with dementia as autonomous individuals, including individuals in decisions about their care journey, and supporting the active participation of individuals in the community (PHAC 2019, p. 6-7). I drew particular attention to these principles because I believe they reflect what was recognized in the YOD gap analysis and outlined in the UN's CRPD, which included the importance of addressing gaps and concerns within the LTC system, and addressing these inequalities and injustices through the recognition and acknowledgement of the rights of people living with dementia.

Although the creation of this report was promising in the sense that a call for change was recognized, it is important to note is that while well-known themes about areas of improvement in dementia care were reiterated, no specific action plans were discussed. The report noted that in "speaking with Canadians, there is a sense of urgency that action should be taken quickly to address the challenges, raise awareness and implement best practices relating to dementia" and that stakeholders "suggested that Canada's dementia strategy include an action plan with targets, timelines and tangible steps that will be taken in the short term as well as in the longer term"

(PHAC, 2019, p. 20). The national dementia strategy was published shortly after this report in June 2019, so it is hard to decipher how much progress has been made since its development. Why it took until 2019 for the recognition of dementia as a national priority is somewhat perplexing, although again, the importance of this document as a positive step in the right direction is unquestionable. What I did notice in the national dementia strategy was suggested steps that could be taken to achieve certain goals, however, specific or ‘hard’ timelines were not provided. Instead, this strategy seems to be a tool from which provinces, territories, and more localized regions can take and utilize to initiate and achieve goals specific to their area, some of which have already been initiated.

The pandemic has demonstrated how the current ways we care for and support people with YOD are not working, are problematic, and inappropriate to the extent with which it could be considered abuse given the neglect of the dementia population during the pandemic. Such neglect is clearly recognizable by the disproportionate number of deaths, with residents comprising 69% of Canada’s total fatalities (CBC News, 2021). It is undeniable that the system has failed to keep individuals protected and safe, a reality contradictory to that which the system claims to do. Phillipson (2020), in recognition of the system’s failures past and present, calls for bold thinking “by the research community about the future of residential and nursing home care: challenging rather than colluding with current models of care” (p. 2). In response to the urgent call for action, this research was designed to ignite the reimagination of what care and support might look like in the future for people with YOD, based on their perspectives.

Chapter 3: Methodology and Methods – Supporting the Telling and Sharing of Stories

Within the interconnected eight-point scaffold of humanist qualitative research (described in Chapter 1), methodology represents the connection between planning and action (Berbary & Boles, 2014). This connection is integral to the research process, as the selection of methodology is not only important for reflecting the researcher's beliefs and worldviews (ontological, epistemological, and theoretical position), but also for shaping the selection of methods and understanding their connection to the desired 'outcomes' (Crotty, 1998). As such, I have selected critical narrative inquiry (CNI) as it aligns with my positionalities as a researcher, and allows for the use of creative and innovative methods to support diverse perspectives to be 'heard' in 'unconventional' ways, thus challenging traditional ways of knowing (Barkhuizen & Consoli, 2021; Estrella & Forinash, 2007). In the context of this research, and as will be explained in the brief rationale, persons with YOD have been silenced and marginalized physically, emotionally, and socially in the LTC system, as the biomedical model has claimed the bodies of individuals as merely an empty vessel through which symptoms of one's diagnosis are displayed. CNI works to challenge such notions, by creating a communicative space where persons with YOD can reclaim narrative agency, and through that, citizenship.

This chapter will begin by providing an overview of CNI as an overarching methodology, including discussions regarding its applications for this project. From here, I move into an exploration of the use of reflective online multimodal methods and collaborative braided narrative as an avenue through which the 'voices' of persons with YOD will not only be 'heard' but 'listened' to. Throughout this chapter, I highlight notions of narrative agency, narrative citizenship, and human rights and social justice orientations as key methodological tenets that will be addressed throughout the various aspects of the research process and procedures.

From Narrative Inquiry to Critical Narrative Inquiry

A Brief Background on the Narrative Turn(s)

"There are no truths… only stories" – *Thomas King, 1993*

Storytelling is not a new concept, but rather a longstanding tradition that has largely emanated from Indigenous cultures (Iseke, 2013). Historically and continuing into present day, Indigenous peoples have used stories for a number of purposes, of which this brief introduction cannot do justice. Two primary functions of storytelling, however, have been to teach individuals how to become better human beings, and to pass down wisdoms such as histories, skills, and cultural knowledge (Lawrence & Paige, 2016; King, 2003, Iseke, 2013). Within such purposes are lessons on reflection, the importance of listening, and respecting and learning from lived experiences of self and other (Lawrence & Paige, 2016). Storytelling has also been a way to convey history across time and space, which has provided a means through which Indigenous groups have preserved their culture (Iseke, 2013; Lawrence & Paige, 2016). Such practices have demonstrated the importance of storytelling for challenging dominant discourses, as the history and representation of many Indigenous cultures are absent or morphed, leaving mainly dominant perceptions to be seen (Iseke, 2013; King, 2003, Sium & Ritskes, 2013). Storytelling has thus allowed for new knowledges to be introduced, which has and continues to influence shifts in societal perceptions and understandings.

Storytelling as an approach to knowledge sharing has become an important approach to research, and has inspired new methodologies to emerge (Iseke, 2013). One such methodology is narrative inquiry, which established foundations within a number of diverse disciplines (i.e., literary studies, historiography, anthropology, psychology, sociology, and the humanities to name a few), and developed over time as a critique of positivist research; a need was recognized to move beyond ‘discovering’ to the acknowledgement of the importance of understanding. As such, qualitative research began to challenge the notion of a single **T**ruth, to a new understanding that there are multiple and fluid **t**ruths. Pinnegar and Daynes (2007) identified several common key themes across the turns that have taken place to set the foundation for narrative inquiry to exist as it is known today.

Firstly, the relationship between the researcher and the researched has moved from “a position of objectivity defined from the positivistic, realist perspective” and “toward a research perspective focused on the interpretation and the understanding of meaning” (Pinnegar & Daynes, 2007, p. 7). This demonstrates the acknowledgement of a relationship and relationality between the researcher and the researched and brings a new awareness to the roles and interactions in the dynamics between the researcher and the researched. Secondly, rather than a focus on generalizability, the development of narrative inquiry has shifted the focus to the ‘particular’, that is, researchers have come to understand “the value of a particular experience, in a particular setting, involving particular people” (Pinnegar & Daynes, 2007, p. 14). Lastly, Pinnegar and Daynes (2007) identified the fourth common turn to be a shift from believing that there is one way of knowing the world (**T**ruth) to understanding that there are multiple ways of knowing and understanding human experience (**t**ruths). Shifts in assumptions throughout these narrative turns has established narrative inquiry as a way to understand human experiences and discover meaning within these experiences.

Constructing and Reconstructing Our Lives Through Stories

Stories are not pre-set, unchangeable destinies, but rather a way for individuals to make sense of their lives, past and present. Dupuis and colleagues (2016c), explained that "[i]n the day-to-day living of our lives, we story our lives and ourselves" and that "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). Such an understanding of stories speaks to how reflecting and sharing stories about our lives, can influence the way that we perceive ourselves as human beings on an intimate level, as well as within broader social contexts. Understandings of our stories are also not stagnant. As we are exposed to new experiences, changing social and cultural contexts, as well as interactions with the stories of individuals around us, our perceptions of ourselves and our stories both past, present, and future may shift. For example, growing up one may fear 'growing old' due to the impending biomedical discourses of deficit and decline that we are so exposed to. However, as one continues to age, reflections on past assumptions may push one to acknowledge the social pressures that framed aging in a predominantly negative way, and through which new experiences and interactions with others may reshape one's perception of aging in a positive way (i.e., retirement, travel, a growing family, etc.).

Despite our ability to derive meanings from our stories, there are societal and contextual pressures that try to manipulate us into understanding our stories in a certain way. For example, dominant discourses around aging and dementia portray how individual lives are *supposed* to unfold, and stories that deviate from these normative standards are considered ‘failed stories’ by individuals who believe in an ‘idealized’ life trajectory (Hyden & Antelius, 2011). Contrary to this belief, and what I believe to be beautiful about the nature of stories, is that there is an unpredictability about which ways stories will twist and turn as they unfold, fostering notions of hope and endless possibility. As such, people living with dementia, from which ‘Others’ tell stories through the lens of biomedical and dementia as tragedy discourses, do not have to accept this story trajectory. Instead, persons living with dementia can expose these harmful discourses by sharing alternative counter-stories about living with dementia, and sharing such stories in ways that may not seem conventional based on ‘normative narrative ideals’ (Dupuis et al., 2016c; Hyden & Antelius, 2011).

What is important to recognize about narratives and narrative storytelling is that there is an opportunity to move beyond the use of ‘normative narrative ideals’ such as speech and text. Hyden and Antelius (2011) noted the value in focusing on “*how* stories are told in interaction using several different communicative modalities (language, paralanguage, gestures, eye movements, bodily positions, material and social artifacts in the immediate context, etc.)” (p. 591), thus valuing the use of all communicative resources in a narrative situation. Dupuis and colleagues (2016c) drew attention to the idea that “[o]ur stories are created through and within our bodies, but our bodies are also an important means by which we come to understand and share our stories”, such that “our bodies are expressions of our stories and our stories are expressions of our embodied experience in the world” (p. 329). To bring all of these thoughts together, we can see that: 1) stories are one way through which individuals derive meaning from their lives pertaining to aspects such as identity, life experiences, and surrounding contexts; 2) stories, and the meanings derived from them, are fluid and susceptible to change; 3) stories are influenced by pressures from dominant discourses; and 4) sharing stories through different modalities can resist and challenge dominant discourses, and open up new possibilities and ways of knowing. As will be discussed in the sections to come, opening up a narrative space for persons with YOD to share their stories in unique ways, provides an opportunity for the reclamation of narrative agency, through which citizenship can be reinstated (Baldwin, 2008).

Engaging Critical Narrative Inquiry

Denzin and Lincoln (2008) defined narrative inquiry as “a form of inquiry that analyzes narrative, in its many forms, and uses a narrative approach for interpretive purposes” (p. 649). However, a researchers’ positionality will influence the way one takes up and uses narrative inquiry. As such, I integrate my positionality as critical researcher to use narrative inquiry not just as a way to understand the unique experiences of persons with YOD, but to utilize the stories in a way that challenges dominant discourses around aging and dementia, and to highlight the urgent need for LTC reform to address the injustices being experienced by persons with YOD in this context.

Given that the ‘voices’ of persons with YOD have been overlooked in LTC, in addition to the harsh realities that are emerging from these homes in the face of COVID-19, I feel that there has never been a more important time to break the silence by using CNI to bring the perspectives of younger persons with dementia to the forefront in the discussions that will no doubt be taking place about the future of care. In qualitative research, “narrative is highly valued because it is rooted in time, place, and personal experience and serves as a vehicle for understanding identity, human agency, and the embeddedness of individual lives in the broader culture” (Daly, 2007, p. 23). As has been unpacked in the previous two chapters, the LTC environment strips persons with YOD of their agentic capacity and dictates a forced identity, and so narrative inquiry creates a space through which individuals can reclaim their narrative agency and citizenship. Baldwin (2008) provided two conditions that narrative agency depends upon, which are:

1) “being able to express oneself in a form that is recognizable as a narrative, even if one’s linguistic abilities are limited
2) “having the opportunity to express oneself narratively” (p. 225)

I believe that the first of these conditions speaks to what was discussed earlier about the importance of not just speech and text in ‘telling’ and ‘listening’ to stories, but also the use of other communicative resources – verbal communicative abilities are only one of many communicative capacities that are helpful in sharing and understanding stories. The second condition I believe speaks to creating a communicative space for, in this case, persons with YOD to connect and share stories in unique and creative ways not only on an individual level, but on a collaborative level as well. Creating this virtual space to share stories through the establishment of an online platform is crucial at a time when many people with dementia are in isolation due to the strict emergency protocols of the pandemic, and a time where serious systemic reform is now more than ever an urgent demand.

Attending to these conditions, this research challenged notions of persons with dementia as ‘lacking agency’ by facilitating self-expression through a range of ways including supporting creative expression; a process which has been recognized as supporting persons with dementia in reclaiming citizenship (Dupuis et al., 2016b, Kontos et al., 2017, 2018, 2020). By valuing experiences beyond that of verbal capacity, and embracing difference through the recognition of creative and multimodal expression, narrative agency becomes a strong tool through which individuals can engage in creative expression and reclaim their rights as citizens.

Using a Three-Dimensional Space to Move Beyond Narrative Structures

To guide this CNI I felt it important to use a framework that aligns with my belief of citizenship as a personal, political and relational construct. I found Clandinin and Connelly's (2000) three-dimensional space reflective of these areas through its attentiveness to exploring the experiences of individuals *temporally* (individually perceived timing of life events), *socially* (the personal, social and cultural), *and spatially* (the physical landscape/environment). In the context of this research, this three-dimensional space creates an awareness to:

1) Temporality: For persons with dementia, time is not always perceived and expressed as the traditional past, present and future tenses, but is often rather a sporadic and episodic experience. As the researcher, I was aware that the stories that emerged from this project may appear differently to what is commonly seen in the narrative research literature, however, it was important for co-researchers to reorganize narratives in a way that would take audiences on a journey (organizing episodic stories into a timely trajectory from pre-diagnosis to hopes and aspirations for the future). The temporality of this research is also an important consideration as the COVID-19 pandemic likely influenced present understandings of experiences, and perceptions of LTC.
2) Sociality: This research explored the thoughts and emotions of persons with YOD as they relate to stories of their experiences, LTC and support, as well as brought attention to events and (non)actions that are taking place in society. In discussions about LTC, attention was paid to the associated relationships and importance of relationships to the well-being of persons with YOD, as well as how these relationships are discussed within the context of care and support. Again, in the face of COVID-19 it was important to gain an understanding of the impact of these current events on perceptions of LTC.

Attentiveness to social space also calls for an understanding of the ways through which stigma, and inequitable unjust treatment are being experienced in the current cultural and social climate.

3) Spatiality: In the context of this research, this component draws attention to the LTC continuum, which can include attention to spaces such as "home care and meal and day programs, hospital-based care, retirement homes, small group homes, supportive housing and assisted-living facilities, and nursing homes" (Dupuis et al., 2012, p. 218). Past and present interactions, as well as future hopes for these areas of care were explored, with specific probing around LTC homes.

Together these components provide a framework that supports inquiry into the experiences of persons with YOD across time, space, and context, while also acknowledging the interactional and relational aspects of these factors in shaping experiences and expressions. I believe that doing so speaks to the personal, political and relational components of citizenship by moving beyond the narrative structures that restrict the uprising of *counter-narratives*. I will now move to a discussion on the ways through which CNI can help spark an uprising of counter-narratives in an effort to dismantle oppressive dominant ways of knowing.

The Uprising of Counter-Narratives: Dismantling Dominant Ways of Knowing

It is important to start by outlining the basic premise behind the concepts of dominant and counter-narratives: dominant narratives are those which present "normatively privileged accounts", and counter-narratives are those which "resist and take distance from such culturally privileged ways of telling" (Hyvarinen, 2008, p. 457). While it is helpful to understand this conceptualization of such narrative 'types', it is also important to note that such distinctions are not simple and clearcut, but rather complex. What I mean by this is that the sedimentation of dominant narratives on our being, consciously or unconsciously influences our perceptions of the world, meaning that in many situations individuals cannot help but be influenced to some degree by the pressure of dominant narratives. With this in mind, using the categorization of dominant and counter-narratives as a heuristic throughout this dissertation, is helpful for understanding the relationship and power dynamics between the two; that is, acknowledging the power of voice for igniting critical consciousness and challenging dominant ways of knowing. In order to awaken a critical consciousness, questions about how things are, and why things are, need to be asked. Gubrium and Holstein (2008) stated:

> Concern with the production, distribution, and circulation of stories in society requires that we step outside of narrative material and consider questions such as who produces particular kinds of stories, where are they likely to be encountered, what are their consequences, under what circumstances are particular narratives more or less accountable, what interests publicize them, how do they gain popularity, and how are they challenged? (as cited in Hyvarinen, 2008, p. 454)

CNI speaks to the questions posed by seeking to challenge established dominant narratives by creating space for alternative forms of knowing to be ‘heard’. As such, the recognition of the power of counter-narratives does not just lie in bringing attentiveness to the alternative discourses, but also in recognizing the ways through which these discourses are presented.

In narrative inquiry there has often been an emphasis on ‘normative narrative ideals’ such as using narrative interviews to obtain verbally communicated stories, which are then transcribed and translated into written text. This in its own way can be powerful; however, where the true power lies is in the recognition of stories that truly represent difference; that is, *how* the stories are told and shared. Critical scholars such as those using CG and CDS, have drawn attention to the importance of creative and multimodal expression as a means through which an individual can resist, communicate, and challenge dominant ways of knowing. For example, Hyden and Antelius (2011) draw attention to the array of expressions and communicative resources individuals engage to share stories, such as "gestures, the linguistic, para-linguistic, non-verbal and other physical artifacts that are used as resources in telling and listening to a story" (p. 590). They also draw attention to the idea that counter-narratives do not just have to be personal narratives but can also be collective or collaborative narratives. In order to be open to a variety of storytelling modalities, the incorporation of flexibility was a key consideration for this research.

The Importance of Flexibility as a Guiding Concept for this Project

Prior to delving into discussions about what inspired this project, methods selected, and research procedures, I feel it is important to explain how this project integrated flexibility from its onset to completion. In creating a research plan for this study, I did not have a sense of what the response to or up-take of this project would be, including the number of co-researchers that would be recruited, their age, type of YOD diagnosis, differing experiences and capacities, how co-researchers might want to participate, and so on. Keeping this in mind I proposed two potential overarching formats for this study (bullet one), as well as other ways to integrate flexibility:

1) In initial discussions with co-researchers (one-on-one when explaining the project, as well as in early group discussions – see Appendix F) I explored whether co-researchers would prefer to create their own individual story and representation, with which a care

partner or myself could have provided support if needed – or – if co-researchers wanted to work together to brainstorm and collectively create a story and representation.

    a. If most of the group wanted to create a collective story and representation but there were still individuals who wished to work independently, then I was prepared to make this possible. If needed, a care partner or myself could have supported the individual through the process, and then braided their story into the collective representation.

2) Also, throughout the project it was important to recognize that each individual might have required different types of support at different times. I remained aware of this, and kept lines of communication open as to how I could best support co-researchers throughout the project.
3) I also recognised that, in the time of the COVID-19 pandemic, persons with dementia might be feeling particularly isolated due to social distancing and strict emergency protocols. Seeing this as an opportunity to connect persons with YOD, this study remained open and flexible to the number of co-researchers who wanted to be included, and I was prepared to adapt the number of working groups as needed so that there were only a small number of individuals in each group.

As it happened, all co-researchers chose to engage in the collaborative processes of this project, and were at a stage in their dementia journey when this could be done independently of their care partner. Another aspect that became clear after getting to know the co-researchers was that they all had strong verbal communication abilities. For this reason, the virtual storytelling workshops ended up largely being verbal discussions, however, throughout the project and beyond the co-researchers have been sending multimodal mediums (i.e., pictures, videos, poems, etc.), which will be used to support and extend their stories in the final representation (see Phase 3 – Mechanics of Story Production).

Beyond these considerations, there were a number of other ways that this project had to consider flexibility to prioritize the needs and desires of persons with YOD who agreed to participate. What is most important to keep in mind is that this project remained open to going where the co-researchers wanted to go – it is after all the co-researchers' stories that make this project, and what, how and why these stories are expressed and represented was up to the individuals and the collective group who shared them.

Methods: Reflective Online Multimodal Storytelling

As a result of the pandemic and the inability to interact with co-researchers face-to-face, I grappled with how to best support persons with YOD in sharing their stories. Considerations were given to co-researchers' preference of communication style, and ways to capture stories of persons with YOD with minimal interference from care partners. Not doing so would add to the exclusion that exists in 'narrative norms,' which prioritize the discursive or textual aspects of stories (i.e., coherence), thus leaving persons with dementia appearing less agentic than what is actually the case.

Research rooted in CDS and CG have demonstrated the importance of using creative and innovative research methods that support individuals with diverse communicative strengths (i.e., Dupuis et al., 2016b; Hyden & Antelius, 2011; Hyden, 2013; Kontos, 2004), something which I was set on using despite the logistical limitations. In acknowledgement of this, I turned to the disability literature and came across a study by Sunderland and colleagues (2015) that fused the world of creative expression and digital storytelling in a project entitled, *1000 Voices: Reflective* *online multimodal narrative inquiry as a research methodology for disability research.* This study took digital storytelling research methods and added a critical twist, arguing that "when used sensitively and flexibly, multimedia narrative methods in particular can enable participants to richly communicate in their own words embodied and emplaced experiences that are relevant and important to them" (Sunderland et al., 2015, p. 50). In the context of Sunderland and colleagues (2015) work, they recognized the lack of representation of disabled people, as I in this research am acknowledging the lack of representation of people with YOD. Digital mediums and online platforms, therefore, have been recognized as an avenue through which the 'voices' typically marginalized and silenced in the virtual space can be reclaimed and used for transformational change (i.e., Gubrium, 2009; Hull & Katz, 2006; Meadows, 2003).

According to Flicker and Hill (2014), a digital story "is typically a 2- to 5-minute short film that synthesizes some combination of voice recording, still images, video clips, music or audio and text" (p. 269). However, in agreeance with Sunderland and colleagues (2015), this research engaged a broader conception of what digital life narrative can entail, which is one that allows for the inclusion of a wide range of multimodal mediums such as "images, audio files, written text or video testimony" (Matthew & Sunderland, 2013, p. 98). For this project, I saw the online platform being an important component for the representation of the co-researchers' stories. When discussing possibilities for representation with the group, the use of the Podcast Series and an interactive e-flipbook became a popular idea due to their interactive and engaging nature and the potential to be used for education and reaching a variety of audiences, as well as for the ability of the e-flipbook to incorporate multiple mediums to share information (i.e., poems, pictures, videos). The creation of an interactive e-flipbook will be discussed further in Phase 3 – Mechanics of Story Production.

Prior to explaining my use of narrative inquiry, I will first provide an overview of the work that inspired this project, which is that of Sunderland and colleagues (2015).

1000 Voices: An overview

Engaging with CDS, Sunderland and colleagues (2015) recognized the “call from the disability movement over the past forty years for the voices of people with disability to be heard in all decision making about policy and provision” (p. 98), and saw the potential of a digital storytelling approach to create a space through which this could happen. As such, Sunderland and colleagues (2015) set out to find creative and inclusive methods from which to collect the digital life stories of disabled people, a challenge which had not yet been widely explored by disability researchers. To speak to unique participant differences and preferences for creative expression, the researchers decided to explore the use of multimodal and intertextual storytelling techniques, which they defined respectively as “text and images that are combined to serve the narrative purpose” and “the shaping of one text’s meanings by other texts” (Sunderland et al., 2015, p. 53). As mentioned earlier, life narratives are about understanding contextualized experiences rather than assuming a historically complete, chronological, and accurate ‘telling’. For the researcher, this means understanding that the stories expressed are likely ‘partial’ stories due to the complexity of the interconnection between “the ‘told, ‘inner’ and ‘lived’ modes of participant narrative (Sunderland et al., 2015, p. 51), which are influenced by a number of contextualizing factors such as cultural, political, experiential, as well as the three-dimensional spaces of temporality, spatiality, and sociality.

The project was initially launched in December 2009 as an international web-based platform where individuals with disabilities of any age could display their digital life stories.

After four years, the study had 148 registered members and displayed 75 stories, the majority of which were in written form, but also included collections of photographs and short films, as well as submissions which utilized multimodal storytelling (Sunderland et al., 2015). One example provided of a multimodal storytelling submission was the submission of “22 poems and one ‘Acknowledgement’ in a collection titled ‘Charlie’s Poems’, which appears on the website as 23 short films with a written title and a text read aloud by the author” (Sunderland et al., 2015, p. 50). As this study took place over an extended period of time, it allowed for the inclusion of an online reflective component through which participants could revise, add to, remove, or replace their digital expressions as individuals gained new understandings and responded to new emerging experiences. In describing their work, Sunderland and colleagues (2015) ended with a detailed discussion of lessons learned and suggestions for the future use of this method in qualitative research. Sunderland and colleagues (2015) recognized that while having a large sample allows for many diverse ‘voices’ to be included and displayed, it creates limitations in bringing together this knowledge in a way that can be effectively used to make others ‘listen’ (a discussion I will return to). Creating a platform where people would be invited to ‘listen’ and hopefully be prompted to act was something that we, the co-researchers and myself, considered as we continued to think about representation. From here I will now move into a discussion on the research processes used, and the importance of integrating flexibility when working with persons living with YOD.

Research Plan and Processes: Applying Reflective Online Multimodal Storytelling

One adaptation that is worth noting prior to examining the proposed processes, is that where Sunderland and colleagues (2015) conducted a large-scale narrative inquiry (i.e., they had

148 registered members and were open to having more), I worked on a smaller scale with six persons with YOD. Firstly, I wanted to make sure I was able to give co-researchers my full attention in terms of being able to support individuals throughout this process. Secondly, it was important to have a small group of co-researchers for creating a safe space to come together for critical reflection and collaboration, and working together to create braided narrative and final representation (see section on the analysis process).

Thirdly, Sunderland and colleagues (2015) noted that while the project contributed to the widespread dissemination of the stories of disabled people into the public arena, the "move from increased visibility to bringing about social change requires further conceptualization and action" (p. 60). Having a smaller group of co-researchers not only allowed for a more in-depth exploration of individual narratives, but also supported a collaborative process of braiding the stories together into a powerful representation; a process through which individuals' stories may be lost in a larger group.

Lastly, qualitative research that uses purposive sampling, as this study did, (see recruitment), does so with the intent to promote the collection of "richly-textured information, relevant to the phenomenon under investigation" (Vasileiou et al., 2018, p. 150). It is not uncommon to have smaller sample sizes in qualitative research, with two well known journals, the *British Journal of Health Psychology* and *Sociology of Health & Illness*, publishing work with as few as six and seven participants respectively (Vasileiou et al., 2018). Rather than the quantity of participants being the sole factor to strong data collection, there are many other factors to consider that contribute to the richness of qualitative data obtained including but not limited to "the quality of data, the scope of the study, the nature of the topic, the amount of useful information obtained from each participant, [and] the number of interviews per participant…" (Morse, 2000, p. 3). Additionally, narrative inquiry is not feasible for studies of large participant numbers, as the goal is to gain in-depth stories, and thick description about a small number of people (Butina, 2015; Ponterotto, 2006).

Often, the strength of narrative inquiry is undermined by the post-positivist ideals of reliability and generalizability. However, narrative inquiry embraces the power of difference, and appreciates that stories will differ based on different circumstances of production, which is seen as a strength of this type of research (Abma, 2003; McMullen & Braithwaite, 2013). In fact, "a focus on generalisability would diminish the value of the local and particular, a key aim and strength of narrative work" (McMullen & Braithwaite, 2013, p. 95). By focusing on the stories told, and not on the number of participants, this research has been able to delve deep into each of the co-researchers' lived experience with YOD within social and structural worlds, and illuminate various roads to the present and directions forward (McMullen & Braithwaite, 2013). I will now move to describing the research process in more detail, starting with an overview of my process, followed by a more detailed discussion of recruitment, the phases of co-creation, and ending with a discussion on bringing the stories together through narrative analysis.

Project Overview[12]:

Gubrium, Hill, and Flicker (2014) outlined a three-phase process that can be helpful in guiding the use of visual and digital methods, which included: Phase 1 – Introduction; Phase 2 – Script drafting; and Phase 3 – Mechanics of story production. I saw these phases as being helpful for guiding co-researchers through my research process and adapted them for the purposes of my research. Drawing on Gubrium and colleagues (2014), and integrating aspects from Sunderland

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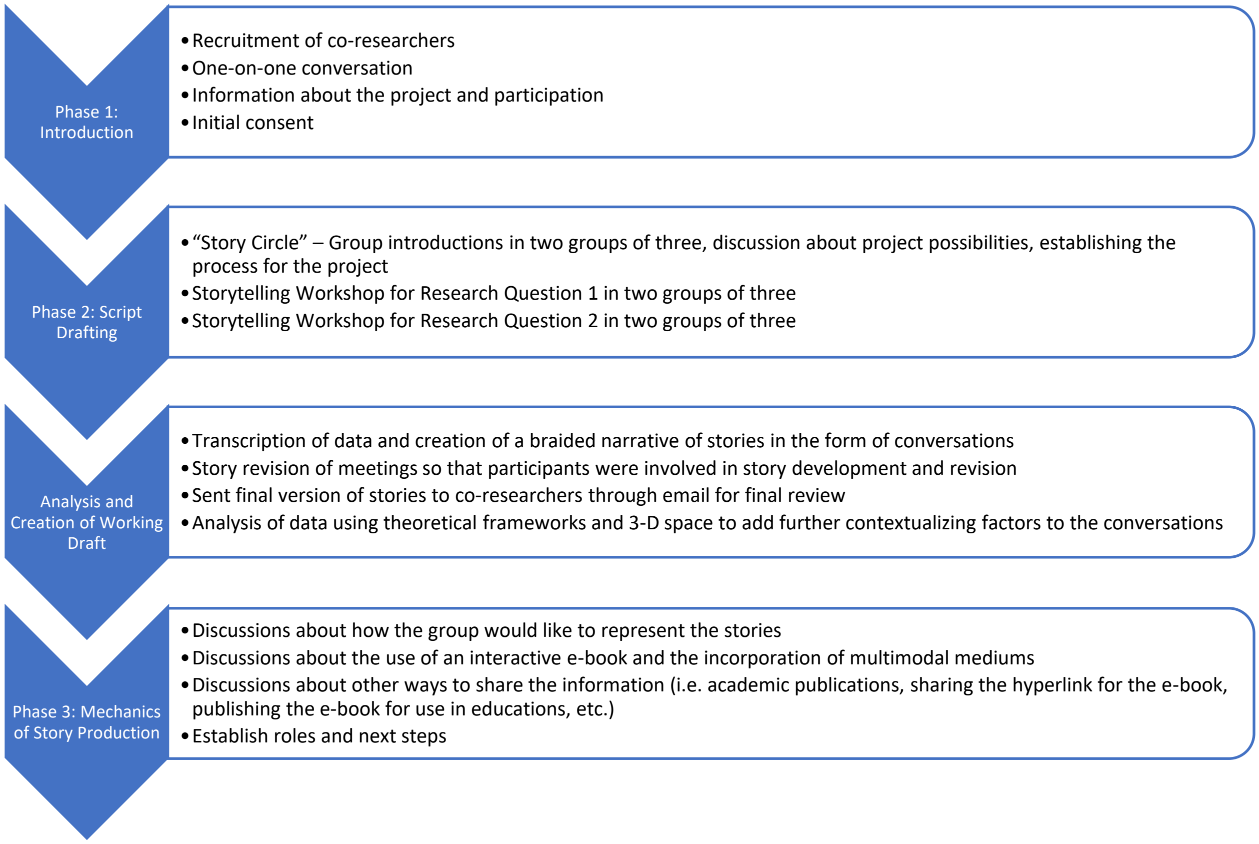
[12] This process was not necessarily linear as different components sometimes occurred at different or multiple times. For example, discussions about what and how to represent the stories occurred at most phases of data collection and revision.

and colleagues’ (2015) research process discussed earlier, the rest of this Chapter outlines these three phases as they unfolded in my process (see ***Figure 2***), starting with the Phase 1: Introduction to the Project.



- Phase 1: Introduction
    - Recruitment of co-researchers
    - One-on-one conversation
    - Information about the project and participation
    - Initial consent
- Phase 2: Script Drafting
    - “Story Circle” – Group introductions in two groups of three, discussion about project possibilities, establishing the process for the project
    - Storytelling Workshop for Research Question 1 in two groups of three
    - Storytelling Workshop for Research Question 2 in two groups of three
- Analysis and Creation of Working Draft
    - Transcription of data and creation of a braided narrative of stories in the form of conversations
    - Story revision of meetings so that participants were involved in story development and revision
    - Sent final version of stories to co-researchers through email for final review
    - Analysis of data using theoretical frameworks and 3-D space to add further contextualizing factors to the conversations
- Phase 3: Mechanics of Story Production
    - Discussions about how the group would like to represent the stories
    - Discussions about the use of an interactive e-book and the incorporation of multimodal mediums
    - Discussions about other ways to share the information (i.e. academic publications, sharing the hyperlink for the e-book, publishing the e-book for use in educations, etc.)
    - Establish roles and next steps

Figure 2: *Overview of Research Processes*

Phase One: Introduction

In this phase, Gubrium (2009) suggested providing an “overview of digital storytelling in which participants become better acquainted with the digital storytelling process” (p. 188). In terms of this project, I interpreted this phase to mean providing an introduction to the research project, including a discussion about narrative inquiry and the possibilities for using multimedia as a supportive storytelling platform. More specifically, after obtaining ethics approval which was confirmed mid-March, 2021, the first phase of this project began and included, recruitment of co-researchers, introductions and sharing information about the project, obtaining informed consent, and discussions around possible tools for representing co-researchers' stories.

Recruitment: Engaging co-researchers in sharing their stories

This research used a purposive, 'criterion-based sampling[13]' technique for recruiting co-researchers. Bryman (2008) explained that purposive sampling is "a non-probability form of sampling [where] [t]he researcher does not seek to sample participants on a random basis" (p. 415). He went on to explain that the goal of this sampling method is to "sample cases/participants in a strategic way, so that those sampled are relevant to the research questions that are being posed" (p. 415). In addition to criterion-based sampling, I also used snowball sampling, which I found to be more effective in my recruitment process. What this means is that I used "initial contact with a small group of people who are relevant to the research topic and then use[d] these to establish contacts with others" (Bryman, 2008, p. 184). Using these two techniques, three co-researchers were recruited via contact through organizations, who then referred three more co-researchers.

As I mentioned earlier, I intentionally was seeking a small number of persons living with YOD so that I could ensure that I was able to adequately support all the co-researchers who agreed to participate. To be eligible to participate in this project, individuals had to meet the following criteria:

- Co-researchers *had to have a diagnosis of YOD, that is, individuals had to have been diagnosed before the age of 65* – This criterion was selected to be in line with the WHO's

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[13] I have put criterion-based sampling in parentheses as I hold tension with this terminology. I feel as though such terminology connotes ties with foundationalist and post-positivist research through the categorization of what is deemed an 'acceptable' participant.

(2012) definition of YOD. The length of time that an individual had been diagnosed was not considered a criterion, as I believe that even individuals who have recently been diagnosed have important experiences and perceptions to share, and contributions to make.

- Co-researchers *had to still be under the age of 70* - Originally, I had intended to recruit people who were only under the age of 65. However, when I started to do my search for co-researchers, I found it was difficult to find individuals who were still under the age of 65. Some of the co-researchers who agreed to participate in the study knew people who had been diagnosed with YOD prior to age 65 but were now older. As I reflected more on this, I realised that although people may be diagnosed with YOD earlier in life, they often continue living with a diagnosis of YOD into later life and still have important stories to tell about their experiences as a person diagnosed with dementia as a younger person. I made the decision to extend my age criteria to people under the age of 70. I felt it important to extend the age distinction as it could provide an opportunity for generational and life stage differences to be highlighted in the sharing of stories and experiences.
- Co-researchers *had to have some level of ability to participate, or, availability to someone who could support their participation* – As this project occurred virtually during a pandemic, I was unable to physically support younger persons with dementia in person. Although this was the case, I did my best to provide support virtually by being available by phone, email, video-chat, or any other means suggested but I also recognised that some of the co-researchers might also need or want the support of a trusted care partner as well. Therefore, I was fully supportive of the collaboration of persons with YOD and care partners, if this was something that was available and chosen by the individual,

however none of the co-researchers requested this. A couple of the co-researchers had care partners close by during the calls in case they needed help remembering a particular story or to answer a question, but the involvement of these care partners was very minimal. Had any of the co-researchers chosen to have their care partner involved at a deeper level, there was eligibility criteria in place to support this.

- Co-researchers *had to have access to some form of communicative device (phone, email, video-chat), as well as any electronic and digital devices they wished to use for this project* – Given that this study had to be conducted virtually, it was important that co-researchers had access to (and were able to be accessed by) phone, email, or video-chat. I also felt that this would help me better support co-researchers as needed. If co-researchers wanted to engage with creative expression such as photography or videography, individuals also had to either have or be able to source the equipment or materials necessary to do so. That being said, if needed, I was prepared to support co-researchers in finding the equipment or materials they needed, such as by looking into ways the local Alzheimer's Societies and other organizations may be able to provide these resources. All co-researchers had access to the materials needed, and thus this support was not necessary.

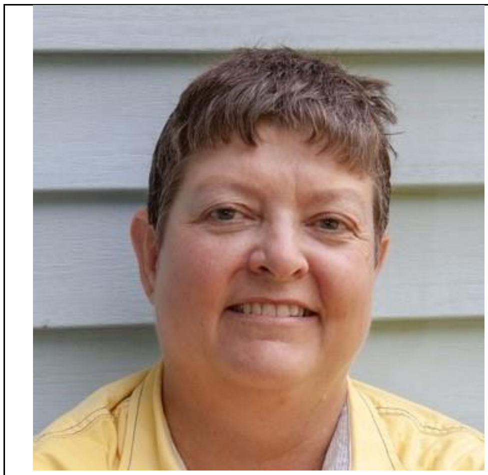
To recruit persons with YOD, I contacted a number of local and provincial organizations such as the Ontario Dementia Advisory Group, Alzheimer's Societies, the Young Onset Dementia Association, the Wednesday Night Joes, and the Boomers Club (see Appendix D). Information letters (see Appendix A), and an email script (see Appendix E) were provided to the organizations who agreed to help bring awareness to this project in their community. Organizations were asked to share the information letters with people meeting the eligibility criteria, from which interested co-researchers contacted me directly using the information provided in the letter.

Meet the Co-researchers

Through the recruitment processes, a total of six co-researchers reached out to me and agreed to participate in this project. To provide the opportunity for co-researchers to share information about themselves that they felt was important, individuals were provided the option to submit their photo and a biography. It was important to the co-researchers to put faces to the stories, which is how this idea originated. All six co-researchers took this option. It should be noted that during the consent process (see Appendix F), all individuals wished to be identified in both the dissertation and any representations to come, including the use of multimodal texts (pictures, videos, audio, poems, etc.).

 Dave Wastle	My wife and I have been married for 41 years and have two grown children and three grandsons. Seven years ago, we were in Provence in France renovating a medieval hamlet as a Christian retreat centre, when we discovered that I have early onset dementia. We moved back to Ontario 6 years ago to be near family and memory resources and programs. Next to faith in Jesus Christ, family and friends, I am very thankful for the following resources: Alzheimer's 101 and Friendly Visits, YODA, and Golf Fore Life. I am able to perform many activities and still score very well in mental aptitude tests. But I do have over twenty symptoms such as social encounter limits, hesitations, unease, forgetfulness ... We are living with this new normal and besides reading, walking, biking, puzzling and stained glass projects, one of the ways that I cope with this condition is volunteering. This has included our home church, a retirement home, our condo building and the Alzheimer's Society. So I say, ask away about life with Dementia, (and don't get me started sharing about our Mediterranean life unless you have some time. :-)

 Rose Ong	What I was – a boring accountant with a very boring life. What I am today – a co-founder of the YODA Group (Young Onset Dementia Action Group), an advocate for people with Young Onset Dementia (YOD), a writer, a poet who is quick to address anyone (esp. politicians) or any group of people as to the plight and stigma we all face as people with YOD. We are not "the walking dead"; we are living our lives to the fullest. We have our limitations, but embrace our challenges and encourage one another to speak up for our rights as Canadian citizens. Married 35 years, mother of two sons and a Nana to one granddaughter, my life is full.
 John Hammel	My wife and I have been married for 30 years and happily live in London Ontario, with our beloved dog punkie. For 26 years I worked as an insurance broker, constantly driving across southern Ontario interacting and socializing with my clients. I was an outgoing person and enjoyed staying busy with various hobbies such as playing hockey, working on the computer, and listening to music. Six years ago, I started to notice changes in my health and sought medical attention. Fast forward two years and I was diagnosed with early onset dementia, evidently forcing me to retire. Although my life has changed my outlook on life has not. I have never been a "what if" person, so when I was diagnosed, I accepted it, and was determined to know more about what was to become my new "normal". My wife and I immediately got involved with The Alzheimer's society and that has been one of the best decisions we have ever made. The Alzheimer's society has provided me with opportunities I never thought I would have in life and more importantly has allowed for my wife and I to cope with the various aspects associated with dementia. I now think of myself as an advocate for early onset dementia and am determined to share my life story with others helping to spread awareness and fight the stigma associated with the disease.

 Mary Beth Wighton	My name is Mary Beth Wighton. I'm 54 years old and have a diagnosis of probable Frontotemporal Dementia. I received it at the age of 46 years old. I am the co-chair of Dementia Advocacy Canada – a national grass roots organization made up of PWD and Care Partners. My work crosses many initiatives including membership on the Ministerial Advisory Board on Dementia established by the Federal Minister of Health providing input into Canada's National Dementia Strategy; the Alzheimer Society of Canada COVID-19 Task Force; a founding member of the World Health Organization project: "Network of expert reviewers for the Global Dementia Observatory." and many others.
 Paul Lea	I am a 69-year-old stroke survivor who is living well with dementia. It was a massive stroke that basically killed quarter of my brain and left me with vascular dementia and other deficits. I am a dementia advocate and a spokesperson for the Alzheimer's Society. A few decades ago, Mark Twain said: "There are two days that are very important in your life - one is the day you were born and the other was the day you realized why you were born." I was born to be an advocate to speak for those who can't and to try to end stigma.
 Kathleen Vanderlinden	Hello there! My name is Kathleen, and I am person who is living with young onset Alzheimer's and Vascular Dementia as a result of my very severe stroke. If I can help anyone live a more happier productive life, then I have fulfilled my wish.

Obtaining Informed Consent

As co-researchers were recruited, I set to obtain consent. Traditional consent processes often reflect a one-time, unilateral transaction that imposes assumptions of ‘cognitive competence’, meaning that to provide consent, one must be ‘evaluated’ and ‘deemed’ able. In recognition of the exclusionary aspects of this for persons living with dementia, Dewing (2007) suggested the use of *process consent*, which is an ongoing process that continues throughout the entirety of the research project and centres around the person living with dementia. By moving away from a uni-lateral process, to one which understands the importance of interdependence and connectedness through relationships, this process “acknowledges that capacity is situational, that capacity can be present even after the usual legal threshold has been crossed and that it is often strengthened or even reinvigorated within an enabling and caring relationship” (Dewing, 2007, p. 13).

In addition to the processes of consent for persons with dementia described by Dewing (2007), Gubrium and colleagues (2014) outlined additional ethical considerations to keep in mind when engaging with participatory visual and digital methods. For the most part, these ethical considerations align with those of Dewing (2007) but provide more specific guidelines for what should be taken into account when engaging specifically with visual and digital methods. I felt that these were also important for me to consider in my process of obtaining consent and throughout the study. There are five interconnected and fluid (do not have to be linear) methods to Dewing’s (2007) process that I now describe. In this discussion, I integrate those considerations proposed by Gubrium and colleagues (2014) that were most relevant to my study.

Background and preparation: In this element, the researcher must make sure ‘permission’ is gained to access the person with dementia “from staff, relatives or another named person” (Dewing, 2007, p. 15). This part of the process is not proxy consent and has been critiqued for first having to converse and negotiate with ‘gatekeepers[14]’ rather than going directly to the person with dementia. Connecting with others who are in connection with or who know the persons with dementia well speaks to the relational aspects of consent and is intended to protect persons with dementia from harmful situations. In the context of this research and as previously described, I reached out to a number of local and provincial organizations as a means to connect with persons with YOD. Through these organisations, I wanted to give people living with YOD the information they would need to make an informed decision about whether or not they would be willing to participate in my project. This step connected me with a few co-researchers, who then supported me in recruiting more co-researchers by sharing the information with individuals who they felt might be interested in participating. This beginning process also allowed co-researchers to contact me at a time that would work best for them, allowing me to gain a baseline understanding about “how the person usually presents themselves when in a relative state of well-being” (Dewing, 2007, p. 16).

Gubrium and colleagues (2014) noted that an important part of this process, especially for ensuring enough information is provided for informed consent, is to address any confusion regarding what the priorities of the project are (i.e., the research itself or the practical implications). To address this concern, the information letter clearly outlined what the purpose and aims of the research were and what would be expected of co-researchers. I also had

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[14] “Gatekeepers are individuals, groups, or organisations who have control or influence over a researcher’s access to participants” (Andoh-Artuer, 2019, para 1)

discussions with co-researchers prior to the implementation of the research, where I re-iterated the specific goals, objectives, and procedures of the project for the research component, from which co-researchers had an opportunity to express any concerns or to ask for clarification. Discussions held at the beginning and throughout the project also allowed co-researchers to express their hopes and goals for the project and what they hoped to achieve through their participation. Overall, the group supported the foundational goals of this project, which was to work together to begin to re-imagine how support and care looks like for people with YOD in the future.

Establishing the basis for capacity: In initial interactions with persons with dementia it was important to be aware of six key areas for establishing a baseline of capacity, including "the person's usual self-presentation; the person's usual level of ill/well-being; how a decrease in the level of this person's well-being may be triggered; how any decreasing level of well-being can be recognized; any significant conversation or behaviour that might be indicative of a deeper psychotherapeutic need/intervention and how the person usually 'consents' to other activities and procedures within their day-to day life" (Dewing, 2007, p. 17). In the context of this research, I documented my interactions with the co-researchers so that I had a description of what these different factors might look life for each individual. In each subsequent interaction, I reflected upon these factors to recognize the extent to which an individual may deviate from their 'baseline' on a meeting-by-meeting basis. After getting to know co-researchers in one-on-one meetings, it became easier to recognize when someone was not having the best day. I found that if co-researchers were not feeling up to the meetings on the day they were scheduled, they would email me to let me know, and we found alternative ways to support the telling of their stories and gain their feedback. In other instances, co-researchers would show up early to our Zoom meetings and I would have some time to see how everyone was doing. In these cases, there were a couple of times I found out about difficult things some individuals were experiencing in their life, and expressed that they should feel no pressure to attend and to take the meeting off; we would then later connect one-on-one or via email.

Initial and ongoing consent monitoring: After initial interactions with gatekeepers and persons with YOD, I worked to gain initial consent (Appendix F). As this study was conducted virtually through video-chats on Zoom and e-mail, I made sure that co-researchers had access to an information letter (Appendix A) and also reiterated the information in initial one-on-one meetings so that any questions could be addressed. After going through the information letter together in the initial one-on-one meetings, we then went through an audio recorded oral consent process that was also briefly revisited at the beginning of every group meeting.

This project perceives consent/assent as a process rather than a one-time transaction. As such, if co-researchers were not feeling up to participating on the day of the scheduled meeting, they would either indicate this to me before hand via email, or come on the call early to say hello to everyone before removing themselves. For co-researchers who remained on the video-call, I would ask if it was okay to turn on the audio-recorder before providing an outline of what the plan was for that meeting, and ask if everyone was okay to continue. With the meetings typically ranging between 1-1.5 hours long, I made sure to also check in around the 45-minute mark to see if co-researchers were feeling okay to continue.

After the initial storytelling workshops were completed, I did a number of check-ins and revisited consent at the beginning of each meeting, as well as one-on-one to make sure that co-researchers were happy and comfortable continuing on with story revision discussions and planning for the representation. In one instance, I recognized a particular member was having a bit of a difficult time and so I checked in with the individual after one of our story revision meetings. The individual shared that they were going through some personal things and was having a difficult time maintaining engagement in the project. At this time, it was agreed that the individual's time with the project had to come to an end and that he trusted the group to continue to incorporate his stories into the conversation pieces and representation. It also agreed that I would share the final stories/representations with him once they were all completed, which I did.

If it had been determined that an individual was not able to complete their own informed consent, a process of assent would have taken place, whereby the power of attorney (POA) would have been asked to fill out the third party consent form (Appendix B) and the co-researcher would engage with assent processes throughout the remainder of the project (Appendix C). For this project, all co-researchers were able to provide their own oral consent and were cognizant in doing so. Also, should any of the creative contributions submitted by co-researchers (e.g., photographs, videos) have contained images of individuals other than the co-researchers themselves, consent would have had to have been obtained from those people (see Appendix I and J). This has not happened yet, however, collaboration with co-researchers on an interactive e-flipbook representation is still in progress.

Phase 2 – Script Drafting Through Storytelling Workshops

Gubrium and colleagues (2014) describe this phase as "a group process for sharing and receiving input on story ideas or scripts" (Gubrium et al., 2014, p. 1607). I interpreted this phase as presenting semi-structured open-ended questions to facilitate dialogue around individuals' experiences and future perspectives about living with YOD. Phase 2 took place in May, with meetings scheduled just over a week apart; a request made by co-researchers to support their recall about the project and the stories shared. During this phase I first met with each group twice (see Appendix G and H), for a total of four storytelling workshops, each taking between 1-1.5 hours to complete. At the beginning of the first meeting, we did introductions and allowed everyone to get to know each other for the first 5-10 minutes. After this, I provided a review of what each storytelling workshop would look like and provided an opportunity for co-researchers to give input on the process; the group was happy to begin engaging with the proposed plan. For the remainder of the first and in the second session, the co-creation of stories focused on exploring their experiences with YOD to date, and then the reimagination of what living well with YOD in the future could look like.

Where one would consider these group discussions focus groups, I prefer to view them as storytelling workshops, as it emphasizes the co-researchers' active role in guiding emergent processes (Abma, 2003). According to Abma (2003), storytelling workshops provide a space for people to come together and "communicate experiences, relate stories to each other and collaboratively create meaning" and also offers a "source for social negotiations and conversations between people" (p. 223). Within this perspective, storytelling is perceived as "a process that cannot be fully designed in advance, because its focus depends on the stories told by groups with a stake in the process" (Abma, 2003, p. 224). I integrated this idea with some of the notions provided in an episodic interview technique, primarily using semi-structured guiding questions to support the telling of experience-centred narratives (Mueller, 2019). Using such techniques provided some guidance to the topics discussed, while leaving room for the co-researchers to be active members of the process, including in story revision, the identification of missing areas of discussion, and selecting particular "episodes" (Mueller, 2019, p. 4) to be included in the final representations.

While ideally only guiding questions would be used to allow for freedom and flexibility in the responses of co-researchers, I prepared some extra prompts in case individuals needed extra guidance. As such, I developed possible prompts to use to help fill out the stories if needed. In ***Table 2*** below, I have aligned the questions and prompts with the research questions posed in Chapter 1, and indicate the relative narrative three-dimensional space the questions are meant to address. Again, the questions and prompts in the first row of the table were the focus of the first part of the storytelling workshop sessions (addressing research question 1), and the questions and prompts in the second row were the focus of the second part of the storytelling workshop sessions (addressing research question 2).

Table 2: *Guiding Questions to Support the Telling of Stories*

Research Questions	**Guiding Questions**
What stories do persons with YOD share about their experiences of YOD and with the LTC system? How do individuals envision their care changing over time? What place, if any, do LTC homes play in their stories of care? What do these stories tell us about how stigma is experienced by persons with YOD in LTC and contribute to the normalisation of inequitable and unjust treatment of persons with YOD? *(see Appendix G)*	• What do you want the world to know about you and your experience of living with YOD? • What has supported you on the dementia journey so far? (temporality) ○ What challenges do you see in the future? (temporality) ○ What concerns do you have about your care journey in the future? (temporality) • What are your perceptions of LTC homes? To what extent do you think LTC homes could support you in the future? (spatiality, temporality) • What is a story of an experience you have had with the healthcare/LTC system? ○ What was that experience like for you? Who was there? (sociality) • What concerns you about the current healthcare/LTC system? (sociality)

	• What concerns you about the current healthcare/LTC system based on the stories that have emerged from the COVID-19 pandemic? (sociality, temporality) • What is a story about a negative experience that you have had with the healthcare/LTC system? ○ What was that experience like for you? Who was there? (sociality) • What is a story about a positive experience that you have had with the healthcare/LTC system? ○ What was that experience like for you? Who was there? (sociality)
According to persons with YOD, what do persons with YOD need to live well that needs to be considered in a re-imagination of caring for persons with YOD? What does a re-imagined approach to caring for people with YOD look like from the perspectives of people with YOD and care partners? What do the stories shared tell us about the action that needs to be taken to re-design the system? What ways can policy makers, healthcare professionals, organizations, and researchers contribute to putting the changes suggested into motion? *(see Appendix H)*	• How do you imagine the future unfolding? (temporality) • What aspirations and hopes do you have for the future? (temporality) • In an ideal world, with no limitations, how do you imagine the future of care? (temporality) What would ideal care and support look like for you in the future? ○ Where do you see your care taking place in the future? (spatiality) ○ Close your eyes… What does it look like? Who is there? What needs to be there? (spatiality, sociality)

Meetings Four-Nine: At the end of each storytelling workshop, the co-researchers and I often talked about ways they would like to share their stories. After having an understanding of what was important to co-researchers, and discussions with my supervisor, I explored with the group how we might intertwine the stories from both small groups. This discussion took place at the end of May, in a 1-hour meeting with all of the co-researchers, where we also did a larger group introduction and spent time discussing topics emerging from the stories shared that the co-researchers wanted included in the representations. At the end of this meeting, the co-researchers had identified a number of separate topics they wanted the conversations focused on. The co-researchers liked the idea of maintaining the conversational, collective aspect of stories we had created in the small groups, and suggested that I take the lead in weaving the stories around these distinct experiences, after which we would get together as a larger group to review, revise and create the final versions. After confirming this plan with co-researchers, I went ahead and started compiling the varying conversations based on what the group had discussed.

The group had decided that meeting every Friday, or in some cases every other Friday, would be best for the group. The morning of the meetings I would send out the stories of focus for that meeting, and during the meetings we would spend about an hour going through the draft stories and making the necessary revisions. The co-researchers consented to me audio-recording these sessions so that I could include their revisions and additions accurately. The larger group meetings were particularly emergent and flexible. During these meetings, additional topics that co-researchers felt were missing were identified as important. For example, it became clear that there was not a lot of conversation in the earlier small group meetings around palliative or end-of-life care, and so the larger group established this as an important topic to cover. They then proceeded to share their stories on this topic while being audio-recorded so that I could incorporate their stories before the final revisions. Although all members agreed to scheduled meeting times, there were some instances when co-researchers could not make it, and so I would connect with them after the meeting to catch them up and provide them an opportunity for their feedback.

Once the stories were compiled and approved by co-researchers, I shared them with my supervisor, Dr. Sherry Dupuis. While we agreed that the stories were powerful, we wondered how they might be used in a more creative way to really help people 'listen' (Sunderland et al., 2015). After reflecting on the desires of co-researchers and their commitment to advocacy, the idea of turning the conversations into a podcast series was created. I emailed the co-researchers to gauge how they would feel about using the conversations to create a series of podcasts that would feature their voices and experiences (essentially the conversation pieces we had collaboratively created) with the addition of me as facilitator of the podcasts who could also bring in context to the topics and conversations when needed. It had been a while since our last communication, so I did not hear back from everyone, however the co-researchers I heard back from supported the idea. The name *Hold on to Your Hats*, was inspired by one of our co-researchers who shared with us his special advocacy hat – a black hat with a blue forget-me-not ribbon on it - that he wears to spark conversations with others about dementia. I reached out to him to ask if he would be okay if we used a picture of his hat as our podcast logo, and he said yes as long as it came with the message "Dementia research gives us hope". The scripts for the podcast series are presented in Chapters Four to Seven of this dissertation.

Our Analysis Processes: Fusing Stories Through Braided Narrative

Throughout phase 2, I drew on different analysis approaches, both on my own and in collaboration with the co-researchers. In the case of narrative research with marginalized populations such as persons with YOD, the analysis process is one that will either support or inhibit the stories expressed being accurately reflected in the representations. What was first and foremost for me was ensuring that the analysis process was inclusive and privileged the voices of the co-researchers.

As a starting point in describing the analysis process, I believe it is important to identify the difference between *analysis of narratives* and *narrative analysis.* Drawing on the work of Bruner (1985), Polkinghorne (1995), described the former as "studies that consist of narratives or stories, but whose analysis produces paradigmatic typologies or categories" and the latter as "studies whose data consist of actions, events, and happenings, but whose analysis produces stories (e.g., biographies, histories, case studies" (p. 6). In other words, where the *analysis of narratives* moves from "stories to common elements", *narrative analysis* moves from "elements to stories" (Polkinghorne, 1995, p. 12). Narrative analysis is the process of bringing together and synthesizing the data, rather than separating it into parts, which by doing so "allows for the incorporation of the notions of human purpose and choice as well as chance happenings, dispositions, and environmental presses" (Polkinghorne, 1995, p. 16). Synthesizing stories provides an opportunity to highlight connections between the meaning of individuals' stories and the practical implications that the stories will have for creating change. What I mean by this is that by not melting stories into one, but rather creating a story that weaves together and pays attention to difference allows for the "presentation of a distinctive individual, in a unique situation, dealing with issues in a personal manner" (Polkinghorne, 1995, p. 18) while simultaneously providing a powerful collective message.

While this project set out to focus on narrative analysis, working with the co-researchers in the construction and revision of their final stories also led to the incorporation of analysis of narrative. More specifically, co-researchers worked with me during our storytelling workshops to elucidate topics of importance to include that lead to the development of overarching and embedded narrative dialogues around particular experiences or "episodes" (Mueller, 2019, p. 4) of their lives. To me, the creation of such topical categories speaks to the analysis of narratives.

That being said, our dialogues from two different groups, across four different smaller group sessions, were brought together to create storylines around particular experiences that would take audiences on a journey from pre-diagnosis to hopes and aspirations for the future. Further, in Chapter 8, a critical analysis of these compiled storylines, informed by four key frameworks -- critical gerontology, critical disability studies, Habermas's communicative action, and Clandinin and Connelly's three-dimensional space -- was provided that explored ways through which society has shaped these experiences.

After I compiled the group discussions, we came together during five 1- to 1.5-hour Friday meetings throughout July and August to review, revise, and add to the stories. For stories we were unable to finish during these meetings, we would use email. The group wanted to make it very clear that the topics of focus are not clean-cut and siloed but rather very interconnected. The four overarching narratives that guided us through co-researchers' experiences from past to future and everything in between, included *Shifting to New Realities*, *Recognizing and Resisting Ostracism*, *Learning from Past and Present,* and *Looking to the Future*. Within these overarching narratives are 11 nested narratives ranging from *"You better hope its not dementia" – Diverse Journeys to Diagnosis*, to *"It's like the Hamster on the Wheel" - Hopes and Aspirations Related to Care and Support*. While time is a very abstract concept, and not always perceived as a linear and straightforward construct, the group felt that presenting the conversations in such a way would take audiences on a journey through their experience. Interestingly, the journey is a common metaphor often used by people living with dementia and care partners to describe the dementia experience (Castaño, 2020; Zimmerman, 2017a, 2017b). Also, presenting the stories in a podcast format allowed the co-researchers' words and stories to be largely unaltered, and for myself as the researcher to incorporate my reflections in a way that did not overshadow the co-researchers' voices.

Throughout the analysis and interpretation processes, I drew heavily on the theories informing this work. As discussed in Chapter 1, the CG and CDS perspectives provide a strong framework from which the systemic oppression of persons with YOD can be challenged. Firstly, using CG to inform my analysis and interpretation allowed for the interrogation of the marginalization and discrimination of persons with YOD based on their age. In the analysis and interpretation then, I explored the ways through which the constructions of third and fourth age categories contribute to the construction and perpetuation of harmful discourses and discriminatory practices that were present in the stories of the co-researchers. CDS on the other hand informed the analysis and interpretation processes by bringing attention to the social and political nature of disability/aging. More specifically, by drawing on the relational aspects of the social model of disability as highlighted by Thomas (2004), I was able to look at the ways through which persons with YOD experience societal and structural oppression in their daily lives as a result of being viewed as "problematically different" (p. 29). In conjunction with this, the CDS framework calls for attention to civil and human rights concerns, and thus I was cognizant of the articles and principles of the UN CRPD, and the ways through which the stories shared reflected how these rights are upheld or violated for persons with YOD.

Within CT, Habermas's theory of communicative action was also used to inform the analysis and interpretation by specifically looking at the relations within and between the systems world and the lifeworld. In this sense, the analysis and interpretation were attentive to exploring the current state of the LTC system in Ontario, how it is experienced by persons with YOD, as well as how co-researchers hope the system will be in the future. By looking at the dynamic between the two worlds, I was able to draw attention to the attempts of the LTC system to control the life trajectory of persons with YOD, as well as some of the factors that motivate such colonization. Conversely, as this project creates a communicative space for persons with YOD, the analysis and interpretation were attentive to the ways through which the co-researchers have and continue to resist (or accept) pressures from the systems world to conform to the prescribed path of care.

Lastly, I used Clandinin and Connelly’s (2000) three-dimensional space to gauge the temporality, sociality, and spatiality of the stories shared by co-researchers. As mentioned previously, persons with dementia experience time in unique ways and so the analysis and interpretation processes reflected on the ways with which the stories were shared, while also respecting how co-researchers wanted their stories to be presented; that is, organizing the conversations in a way that took audiences on a journey through their experience from past to future. The sociality of the stories brought attention to the thoughts and emotions of co-researchers as they related to different stories, the events and (non)actions by society pertaining to inclusivity and change, the broad array of relationships experienced and the importance of such relationships to the well-being of persons with YOD within the context of care and support, as well as understanding the ways through which stigma and unjust treatment are being experienced in the current cultural and social climate. Additionally, since this research took place during the COVID-19 pandemic, it was important to address the additional impact of these current events on perceptions of the LTC system. Lastly, spatiality framed the project within the context of the Ontario LTC system, with specific probing around perception of LTC homes, as well as for exploring where persons with YOD hope and foresee their care taking place in the future. These overarching frameworks helped to contextualize the individuals' stories and experiences and provide a critical lens from which others can interpret the stories.

Braided Narrative.

A braided narrative is exactly what it sounds like – it is the weaving together of stories in a way that shows individual 'strands' (an individual's story), as well as the interconnected (relational) nature of this 'strand' with other 'strands' (other individuals' stories) (Bancroft, 2018). This technique was used to weave the conversations of all co-researchers together in a way that allows audiences to follow each individual through the various collections of stories and nested narratives. Braided narrative also allows for individual and collective stories to be woven together with the theoretical and contextualizing factors that guided the analysis (Quinones, 2016), as well as a way through which to integrate multimodal mediums into the representation (Marino & Jacobson, 2020). Bancroft (2018) described the power of a braided narrative in encouraging "readers to hold multiple, often incommensurate, subjectivities in [their] minds simultaneously, pushing [them] to embrace new channels of responsibility that recognize many distinct subjects" (p. 268). In line with Polkinghorne's (1995) narrative analysis, individual and collaborative stories were weaved together in a conversation presentation, while along the way identifying elements and influencing factors that have contributed to the stories expressed (contextualization by temporality, sociality, spatiality, and relevant theoretical frameworks). This therefore allowed this project to "identify action elements by providing the "because of" and "in order to" reasons" (Polkinghorne, 1995, p. 18).

Braided narrative practices have emerged from literary scholars who explored the power of contemporary novels that integrate the viewpoint of "multiple narrators who tell distinct, sometimes incommensurate, stories" (Bancroft, 2018, p. 262). Where I feel the power of the braided narrative lies is in ensuring that multiple and diverse experiences/perspectives are presented, recognizing that not all people living with YOD will have the same experiences, and in getting the audience to ‘listen’. The emphasis on difference urges audiences to shift the way they might have previously interpreted “collective injury" (Bancroft, 2018, p. 268) as a collection of experiences that are ‘one in the same’, to an experience that is seen as unique yet in ways interconnected. Had narratives been created/presented individually, or generalized into one compiled story, parts of the YOD journey would be missed. What is powerful about braided narratives, is that intertwining participant stories together allows audiences to gain a more complex understanding of the storylines, where audiences can ‘fill in’ gaps or extend their understandings about certain topics based on stories shared by other narrators (Bancroft, 2018).

Curtis and colleagues (2013) used a similar metaphor in the idea of braided streams. Within their description of processes, they drew on a definition of a braided stream provided by The American Heritage Science Dictionary (2005), which explained that: “Braided streams form where the sediment load is so heavy that some of the sediments are deposited as shifting islands or bars between channels” (n.p.). What I like about this idea, is that it reflects the notion of sedimentation, whereby over time, the pressure of dominant discourses amounts in such a way that blockages to critical consciousness are formed but can shift and change if influenced. In the context of this research, this can be applied to the ways through which co-researchers navigate dominant discourses and discriminatory practices, and the ways that their interconnected stories hold tension with or support one another’s journey to peeling away the layers of sedimentation through dialogue and the application of critical consciousness (Freire, 1970). Storytelling workshops provide a “reflective and collaborative space for analyzing injustice and oppression and articulating a more hopeful future” (Gubrium et al., 2014, 1607).

As briefly mentioned above, the braiding metaphor has also been used to describe the "braiding of theory, qualitative research strategies, and sociopolitical consciousness as an integral part of the research process" (Quinones, 2016, p. 341). To me, this means framing the research within critical theoretical frameworks, including everything from the development of research questions to the selection of methodology, to the analysis, interpretation and representation. Inspired by the use of multimedia in the work of Sunderland and colleagues (2015), this project also sought to braid in multimodal texts into the stories. Looking to the field of literary journalism, braiding has been defined as a process "in which two or more media appear together to create combined meaning" (Marino & Jacobson, p. 466), from which it was suggested that a *deeper* meaning can be derived compared to using only one form of text. As such, and which will be described in the following section, beyond this dissertation co-researchers and I are continuing to work on creating an interactive e-flipbook that integrates multimodal texts.

Phase 3 – Mechanics of Story Production

In the digital storytelling context, Gubrium and colleagues (2014), describe this phase as the last part of the workshop where the facilitator (researcher) and participants come together to compile their stories and multimodal texts in a digital representation. In the context of this research, this can be seen as being done in two phases. The first phase occurred during Phase 2, when co-researchers were active in creating the podcast script representation. Secondly, it was important to the group that their stories be shared to broad audiences as an educational tool about the realities of living with YOD, and possibilities for moving forward to a brighter future. As such, beyond this dissertation, co-researchers and I are taking the braided narrative to a further extent by working on pulling together an interactive e-flipbook compiled of their biographies, podcast scripts and audio, videos, poems, and links to helpful resources and information. Co-researchers have been active in determining what should be included in the e-flipbook, sending me content and links to resources through email. I am putting this information together for the e-flipbook and will share it with co-researchers for editing prior to sharing the html link that will be able to be disseminated widely.

The co-researchers are eager to have their stories shared in a way that reaches a variety of groups, such as policy makers, educational institutions and healthcare professionals, academics, and the general public. In addition to the publication of academic papers, the interactive e-flipbook will be an important way to access individuals beyond the academic realm. By doing so, this research hopes to widely disseminate and share the ways through which the existing inequities and injustices can be addressed, to open up spaces for dialogue and critical reflection, and spur systemic change into motion.

Ethical Considerations in the Construction of Stories

There were a few ethical considerations I needed to be aware of as we worked together to construct stories on the lived experiences of persons with YOD. Gubrium and colleagues (2014) identified the possibility that the stories shared may misrepresent persons with YOD and care partners or reify stereotypes, and therefore highlighted the importance of being attuned to this and having a process in place to ensure co-researchers were comfortable with the stories shared. To make sure the stories were true to what the co-researchers intended and were represented in a way they supported, the group worked both independently and together to create and revise all of the stories and brainstorm a plan for representation. As outlined in the previous sections, this was primarily done through larger group Zoom meetings and email.

In terms of misrepresenting or reifying stereotypes, Gubrium and colleagues (2014) suggested that the facilitators (i.e., myself as the researcher) “engage in critical dialogue with storytellers or audiences to challenge messages” (p. 1607). This refers to Freire’s (1970) processes of *praxis* described in chapter one, which was used intermittently throughout the project to guide co-researchers in critical reflection about both their experiences in the research process as well as about the stories they were creating. I drew on, adapted, and added to some of the reflective questions outlined by the authentic partnership approach (Dupuis et al., 2012b, p. 442) for this purpose, such as:

- What are the goals and expectations of the group as a whole?
- How can we support different styles and types of contributions?
- How can we ensure that all perspectives are understood?
- What is working well? What is not working well?
- How are we demonstrating that we value all perspectives and contributions?
- What assumptions are reflected in the stories? Where are these assumptions rooted?
- How do we feel about the final stories shared? What could we change or improve in future storytelling processes?
- How might other people living with YOD be impacted by the story? What stories are missing/left untold?
- How can we use what we have learned to move forward?
- What have I/we learned about ourselves during this process?
- How have my/our assumptions changed over time? (p. 442).

While I had these questions in mind and was able to incorporate them as needed, what was interesting was that the group was naturally very comfortable with one another, and critical of the current state of the healthcare system as it pertains to persons with dementia. Each co-researcher knew at least one other person and became quickly comfortable with the remainder of the group. I think one thing that supported this sense of comfort and bonding was first splitting the co-researchers into two small groups before combining into one larger group. This provided a space where a few co-researchers could build a sense of rapport and trust together and with me, before they did this with the larger group. In terms of critical thinking, co-researchers were always questioning *why* things were the way they are and suggesting alternative ways things could be done. The group also expressed that they really appreciated the group interaction for challenging their current ways of thinking and gaining other peoples' perspectives.

When it came to the research process, there were regular check-ins and consistent communication about what was working well or what needed to be adjusted to best support everyone. Changes to the process were adjusted as needed. This included adjusted the time between meetings depending on the groups needs and preferences, as well as providing stories for review through email in addition to the story review meetings.

Gubrium et al. (2014) also emphasised the importance of power sharing in the construction of stories, stating: "Storytellers are encouraged to tell their own personal stories; however sometimes tensions arise between emphasizing processes versus products. Facilitators may help "shape" the narrative to produce stories that will resonate with audiences, inadvertently imposing their own agendas. Sharing power often means losing control over messaging" (Gubrium et al., 2014, p. 1607). As I have mentioned throughout the methods section, collaboration with co-researchers was of the utmost importance to me throughout all phases of this project. To do so, I continually checked-in with co-researchers throughout the research process and was attentive to the co-researchers' well-being and autonomy of 'voice'. I tried to gently guide the conversations with the interview questions as a catalyst for conversations and the sharing of stories, and then removed myself to the extent possible while being there as a supportive resource and attentive listener. Working collaboratively on the braided narratives was an important part of our research process. Although I added my own reflections, interpretations and understandings of the connections between the stories and surrounding contexts as part of the analysis, I tried to keep this minimal in the podcast scripts, and used the discussion in Chapter 8 to elaborate further. I also made sure that the co-researchers had the final say on the stories that would be shared.

In the following four chapters, four overarching narrative topics will be explored – *Shifting to New Realities, Recognizing and Resisting Ostracism, Learning from the Past and Present,* and *Looking to the Future* - within which 11 embedded narrative storylines reside. These narratives are presented in the format of a podcast script, where I act as the host of the *Hold on to Your Hats* podcast series, a series that was designed to engage younger persons with dementia in dialogue around diverse topics.

Chapter 4: Braided Narratives Part One – Shifting to New Realities

Hello everyone, and welcome to our podcast series, *Hold on to Your Hats*, where myself and six individuals living with YOD engage in dialogue about some of the lived experiences of younger persons with dementia, past, present and future, including a reimagination of what the future of care could look like. My name is Sarah, and I will be your host, and with me I have John, Kathleen, Paul, Dave, Mary Beth and Rose (see Meet the Co-researchers). This podcast provides a platform through which the voices of younger persons with dementia can be brought to the forefront, a group whose stories are largely overlooked in society. Through these podcasts, this team of experts hopes to raise awareness about YOD, the associated challenging experiences, and the steps that need to be taken to address such challenges. Of utmost importance to the team is to shed light on the inequities experienced by individuals with YOD, and to use these stories as a direct message to healthcare professionals, policy makers, and government officials about the urgent need for change. As Rose said, "I think it's the responsibility of each of us that have young onset dementia to speak up for those of us that can't". For these reasons, we have decided to bring you a podcast to embrace and reflect our team's passion for and involvement in advocacy, education, and raising awareness about important issues in the lives of younger persons with dementia. In Part One of this four-part series, we will explore four key topics that help shed light on the experiences of people with YOD, which include: "You better hope it's not dementia” – Diverse Journeys to Diagnosis, “You can’t drive anymore” - Experiences of Losing a Driver’s License, “They weren’t downsizing, I just got the boot” – Forced Transitions Out of Employment, and “How you have to give up things is ridiculously hard” - Navigating Financial Challenges.

Podcast 1A: “You better hope it’s not dementia” - Diverse Journeys to Diagnosis

♪ INTRO MUSIC ♪

Sarah: Alright, welcome everyone to this week’s podcast on our first topic about diverse journeys to diagnosis. John, lets start with you. Could you tell me a little bit about your experience through the diagnostic process?

John: I ended up going to five neurologists. The first, in my opinion, thought I was faking because basically on the cognitive test he would give me the answers. Why do a test if the doctor's going to give you the answers? I really thought his opinion was that I was faking it. It was another two years down the road and five neurologists, trying to figure this out. They knew something was wrong, but they never could pin-point it. It was the fourth neurologist that was helping with the migraines, and he clued in and then sent me to a cognitive neurologist at [a Hospital]. That's when I was diagnosed. But first, the neurologist put me on antidepressants to rule out any other illnesses, and bloodwork. Then a month later, I went back and I got the diagnosis of probable Alzheimer's. He then told me I had to retire. Once my Life Insurance License expired, I fully retired. I then went to the Alzheimer's Society and said, “well, I'm retired, how can I help you guys now?” That's how I got into doing the volunteer stuff with the different groups, whether it's the Murray Alzheimer Research and Education Program, MAREP, or all the different study groups like this one.

Sarah: Thanks for sharing your experiences, that certainly is a lot to unpack. You know, we so commonly hear that the diagnostic process is lengthy and difficult, but to be perceived as “faking it” must have been discouraging to say the least. It sounds like your journey was not easy, but I think it is amazing that you were able to turn your challenges into an opportunity to engage in the community in new ways through volunteering. Kathleen, what about you? What was your experience like?

Kathleen: Well first I just want to say that it sounds like you had quite a challenging experience, John. I was very lucky, my family doctor is really good and up-to-date on everything and she was the one who said, OK, I think there might be something to look at, so I'm going to send you a referral to this hospital because they have an excellent geriatric clinic there. I saw the head, he was so terrific. He was young, up-to-date, and clear as a bell on everything. He looked at the whole picture of me, did an MRI and all sorts of things and said, “you have Alzheimer's, early onset Alzheimer's and you had a stroke”. Vascular dementia is a result of having a stroke. It was really good and he wanted to know how I'm feeling and how it's affecting me and he told me, “come back in two weeks, I'll want to talk to you then and see how you're doing.” He was terrific.

John: It was nice hearing your story, Kathleen, about that positive experience going through the doctor, because I don't hear that that often. It was neat to hear your story, it was a more positive experience of getting your diagnosis. Whereas I had to really proact to really push to get my answers… I look at the positive aspect of getting the diagnosis. I look at it as OK I have to get my affairs in order, but I proacted to that. So the nice part is, great, I can retire now and now I just have to deal with this dementia aspect of it and change how I do things. I think that's why they like me joining these groups is because I look at the positive aspects of it, which I’ve always done on everything. There's good hope in it and here's what you can do versus what you can't do. And that's one big thing that I've done.

Mary Beth: That’s a good way to look at it, John. It took four years to get a diagnosis for me. I think I've been diagnosed with 12 different things, and it just went on and on and on. So John, I'm like you in that I was happy to get the diagnosis because then you can say, OK, now I can work on something. And then figuring out that I am going to live longer than they say because I'm going to choose to ignore it, you know what I mean? It's so important that we have the appropriate information given to us, because it really affects how a young onset person could move forward, within their life.

John: For me, we were talking about the healthcare system, having the family doctors get a whole lot better educated about young onset. Even two weeks before I got diagnosed, my family doctor says, “no, you don't have dementia.” Then we got the letter from the neurologist stating that I have Alzheimer's. I found him not very helpful because I was high functioning and he missed all the signs, I find that frustrating. I found it disheartening and frustrating going through five neurologists to get diagnosed, and that shouldn't happen. They should be a whole lot better at picking up the signs of dementia than what they are. I find that really, really bad in the healthcare system.

Sarah: It is clear that the diagnosis process is complex. I cannot even begin to imagine the emotional rollercoaster that this journey has created for you, and many individuals who have gone through a similar process. There are clearly systemic challenges to the diagnosis of YOD that need to be addressed, including as you say John, increasing education and awareness amongst healthcare professionals.

Dave: I agree. I was just wondering John, when you were mentioning about getting a diagnosis, I wonder if there's some written or unwritten quota mentality out there. I don't know how else to put that. Are doctors less inclined to diagnose some things because they're told there's only so much in some sort of budget or allocation? Are there compulsions in the medical field, generally GPs where it all starts for us, that they are hesitant not just because it's hard news, but because there's some sort of limitation out there that's not too clear? I don't know, just a question because that should be clarified.

Rose: That’s definitely a possibility, Dave. I also wonder about the tests that they’re using to diagnose individuals with young onset. I began talking to my GP, and she put me through the MMSE tests, the Mini Mental State Exams, and I would just fly through that, that was not an issue. I really question whether that test is a good test for determining dementia because that test was not very good for identifying what I was experiencing. So she referred me to a neurologist who I saw on a six month basis for a while. She wouldn't give me any kind of a diagnosis, she wasn't sure what it was all about. I started that journey when I was 51. It took me a good eight years to finally get the final neurologist that I saw, and she said, “yes, you have young onset dementia.”

Sarah: Those are both really interesting points that I had not considered before. I feel like people who know about YOD, know that the diagnostic process is often difficult and lengthy, but why isn’t anyone doing anything about it? If we know this, what are the factors preventing change, and how do we address them? I know that there is literature out there that indicates the comprehensive processes that need to be explored, including different examination tools, but are people questioning the appropriateness and effectiveness of these different assessment tools or different assessment processes?

Mary Beth: What is also concerning is that in some cases, the diagnosis does not stick. Our current GP, she’s pretty good. She's still encouraging me to be very active, as active as I can be. I feel very fortunate that I have her. She keeps prompting me to go see a different doctor or neurologist or something else, and I just said, no, I'm not going. What happens sometimes, and I know friends of mine that this has happened to, is if you go to a different doctor they actually go back through all of your files and they re-diagnose you. And instead of having Alzheimer's, you don't have anything. And so these are people who have lost their jobs or are on some type of assistance, and then you're told no you don't have it. I actually refuse to go to see more doctors. I'm not going, I have dementia and that's it.

Sarah: Wow, that really happens? That is an experience I have not heard about before. The impact that must have not just on the individual, but also the family, has to be devastating.

Rose: Absolutely, that would be an awful experience, I can’t even imagine having to go through that. One of the things that I would really like to see is more timely diagnosis. If we know what's wrong with us then we can at least attempt to delay it. I wasn't able to claim any kind of disability because I hadn't been diagnosed as having young onset dementia yet. And even if I had been, I don't think young onset dementia is considered a disability yet. I think that's still working towards the road.

Mary Beth: I agree, Rose. Timely diagnosis is very much needed, but also having a more compassionate experience is necessary as well. I had someone say to me, “you better hope it's not dementia, because if it is, it's game over”… What happens for many of us at the time of diagnosis is you're literally told, “go home, and get your affairs in order.” And they're still doing that, even though there's been headway made. But make no mistake, you are definitely given the diagnosis of “you're going to be useless”. And so that mentality of putting us into end phase dementia is really detrimental to everybody, not just the person living with dementia, but to their family. That's why my comment about young onset and the lead up and then the actual diagnosis of a young onset person is really important because of the necessity to highlight, hey listen, if you got it, it sucks but you know, we've got a whole lot of living left and let's focus on that.

Rose: I had a similar experience, Mary Beth. The final neurologist admitted, “yes, you probably have young onset dementia,” but her advice to me was to get my affairs in order. And to me, that says that your life is over. I don't know how else you could describe what that comment means to somebody. To get your affairs in order, that means you're going to die, and there were no resources offered to me. I went home and I just kind of scratched my head and thought, what the hell am I supposed to do?

Sarah: I find it shocking that those are the ‘words of wisdom’ being passed on by diagnosing physicians. These experiences sound so similar to what Kate Swaffer termed Prescribed Dis-engagement, whereby physicians are quick to prescribe a future of deficit and decline, and social death for individuals who have been diagnosed with dementia. It is interesting how Kathleen described a different experience, and we can learn a lot from her stories about what needs to be in place to support more compassionate diagnostic experiences. It begs the question how do we ensure more consistent, compassionate approaches?

Paul: And then also referrals. References. When I was diagnosed, I wasn't told to go talk to anyone to help me, my daughter had to help me learn how to cope and a bunch of other stuff. I found Alzheimer's Society through MedicAlert.

Rose: I've been investigating that stuff too. I had tried to contact the Alzheimer's Society back when I first got my diagnosis about six years ago, and I was very disappointed in the way that I was treated. I got the distinct impression that they were much more comfortable dealing with caregivers than they were dealing with people with dementia.

Sarah: What is apparent to me through this discussion is the need to improve the diagnostic processes for younger persons with dementia on a number of levels. This includes but is not limited to aspects such as increasing awareness and improving education, questioning current assessment tools and addressing lengthy timelines, as well as ensuring better support for individuals and their families as they transition into this new chapter. I think bringing these stories to the forefront will help to shed light on the challenging experiences all of you and many others have had in the early phases of this new journey, and hopefully act as a catalyst to make potential changes into realities. I think the stories will also be influential in challenging dominant narratives around aging and dementia by demonstrating resistance to notions of Prescribed Dis-engagement, and illuminating a passion for living life to the fullest in new ways. I would like to thank you all for your time participating in this important discussion. I invite all listeners to join us on next week’s podcast, “You can’t drive anymore” – The Experiences of Losing a Driver’s License.

Podcast 1B: “You can’t drive anymore” - Experiences of Losing a Driver’s License

♪ INTRO MUSIC ♪

Sarah: Welcome back everyone, thank you for joining us again. On this week’s podcast, our team will delve into a common experience for people diagnosed with dementia, the experiences of losing a driver’s license. I’m going to open this up to the group. What was this experience like?

Mary Beth: I had my license revoked on the spot, without any understanding by the doctor of whether or not I could drive. She assumed I couldn't drive because of the diagnosis, which is probable frontotemporal dementia. What it did was it took away my independence in one second and it was not something I was prepared for. I went into the meeting and I had driven us there, go out of the meeting, and Dawn has the car keys. I've never driven since, nine years ago. I promised her I wouldn't, and that's probably the only reason why I don't. I couldn't drive now, but nine years ago I wouldn't have been the best driver out there, but I wouldn't have been the worst either. The process of how that happened, I still think is wrong, but she told me “legally, I have to do this.” If you want to try for your license again, it's going to cost you $350. I'm already stuck for cash, where am I going to get $350 from. So that's what happened and as someone young, I was always the driver for my family. That was a big deal.

Sarah: Driving provides autonomy for many people; I know it has for me. Since the minute I was 16 I’ve had my driver’s license. It is questionable that there was no process to determine perhaps a more gradual transition out of driving, but rather an immediate acceptance of the governing rule that diagnosis is equal to a license being revoked. I know it is different on some level, but this reminds me of the statement “innocent until proven guilty”, whereas here it is very clearly “guilty until proven innocent”. Surely there is a better evaluative process that can be used for individuals and their families who are still confident in the person’s ability to drive.

John: I can relate to Mary Beth’s story, because just recently my family doctor retired because of COVID, so a new family doctor came in, looked at my chart and said, “I want to take away your driver's license.” He never asked me anything, he just looked at the chart and said, “I think I'm going to take away your driver's license.” And I said, “Why? My driving is perfectly fine.” Then I presented my argument, I said “We've already come to the conclusion that other family members can decide when I am no longer able to drive. Just because you see the word dementia in the chart, does that mean I can't drive? People that drive with me or go with me, say my driving is actually perfectly fine there's absolutely nothing wrong with my driving.” He hasn't really brought it up since. But I did find it strange like you ran into Mary Beth, that just because you get a diagnosis of dementia, they automatically think you can't drive when there are other alternatives to actually make the decisions. Family members can actually decide and say, “hey, this person should have their license taken away.”

Sarah: This is another complex issue for me because the safety of others is also at stake. But this brings the process into question again for me. John, you mentioned that initially your license did not get taken away by your family doctor, yet Mary Beth’s doctor felt the need to revoke the license immediately. What is at the root of this? Does this not speak to the stigma associated with a diagnosis of dementia? Is it a legality issue or more so the fear of being sued in the event of an accident? Is there a way to adjust the process to satisfy both sides of this debate in a safe and just way? There is a lot of inconsistency and ambiguity around this topic that could benefit from a critical re-evaluation of current processes, and more clear articulation of the ongoing challenges for ‘both sides’.

Kathleen: I agree with what both John and Mary Beth had to say, alternative processes and actions need to be explored. For me I lost the ability to drive when I had my stroke. Right away it was taken. And I said, “That's fine”, because I do not want to cause death. But it was hard because here I was at 39 and I couldn't drive anymore. I was very proud and it was hard to say I need help. “Can you take me to something” because when Rob was at work that was really difficult because I had to find somebody to take me somewhere. That was so hard and so difficult to admit to myself.

John: Yeah, it is hard to ask for help. I think for people who can and wish to continue driving should have that option. I really think that's an area that they do need to change, where they should have the actual family members decide and go to the doctor to say when the person should have their license taken away. I know some spouses or caregivers will be in denial about that, too, but they'll leave it into the family member's hands when you can clearly see the person should not be driving. I find with young onset and what I also explained to the doctors, I don't have glaucoma. I am very strong still. I have fine reflexes, different than a person with late onset dementia has. There is a big difference between the two, taking a person with a late onset diagnosis of dementia versus a person with young onset dementia. There's a whole lot of different aspects in play there.

Sarah: You raise a few good points here, John, about alternatives to existing processes and making sure that the parties involved are open and honest about changing abilities with respect to driving. As it is such an integral part of autonomy for many, I think it would be beneficial to reappraise existing processes. Within this group alone, it is interesting to see the varying levels of comfortability with driving, which sheds some light on the benefits of more heavily involving persons living with YOD and their families in the decision-making process.

Paul: I loved driving but recognized myself when it was no longer safe to do so. I was taught by the best teachers in the world, and that's the army. I was in the Canadian army for three years and I used to love driving on streets and everything else. In 2010 after the stroke, I got into my car and it felt kind of weird, but I drove out onto the street, and went to drive away and I don't know why now, but it took me a half hour to back up and back into my parking spot and I got scared. I sold my car because I didn't want to hurt anybody. I let my license slide, it wasn't taken from me. I let it slide because I didn't want to drive anymore. I was also in a research project on driving and they had a simulator. When I finished that, I said, “Well, I guess I'm never going to drive again.” So, my biggest challenge now is riding a bike.

Sarah: I didn’t know that about you, Paul. Thank you for your service. That must have been a scary and surreal experience for you as someone who had loved driving so much in the past to then not know what to do. I think it is great that you have volunteered your time to participate in research projects related to this experience that is challenging for many living with YOD. The stories shared in this discussion really highlight the complexities of this issue, and direct future efforts in terms of critically evaluating existing and alternative processes. Thank you all again for your time today. We hope you will join us all again next week in our dialogue about forced transitions out of employment.

Podcast 1C: “They weren’t downsizing, I just got the boot” - Forced Transitions Out of Employment

♪ INTRO MUSIC ♪

Sarah: Hello everyone on this sunny Friday afternoon. Welcome back to our podcast series, *Hold on to Your Hats,* where myself and six individuals living with young onset dementia dialogue about their complex and challenging experiences, past, present, and future. This week our team of persons living with young onset dementia discuss their experiences of being forced to stop working post-diagnosis, and often times well before ‘retirement age’. Mary Beth, when did you know working was no longer an option and what was that like for you?

Mary Beth: I was 46 when I got my diagnosis and stopped working. I was getting things confused. Numbers just didn't mean anything anymore. I was very irritable. My whole disposition was changing. I was pissed off at people, I was acting unprofessionally. So, absolutely no, there’s no way I could have kept working. I used to call myself retired just because it felt better. It's interesting because now I'm 54, my friends are 55. They're starting literally to retire. And I'm thinking, oh, OK, this is good. Now I'm part of the group and we're all retired and it almost makes me feel better because you always want to be able to contribute, and when that ability goes away, it's really not a good feeling. So much is expected of us between that age of 45 and 65. This is when you're getting the mortgage paid off and you probably have a car payment still. You have this, that and the other thing you're trying to save up for so that when you are 66, you have money to retire. Well, we can't do that.

Sarah: Mary Beth, your story speaks to the pressure individuals usually experience between the ages of 45 and 65, a time where as the literature points out, is a time where many individuals are still employed to help support dependent children or parents, along with a number of other financial obligations. It must be scary to lose that source of income. I also find it interesting that it became an uncomfortable space for you in terms of “feeling out of place” and “losing the ability to contribute”. What I hope everyone here can agree on is the amazing contributions all of you have made, and are still making in the lives of persons living with YOD, even for example by agreeing to participate in this podcast. Rose, what was the transition out of working like for you?

Rose: I also started to notice some challenges with my work. I was working in accounting and I had to leave my profession behind at 51 years of age, just because I couldn't keep numbers in my head for long at all. My employer said they were downsizing, but they weren't downsizing. I just got the boot. I haven't been able to work in my chosen profession ever since then, I'm 63 now. I really want to see all of these different dementia groups trying to collaborate their ideas and making a difference. I've gotten to know people from all over the world with this Dementia Alliance International and some countries have really good ideas as far as the way people with dementia ought to be treated; how to work with somebody that has speech problems or whatever the issue is. They all have limitations, but they also have strengths. And that's what we need to start building on is the strengths.

Sarah: I love that idea, Rose. There needs to be a much greater systemic responsibility to inclusivity, and recognizing and acting on the changes needed to make that a reality.

Dave: I agree, that’s a great point, Rose. In my case I started to have less risk analysis than was appropriate and I wouldn't necessarily do the same safety things. That became a pretty high concern. My wife would challenge me on it, say "you really think you want to do it that way?" My life was in renovations and taking care of buildings and all sorts of tools, so it was a challenge to adapt to more caution.

John: I can relate to the experiences you all have shared so far. I was making way too many mistakes that I was not seeing because a lot of insurance is paperwork that you have to do. If you're getting names mixed up, and dates mixed up and getting all confused on your paperwork, the doctor said “you're running into a legal liability.” I think it was important that I did retire from that, and that's how he explained it to me. It made total sense. Actually, there's a bit of relief that comes into play because it took out the frustration since I was making so many mistakes. Working in my field really was not an option because of what I did.

Paul: There are definitely challenges to working after a diagnosis, but if there were more supports in place more people with dementia would be able to find employment. There are some people who have dementia who are still working and they're doing OK. The employer knows, they're understanding and dementia friendly, and the whole thing has to do with education. It's making people aware, it's like cancer. It's OK to have cancer and work.

Sarah: It must be frustrating when you start to experience challenges in a role that you had been so comfortable in before. If more supports were in place, more individuals living with dementia would be able to stay in their jobs, contribute to their companies in different ways, or find new employment opportunities. Removing the stigma from the ideas people have about what it is like to live with dementia would be an important part of this process, as you mentioned Paul.

Rose: Absolutely. I think more awareness and more education would help employers be more flexible and adaptable in supporting people with dementia. The biggest thing that affected me was I couldn't keep numbers in my head anymore, and I was working in accounting. If you can't keep numbers in your head as an accountant you're not worth anything anymore, right? So, I had to abandon that job. I couldn't think of another job that I could take on where I would have been trained as well as I was trained with accounting. I wish there had been somebody that could sit me down and run me through a few tests and tell me what I could have still been qualified for, because I really couldn't think of anything. Once you lose the ability to work with numbers, apart from maybe childcare or something like that, there is not much else I'm aware of.

Dave: Which would include vocational aptitude testing. Doing online testing with some coaching, "oh, you'd be good at this" or "have you ever thought of this because you answered yes, yes, yes over here and no, no, no, over here." It's zeroing in. "Have you ever thought of trying farming? Or operating bungee jumping?" Whatever, you wouldn't necessarily think of.

Paul: Great idea, that would be helpful. Three years ago, I decided I was going to try and get a part-time job and I decided to be a crossing guard, which I thought was good because I love kids and I can help them cross the street. I signed up, I got trained and I had my first assignment, which was Royal York and Bloor and it's a four-way intersection with stoplights. There was a crowd of people on one side and another crowd on the other side. After the light changed three or four times, I froze, I couldn't figure it out. Where do I go? I got scared and I just went back, turned the stuff back in and said "I can't do this." I thought I was OK, but really I wasn't.

Dave: Very brief comment about your crossing guard story, which I thank you for sharing. Well, you were kind of flung into the arena without special training.

Paul: I actually had training.

Dave: Yeah, but I mean special training because of our condition. That wouldn't probably have been even a thought.

Paul: I didn't let them know.

Dave: Ah there we go. Would they have necessarily done something different? Who knows?

Paul: I think if they'd sent someone with me to monitor what I do then I think that would have been OK, but I was there on my own, I got panicked and I said "I can't do this.” I didn't let them know because, first of all, I thought it would cost me the opportunity. Basically that's it, I thought it would cost me the opportunity to have a part-time job. So that's why I didn't tell them. It's one of the few cases I don't say that I've got dementia, but it's work you know, I didn't want to tell them that I have this condition and these cognitive issues. I thought of being Walmart store greeter. After the crossing guard incident, I didn't know whether I should try it or not.

Sarah: I’m sorry to hear that you did not have a great experience trying to get back out there Paul, and that you felt sort of a looming pressure to not disclose your diagnosis in fear that it would deter them from hiring you. What you and Dave talked about in terms of having specific and more supportive training would have been helpful in instances like this. What your stories highlight for me is that there are cognitive changes that happen with dementia but the fact that our society is not prepared to support people with YOD to continue to be included in the workforce is discrimination. Next week, in the final podcast of Part One of the series, we delve more deeply into the consequences of this exclusion and discrimination by exploring the financial challenges that are often experienced after diagnosis. Join us then! Thank you everyone.

Podcast 1D: “How you have to give up things is ridiculously hard” – Navigating Financial Challenges

♪ INTRO MUSIC ♪

Sarah: Hello everyone, and welcome back to our final podcast of Part One in the *Hold on to your Hat,* series. As a reminder, last week our team of persons with YOD shared stories of their forced exit out of employment with their diagnosis. This week we explore some of the consequences of that. To close Part One, our team describes the financial challenges experienced after receiving a diagnosis of YOD. John, I’m going to start by opening the floor up to you.

John: One of the biggest challenges I find with young onset dementia is the financial challenges. You have to stop working when you're not ready to retire and then you're told you have to live on a Canada Disability Pension. This is only about a thousand bucks a month. It can be less for some people. That's a big shock to the system when they're not ready to retire. There can be a whole pile of financial obligations for people with young onset dementia versus people that are on a Canada Pension Plan. So, it is a big financial struggle living with young onset dementia.

Mary Beth: Yes John, financial challenges are definitely a concern for individuals with young onset. I have a diagnosis of frontotemporal dementia, which Dawn and I have found has created some unique financial challenges. It is well-known with FTD, that there are very serious issues that can arise with money. For me, I had a significant change in financial judgement. People with FTD may accrue large debts due to changes in spending and poor financial judgement. In retrospect, Dawn often cites a significant financial loss as one of the first signs of change in my cognitive behaviour. I was unaware of my declining financial abilities.

Sarah: That’s an interesting perspective, Mary Beth. I had not considered the unique financial challenges that might come with different diagnoses.

Kathleen: Yes, that is an interesting point, Mary Beth. My struggle is if I didn't have Rob, who's my husband, by me, I don't know what I'd do, because he has to make all the money and it's so tough. We have to weigh everything out, like, do we really need this and yes, we do, but maybe not now and it's really tough. How you have to give up things is ridiculously hard. It's very challenging.

Mary Beth: Kathleen, I think you really make the good point about the support of the care partner, if there is one, many people live alone, I don't live alone. But in that relation, whatever help and support, financial and otherwise, that Dawn can get is really what it's about… And so much of it is expected of us, as you know, between that age of 45 and 65. This is when you're, you know, to John's point again, getting the mortgage paid off, you probably have a car payment still. You have this that and the other thing, and you're trying to save up so that when you are 66, you have money to retire.

Sarah: This conversation got me reflecting again on the importance of family for supporting people with YOD and the pressures that must be put on one person when the person with YOD is forced out of the workforce. And, what would one do without a care partner or what if the care partner had not been employed previously? That must be a challenging experience to then go and seek employment.

Rose: Well for me when I first retired, I did not have a diagnosis of dementia and that's why I couldn't claim a Canadian Disability Pension. It took me eight years to get the diagnosis. That's one of the reasons why I tend to harp on about providing a timely diagnosis. I had to wait till I was 60 to be able to access my Canadian Pension, and my Canadian Pension is only $130 a month because I chose to stay home with my kids. OK, so I don't know about anybody else here, but what can you do with $130, honestly?

Sarah: That’s awful, that really is nothing with the cost of everything today.

John: Yeah, and on top of that we can't access our RRSPs because we're taxed differently than you are when you are older, after age 65, and can access them as Registered Retirement Income Funds. You're taxed differently. So that's one obstacle that we run into as well.

Mary Beth: Just going back to what Rose was saying, I think there was one more really good point that was made there, and that was that there's a real diversity of that pension plan. In particular, women have less income, because it's usually the man that has a full pension versus a woman. This is why dementia is very much, again, a women's issue. Also, in that middle age, you're helping to support your young adult children as well, you know, whether they're in school or trying to get their own life up and running.

Sarah: The emotional, social and physical labour that goes into running a household, still largely taken up by woman, is so undervalued in our society. This can have serious implications for woman, making them even more vulnerable to financial challenges in the context of YOD.

John: Yes, well said, Mary Beth and Sarah. I would say better financial stability is needed to live well with young onset, especially to help keep us in our homes for longer. It takes money to live these days, so if you haven't got that money to do extra things. Just to put a tank of gas in your car is a big challenge. Sometimes I can't go away for a few days because I've got to wait for my pension cheque to come in before I can fill it up. So financial stability is a big thing. And to be able to continue doing your hobbies and doing other things costs money, nothing's cheap anymore. So that is a big, huge obstacle … One thing I'd also like to add is your home modifications, and your devices that you need, whether it's like a walker etcetera.. these devices are out of pocket money now, they should actually be covered through the government… So they're cutting into that Canada Disability Pension that you get paid for disability therefore you can't afford them. These things should be covered by the government.

Sarah: Your stories highlight how the financial challenges that come with forced retirement impact all aspects of your lives. I'd like to touch on a couple things you have brought up, John. We all need to have money to put food on the table, a roof over our heads, clothes on our bodies and so on. And as citizens do we not also have the right to have access to those things that bring us pleasure in life? You talked about the financial challenges you have had and how that limits your ability to continue enjoying your hobbies, and other recreation and leisure activities. I feel that such an important part of living well is doing things you love and that bring you joy. I don't know what I would do without my hobbies, they keep me sane! The other thing I wanted to talk about was all of the home modifications and other supports that are needed to help individuals living with young onset, but that come at an additional cost. With many individuals and their families having to spend money on this, there really cannot be much money left to support day-to-day living. Does anyone have anything to add to that?

Mary Beth: Yeah, you have to pay for them out of pocket, or they only help you financially if basically you sell your house, you get rid of any kind of savings so that you're proving that you're destitute, then they'll say, OK, but it's like keeping people poor. If you apply for different loans or things like that for structural modifications to your home, like outside put out a ramp for instance, they ask you everything about your finances. So, you're only going to get support if you literally make no money and it's a huge and long process, and you hear that a lot. Also, because we're not on a plan, our medication costs a lot of money. I don't know what that's like for others.

John: We had to go on the Trillium Plan.

Rose: What is the Trillium Plan?

John: Trillium is in Ontario, where the amount of medications that you pay for is based on your income and for most people, the deductible for the Trillium Drug Program equals about 4% of the household income after taxes.

Mary Beth: Yeah, it’s to help people with a lower income, regardless of where you live, sex, or anything, it's just based on income to help get medication at a cheaper amount.

Sarah: It is hard to hear that people are forced to prove a state of desperation before the government steps in with more financial support. I know there are challenges for ideas such as bringing in a universal basic income, but the stories you have all shared about financial obligations from medications to home modifications, and still having to support family members, warrants a deeper exploration into how the system can address such challenges.

Rose: Absolutely. The other thing I don't understand is why more people aren't on tablets, you know, because when I was first introduced to mine, I had been pretty good up until that point with computers and all that, but I just found the tablets were so much easier to understand and how to use them. I wasn’t doing you know documents or anything like that, but you know for playing games, for communicating with other people… So, I really don’t understand why more people don’t use tablets.

Paul: The problem is cost.

Rose: Well, I got mine for $158, which I thought was fairly reasonable.

Paul: OK, not everybody has extra cash, especially nowadays with the impact of the pandemic.

Rose: Well going back to John’s point, there needs to be more financial stability to support people with young onset dementia. Couldn't this be something the government subsidized or, you know, paid for out front, just to give people with dementia more of a connection to the outside world?

Paul: Yeah, that's important. But maybe if we put our heads together and get in touch with people that we know, they could form a group who seeks out technology, laptops or tablets and somehow work on doing something about price, bringing it down. With the homes, especially the for-profits, there's no way that they would think of doing something like that because it cuts into their profits. But if the government gets involved, I mean, that's something, Rose, we could talk about when we have the meeting with the NDP.

Rose: Yeah, I could see that.

Sarah: Interesting discussion Rose and Paul. Technology can really be a helpful tool for staying connected and in supporting individuals with dementia through the various applications that are available. They have become a necessity during the pandemic, but many people do not have access to the technologies needed to stay connected. This can leave people feeling isolated and alone. More needs to be done to address the financial challenges experienced with young onset dementia, that your stories so clearly reflect. I love that you are already exploring your advocacy roles as a means through which to raise these issues of inequity with politicians. This wraps up Part One of our four-part series. Thank you all again for your time and for sharing your experiences with us today. Join us next week for our kick-off to Part Two, where we delve into the power of stigma and its impact on relationships. See you then!

Chapter 5: Braided Narratives Part Two - Recognizing and Resisting Ostracism

Hello everyone, and welcome back to our podcast series, *Hold on to Your Hats*, Part Two, where myself and six individuals living with YOD will be discussing the power of stigma and its impact on relationships. Stigmatization is one of the greatest societal challenges that persons with YOD experience, as it is largely responsible for many discriminatory practices that individuals undergo in their day-to-day lives. In Part One of the podcast, we unpacked some of these experiences, such as a difficult and lengthy diagnostic process, forced retirement through loss of employment, loss of a driver's license, which has serious implications for continued access to community and community life, and lack of adequate financial support and associated challenges. Our team of experts has asked for us to also include the impact that stigma has on relationships within Part Two, to emphasize the implications that dominant discourses of ageing and dementia have had on peoples' perceptions of, and interactions with, younger persons with dementia. Throughout this dialogue we explore these challenges, as well as how persons with YOD navigate and resist such experiences.

Podcast 2A: “Stigma follows us wherever we go” - Stories of Stigma and Challenging Stigma

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Sarah: Welcome to this week’s podcast, “Stigma follows us wherever we go”, stories of stigma and challenging stigma. I would like to open the floor to the group to get us started. What would you like us to know about your experiences with stigma?

Rose: I think this might be a good time to share a little story of something that happened to me recently. I was trying to sign up for a MedicAlert bracelet, and the girl I got at the telephone number took down a lot of details and it took us almost 20-minutes to go through all the information they need. When I started to list my physical ailments, she said, “oh, my gosh”, she said, “I can't believe you have dementia”. She was so completely shocked. She'd been talking to me for like 15, 20-minutes already and never got an inkling that I had dementia and it just totally blew her away. I think that's the type of stigma that follows us wherever we go. As soon as people know that we have dementia, all of a sudden we've lost our brains, we no longer have feelings, or we certainly can't string words together in a sentence, and things like that. And for me, it's been totally different. I've had my diagnosis now for 13 years, almost 14 and it took me eight years to get a diagnosis to begin with. Now, I knew I had early onset dementia, but I couldn't get a doctor to give me that diagnosis for eight years, and I saw my GP and I saw four neurologists, and everybody was hesitant to say the words. Nobody wants to give that kind of a diagnosis. They tell you to get your affairs in order, and that your life's over, more or less over ... So I joined a couple of different groups. I'm not ready to die yet. I've got a lot of things to say as Paul will testify, he's heard a lot of it through these different groups we're involved with ... but that's what I want people to know is that I'm very much alive and I don't know how much longer I have but I'm going to live each day to the fullest and just try to get people to understand what dementia is all about.

Sarah: Thank you for sharing that story with us, it really highlights the assumptions people have about what people living with dementia ‘should be like’. I think it is very powerful that you resist these assumptions by becoming more engaged with your community, particularly through advocacy.

Dave: Yeah, I have also found it helpful to join a couple different groups. The Alzheimer’s Society has been very foundational for me and just being in a room of people, who have a similar story and being able to appreciate that … oh, it's OK, we can talk about this. We knew nothing about it. My vision was that everyone's vision of dementia is that it’s for the aged, decrepit, in a home, doddering. And here were all these people my age trying to come to grasp it together, and that was so healthy.

Sarah: What has struck me about what you have said, Dave, is the comment about “oh, it’s okay, we can talk about this”. That brings attention to the idea that there are perhaps individuals living with YOD who are in ‘denial’ about their diagnosis and/or are fearful to share it with other people because of the stigma that comes with it. I think this also demonstrates that having social groups for younger persons with dementia is important for creating a space for individuals to connect and bond over similar experiences, challenges, and ways forward.

Rose: I think there are people who have that vision of dementia, Dave, and there are many misconceptions that our society needs to become aware of. For example, one researcher does a very good job of explaining how a person should approach somebody with dementia, how they should not ask too many questions, or stick to one topic at a time, don't compound questions and things like that. I think she can certainly write some good guidelines for not only what you want to say to somebody, but how to listen to somebody as well ... because those two factors are what are most influenced by dementia, right? Is the way that you approach a person and how they react to your approach. In one of our earlier discussions, somebody said something along the lines of sometimes a person's dementia causes them to be aggressive or violent. It's this researcher’s idea that those people are not naturally violent or aggressive people and that their reactions may not be about dementia. They get that way from not being listened to and not being acknowledged. Perhaps in a nursing home, maybe they're having a craft time or something, and that person just doesn't want to do crafts, you know, that type of thing. So, I think communication is definitely an important factor here. And education - educate, educate, educate. That's where we are as a country right now. We need education on dementia because people just don't know.

Sarah: You bring up a great point about relationality, Rose, in that people need to learn how to be with and interact with different people in different ways. We need to be aware of the ways that our expressions and actions might affect other people. It is also important for people to be cognizant of other factors that persons with dementia interact with on a day-to-day basis, such as the surrounding environment, and be aware of how that may support or inhibit their experiences. These considerations speak to the social relational model of disability I have read about. In that model, disability is not IN a person; disability happens as a result of oppressive external and systemic factors in the world that shape the experiences of people living with dementia, often times in harmful ways.

Kathleen: Exactly, Rose and Sarah. We need to educate people. I was just going to say for me, it's ending the stigma. One of my pet peeves is when, for instance, I go outside and Rob is with me, and people say to him, “how's Kathleen doing now? How is she doing with the Alzheimer's and everything?” I say, um I'm right here. You can ask ME, I'm just fine. Like that drives me crazy because I'm not any different. I'm in the fairly early stages of dementia. And, sorry, I dislike the word dementia too because it's so broad and makes us sound older or I don't know what it is, I just don't like the word. But anyway, we have to say it.

John: Can I comment on that for you, Kathleen? The word dementia doesn't bother me in the least. I look at it as it's just a word, like any other word with disabilities. It's how it’s defined that matters. I tell them what it's like for me with dementia that makes it not so bad. So that's where you can look at the positive aspects of it. Dementia for me, I can still do a lot of things, I'm just slowed down but I can still drive a car, I can still do a lot of things. I just get tired a lot easier. I do things for a certain amount of time, but that's what dementia is for me. So really, it's not so bad.

Kathleen: That's very good. Thank you.

John: This is how I would portray dementia to other people. Then it takes the stigma away like you were talking about. So that's why I like doing talks because you get to share the positive aspects of it and make it sound like it's not a terrible thing. It's just a disease just like anything else is, it just has its own characteristics.

Kathleen: OK, that is very true. Yeah.

Sarah: What an interesting way to look at things, John. I think it’s great that you challenge peoples’ assumptions about what it is like to live with young onset dementia in subtle but powerful ways. These counter stories are impactful in reshaping what peoples’ perceptions are, and in dismantling the stigmatizations that have become sedimented in our society.

John: Exactly. For me, I look at it as just a product of educating the person. It doesn't bother me mainly because that's my personality, I don't let things bother me at all. I look at it as more of an educational tool. So, it's kind of like what Mary Beth was saying, “you don't look like you have dementia” ... I kind of do a similar thing, and say follow me around for a day, then you will really know what it's like. I maybe look good now, who knows in five minutes I could be very confused and disoriented or get mixed up. If you try to rush me out the door, you'll really see what dementia is like. You can't rush a person with dementia. There are certain aspects you don't see.

Dave: Yeah. If we all do our bit, find the niche where we can be vocal and effective. That's wonderful.

Paul: Yeah, that’s right Dave. I enjoy finding ways to educate the broader public about young onset dementia, and there is a caregiver and advocate who is a huge help to me. He pushes me and he gives me opportunities like the Alzheimer's Society does, to talk to and educate people to try and make them understand that we're not the walking dead. We're still alive. We still can contribute. And we have a voice. And to all those people that are living with dementia or Alzheimer's, they're not alone. That's the big thing.

Rose: I think what you’re doing is important Paul, especially because the voices of individuals with dementia are often overlooked. We're the ones with the lived experience and we're the ones that should be contributing towards the things that we need. You know, exactly what you're asking here - what is it that we would look forward to in the future type ... It's those needs that we're much more aware of with young onset or early onset dementia, than we are later on when we're less lucid and less verbal. I think it's the responsibility of each of us that have young onset dementia to speak up for those of us that can't. That's what I'd like to see come out of my advocacy, would be giving people with young onset dementia much more of a voice, much more of an influence on politicians, on doctors and the way they handle things. With those outside people, they're not the ones with lived experience, it's us. And that's one thing I'd like to see established.

Sarah: Absolutely. You’re right, Rose. The voices of younger persons with dementia are restricted or overlooked in many ways. I love the idea of a collective movement, so coming together in different communicative spaces to share about your experiences, and to challenge politicians and healthcare professionals to answer the call for the urgent need for change.

Paul: Exactly, and Rose brought up a good point. We both are involved with Dementia Advocacy Canada, and we are going to be having a meeting with the federal Minister of Health, to push forward the idea that we're people, we have these situations ... Why hasn't the federal government been more proactive? There is a dementia strategy, but nothing's been done with it. And that's one of the reasons I became an advocate, because I knew there are lots of people, and I met them, and they were surprised that I talk about my situation. And it's "aren't you embarrassed, aren't you ashamed?" No, because there's a lot of people out there who need to hear from someone else living with it … that life is OK and it's OK to say you have dementia. Not to be afraid or ashamed. Like I said, that's one of the reasons why I became an advocate.

Rose: Having public awareness is very important to me. I just want to be treated with respect. You know, I've lived a full life. I've raised two boys who both turned out to be wonderful sons, and I've contributed to society up until this point, right? And I just feel like it's my tax dollars that go into our Ontario Health Insurance Plan system, our federal system. I don't understand the Canadian government that well, I wasn't born in Canada, but I feel like I'm contributing as best I could to this society, and I just would like to receive the respect that I believe I’m due.

Sarah: Something needs to be done, something needs to change. You’re right, Paul, to question the lack of action. The dementia strategy has been out for a few years now, why has nothing changed? Why are younger persons with dementia still not feeling heard? This was a great discussion everyone. I feel that the stories and perspectives shared here today really shed some light on common experiences individuals with young onset dementia have with stigma, how to resist and navigate such experiences, and how to use collective voice to advocate for change. I hope that you will all join us for our final discussion in Part Two of our series, where we continue to explore the impact that stigma has on relationships.

Podcast 2B: “They don’t want to be part of your life” - The Impact of Stigma on Relationships

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Sarah: Good evening everyone, and thanks for joining this week’s podcast of *Hold on to Your Hats*. In this podcast, I meet weekly with a group of six people living with young onset dementia to talk about their experiences. Last week we began exploring experiences of stigma and continue that conversation tonight by discussing the impacts that stigma has on relationships. Let’s start with you Mary Beth. What were some of the things you noticed in your relationships after diagnosis?

Mary Beth: I think one of the things that happens is that there is an incredible amount of stigma associated to a person's disease. When you show up, you're physically the same, but it’s very hard for some people to be able to accept your diagnosis. That's what I found, I accepted my diagnosis actually fairly quickly because the four years leading up, but when I announced it, people kept saying, “well, you don't look like you have dementia”? Guess what, I do, you know. So to fight that stigma, even within your own family and friends, it's difficult. It's like, your mind still seems to be working as it was always, I just produced a book. But what they miss is the part that Dawn sees every day. That's the part they miss. They see me at my best. And it's a struggle for them to take you from where you were as they knew you, to a person being sick.

John: Yes, it can be an adjustment for friends and family. I guess one thing is being with young onset, everybody has busy lives, and everybody's got stuff to do. It's just another thing to pile on top of their plate that they might not have time to deal with the person with young onset in the family or friend. When I run into it, I run into it ... If I don't, it's out of sight out of mind. And then there's people that want to keep in contact with you and they will want to hear what's happening with me. I think that has to do with everybody is just plain busy.

Kathleen: Sometimes I also find that some family and friends don’t understand the ups and downs we experience day-to-day and I find you just have to say, you know what, no, I'm sorry, I can't do that today. And I'm sorry if that offends you, but I just can't do that and hopefully they will understand. But I can't say no, I cannot say no to people when they ask, I say sign me up, sign me up. And then I realized, oh, my gosh. I'm nuts because how can I do this? I really can't.

John: How I have done it, Kathleen, is taking it day by day. If I'm having a bad day where the brain is just not working at all I might have a Zoom meeting or something that is going to take a lot of brain power and that is OK. I can't do this today, it’s like picking your battles.

Kathleen: Yes.

John: So yeah, I had yesterday where I had a Zoom meeting, but no I didn't and I watched the movie The Father instead.

Sarah: One thing that caught my attention right away, and what I think is unique to the young onset population, is the amount of disbelief that people have that younger adults can actually be diagnosed with dementia. It must feel like an uphill battle when the people closest to you are not believing you at a time when you might really be wanting their support. What I can also really see coming out of the discussion so far, is the extent with which friends and families might take on discourses of dementia as tragedy, where the assumption is that the person they knew is no longer there. How do you approach people who might hold such assumptions?

Dave: Yeah, sometimes it's hard to gain a level of understanding from people close to us. I always start with the phrase, "I have memory issues". So it's a bit of a gentler introduction to the topic.

Rose: I used to do the same, well up until I got my diagnosis, I would say, "oh, I've got memory issues" and people are generally pretty patient or have been pretty patient with me. Now, I just come right out and say I have young onset dementia.

Dave: Yeah, I make the judgment per case, if I already know the person enough to judge their tolerances and openness, sometimes you can tell from what you've encountered already.

John: And there are going to be times where some people just don't want to understand or to be involved. I think sometimes communicating to the ones that want to be communicated to. Some people just don't want to hear it. Some people say, "oh, you got dementia, that's bad, I don't want to hear anything about it," whereas other people want to hear your journey and ask "how can I help you?" I do have some family members that like to keep in touch and like to hear what I'm doing and what I'm able to do, and they like to hear about me going through this process. I find it important to engage with those people and the ones that don't, oh, well. It is what it is, they'll reach out whenever they want to. I would leave it up to them. If they want to find out, they'll call me. They'll let me know. And the other ones that still keep engaged, I keep engaged with them. I find that very important.

Paul: I think that's a good way to look at it, John. And then there are people who have disinterest like they're not interested or they don't care, and they put everybody with various kinds of dementia in a certain group. All your friends leave you, they don't want to be part of your life because they don't understand or don't want to. In general, we want to make people aware that young onset is a real thing. It's not a figment of anyone's imagination. And we have a life. You know who else misunderstood my experience? My doctor ... I complained for three years of having various issues, memory, confusion, numbness and tingling, forgetfulness ... that's memory ... Anyway he called me a hypochondriac.

Dave: Oh, dear.

Paul: Yup, and he was my doctor for 30 years, he was like a friend, and funny enough, a month after he said that I had the massive stroke, and all he could say to me was I told you to quit smoking.

Sarah: I’m sorry to hear you had those experiences, Paul, with close friends and your doctor. We can see through the discussions that friends and family are clearly susceptible to the impression of dominant discourses, but it is concerning that healthcare professionals too, are unable to be critical of harmful assumptions and who play a role in their reproduction. I think this speaks to the power that physicians and the healthcare system have on shaping the everyday lives of people living with dementia.

This wraps up Part Two of our four-part series. Thank you all again for sharing your stories with us. Next week we will begin to take-on the first of three topics in Part Three of our series, where we explore what experiences are like for younger persons with dementia in the current system of support services. Don’t miss it! See you next week.

Chapter 6: Braided Narratives Part Three – Learning from the Past and Present

Greetings all! Welcome back to Part Three of our podcast series, *Hold on to Your Hats.* Over the next three weeks, six individuals living with YOD will be sharing with us their experiences with the current system of support services. In the first week, we will gain a deeper understanding of the ways that dominant discourses and associated systemic injustices become apparent in the provision (or lack thereof) of appropriate support services for younger persons with dementia. The following week we will explore our YOD experts' perceptions of LTC facilities. In the last podcast of Part Three, we cover one topic that our experts felt was particularly important to include because of the recognition that it is often not discussed due to a lack of comfortability and stigma associated with death in Canada. This topic is palliative and end-of-life care.

Podcast 3A: “Oh no sorry, it's only for people 65 and older” - Current Realities of Community-Based Supports

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Sarah: Hello everyone and thank you for joining this week’s podcast, *“Oh no sorry, it’s only for people 65 and older” - current realities of community-based supports*. Let’s get started. What would you like us to know about your experiences with support services in your area?

Kathleen: I talk with the Alzheimer's Society, and before the pandemic I talked about what living with younger onset dementia is for me. When I talk about it all the people there say, “Woah, I didn't know that there was such a thing and what you go through” and so at least they're aware that it might affect them someday. Also, going through the Research Institute on Aging has been fantastic for me. They are so good, they do wonderful things. Going to the Young Onset Dementia Association program is good too because we can all share our feelings and how it's affecting us and how we keep going on and we have fun, we do wild things.

Sarah: Thank you for sharing that, Kathleen. I find it surprising how so many people are still unaware that dementia can impact younger adults. I think it’s great that you have been able to find a support program where you can connect with other individuals living with similar experiences. Anyone else?

John: I'd say the Alzheimer's Society because they give you good guidance, that that's a thing I do like. They point you in the right directions and give you helpful tips. They have support groups and lead you to other avenues like the Murray Alzheimer Research and Education Program or other channels to help you out. My wife, Diane, too, because she has to put up with me, like the going through sundowning. It's not pretty because I just feel so irritable and anxiety kicks in and they have to put up with that as your caregivers or spouses. Also going to this care centre before COVID because they have a support group there. So going to the different places that are able to help you out and give you supports that you need.

Kathleen: I couldn't have existed without the Alzheimer's Society. The staff at the Alzheimer’s Society say, “why should you just give up and roll over and basically die? Keep fighting, keep going on.”

John: Yeah, you’re lucky if you’re able to get the support you need early. In London, I only know maybe a couple of people with young onset. The sad part is that I find the people in London with young onset are farther advanced because by the time they get the support, they're ready for the nursing home. They're either noncommunicative or they need so much help that they're at the stage they need to go to the nursing home.

Paul: That’s exactly it, John. You know, I never mentioned this, but for six years after I got out of the hospital, life was hell. All of this was because of no referrals, no references, no one to help guide me through. I stayed inside, I did not go outside. A couple of times I went out and literally ran back into my apartment. My daughter would come with me to my doctor's appointments and any other appointments. I have to have someone with me because I would get lost. I mean, I did get lost once and I panicked. It got to a point, going back to the type of person I am, that I had to find ways to live with this and make life work. Going back to tech, I'm thinking, OK, I go to Google Maps, I type in the address, and then I go to street view. I go up and down all over the place so that when I do go to that address, I won't panic because it looks somewhat familiar. That started basically in 2016, but for six years it was hell.

Mary Beth: I’m sorry to hear about your experience, Paul. One of the things that Canada does not do well is at the beginning, going back to that point of navigation, you have that diagnosis, then what? Not all Alzheimer's Societies work very well, mine didn't. Then you have to start to look around, and what we're missing is navigation into opportunities almost immediately. It's the division of peer support that's so important that has to be ramped up here in Canada and that's in informal, formal, online, and then your community supports like the Alzheimer's Society or whatever else. That whole system really does not exist here where I live, or exists in pieces. I think for young onset, it would make a tremendous difference if we were able to get plugged into these peer supports early, quickly, and in the right way. Don't just send me to something because I'm under the age of 65 and that's what that one's for. I got sent to one and they're singing, Old Bus Driver Speed Up a Little Bit. I thought are you kidding me, it was incredibly insulting, and I walked out I was so pissed off. Just because you have a brain injury doesn't mean that you revert to being a baby, you know? So it is very insulting and has really left me gun-shy to go to many things.

Sarah: That must be scary to feel that level of uncertainty after being diagnosed, and frustrating when something is finally suggested that does not reflect what meaningful engagement is from your perspective. What does everyone else think of this?

Dave: Educations is needed for everybody. There are so many misconceptions out there and the information about where to send people. I mean, your doctor should have sent you to the Alzheimer's Society, they're a wonderful resource. I went through their whole one-on-one program with my wife, and it was just excellent. I ended up with a friendly visits program fella and we've been friends ever since. He's a young college student, just a wonderful experience. There needs to be education so that there aren't all those people falling through the gap. It should be known by the medical professionals a whole lot more where to send people.

Rose: I've been investigating that stuff too, Dave. I had tried to contact the Alzheimer's Society back when I first got my diagnosis about six years ago, and I was really very disappointed in the way that I was treated. I got the distinct impression that they were much more comfortable dealing with caregivers than they were dealing with people with dementia.

Dave: It's not uniform right across the province. It would be nice if what I received here was everywhere, from what I've heard from people. I've had really excellent care from Alzheimer's Society, Social Services. The programs and availability have been terrific, just absolutely terrific for me, but I know it's not like that in most of the province, in the country. So, to get it all up to the best it can be would be wonderful.

Sarah: Why do you think there is such an inconsistency in the operation of support services? Or, what do you think needs to be done to address this?

Rose: I've been trying to get involved with these different groups, and I am trying to stress the importance that we start collaborating. I think I was using the Alzheimer's Society as an example. What they do is very good for caregivers, and I guess ultimately that helps a person with dementia when their caregiver is being well supported, but I don't see a whole lot in the way of support for people with young onset. I'd like to change that if I could. I've been bringing in ideas from different groups that I've contacted, and I just hope that we can lose some of the pride and gain a bit of whatever it takes to really make a difference for people with young onset.

Sarah: That’s a great idea, Rose. I think collaboration and sharing information across different organizations would be helpful for improving consistency and quality of support services for younger persons with dementia. I’m going to open the floor to the group, what challenges have you experienced with support services in your area?

Mary Beth: I got a pamphlet and on the top of the pamphlet it said frontotemporal dementia. I showed the Alzheimer's Society two weeks later, and they said “Oh, well, we don't know anything about this.” Oh, then why are you here? So, then they would say, “Oh, yeah. Well, I want to tell you about these programs. How old are you again? Oh 46? Oh no sorry, it's only for people 65 and older. Oh well how about this one? You can sing.” Oh great I can singgggg. How about the little red school bus song? No, thank you. I mean I'm making jest of this, but it's all happened to me.

John: I run into the challenges of similar things, the young onset versus late onset. There is a big difference between me being 80 and me being 52 or 53 getting diagnosed. I don't want to go and listen to music from the 40s. I know there's a young onset group in Toronto. I guess there's also a big group in Waterloo, but there is a long waiting list to actually get in. That's just plain stupid. Why is there a wait list at all? You should be in as soon as the diagnosis, you're in!

Sarah: That sounds like a very challenging experience. It must be difficult when you want to engage with recreation and leisure that you find meaningful, but that isn't available for various reasons, whether that be issues with availability or accessibility or appropriateness. What else do you think needs to be considered when thinking about community-based supports?

Mary Beth: I think community-based supports are incredibly important. We need to figure out how, as a society, to work moving forward in intergenerational relationships where it's not one-sided, it's give and take, it's a true relationship. I think those are important because we have many people within our communities that are so isolated and so lonely, whether you live in a town of 500 or you live in a city of five-million. Loneliness and isolation exist, period. How can we be a much more gentle society to each other and get plugged in with our neighbor? Like how many people even know their neighbors? We have these huge hurdles that sometimes are put in front of us. Community-based supports are incredibly important, and how we move out of the isolation. So, community gardens, for instance that can help feed the poor, that can provide work for people who need work.

John: Those are great ideas, Mary Beth. I also think it's very important to have specific support programs for people living with young onset too. I think it helps the faster decline because it gives them stuff to do, gives them hope and keeps their mind engaged. Even the spouses, they don't like going to spousal groups when the person is 20 or 30 years older because they can't relate, it's totally different. You don't have things in common other than the person with dementia, that that's the only commonality that they do have because of the big age gap.

Sarah: Absolutely. Mary Beth, I think you raise an interesting point that in addition to providing age-relevant programming, it is also important that we have opportunities to foster intergenerational connections ... And John, I think you raise a good point about the importance of also having specific age-appropriate supports, for care partners as well, for social and relational reasons.

Rose: Yes, exactly. I think socialization is something that is very important, and becomes more important as your dementia increases. I've made connections with a couple of different chat groups I get together with on a weekly basis, people that know what I'm going through because they're going through it, too. I've really drawn a lot of strength and everything from these people that don't know me from Adam right? But they're my brothers and sisters now.

John: For me, I think keeping busy in activities is helpful too. I hear a lot, “try to do this to engage your brain.” What I educate people about is I can't do that anymore and that doesn't engage my brain, that kicks up my anxiety. A lot of people think if you push yourself or if you try, you can learn new things and I tell them, no, I can't learn new things because my brain does not work that way anymore and then the anxiety kicks in and I get frustrated. It's actually better off to do the things that I can do and just work on those, so I find that important.

Dave: It would be nice if things can open up with COVID out of the way. We all hope for lots of things when it's out of the way. That cruise we're all waiting for. Or chance just to communicate with people and share in these programs and maybe help see that the Golf Fore Life program starts up again, too, like just to be advocating when we can get together with people.

Sarah: Yes, I feel that Dave. COVID has really had an impact on our ability to socialize and engage in meaningful activities. For anyone who is unaware, Golf Fore Life is a program that was developed to support golfers living with dementia so that they can continue to play. More information about the program can be found by contacting the Alzheimer Society of Waterloo Wellington, or by visiting their website.

John: I agree with Dave and Sarah. COVID makes you feel isolated because I'm a very social person. I liked getting out, I love going to Circle of Friends and going to all the Alzheimer's social events. I really, really miss them. Then on the other hand, my apathy kicks in and I kind of like being at home.

Dave: I was in the Golf Fore Life program - it's gone. I was in the friendly visits - that's gone. I even volunteered to be doing friendly visits, but the several months now and they haven't contacted me. Things are falling through the hole.

Sarah: I can only imagine the impact COVID has had on your ability to socialize and engage. What are some ways you have been able to stay engaged during this time?

John: I like that the Alzheimer’s Society has added Zoom classes during COVID because we can stay at home. That way when you have apathy days and you don't feel like going out, you hop on the Zoom classes, which are really, really good and which I really like. The only bad part is you miss that social contact, and when you have an infectious disease out there it’s hard to get that social contact. I've suggested some outside meetings, but it does make it very difficult to go to outside meetings and control people. You've got people in more advanced stages where they don't understand the social distancing and they don't understand they have to keep their mask on. So, it does bring up more challenges that way.

Sarah: Not having the in-person socialization must be difficult, but I am glad to hear that the development of virtual programs is helping. It is frustrating to hear about the inconsistencies in the provision of support services between communities that you all have brought to our attention, and how there is a severe lack of age-appropriate services available. On top of that, it sounds like there are some real challenges in terms of accessing meaningful recreation and leisure opportunities within the community. I also understand from our conversations today how much of an impact COVID has had on creating further difficulties in these areas. Hopefully we are nearing the end of this particularly challenging time. Thank you everyone, this was a great discussion. I feel like the stories shared really shed some light on the gaps in community-based supports that exist for younger persons with dementia. Please join us next week, where we will unpack our experts' perceptions of long-term care facilities. Tune-in then!

Podcast 3B: “You hear the lock behind us” - Perceptions of Long-Term Care

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Sarah: Hello, and welcome to this week’s *Hold on to Your Hats* topic, *“You Hear the Lock Behind Us” – perceptions of long-term care.* I know the group is particularly passionate about this topic, so let’s jump right in. I’m going to open the floor to the group. What are your perceptions of long-term care homes?

Mary Beth: In Ontario in particular, long-term care is an absolute disgrace. It is taking advantage of individuals and couples. It is taking money from not just couples and family, but also from taxpayers’ dollars. It's a human rights issue that we are trodding on these individuals, where there are three, four people to a room. Dementia is the only disease left in which they are still confining us in long-term care, right? You still hear the lock behind us. We didn't do anything wrong. We have a disease and yet we are locked into facilities within long-term care. 1970s Canada was supposed to be shutting these things down, institutions. We're still in institutions. Make no mistake. That's still happening to us. And during the pandemic, you know, we have doctors coming to Dementia Advocacy Canada saying, do you understand how many more drugs are being administered right now to people living with dementia? So, doctors themselves are recognizing within long-term care and COVID that they're overprescribing. And it was getting better because there was education but as soon as COVID hit, people are back to comatose again. We should be fighting for the human rights of these individuals who are being placed into long-term care. We are doing it all wrong.

John: I think it's more or less they turn long-term care into a factory where it's get em' in get em' out when they die and that's the sad part. They've taken the personality all out of it. All the personal care is actually really taken out of long-term care.

Sarah: Those are some powerful messages to get us started. Also, for anyone that would like to find out more about Dementia Advocacy Canada, visit their website at dementiacanada.com. Does anyone else have anything to add?

Kathleen: For me, I go to a long-term care home where I live and I think they really are great because they have set up a village and so you can go in and you can buy stuff and there’s a little shop and they have beautiful sitting rooms and beautiful areas and you can make your own food, or you can have it delivered. They all sit around tables that are very nice with candles, well I mean fake candles, but it is all very nice. Then they have a section where you can you have your own apartment, your own abilities to make meals and it looks like a normal home, and it's very nice and very good, and they don't talk down to you. There still is a long way to go because they’re trying to listen to us and to hear us, and they've made changes, which are great. That being said I don't I think that that's where I want to go, but I really don't want to go anywhere, I want to live at home.

Sarah: Yes, that’s understandable. I think what you have shared about the aspects of this particular home that you find appealing can be helpful in re-imagining what particular environmental and social aspects of care should be considered in the future development of care and support services.

Paul: I wouldn't go to a long-term care home. Not the way things are now.

Rose: Yeah, I would have to agree with Paul. I don't think I ever would want to go to an institution, unless maybe I was just totally by myself and had lost everybody in my life. Maybe then I might appreciate going to some kind of an institution, I don't know. But at this stage of the game, with everything that's come to light, I think you'd be crazy to want to go there. Especially people living with dementia there at some point in their life, they become somewhat immobile, maybe entirely immobile, they lose the ability to speak. Nobody's making any effort to communicate with them, right? I can understand it's so much easier to just give them a pill and let them sleep the whole day and night, but that's not the way I want to live.

Paul: The key word that Rose just used was institution, because an institution has rules and they have penalties for not following the rules. And a structured - eight o'clock in the morning, breakfast. Twelve o'clock, lunch. Three o'clock, snack. Five o'clock or six o'clock, dinner. And then a snack in between. It's all programmed. And most places don't have the ability or the desire to make the residents feel comfortable or that they're part of a good thing. Because I mean, a lot of them sit there and they vegetate because they have no stimulation. And could you imagine me in a home? I mean, I probably would drive the staff crazy, like I would play, I would get a big board and say, let's play hangman and then put a bunch of lines and say OK. It's like playing bingo. I would want things to stimulate me and everything around me.

Mary Beth: I was using the word institution and I used to get in trouble because I'd be in front of long-term care organizations, and they would say “we're not institutions, we're homes” - really? And it's been interesting to watch the word ‘institution’ come back. People living with dementia are still being locked up, technically, right? We have a disease. We haven't done anything wrong. I'm not going to long-term care, period. I've had that discussion with Dawn, there's Medical Assistance in Dying, MAID, and I'm going to be using that because part of young onset too is if I go into long-term care, my finances follow me, which means Dawn doesn't have that income. So here we are two young women, where all that money follows me, so now what happens? How is she going to be able to afford our home? There is no way I'm doing that so I have created an exit strategy and it's not long-term care … For most individuals with young onset your income already has been decreased quite a bit and who's got another what is it? $2200 bucks per month? We don't. Again, we still are young, we have two young daughters in their twenties who have kids or will have kids. Most families support the young not the person who is 54 years old. You can't live like that.

Sarah: It is heart wrenching to hear some of the realities you all speak of, such as being perceived as uncommunicative, being subject to the overuse of medication, being forced to follow a rigid schedule, and feeling locked in a secured facility to name a few. On top of that, Mary Beth you bring us back to the discussion around financial difficulties we had in Podcast 1D. Long-term care sounds like it would be inaccessible for many families.

John: Yes, absolutely. And speaking of age, one of the bad parts with it is basically a person, let's say in their fifties being homed basically with the people in their 70s and 80s. There's two different types of demographics there and I know another person that basically said the same thing, she was put in a home, but she didn't have dementia, she had a mental illness and "I don't belong here because everybody is so much older than me, I don't connect." That's one of the problems with people with young onset being put in a home is they don't fit in, they don't feel like they fit in and that they feel out of place and no wonder they run into problems of things where they don't recognize things or whatever, because nothing's in the norm, because they're not used to being around people twenty years older than them living with them.

Dave: That would be very different being in a long-term care place and being young. I have maybe met someone in that category once when I was working servicing equipment in a retirement home and there was one fellow who was, oh, I don't know, maybe in his 50s and he was uniquely in this retirement home and feeling kind of out of it because he would go and take the bus and go places. He was obviously pretty coherent and yet he was in a retirement residence like that. So how the fit can be made more appropriate, that could be a real question because you wouldn't be necessarily with your own peers.

Kathleen: Yeah, maybe if there was a way that they can build something for people with young onset dementia. I don't know, just throwing it out there.

John: That's an interesting idea, Kathleen. One thing I'd like to add is I wish they'd have these dementia villages in every city, whether it's more like a retirement home versus a long-term care home. I've been to some in London where you're not allowed to go outside because the doors are locked. And I said, well, what if the day is nice outside? I'd want to get out. Especially if you get a nice spring day after being cooped up all winter. It's kind of nice to go on outside, even if it's just for five minutes, where that may not be possible in some of these long-term care homes, whereas I like the idea of the dementia villages where you are monitored, that makes sure that you're properly dressed when you go outside, but you still want to go outside, even if it's just a few minutes to get some fresh air. Whereas some, it's just not allowed. I think they should make the dementia villages.

Kathleen: That's why you should come and live at the home that’s by me. If I have to go anywhere, that's where I want to go, because they have several in the city that are like that and they're just fantastic. The one right around the corner from me, you can go out and walk around the outside and they have a mini-put golf and they have a gazebo and they have all sorts of trails. And someone will even walk with you and you can go across the park and go and see the ducks on the water and oh, it's so beautiful.

John: And that's why I wish that they would have places that you could come and go and still be monitored. That way you're not feeling like you're locked in jail.

Kathleen: And it should be you can go where you want to go, not just go wherever they have a bed or a space for you.

John: If all long-term care homes utilized the same type of activities and best practices for people with dementia, that wouldn't be an issue. One thing I'd like to add is I think a lot of these places, you should be allowed to have your spouse live with you, without the burden of finances to live out the rest of their lives. Not just having the person that needs to go to long-term care. I think it would be a whole lot better and something that they need to work out. I think this could be something that is achievable.

Sarah: I’m glad you brought attention to that idea, John. It must be hard to be separated from a loved one, and as Mary Beth pointed out, it also contributes to the additional cost of carrying two living expenses. As you say John, I think that is an important and achievable hope to have. Does anyone have anything to add here?

Kathleen: That's also where I said, “Rob would you want to live there with me?” And he said, “for sure” because in the building they have these apartments and he said, “oh, yeah, I'd live there”, but again, it's money. But the laundry's done for you and they come in and clean for you and do all that stuff, and if you don't want to cook your own meals they will cook and you can meet with other people and socialize, and I think it would be great.

John: Yes, it would be really nice to have our partners be able to live with us. The other challenge I worry about with long-term care is the spread of disease or infection. Being locked in your room if an infectious disease is going around, is again like you're in jail. So that's not a good solution, especially with a person with dementia because they don't understand.

Kathleen: Oh, yeah.

Sarah: Ah yes, that’s a particularly important consideration right now with the spread of COVID. Could you expand on your concerns, John?

John: So, you've got a major problem there, an then it goes back to the PSWs that have a lot more work to do because you have to adhere to infectious control procedures. And so that takes more time and takes away from resident care. You've got a major issue when stuff like that does happen.

Rose: Oh, that's a big one. I've been gathering information specifically with COVID in mind and long-term care homes, and it does not look very good. I heard this statistic at one point, but I'm not sure exactly where or who said it, but I was told that 80% of all of the COVID deaths across Canada, 80% of those were in long-term care. And of that 80%, 80% again were people with dementia.

Mary Beth: If that doesn't really tell us what's going on, I don't know what else does ... And those are government figures, that wasn't stuff that you know people came up with. Those are government figures. How is it that 80% of your population with the same disease dies? Well, obviously, we're doing something wrong.

Rose: I just I don't have a whole lot of faith in our long-term care opportunities at the moment. I just, I just really feel for the most vulnerable who are in these situations, and I can understand why so many deaths were people living with dementia, because once you get to the point where you can't speak, you're the most vulnerable person in the room. Anything could happen. You're not going to tell on anybody because you can't communicate, right? So they're free to do anything they want with you. That's what I'm afraid of.

Sarah: I am at a loss for words being reminded of the disregard for human life that has been exposed through long-term care home deaths during COVID. I think it sheds a very bright light on the harmful systemic downfalls of this care model in its current state. Where do we go from here?

Mary Beth: People have been telling the government for years they don't want to be in long-term care and yet money is still being thrown at it. Hopefully, this will switch that you need to start listening. First of all, we said we didn't want to be part of long-term care. I believe it's 95% of Canadians, it's either 85% or 95% that want to be aging in their home. And so, we must make a community strategy in order to enable that to happen.

Paul: Good point, Mary Beth. Until then, we need proper training for the staff. And also, additional training on seniors living with Alzheimer's dementia, common practice, when someone comes in as dementia they'll give them a sedative to knock them out so that they don't become agitated or they don't cause problems and they won't go out and walk around. And, you know, that's a big thing. The training is the first. Do not medicate to keep a person in a room. The training and the education – those are the two big things. Education for the PSWs that work in the home so that they have a better understanding of what their residents are all about. Education, I think, is the big, big problem … The staff are overwhelmed in some cases, and that's not their fault. It's the fault of the administration running it and the government. But with this education, they should get an increase in pay a little bit so that they'll enjoy working at the home. And with this COVID business, we're still going to be in this a year from now and because of the finances, there's a lot of the PSWs who will work in multiple homes, part-time to try and augment the money that they need. So that to me, that's important.

Dave: It's great when the people can keep their dignity and be treated like adults with full emotional gear running, which may be the one of the biggest things that they can be trained in is to realize even if mental capacities have declined a lot, they're emotionally likely quite in touch. And to be treated the same would be a big, big plus for keeping people with dementia as alert as they can be, because they will respond to any of us when emotions are hit in real care.

Paul: Great point, Dave. There's also another thing, technology. Seniors in homes, they basically don't have any access to technology. They can't do FaceTime or Zoom with their family because they don't have an iPad or iPhone, or a smartphone. There should be kind of a push by the government to allow Wi-Fi in the homes and maybe have a couple locations like workstations with a computer and having someone on staff who is knowledgeable and patient. That's the big thing, patience. I think that that should be a priority because they're basically alone and in some cases they feel isolated. And I mean, they're scared.

Dave: It’s a long list now you've got stowed up about communication of these priorities in the long-term care facilities, improvements and general awareness, it's quite a package. It's a lot to try and get changed.

Paul: So awareness, awareness, awareness of the struggle of people in long-term homes, the ability to listen to complaints, to problems, to situations and to react to them, not put them off to the side and give it to someone else; maybe a secretary or a deputy minister or something like that, to act on the recommendations that have already been put forth.

Sarah: You have all brought attention to so many important perceptions and considerations about long-term care homes. Paul, I like that you ended with the need for not only awareness but also action, and I think in light of everything that has unfolded over the past couple of years, the need for change is beyond urgent. Thank you to our experts for being so open in our discussion today. Next week, we will explore the current realities of palliative and end of life care options and considerations. Tune in then.

Podcast 3C: “It’s a complicated topic” - Palliative and End of Life Care Options and Considerations

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Sarah: Welcome everyone to this week’s podcast, *“It’s a complicated topic” – palliative and end of life care options and considerations.* From my previous discussions with the team, it became clear that more information about and accessibility to palliative and end of life care options is needed. What do you think is important for people to know about this topic?

Mary Beth: We haven't talked about a couple of topics actually, that I think we just continue to neglect talking about it. I don't know if that's because of where we are in our dementia journey, but it is palliative care, and it is end of life care. These are just two topics that whatever your beliefs are, doesn't matter, but we have to start talking about this and getting people to understand what you as an individual want. To share something very personal, yesterday, I had an appointment with my doctor and she told me that years ago I'd asked about Medical Assistance in Dying, M-A-I-D. She said, I'm now available to put in an application for it. So, it's knowledge, right? It's getting people to talk on those uncomfortable conversations.

Kathleen: I think we should include it in our stories, because I know it is very difficult to talk about, but it has to be, you have to talk about it.

John: Yeah, I agree with you, Kathleen. And the sooner the better, because you don't know how quick or fast the dementia pathway is going to go. The sooner your thoughts and expressions can be expressed, and then people will know and then that way it can be documented for you. That way, it makes your pathway a whole lot easier or it's done the way you want it to be done.

Sarah: I’m glad you all have brought this topic into the light, and I hope it encourages other people to be more comfortable talking about this. What else do you think is important to know?

Mary Beth: This is definitely something that's been fought hard for by many people with dementia ... it's not necessarily agreed upon, right? It's a controversial method, but, there's no way I’d put my family through that. I was the first person because of the changes in MAID at the parliamentary level and the legality of it all, I was the first person my doctor had talked to. They call it track-two where there's an unforeseen date.

So, this is all very new for us. Again, whether you believe in it or not, it's about having information and access to it.

John: There's also government forms, they're online that you can fill out about this. It's through the provincial government. I already filled out mine. I find it important that people do that, but a lot of people don't know that that's available.

Paul: I didn't know that.

Kathleen: I didn't know that.

Rose: Yeah, I didn't either.

John: Me personally, I'm not considering the MAID route and I've already got my stuff all outlined on what I want to happen, and then again, that goes into the forms that I was talking about because it does outline exactly what I'm looking for. So, it's all documented.

Paul: Talking about MAID, does the Power of Attorney have a say in it?

Mary Beth: They don't have a say in it, Paul, because the Power of Attorney does what you direct that person to do. My doctor told me yesterday that there are regional coordinators and so you're given a name and then you follow that process and then that goes into a file and then legally, that's what you're entitled to. So, if your concern of someone not following through, they can't change that.

Paul: Can it be challenged by another family member?

Mary Beth: It can't be. Technically, probably, yes. But that's why it's important if you are thinking of it, to do it sooner rather than later, because they're probably tests to make sure that you're competent to agree to this. And this is what John was saying, the sooner the better really the conversations with your doctor, because this is all legal now.

Kathleen: Yeah, I've decided I'm going to go with MAID too ... Because it's probably the best route for me to go with.

Sarah: That must be a difficult decision to make. If you don't mind me asking, what's the process that you have to go through to come to that decision?

Kathleen: Well, first of all, I had to find out all about it, and then come home and really, really think about it. I sat down with my two boys who are 22 and 26, and I said, "This is really the way I want to go but how do you feel about it?" Because if they didn't agree, I didn't want to go that route then. But they say "We're on the same page as you because we don't think that you've been so active and so go, go, go, go and we don't think that seeing you lying like a vegetable is really living for you either. We want to do whatever you want to do.” So that so good. And they said, “you know what, if we were in the same position and had dementia, we would probably choose to go through MAID too.” So, yeah.

Sarah: Thank you for sharing that with us. Does anyone have anything to add to that?

Mary Beth: It's a complicated topic, and there's a whole lot of thought that goes into it. There's a whole lot of reasoning, there's a whole lot of well at least for me, balancing of your religious beliefs versus what this is suggesting. There's a lot of parameters and variables you know, a lot of things to need to think about.

Sarah: Yeah, absolutely. I don't know if you'll be able to answer this, but if the system were different, where individuals with young onset were better supported in living well with dementia, do you think that decision would be different?

Mary Beth: Well, you bring up a good question, Sarah, and this is what the MAID people are worried about is that we're making decisions based on, for instance, income. We can't afford it. We can speculate this is going to change, but this is something that we've known about already now for what a hundred years. We're still talking as government officials with budgets in the term of beds, “We're going to add 5000 beds.” You're not adding 5000 beds, you're adding 5000 homes. So, the significant amount of change necessary for government and for organizations to really get their head around it, I mean, it all has to change. It's like you have to throw it all out, put in new ground and new grass and start again. That's what some people are actually saying about long-term care, it's time to dismantle it, not add to it. And so much of the same can be said for MAID. I can't even fathom the question almost because I just don't see it as realistic for us, if that makes sense.

Sarah: You raise some great points, Mary Beth, and I think many people would agree that some drastic transformations and shifts are needed in the healthcare system to better support younger persons with dementia in living well. What you said about almost not being able to fathom the question really strikes me, and I think highlights the overwhelming extent of the change that needs to occur. I can only imagine how disheartening that must feel at times. I hope throughout Part Four of the *Hold on to Your Hats* series, our team can come together to discuss reimagining the future, and provide a greater sense of the paths that can and should be taken to create a more positive dementia journey. That being said, please join us next week for our discussion about our experts’ personal hopes and aspirations for the future.

Chapter 7: Braided Narratives Part Four –Looking to the Future

Greetings all! Welcome back to Part Four and the finale of our podcast series, *Hold on to Your Hats.* To close out the series over the next two weeks, six individuals living with YOD will be discussing ways that we can re-image what the future could look like. During these weeks we will take a deep dive into the hopes and aspirations our team has for themselves, and for the system of care. We begin now with our first podcast in Part Four, hang tight!

Podcast 4A: "Dementia's given me something to get excited about" - Hopes and Aspirations for Living Well with Young Onset, Now and in the Future

♪ INTRO MUSIC ♪

Sarah: Hello everyone, and welcome back to our podcast, *Hold on to Your Hats.* In these last two weeks, our team of experts with YOD will be discussing with me their hopes and aspirations for the future, both on a personal level, and for the system of care. We begin today with the prior. What hopes and aspirations do you have for your future?

Mary Beth: I guess I find that hard to answer because I don't consider it to be even within the realm of possibility. The ideal world with no limitations. I'm always going to have limitations. I guess I hope from a physical perspective that I stay as strong as I can. Maybe that we live as stress free as we possibly can and that I'm as healthy as I possibly can be. I hope that there's an income so that Dawn doesn't have to worry about working, which she does.

John: Yeah, I understand Mary Beth. One thing I did just after my insurance broker license expired is I went to the Alzheimer's Society and I said, “OK, I'm no longer working now, how can I help you out?” So I more or less volunteer with the Alzheimer's Society. I look at the dementia aspect as I have to redirect because you have to fill that void now, so why not fill it helping out the Alzheimer's Society with things that I can do. That's one thing that I've learned is, to do things that you can do, not what you can't do. I have found that very important to be able to continue doing that. It gives you purpose and builds up your self-esteem, that you're able to do stuff. You’re not sitting at home watching TV all day.

Dave: Giving back is important to me too, John. I like to keep busy because I'm struggling with social engagement. Now we have COVID on top of it, so trying to find ways of getting out and not being totally idle. I was volunteering at church doing maintenance repairs because I was a carpenter, and that ended with COVID, and I was volunteering at a retirement home and then COVID came along and put a hold on that one. So, getting out of the shell and finding manual things to do helps me a lot, and getting engaged in things like this.

Rose: Yes, COVID has put a damper on many things. I've never been a public speaker or anything like that, and I'm fairly timid believe it or not. Paul might have a different opinion, but I've always been kind of quiet and I think dementia's given me something to get excited about. I agree with Dave that staying busy seems to keep my mind generating. It keeps you more in tune with the rest of the world more than anything else. I could quite easily sit here in front of my computer and I could stay busy all day long. I would much rather - well it's still on the computer right now as far as Zoom calls and all that - but I'm communicating a whole lot more than I ever did in my life. I'd say that that’s probably one of the biggest differences since I've come down with this thing. Staying busy, but not just busy. I'm trying to get involved in dementia related activities as far as Dementia Advocacy Canada, and Dementia Alliance International. I actually found a couple more names I need to check out of different organizations.

Sarah: It is so interesting to hear all of your personal hopes and aspirations so far. What I’m noticing in what all of you have said to this point, is the importance of social engagement and giving back to your communities. Paul, how about yourself?

Paul: For me personally, I miss going out and talking in front of a large crowd. I also miss the television interviews I've done. I've thought about getting in touch with a representative I know at City TV. She interviewed me once and I would like to see if she'd want to do a follow-up. The same with this representative at CTV. See if they want to do a follow-up because both interviews were two, three, maybe four years ago. I miss the standing up in front of people and telling my story. The last time I did that

COVID happened, and a lot has changed since then. There's a lot more information out there, as well as a lot more interest in what life is like living with Alzheimer's dementia and COVID. So that's what I'm looking forward to.

Rose: That’s a great idea, Paul. I think what's important to me is that we are allowed to have a voice in our community. I know at some point in my life I will be beyond making decisions for myself, but between now and then, I want my voice to be heard. That's what I'm looking for more than anything else. I love my family, I have them around me, that is very important as well. I tend to have a broad vision when it comes to my life and how I interact with people and things like that. I see the big picture a lot clearer than just my own situation, my own circumstances here. I see some people with young onset dementia as being the ones that need to take the lead in explaining dementia to the world.

John: Absolutely. I think that it gives you peace of mind and a self worth that you're able to do things as opposed to “you have dementia” where people put you in a corner, out of sight, out of mind. If you're able to participate and do things and just continue a normal life, that gives you the dignity to carry on. I like doing my hobbies. I like doing the woodworking, I like doing a bit of photography and doing my art resin. I've learned to do projects that are only about three steps because I find anything more than that gives me brain overload and then you get mixed up and confused. So, I've learned to do projects that are just simple steps to do. I’m still doing the computers and then when COVID is over, I will mix in more social events and be able to not have as much debt as I do, but I'm kind of working on that right now. Or win the lottery and then have unlimited money that I could do a lot more things with.

Sarah: That’s very interesting. You have just highlighted another element to the importance of social engagement and giving back I mentioned earlier. Not only are these kinds of activities meaningful and purposeful for you, but they also challenge dominant narratives around aging and dementia. John, your point brings me back to the literature around constructs of the third and fourth age, where in short, individuals with young onset are often thought of as being in the fourth age and only thought about as their diagnosis and of deficit and decline. By continuing to participate in hobbies you love, and being active in your community, you are able to challenge such harmful stigmatizations.

Paul: Yes, I agree Sarah. John, those are some great hobbies you mentioned. I bought myself a helmet and I have every intention of riding a bike. There's a bike share program in Toronto and it's right outside my apartment building. It's been there for two years. Two years ago, I bought my helmet. I'm not ready to get on a bike, simply because of low peripheral on the left side, but also balance issues. I keep having these dreams of riding the bike along Queen Street. In the summertime, I walk 10 kilometers every day. I have my music. I just walk along the lakefront. I love seeing the people and the kids playing, and I never knew that Ontario had an egret, which is a white bird with long legs, they're about two feet long. There’s also a Comorant, which is a fascinating bird. It's black and it's sleek, it's streamlined. It flies along the surface and it dives into the water. And 15, 20 seconds later, it's about 500 feet away from where it used to be. The thing I love about this bird is when it's sun's itself, it looks like a bat symbol from the Batman character. It's a cool bird.

Sarah: That’s very exciting, Paul. I love that you are looking for opportunities to enjoy your hobbies, learn new ones, and take time to see the world around you and get pleasure from that. Anyone else? What other hopes and aspirations do you have?

Mary Beth: One thing I have loved to do is advocacy work, and so aspirations and hopes is an interesting question for me right now, because of my considerations of moving away from this full-time role, and looking for the hope to be a great grandma to our grandson. Then we're going to be having a granddaughter in the next month, and one of the reasons for pulling out of so much advocacy work that I'm doing. I want to be a good grandma. I want to be plugged in, I want to be supportive, I want to be fun and memorable. I think for the aspiration, this goes to our family motto, Carpe Diem. To aspire to be that best person every single day, because there's lots of days that I certainly don't aspire. I'm tired, I just want to sleep, just leave me alone. So that aspiration is definitely to be the best I can, whatever it is I'm doing. Whether that's being a grandma, whether that's doing work for Behavior Supports Ontario, which I do part-time. When Dawn turns 50, we're really hoping that we can do a family trip to the East Coast and spend a month out there. If you think of your life at the beginning, middle and end, I'm nearing the end, and so things like this, you're on a time limit. Five years from now, it's not going to happen. Even a year and a half from now, there's a lot of ambiguity there because I don't know how quickly I'm going to start to deteriorate. It's the unknown that is so frightening, really. It becomes a matter of really bubbling up those aspirations and those hopes and then putting a framework around it. How can this actually happen? What do Dawn and I need to do for us to go to the East Coast? Those are big ones. Those are the ones that keep me getting up every day.

John: Those are some great aspirations, Mary Beth. I hope to basically not change and be like this so I can continue doing the activities that I have been doing. It would be ideal to go travel, but I need helpers with that because I can't drive very long before my brain gets tired. So, yeah, that would be ideal to do that and be as active as I possibly can, as long as I can.

Paul: I plan on living to 100, because I want to get a letter from the King of England and from the Prime Minister because the King will be - it could be Charlie, it could be William - but I want to get a letter from him, congratulating me on a hundred years of life.

Kathleen: Yeah, me too... And just to have my family around me is so important to me, because family is everything to me and having animals and being near water, that would be great.

John: I agree with you, Kathleen. It would be me and my wife and my dog in my home, but living obstacle free. I know eventually I won't be able to live in my home because it's got stairs in it. An ideal would actually be a one floor place to go to and then to be able to go outside but still be supervised where I can still go out but I don't wander off, and still be able to do things that I want to do. Then, to have Dianne be able to go on to do whatever she wants to do and have somebody here to look after me. That would be the ideal, to keep me safe 24/7; No stress on Dianne with us being able to do whatever we want to do or need to do throughout the day. Safely.

Kathleen: Family and everything is my be all and end all. I'm very much a positive person, and I just want to go on. I mean, yes, I have thought about dying and I want to die with MAID. I think for me, it's the power of positive thinking. I just want to be in a place where I feel safe and invigorated, and ready to keep going and keep fighting. I just haven't thought about the end because I don't think I'll ever get there, and I'm keeping that going in my mind.

Sarah: What amazing hopes and aspirations you all have. I think so much of what you have all shared provides powerful counter-narratives to the biomedical and dementia as tragedy discourses that we so often hear. Mary Beth, I think there is one question that you raised that can help everyone take a step towards achieving their hopes and aspirations, which is “How can we make this happen?” I can only try to imagine the added challenges and roadblocks that persons with young onset may come across, but I think there is a certain power in vocalizing such constraints to a point, as it opens possibilities to navigate them. Thank you everyone for joining us here today. Tune in next week to explore Part Four, and the finale of our podcast series, where we reimagine what the future of care and support could look like.

Podcast 4B: “It’s like the hamster on the wheel” - Hopes and Aspirations Related to Care and Support

♪ INTRO MUSIC ♪

Sarah: Happy Friday everyone, and welcome back to our podcast series, *Hold on to Your Hats*. Today, in the final podcast of this series, six individuals living with young onset dementia dialogue with me about reimagining what the future of care and support could look like, and related actions that should take place. Let’s get started. What would you like to share?

Mary Beth: Thanks, Sarah. I’m glad we are flipping the aspiration in hopes, because I see it as two. I see it as personal, and then the second really is the aspiration and hopes of our advocacy work. The Canadian National Dementia Strategy actually is called *Together We Aspire*. I was part of the group that made the National Dementia Strategy, and I think we do have to aspire to be more welcoming, a more intelligent and more well-educated country who's plugged into looking at dementia within the human rights vision and lens than we are now. I hope that the Federal Minister of Health gets the OK from the Prime Minister to make dementia a priority, because as it stands now, it is not on the priority list.

Kathleen: Yes absolutely, Mary Beth. The humanity piece reminds me of a conference I went to last year with Dr ... shoot oh no, oh man, I've forgotten his name. Anyway, he was talking about how empathy, kindness and compassion, are so important. He works as a trauma doctor and he was saying, how if he can get all his doctors to agree, that not just like, “OK, see ya here you go, here's your medicine” and have them talk to you and find out the whole picture, that would be so much better. And he's really doing that.

Sarah: Interesting. Mary Beth, I like that you raised the importance of using a human rights lens as a guiding framework for the system of care. With dementia now being considered a disability, the Convention on the Rights of Persons with Disabilities can be used to bring attention to the unjust practices and systemic inequities that occur for diverse groups, in this case, younger persons with dementia. And Kathleen, you raised one component that can begin to help improve the system of care. What you described reminds me of the relational caring philosophy, where we not only have to understand the individual, but also the broader picture of other interconnected factors. Anyone else?

John: My thoughts on that are similar to Mary Beth’s. They talk about it saying it is a priority, but they don't act like it's a priority. That is my feeling on it – “it is a priority, we're going to do lots about it” and then nothing gets done. And it's like the hamster on the wheel.

Rose: Yes, I agree with that too. The publication of the Canadian National Dementia Strategy didn't come out until 2018, and there has literally been nothing done since then as far as the government's involvement in that supposed dementia strategy. It says right in that, this document is like a beginning, getting the ball rolling type of thing, and that it should be updated on a yearly basis. It has not been updated. Nobody's even looked at the thing in the last three years. I think the government has failed us as far as people with dementia and giving us a voice. I think they've totally failed us because just because you have a dementia strategy doesn't mean you're going to implement any of it, right? So that's my feeling on it anyway.

Sarah: Exactly, there needs to be an action component as well. What do you think would be important next steps to start implementing frameworks, such as the Canadian National Dementia Strategy?

Paul: There needs to be more advocacy. For example, there's a lady from the news I know. She's in the news all the time. I know her, I've met her. She's a very strong advocate for government regulations. She chops them down, spits them out. We need more representation for residents in LTC homes. There needs to be someone who is the overall spokesperson, and they would go to different homes, put down complaints and then put them in a paper and present it to the government.

Rose: Right now, I'm trying to identify a list of things that the government could do in order to make dementia more community friendly, or the other way around the community dementia-friendly, right? We put together a couple letters and working with a couple of other members with the Young Onset Demetia Advocacy group that I'm involved in. One of the big things that I think the government could do would be to educate and by education, I mean run TV ads, billboards, all of that. Use the media. They've done it before with other things. Why couldn't they do that for dementia? Just to start educating people and from there, it could go into discussing, how can your workplace be more dementia friendly? And, maybe even go into the schools and teach kids about your grandma, your grandpa, your aunty, whoever. To open up the conversation, in a lot of different venues is what I would like to see happen.

Dave: I love the idea of dementia-friendly communities. The Swedish villages that are set up like rural streets and everything carries on with people out on their front porch and a sense of community. Those look wonderful. They really do. That would be really ideal.

Kathleen: Yeah. That's in the Netherlands, they do that too, and it's fabulous.

Paul: And Norway.

Rose: Just about every European country has a strategy in place for their people with dementia.

Sarah: What are the aspects of those models that you like?

Mary Beth: I think there's a few good models out there. Definitely smaller homes in which people living with dementia are supported and they're part of the community, a small community. Depending on the model that you pick, sometimes there's five houses that support each other. But I'm not going. This is it for me. This is my home and that's where I'm going to end up.

John: Yeah, and I think staying in your home should be made a more feasible option. I would say if the ideal is to live in your home and live comfortably once you start needing help, have the care come into your home free of charge where it takes all the stress off the caregiver. That way everyone can live a normal life and still get the help from a person coming in, even if it means 24-hour care. Having a person come on in and help out with all those daily activities. I think that's important. I can't see why it wouldn't be cheaper to do it that way.

Sarah: You raise an interested point, John. Mary Beth has talked about all of the funding that has been going in to building and funding long-term care homes, but what if this money was reallocated?

Mary Beth: Exactly. It also might be more feasible if there were more rehabilitation options. We toss that word around a lot. Let's say someone fell and broke their hip, and they need rehabilitation service. People with dementia are many times not given that service. The reason is because the therapist says, “I try to rehabilitate them, but they can't remember the directions.” We're crossed off before we even get going. And imagine if we could have rehabilitation as one of the potential sources of support. We have the services to help us continue to speak well, to help us strategize on memory things, for example, how to use a phone. We continue to know how to use it. That's their job to figure it out, how to help us remember it. You can't just go in and say, “Oh, they don't remember.” So, the whole area of rehabilitation is a huge area and it's not tapped into. But imagine if we did.

Sarah: Yes, absolutely. I think what you’re saying Mary Beth also speaks to our discussion in Podcast 1C about being forced out of employment and the challenges related to finding new job opportunities. Rehabilitation in this sense could be helpful in preparing and supporting younger persons with dementia who want to remain in the workforce, and would also assist in offsetting some of the financial challenges we spoke about in podcast 1D as well.

Dave: That’s a great point, Mary Beth. Other supports that I think would be helpful come from technology. I was introduced to technology help from a company that presented at Young Onset Dementia Association about a tablet that they were developing. It was a screen that was very simple, but it had all the person's likes and dislikes and needs and aides to help them, anyone dealing with them, to understand them better. “Don't come suddenly like this” or “they've got an allergic reaction to pets” or all kinds of things that you can put in it that are the personal bugbears and desires and likes of the individual. If you could just glance at a screen and know all their likes and “oh, don't do that” and “here's who you should contact” that would be great. It was all in one screen with the date and time for them, and just a real resource that was really simple. There are lots of good ideas for tech applications, but maybe they need better funding or understanding at a government level that this is a really good set of tools.

Paul: I am also a big believer in technology, Dave. What I foresee or what I want in the future is accessibility to everyone of technology in the homes. I kind of see myself as a developer because I have ideas, I just can't implement them. But like Dave's app that he talked about, I want to develop an app to help people who are lost to be able to find their way home, but you have to have a smartphone. Not everybody has that. I mean, I got lost and I didn't have my phone with me. If I had it, I would have been OK. But there's other areas that I have ideas that could help people living with young onset dementia. I just don't have an understanding how to get through the process. And I'm impatient.

Sarah: That’s a great aspiration, Paul. I think the pandemic has also shed light on the importance of increasing accessibility to technology in the homes, as with the existing dire structure of long-term care support, technology was the only means of communication with the outside world.

Dave: Yes, accessibility is key. We talk about getting the information out there, but here I go to the Young Onset Dementia Association and I know about the Alexicom app, but many of you didn’t. Getting this information back and forth and amongst the community, it's tricky. We need to make it easier to search for aides like that. If you feel like suicide here's a site, you feel like you're going to have a baby and maybe you need to talk to someone, there's a site. Is there one for dementia?

Rose: Good point, Dave. Accessibility to helpful information about supports for young onset is definitely a challenge. There's a couple of other groups I want to get involved with, and one of the things that I'd really like to see come out of my discussing things with these different groups is I'm hoping that we can start collaborating between them, because I've kind of got the impression that a lot of people - like say the Alzheimer's Society, OK? They know what they're doing and they're not interested in sharing their ideas or anything like that with anyone. They'll just do what they've always done and they seem to be quite happy with that. And I've been trying to push them a little bit more to get more involved with young onset dementia, because they don't really have a whole lot of anything in their policies related to young onset.

Paul: Where research is now for dementia, cancer was 30 years ago, you know. So I mean the research on dementia, you got the talent, the tangles, and trying to understand them, and it's going to take time. A long time. Maybe 30 years from now they'll realize what the cause is.

Dave: Rose and Paul, I think you're both right that more research and collaboration is needed to improve knowledge and supports related to young onset dementia. Just a quick note on what I'd like for the future. It was an idea of my wife's to establish a respite facility that would give caregivers a little longer a break and give the residents when they came for the week, a vacation atmosphere at the respite centre. If it had a big open area, you could make it like a cruise ship and have a festoon with tropical things and make everyone feel they were on some special vacation so that it was great for both the person doing the care and the person needing the care while the caregiver got away. She even investigated a church that was for sale and toured it and saw the possibilities in turning some empty buildings into long-term, short-term, a whole week respite. Respite can be two days now or some very short little periods, but to give a person a real break it would require a set up like that.

Mary Beth: That's a really creative idea. I think better system navigation would also provide more support for care partners and individuals with young onset. Within the regional Local Health Integration Networks, they put in these Care Coordinators, which sounds great but let's be realistic. Does it really fit what it is we need? And the answer to that is no. There's not enough of them so you're onto this waitlist until it's your turn. One of the strategies that many different countries in Europe use, is the idea of navigator's and when you get diagnosed, you get this navigator. In Scotland for instance, you get a navigator for the very first year of your diagnosis. You know whoever it is talks to you whenever you want whatever you need, that person is going to help you get from a diagnosis to get the support you need to live well with the disease, and then move on to some other supports. That's what I want. I want someone who's not just going to be within the year, but I want someone who's going to, at the time of diagnosis, help Dawn and me go all the way through including palliative care when I pass. And that's the important conversation that we have to have, because otherwise you are just talking aspirations, you are just talking dreams. This can be realities because we know they work. We know we can look to other countries because it's within their actual plans. So when does Canada pick up and start saying, "Hmm OK, well maybe it's going to help with COVID and the long-term care scathing report that happens?"

John: I think it would, yeah, because that way they can do the calling, they can get the resources that you need for you, they can fill in the gaps that you need so you're not stressing out your caregiver who doesn't know where to go, and it's their job to do that. I think it would make the world go around a whole lot better and keep those emergency calls out of the hospital, too.

Sarah: Collaboration, system integration, and navigation are three things I am noticing are repeatedly emerging from this discussion. What do you think one action would be that could help make this a reality?

Mary Beth: What I would like to convey is that we need navigators who are well-educated within not just dementia, but how support and care work in Canada. I think for care and support, I'd like to see a 1-800 number. Dementia doesn't shut off at five o'clock, doesn't shut off Friday at five o'clock and start up again on Monday at nine. This is how we handle dementia right now. There's less staff on the weekends, there's less staff on during the night in some of these long-term care homes, and we need to look at that differently to balance it differently. The 800 is the 800 number and we've been talking about this forever and for whatever reason, the government and the Alzheimer's Society of Canada have not embraced that. When you provide a support that's well educated, really understand where you're at in your local community, then it can change. It can help me be happier, it can help provide services that perhaps you didn't even know existed. So much can happen to allow for better care and better support, and navigation is a big one. Again, like a 24/7 800 number to be national-wide, I think is extremely important.

John: I kind of want to throw a question at that. What would this 1-800 number do?

Mary Beth: So, you know when you got diagnosed, John, and the first thing my doctor said was, “the Alzheimer's Society will get a hold of you, you're going to be put on the waiting list.” So after the diagnosis in which my license was revoked immediately, I was given a diagnosis that I was going to die and there was no cure. So, I went home. Dum da dum da dum.. waiting for this phone call, which came about two to three weeks later. Imagine John instead, you get home, you go OK, what the hell just happened. I'm on the 800 number, I just got a diagnosis, this is what happened, and within minutes that person can tell you, “OK, here are some of the things that you should think about right now” or “Hey, is your partner there? Why don't we have the two of you on the phone call so you both can hear the same thing?” It's a thing you need to remember is that, yes, you have a diagnosis, but you're not in the end stage, you got a lot of living left to do. Imagine the difference a diagnosis could be and access to care and support is if we were talking to someone whenever we needed to talk to someone.

John: Dianne, liked that comment. Yeah, she really liked that. I think it's important that they do call and have that chat and then try to set stuff, because I know some people there is such a big shock when they get home from the diagnosis and if they did get the call from the Alzheimer's Society, they're kind of lost.

Sarah: I think that would be a great start, Mary Beth. This discussion has shed light on different areas of the system that we need to focus on improving. For example, improving system collaboration, integration, and navigation, while using guiding frameworks for the development of care and support services, such as a human rights lens and relational caring philosophy. Doing so would lead to healthcare services that better reflect the needs, desires, and basic human rights of younger persons with dementia and their families, while providing a more comprehensive support network.

Thank you to our experts for all of your valuable stories and input over the past 11 weeks. You have all brought us on a journey from *Shifting to New Realities* through the diagnosis process, to *Recognizing and Resisting Ostracism* resulting from the stigma you experience in your day-to-day lives, to *Learning from the Past and Present* by highlighting the current challenges and gaps in our system, and lastly to *Looking to the Future*, by sharing insight into what it would mean to live well with young onset dementia on both a personal level and a healthcare system level. This wraps up series one of our podcast, *Hold on to Your Hats.* Thank you for listening and stay tuned.

Chapter 8: Distillation of Narratives, Impact, and Future Implications

Reflections on Curating the Podcasts

Bearing witness to the telling and construction of the co-researchers' stories was a humbling experience. Our conversations were deep, authentic, and often emotional. In curating their stories, I was eager to provide a comprehensive representation of the injustices experienced by younger persons with dementia, how such experiences are interconnected, and the ways through which co-researchers are resisting and acting to create positive change for the future. I was also committed to ensuring that co-researchers were actively included in decision-making throughout the process so that the final reflections of their lived experiences would be what they wanted. While co-researchers helped in the revision of the stories, I think it is important to reflect on my subjectivity and connectedness to this field as the individual who facilitated and compiled the discussions.

At the time I conducted this research, I was a 31-year-old PhD Candidate living in Toronto, Ontario. Throughout the entirety of this project, we were amid a global pandemic, a time where undeniable ageism reared its head, and where the lives of older adults and persons with dementia were devalued. I felt sad, helpless, and frustrated by the thought of so many individuals and families who were suffering, and often thought about how I would feel if my family were going through something like this. As I mentioned in the foreword of this dissertation, my Nana died from Alzheimer's disease, and my uncle is currently living with YOD. My Nana spent the last years of her life in a LTC facility where I saw the challenges and limitations of such an environment; an experience that catapulted me into this field with a hope that I would be able to make a difference. I thought many times throughout this project how grateful I was that my Nana at least did not have to experience the atrocities that many residents are undergoing during this time, and that despite the lack of community-based supports my uncle was still early enough on in his journey to be at home and supported by family. What the pandemic has done is bring attention to the injustices and inequitable treatment of persons with dementia and highlighted the urgent need for change. While conducting research in a pandemic had its challenges, the messages that have been curated through this project provide a starting point for recognizing and addressing the dominant discourses and discriminatory practices that impact younger persons with dementia, and suggestions for how to create a more positive path forward.

Connecting the Interconnected: Linking Narratives to Literature and Theories

Listening to the stories of the co-researchers throughout this process reminded me how little current literature has explored the experiences of younger persons with dementia. Very few qualitative studies have engaged individuals with YOD (Greenwood & Smith, 2016), often focusing instead on the voices of care partners, and to a lesser extent the inclusion of persons with LOD. While the stories shared reflected some of what we know about YOD in terms of experiences such as difficult and lengthy diagnostic processes (Alzheimer's Association, 2006; ASC, 2016; Ducharme et al., 2014; O'Malley et al., 2021; Vieira et al., 2013), experiencing the loss of a driver's license (Shnall, 2009; van Vilet et al., 2017), and loss of employment and the financial impacts (Jefferies & Agrawal, 2009; Oyebode, 2015; Shnall, 2009, Swaffer, 2015), this research tells us a lot more.

Firstly, using narrative inquiry in a group setting, co-researchers were supported in telling their own stories, sharing those stories with others, hearing the stories of others, and reacting to those stories. The array of experiences shared raised questions for co-researchers and the discussions delved deep into the various factors that shape the lives of persons with YOD within each of the topics discussed, demonstrating the complexity and diversity that exists in the YOD journey. Secondly, in addition to providing a different lens to some of the common themes discussed in the literature, this research also began to unpack some areas that have not yet been explored from the perspectives of younger persons with dementia. Perceptions of LTC facilities, palliative and end of life care options and considerations, and hopes and aspirations for the future are topics that emerged from this research that I have not been able to locate in the academic literature. Thirdly, because this study was grounded in a critical theoretical framework, it forced me and the co-researchers to think more critically about power and *what* it is about our society that creates inequitable living for persons with YOD, and *why* these experiences have yet to change. Lastly, this research provides an action component in the creation of the Podcast Series and integrating them with different mediums to create an educational interactive e-flipbook we are currently working on that can be distributed widely. We hope this will be used as an education tool, and for opening up conversations among healthcare professionals, policy makers, and government officials to critically reflect on the experiences of younger persons with dementia, recognize and acknowledge the urgent need for change, and think about suggested steps forward.

A Theoretical Exploration of the Podcast Narratives

Clandinin and Connelly’s (2000) three-dimensional space provided a comprehensive framework through which we can look at the stories shared. As a refresher, this three-dimensional space includes temporality (past, present, and future), sociality (the personal, social and cultural), and spatiality (the physical landscape, environment). The interconnectedness of time, personal reflections, social relationships of inclusivity and exclusivity, and the impact of one’s surroundings were evident throughout the various stories. The following paragraphs will use this three-dimensional space, in addition to critical theoretical frameworks, to generate a deeper understanding of co-researchers’ inward and outward reflections on the past, present and future. I will follow the stories through their trajectory, and close with a discussion on the interconnectedness of stories.

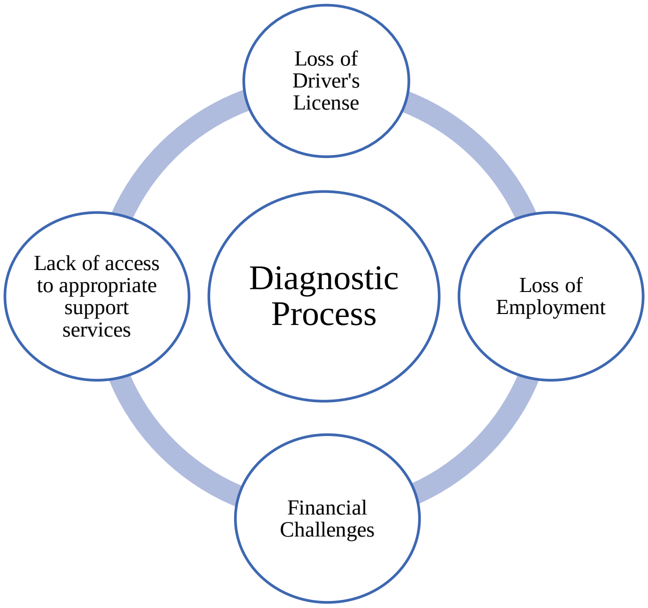
Theoretical Reflections: Shifting to New Realities[15]

Research question addressed in the following sections: What stories do persons with YOD share about their experiences of YOD and with the LTC system?

Shifting to New Realities: Overview of Key Messages

Core Challenges Identified by Co-Researchers

Discrimination and Marginalization



Possible Action Items:

Supporting Full Citizenship and Human Rights

Improving the Diagnostic Process:
- Early referral to memory clinics or specialists
- Examination of the applicability of diagnostic tools for different types of dementia

Supporting Mobility and Continued Access to Community:
- Exploring existing forms of testing/processes that have been used to examine the driving capabilities of older adults and persons living with dementia
- Financial support for alternate testing measures
- More research around this experience and possible process improvements in the YOD context
- Improved access and affordability of recreation and leisure opportunities

Supporting Meaningful Employment/Occupation and a Liveable Income:
- Improved access to rehabilitation supports such as vocational rehabilitation
- Increased access to information about applicable financial supports (which should outline available supports for both disability and dementia)
- Increased provision of financial supports from the government and organizations
- Consideration of a Universal Basic Income

Ensuring Equitable Access to Appropriate Support Services:
- Increased education and training for healthcare professionals about helpful referrals pre- and post-diagnosis
- Removal of stringent and exclusionary eligibility criteria
- Development of more relevant and desired programming

Figure 3: *Shifting to New Realities - Overview of Key Messages*

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[15] Figures 3-6 provide a summary of the key messages for each respective *Theoretical Reflections* section, and demonstrate the interconnectedness of the embedded narratives, as well as possible action items.

Beginning with braided narratives part one, *Shifting to New Realities,* we started our discussions at a time where co-researchers were recognizing the initial changes in their day-to-day lives and began their search for a diagnosis. Looking at Podcast 1A, the contrasting experiences of John and Kathleen in the diagnostic process, we can reflect on what some of the differences were using the three-dimensional space. First, is the importance of time. John speaks to the impact that a challenging, lengthy, seemingly never-ending diagnostic process can have on one's life. During the more than two-year period that John was seeking a diagnosis, he was put on medications for illnesses he did not have and spent considerable time at appointments with five different neurologists. Without being able to pinpoint the changes one is experiencing, how is one to cope or adjust? For at least two-years, John was in a liminal space of unknowing and uncertainty. John was relieved to finally get a diagnosis of YOD, so that he could move forward in a new journey and begin to plan for the adjustments that he would need to make.

Second, is the importance of the reactions of healthcare professional(s) and available social support. Kathleen's positive experience obtaining a diagnosis was largely due to who she came in contact with early on in the process. Right away, Kathleen's doctor believed her, where John's did not. As such, the doctor referred Kathleen to a specialist who did a comprehensive exam, and was able to connect her stroke to the onset of vascular dementia. Although not clearly stated, it does appear that education and awareness about YOD played a role, and a lack of this knowledge and awareness in John's experience. Education and awareness were brought up many times by co-researchers, as will be highlighted in the stories about hopes and aspirations for the future.

Third, is the importance of the environmental contexts, including access to memory clinics or dementia specialists. Kathleen was referred to a specialist at St. Mary's Hospital, in the

Kitchener-Waterloo Region. Co-researchers believed that one of the reasons to explain the difference between experiences is that Kathleen lived in an area that had awareness about and specific supports and programming for persons living with YOD, with connections to large organizations and groups such as the Alzheimer's Society, the Murray Alzheimer Research and Education Program, and the Research Institute on Aging. Living in a region where there is particular expertise and knowledge of the young onset population, and aware of and access to this knowledge, could be one contributing factor in the differing experiences between Kathleen and John (Middlesex County region).

Dominant ideologies relating to aging and dementia lead to the stigmatization of younger persons with dementia, and the use of discriminatory practices. For example, John was told numerous times by his doctor that he did not have dementia, and John believed that the doctor thought he was 'faking it'. This displays the ageism that persons with YOD are often exposed to where their concerns are dismissed, and they are told *"you're too young to have dementia."* If fortunate enough to be believed, you are then sent for diagnostic processes designed for older adults. For example, Rose highlighted that the tests she was put through during the diagnostic process did not feel relevant or appropriate. The heavy reliance placed on 'normal' memory-focused cognitive screening, such as with the MMSE, is recognized as one factor inhibiting timely diagnosis (Draper & Withall, 2015). There are in-depth processes and alternative examination tools that exist and require further investigation with rarer forms of dementia. Draper and Withall (2015) suggest early referral to memory clinics, or if not available, specialists with known knowledge of dementia, who are more likely to be aware of the comprehensive processes required. Once the diagnosis is confirmed, further discriminatory practices unfold.

The experiences of individuals with YOD are unique, and dementia presents in varying ways to how it is experienced by persons with LOD. Continuing with Podcast 1A, Dave questioned why it is so hard to receive a diagnosis. There appears to be little transparency in the healthcare system about why the challenges that have been expressed have not been addressed. What needs to be done to create more timely diagnosis? Are there systemic factors that are discouraging healthcare professionals to avoid giving such a diagnosis? It should not take eight years. It is at this point that I am drawn back to Habermas's theory of communicative action, where the systems world exerts power and control on the lifeworld, in this case, the life trajectory of persons with YOD. For example, Edgar (2006) described that each system within our society develops over time, and that the principles and practices that are used become deeply engrained. When it comes to the diagnostic process, we can see that the system is often so rigid in their understandings of age and dementia, that persons with YOD must undergo a number of misdiagnoses before obtaining a diagnosis of dementia. Even when dementia becomes acknowledged as a possibility, existing diagnostic tools are used without question when they may not actually be suitable, leading to further complications and delays in the process. Misdiagnosis is one such complication leading to possibilities of being undiagnosed, an experience I had never heard of before. After interacting with a number of persons with young onset over the years, I had become enlightened to the major life shifts that occur with a diagnosis; life changing to say the least. I could not come to understand even the possibility of being un-diagnosed and the impact that this would have on individuals with young onset and their families.

There are many situations throughout the journey of younger persons with dementia, where the healthcare system and healthcare professionals hold a position of *power over*, which is prominently reflected in co-researchers' stories about losing their driver's license in Podcast 1B. I found this to be a slightly more complicated topic, as the health and safety of others is also a consideration. That being said, I believe that John's experience raises important questions about the process of revoking a license on the spot. While it is a somewhat controversial topic due to the potential safety concerns at hand, which is reflected in the differing opinions of existing research, I think that the decision to revoke one's license at the point of diagnosis reflects the biomedical and dementia as tragedy discourses. If an individual is in the very early stages of a diagnosis, or has a slow progressing dementia, it could be said such individuals could still have the capacity to drive and should not be stripped of their license prior to alternate testing (Fox et al., 1997; Kapust & Weintraub, 1992; Ott & Daiello, 2010; Toepper & Falkenstein, 2019). There is a lack of research on this topic in the YOD context, and thus more research is needed to explore the impact of YOD diagnoses on driving ability and associated cessation processes. Some doctors, as in John's case, seem to recognize that and allowed John to keep his license until it was later questioned by a new doctor. This is also a reflection of the power that physicians and the healthcare system have in controlling the everyday lives of people living with dementia; the colonisation of the lifeworld by the systems world. Why isn't this more of a conversation? Is there a way that the individual in conjunction with family or other care partners could be more heavily involved in decision-making processes? A relational approach would support this by considering the implications of decisions on everyone involved and prompting consideration of how to support people with YOD in relational ways, so they are adequately supported no matter what the decision (Holstein et al., 2011; Jonas-Simpson, et al., 2021; Mitchell et al., 2020; Thomas, 2004).

One insight into this question stems from Mary Beth's statement about the costs associated with re-testing to reinstate one's driver's license, which further reflects the power of the systems world and provides insight into the potential of economic drivers within decision-making processes. Instead of focusing on the well-being of individuals, the system prioritizes the generation of profitability by stripping individuals of their license and charging the individual to prove that they are still capable of driving. If the doctor is concerned about the individual's driving ability, should there not be a different process that does not come at a cost to the individual who is already likely undergoing (or will be undergoing) financial strain since diagnosis?

Kathleen's and John's stories in Podcast 1B about no longer having a license, speaks to the importance of sociality through the relationships that provide support for them. For Kathleen, while difficult to ask for help, she has brought attention to the support of her partner, Rob, as well as others who she has reached out to for support since losing her license. John, too, has a partner who he is able to depend on and feels as though family members / care partners should be more heavily included in decision making processes. This made me reflect on what it would mean for people living with dementia to be in communities that were dementia inclusive and ensured there were other ways that people with dementia, and all citizens, could get around when the time comes that it is no longer safe for them to drive. Where Kathleen and John discuss the support of others, Paul speaks to his desire to learn how to ride a bike to stay mobile. Paul has a support network but does live alone and so learning to ride a bike is how he has chosen to adjust to the loss of his license. This to me reflects a healthy outlook on what recreation and leisure can mean for persons with dementia, as opposed to the prominent 'treatment' approach that it is often morphed into (Mitchell et al., 2020). The desire to learn a new skill, to transform with loss, post-diagnosis demonstrates a strong counter-narrative to that of biomedical and dementia as tragedy discourses, and enforces one such way through which recreation and leisure can support individuals in remaining connected with the community and contributing to one's well-being. This reflects one component of Barlett and O'Conner's (2010) framework towards social citizenship, where moving from a place of comfort to a place of growth is discussed. Within this, Bartlett and O'Conner (2010) identify growth as meaning "to be able to develop different aspects of oneself in the context of having one aspect deteriorating" (p. 40). In this case, growth came with Paul's recognition of no longer being comfortable to drive, and therefore becoming determined to learn how to ride a bike.

I think it is important to recognize here the dichotomy between 'tragedy' discourses and the notion of 'living well'. McParland and colleagues (2017) raised the important concern that in an effort to support the emancipation of persons with dementia from 'tragedy' discourses, there has been too much of an emphasis placed on 'living well' discourses. Doing so not only contributes to the reinforcement of 'successful aging' discourses, but also takes away from the complex and diverse experiences of living with dementia. As such, I believe it is important to recognize the "fluid nature of the dementia experience" (McParland et al., 2017, p. 258), therefore moving away from the dichotomy of discourses to a recognition of "the multiple realities of dementia necessary for social inclusion to occur" (p. 258). This notion is further supported by the social relational model of disability, where the dichotomy of impairment and disability was removed, and replaced with the notion of inclusivity and finding ways to support all who are perceived as 'problematically different' (Thomas, 2004).

There is a societal confusion about who it should be supporting and in what ways, particularly given the third and fourth age categories, whereby older adults are divided into the third age (65-79 years of age), denoting activity, healthy and productive aging, and the fourth age individuals (80+ years of age) denoting deficit and decline models of aging. Younger persons with dementia do not fit 'neatly' into either of these labels, often resulting in a lack of available supports. This got me reflecting even further, what comes before the third age? With some individuals being diagnosed well before the age of 65, I realized that persons with YOD are actually nomads within multiple constructed age categories. Although I could not find the associated ages, Laslett (1994) provided a description of each of the four ages as follows:

> First Age: Immaturity, dependence, socialization and education
>
> Second Age: Maturity, independence, child production and child rearing, responsibility, earning and saving.
>
> Third Age: Era of personal fulfilment.
>
> Fourth Age: Final dependence, decrepitude and death. (p. 439)

What is harmful about these constructions is the pressure for individuals to conform to 'normative' life patterns and a certain identity. Before the development of the third age, individuals moved directly from the second age to the fourth age. The development of the third age was to provide a positive counter-narrative to replace notions of older adults as representing 'deficit and decline', to an image of older adulthood as continuing an opportunity for "active, healthy and productive aspects of aging" (Grenier and Phillipson, 2013, p. 57). My argument is that these categories are problematic and do not reflect the diversity of lived experiences in the world. The social relational model of disability, and citizenship within a lens of differentiated universalism, provides all individuals the opportunity to be themselves through the embracement of difference, such as "different identities, sexualities, lifestyles, cultures, worldviews, meanings, narratives" (Bartlett & O'Connor, 2007, p. 112), and so on. Rigid constructions of age produce exclusivity in society, such as within support service provision, by forcing people to fit neatly into categories defined by inclusion/exclusion criteria. Doing so places the decision about the applicability of the service in the hands of the organization, as opposed to the person seeking support, further restricting support options for the individuals who need them. Defining people by a set of characteristics reflects a component of the framework towards social citizenship where it is suggested we move from identity to social positions (Bartlett & O'Conner, 2010). In this perspective there is a shift from defining people based on characteristics, to one that perceives identities as intersecting and fluid. By respecting the plurality of social positions that one individual may hold, the limitations of creating rigid inclusion/exclusion criteria for support services become clearer. Barlett and O'Conner (2010) would recognize such limitations as being an infringement on the "freedom from discrimination" (p. 47) component of social citizenship, through the denial of access to certain services. This is a discussion that we will return in the section on *Learning from the Past and Present*.

One area where community supports would be helpful is in the rehabilitation of younger persons with dementia into the workforce (discussed further in *Looking to the Future*), for individuals who wish to do so. Mary Beth's story in Podcast 1C about being forced out of employment, and the pressure she feels as a young adult to contribute very much reflects discourses of 'successful aging' produced in the third age. The pressure to contribute created by the third age category, and the stigmatization of dementia as a fourth age category construct, has left individuals with YOD to feel diminished because of their inability to 'economically contribute' to society. I perceive such divisions between the third and fourth age to be driven by the Political Economy of Aging (Hendricks & Leedham, 1992; Minkler, 1996), such that the third-age category was created out of a desire to extend expectations of productivity and minimize the ‘economic impact’ of populations of ‘deficit and decline’ (Grenier & Phillipson, 2013). The stories shared by co-researchers highlight the humanistic perspective within CG, where we can see the ways through which the macro-system’s economically motivated divides of the third and fourth age, impact the daily experiences of persons with YOD (Baars & Phillipson, 2013). This is reflected in Mary Beth’s statement about telling other’s she was retired, as well as her describing the pressure to contribute and handle the financial obligations often present during this age range.

Although Mary Beth was experiencing frustrations of her own, I think it is important to recognize that if the system were structured differently, she may not have been so discouraged that she could no longer work. This is not to say that persons with YOD should feel pressured to continue to be employed; rather, if that were what they would like to do, the system should be more flexible in supporting this. This brings us back to the social relational model of disability, whereby disability is viewed as an outcome of cultural and social processes rather than biological deficit (Thomas, 2004). From this lens, the focus is shifted from the perception of persons with YOD as ‘problematically different’, to one where the systemic and social relationships that perpetuate inequities are recognized. Here, persons with YOD are no longer reduced to being objects of labour-power, but rather human beings who can contribute in different ways, economically or otherwise. This acknowledgement of difference is also present in Bartlett and O’Connor’s (2007) discussions around citizenship, whereby any and all differences are celebrated, and exclusionary notions of citizenship are rejected. From this perspective, “citizenship moves beyond a status bestowed ‘from above’ to something individuals achieve from themselves, through the power dynamics of everyday talk and practice” (Barlett & O’Connor, 2007, p. 112).

Using this research as a communicative space for younger persons with dementia, we can see throughout the discussions a raising of a critical consciousness, a process Freire (1970) termed, “conscientização” (p. 35). From Rose pointing out in Podcast 1C that the system should be drawing on other countries who have learned how to support others with disabilities and acknowledging the need to start focusing on strengths rather than ‘deficits’, to Paul identifying the need for better supports and training, to Rose and Dave raising ideas about vocational and aptitude testing; all of these considerations align with the social relational model, questioning the status quo, destabilizing idealized norms, and prioritizing human variation (Jones, 2006). More specifically, the co-researchers clearly identify the ways through which society can be transformed to be more inclusive of persons with YOD. By disrupting dominant biomedical discourses of deficit and decline and refocusing on systemic weaknesses, it becomes clear that often times persons living with YOD desire to continue to work in some capacity and it is the system that needs to adapt and become more informed and supportive. Any resistance of the system to do so, demonstrates the power of a non-impaired social status in keeping the segregation of the ‘problematically different’ to the peripherals of society. That being said, for individuals who do not desire or are unable to continue engagement in the workforce, it is important to recognize that contribution to society comes in many different forms. For example, Bartlett and O’Connor (2010) move away from the perception of citizenship that solely reflects a focus on “legal rights and civic responsibilities” (p. 32), to one that values “social practice” (p. 32). This can mean a multiplicity of things, however, some examples include recognizing contributions to “political campaigns, self-advocacy groups, public meetings, conferences, and research studies” (Bartlett and O’Connor, 2010, p. 4).

This is reflected further in Barlett and O’Connor’s (2010) framework towards social citizenship where they discuss the importance of moving from inclusion to participation. Here, there are a few limitations of ‘inclusion’ highlighted, with one being that it does not look at a person with dementia’s contribution beyond their role in their care environment. Barlett and O’Connor (2010) argue that this conceptualization needs to be broadened to consider the “broader spectrum of social activities and process that people with dementia have a right to or might wish to participate in” (p. 44), which beyond employment also include engagement in meaningful activity, advocacy efforts, participation with boards or committees, voting, and so on. Such a recognition of participation highlights the agency that persons with dementia have, countering dominant narratives of ‘incapacity’. The ripple effect that began with a difficult and lengthy diagnostic process is undeniable. Adding to our discussion about the third and fourth age, it is clear that society believes in the importance of being a productive and contributing member of society. With such constructs in place, individuals with YOD are unfairly categorized in a nonexistent realm somewhere in between the two, which contributes to society’s refusal to allow persons with YOD access to meaningful employment, amounting to serious financial implications.

The stories shared show us the ways with which the system is structured to oppress the ‘problematically different’ through the creation of financial instability. Persons living with YOD are often forced into early retirement at a time when they have a number of financial obligations, such as dependent children or parents (Jefferies & Agrawal 2009; Shnall, 2009), mortgages, car payments, and day-to-day living expenses. Being forced out of employment prematurely results in fewer financial supports being available (i.e., Canadian Pension), and when received, is still often not enough to support the individual and their family. Related to this, co-researchers also discussed the unfair and clearly gendered implications of work structures, the gendered division of labour and time, and the value that is placed on public sphere contributions (e.g., politics, rights, status quo), over the private sphere (e.g., activities of daily maintenance, emotion, 'otherness') (Lister, 1997). This is reflected in the statements co-researchers made in Podcast 1D about women only being allotted partial pensions in situations where they stayed home to raise the children and be a homemaker, resulting in further financial disparities as the economic contributions of such a role in society are still largely overlooked.

For me, the exploration of these shifting realties of persons with YOD demonstrates a strong reflection of the power of the systems world over individuals in the lifeworld. All answers point to 'no!": you cannot drive, you cannot work, we cannot support your financial stability. What are persons with young onset and their families supposed to do? The system is setup to perpetuate ageism by reinforcing 'apocalyptic demography' narratives (Robertson, 1990), where society is encouraged to believe that the aging population (including persons with dementia) are unable to contribute and are a great economic burden; wherein reality, the system has created an inflexible environment with no alternatives other than to be at the hands of normative society.

One consideration that has been gaining in popularity to close the growing inequality gap for Canadians, is the idea of a universal basic income (BI) (Canadian Index of Wellbeing (CIW), 2016; Mulvale, 2019; Segal et al., 2020). While this has been on the proverbial radar for a number of years, the onset of the COVID-19 pandemic deepened the existing economic disparities, disproportionately impacting marginalized groups within our society (Segal et al., 2020). A universal BI guarantee would mean:

> A comprehensive social safety net that includes access to housing, childcare, mental and physical healthcare, disability supports, education, internet access, and the many other

> public services essential to life in a high-income country. Residents with no other income would receive the full benefit which would be sufficient to ensure that no one lives in poverty, while those with low incomes would receive a reduced amount. (Segal et al., 2020, p. 5)

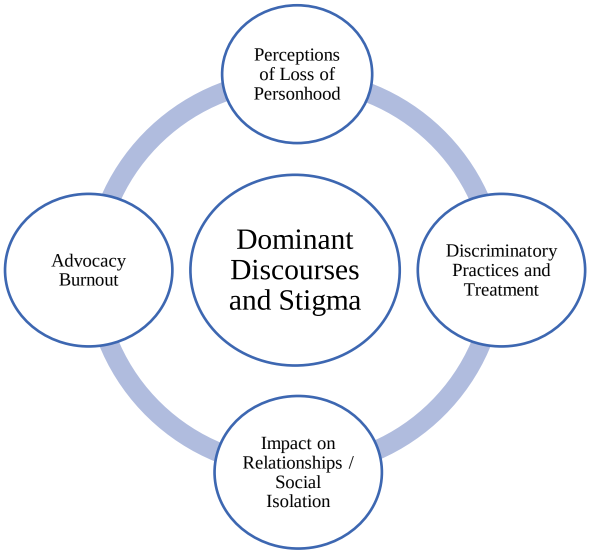
Shifting the focus to a steady state-economy and away from economic growth through the adoption of a universal BI would provide all members of society an opportunity for economic security, lowering social inequality (Mulvale, 2019). For persons living with YOD, this would mean reducing the financial instability caused by forced unemployment and pressure of financial obligations with a lack of support from governmental bodies, to providing an opportunity to restore personal autonomy and to live a life “beyond paying the bills” (CIW, 2016, p. 8). In addition to this, the CIW (2016) provided a number of other suggestions to support this movement, including but not limited to creating more accessible opportunities for Canadians, and to ensure “universal access to leisure, arts, culture, sport, parks, and recreation to enrich lives” (p. 8). The use of such a comprehensive plan could have life changing implications for groups perceived as ‘problematically different’, by reducing marginalizing factors such as economic oppression and social exclusion, and increasing opportunities for financial stability and equal access.

Theoretical Reflections: Recognizing and Resisting Ostracism

Recognizing and Resisting Ostracism: Overview of Key Messages

Core Challenges Identified by Co-Researchers

Discrimination and Marginalization



Possible Action Items:

Supporting Full Citizenship and Human Rights

Interconnected Ways of Addressing Core Challenges:

Resisting to Dominant Ways of Knowing, Thinking, and Being:

- Resistance through words, actions, and advocacy in micro, meso, and macro communicative spaces
- More extensive inclusion of youngers persons with dementia in research and initiatives (e.g., program development, policy changes, implementation of strategies and frameworks)
- Joining forces with other advocacy movements, such as the Disability Movement
- Implementation of awareness raising campaigns (e.g., about dementia, the value of contribution in its various forms, the systemic and societal changes that need to come to fruition)

Improving Provision of and Access to Support and Advocacy Groups:

- The development of more communicative spaces to support younger persons with dementia coming together in solidarity to share like-experiences and engage in critical reflection and action
- Expanding the YOD advocacy network will support the relief of ‘advocacy burnout’ by sharing the work amongst a larger group of representatives; this will also broaden the spectrum of inclusion through making purposeful efforts to seek individuals with YOD who may be experiencing isolation or intersecting marginalization’s that are not yet represented in this community

Nurturing Relationships and Building Strong Support Networks:

- More research on the nature of changing relationships in the YOD context and how to navigate or influence such experiences
- Awareness raising campaigns and eliminating stigma
- Improving access to support and advocacy groups

Figure 4: *Recognizing and Resisting Ostracism - Overview of Key Messages*

It is not new knowledge that persons with dementia are subject to harmful stigmatizations around ‘deficit and decline’ and the ‘tragedy’ of their lives (Mitchell et al., 2013). What is less understood is the double burden of stigma that individuals with YOD experience, as in addition to common stigmatizations of dementia, the age and appearance of individuals with young onset does not match society’s stereotypical view of what it ‘means’ and ‘looks like’ to have dementia. In Rose’s first story in Podcast 2A, she explained how she feels when people find out she has dementia. Similar to what was discussed when exploring the experiences of losing a driver’s license and being forced out employment, dominant discourses are reflected in the judgement about and actions towards younger persons with dementia. For example, biomedical discourses perceive persons with dementia as lacking personhood, and solely being seen as their diagnosis (Mitchell et al., 2020), and is reflected in Rose’s perception of being viewed as “we’ve lost our brains” and “we no longer have feelings.” These statements also reflect dementia as tragedy discourses through the dehumanization of persons with dementia, which is further exacerbated in statements such as “They tell you to get your affairs in order, your life’s over more or less.” This clearly reflects dementia as tragedy discourses described by Mitchell and colleagues (2020), where some metaphors included “the funeral without end” and “a living death” (p. 4).

Despite being subjected to such disheartening experiences, Rose clearly resists these notions of being the ‘walking dead’. Her message in Podcast 2A was loud and clear – “I am very much alive” and “I am going to live each day to the fullest”. Her resistance of such stigmatizations lives not just through her words but her actions. Rose has joined a number of different groups, a couple of which involve advocacy efforts to educate society about YOD. Rose was not the only one. In fact, all of the co-researchers have become dementia advocates to varying degrees, including through their participation in this research, as a way to challenge the misunderstandings about YOD. Such actions reflect the co-researchers' journeys to reclaiming their citizenship by seeking out opportunities for social action (Bartlett 2014, 2015). As the conversations continued, we saw further resistance through dialogue with others; challenging misunderstandings, questioning the taken-for-granted, and connecting with advocacy groups.

With regards to Clandinin and Connelly's (2000) three-dimensional space, I think Rose's story particularly highlights notions of temporality and spatiality/sociality. In a number of Rose's stories shared in Podcast 2A, she brings up the eight-year period it took her to finally obtain a diagnosis. Throughout our discussions, I felt Rose's (very understandable) frustration about this. The other aspect of time I see Rose talk about is that her diagnosis happened almost 14 years ago. What I take away from this message is that Rose has been living with stigma for a very long time, but despite this, she is very much determined to keep *living* and contributing. In terms of spatiality/sociality, Rose's geographic location contributed to the availability of and access to supports, including who Rose uses as her general practitioner, and the four neurologists she was referred to. This is an example of how geographic location can influence who one comes in contact with, and how these contextual factors can shape the experiences of individuals living with YOD.

What I find interesting and prominent as I reflect on Podcast 2A, is co-researchers' active and intentional use of varying communicative spaces to resist dominant discourses and discriminatory practices. For example, co-researchers found it helpful to join dementia support groups, especially those designed specifically for persons living with YOD, as it provided a space to share like-experiences and become critically aware that stigmatizations of dementia - such as it is a disease of the "aged, decrepit, in a home, doddering" (Dave, Podcast 2A) - does not define them. In our discussions, co-researchers also shared the ways that they resist stigma in one-on-one conversations with others, by for example positively (re)defining what dementia means from their perspective. Paul and Rose also shared their passion for opening up spaces of dialogue with the broader public to challenge stigma and educate people about the new realities of living with dementia. This commitment to “uniting with others to make a difference” (Bartlett & O’Connor, 2010, p. 46), highlights the importance of moving from the idea of attachment towards solidarity within social citizenship. Such a shift recognizes moving from a feeling of psychological connectedness, to one the incorporates the power of using this connectedness for action.

There were tensions for me here as some of these approaches were positive while others reproduced the very dominant discourses the co-researchers were concerned about. For example, in Podcast 2A Kathleen shared that when her and her husband are out and run into people they know, that people will often speak directly to her husband about her, under the assumption that she is no longer an agentic person who can speak for herself; another violation to the “freedom from discrimination” component of social citizenship (Barlett & O’Connor, 2010). John’s response to Kathleen’s story was to emphasise the importance of opening up dialogues with people, to use the opportunities to educate others and to show resistance to such assumptions; an approach Dave also agreed was critical to challenging stigma. Every conversation counts and contributes to the raising of a critical consciousness in others. In terms of the components of the lifeworld (culture, society, and personality), such conversations begin to chip away at the level of mutual understanding, meaning to challenge and renew cultural knowledge (Thomassen, 2010). Kathleen also brought up tensions she holds with the term ‘dementia’ because of the negative connotations it represents where it “makes us sound older”.

What this reflects, and is reflected sporadically throughout the stories shared, is the way through which co-researchers have in some ways accepted discourses of dementia as associated with old age to help separate themselves from fourth age stigmatizations of LOD; this brings us back to the discussion had earlier about the blurred lines between dominant and counter-narratives in Chapter 3. That is, some co-researchers may in certain instances perceive deficit and decline models of LOD to hold true for the older adult population, but reject that such judgements are not applicable to younger persons with dementia. In other instances, such as in discussions about human rights and living with dignity that arise throughout the discussions shared in Podcast 3, *Learning from the Past and Present*, and Podcast 4, *Looking to the Future*, there is the presence of critical consciousness that is in tension with the dominant assumptions that have sedimented over time. In these moments, persons with YOD describe parts of their advocacy that extend beyond young onset populations to include all persons with dementia in their quest for justice.

In Podcast 2A, Paul and Rose also highlight how they have turned to public speaking as a way to bring the voices of persons with YOD into the conversation, as the driving force of the conversation. Emphasis is placed on the importance of advocacy, education, and awareness raising. In a similar regard, Paul and Rose talk about their advocacy group's effort to directly open communicative spaces with government officials, a way they see as important in bridging the systems world and the lifeworld. While the systems world is resistant to change for fear of losing 'power' and 'profitability', the more dialogues that can be opened, the more likely it is that small changes at the level of the systems world will begin to unfold, slowly contributing to larger transformational shifts over time. YOD advocacy groups in Canada have made great strides in becoming recognized at governmental and policy levels, and while change is slow, it demonstrates the power that counter-narratives and collective representation can have in making a difference. Examples provided in our discussions included: contributing to the development of the Canadian National Dementia Strategy, writing letters to the government about how to make the community more ‘dementia-friendly’, and meeting with the Federal Minister of Health to discuss the implementation of desired changes. Such efforts of younger persons with dementia to campaign for social change are also documented by Bartlett (2015). Bartlett and O’Conner (2010) reflect on such engagement in their framework towards social citizenship where a shift from comfort to growth, and from attachment to solidarity are discussed. Within this, the idea of growth “recognises a person’s inner hopes, desires and capacity to contribute to life” and can include “developing into an effective advocate” (Bartlett and O’Conner, 2010, p. 40). Extending on this idea, is the power of persons with dementia coming together in solidarity to use their social connection for action and change (Barlett & O’Connor, 2010).

These discussions around experiencing stigma again make me think of the social relational model of disability, in that the conversations shed light on the systemic and social relationships that perpetuate inequities and the ways it has shaped the experiences of persons with YOD (Thomas, 2004). It also reminds me of the similarities of the disability movement, through which disabled people advocated for their rights to be upheld and for voices to be heard, and the advocacy movement of people with YOD. Even with the progress made over time through the disability movement, such as through changes in policy and the development of the CRPD, there is still so much to be done. Paul’s and Rose’s discussion in Podcast 2A about the disproportionate level of advocacy efforts versus actual change speaks to this and brings to attention the systemic inequities that are experienced by persons with YOD. To what extent are their perspectives (de)valued and how does stigma play into the devaluing of their perspectives and experiences? Rose expresses her frustration about her contributions being solely valued in terms of labour power. How do we transform society so that different types of contributions to the world can be valued and recognised?

With persons with YOD being young in age, it is not expected that they are living with dementia, making their disability very much invisible. This becomes a challenge for persons with young onset, as in the case Mary Beth shared in Podcast 2B when trying to open up about her diagnosis to others. To receive a response of “well, you don’t look like you have dementia” must be a difficult one to navigate. It is almost as if in some cases, friends and family have a more difficult time coming to terms with the diagnosis than the person experiencing the diagnosis. Dementia has only recently been recognized as a disability, although the lines remain blurry for persons living with young onset. Some co-researchers were unaware if YOD was also considered a disability alongside LOD. This is rooted in the complications presented by the constructions of the third and fourth age categories, whereby the realities of living with YOD are largely misunderstood.

When exploring the co-researchers’ perspectives around coming to terms with one’s diagnosis in Podcast 2B, time was a factor that varied between individuals. In Mary Beth’s case, she talks about accepting her diagnosis fairy quickly, whereas Rose and Dave both say that they initially introduced people to the topic by saying they had ‘memory issues’ as a ‘gentler introduction’. Very early in the process, people living with YOD are very aware of the stigmas associated with dementia and how it might change their relationships. They choose with careful consideration and intention how they will tell others about their new diagnosis. I also noticed that co-researchers were discussing time with respect to social interaction. In Podcast 2B, Kathleen talks about how she ends up saying yes to requests so often that her time gets stretched too thin and she becomes overwhelmed by the commitments she's agreed to. Similar challenges have been documented in the dementia advocacy community, whereby persons with dementia have felt the burden of the substantial time commitment to various advocacy efforts (Seetharaman & Chaudhury, 2020). In other cases, such as John's, he speaks about the time other people have for him post-diagnosis and vice versa. Both John and Paul agreed that it was best to invest time with people who still take an interest in their lives and want to learn more about their new experiences rather than distancing themselves from the situation.

The relationships persons living with YOD have with people around them clearly shape their day-to-day lives, including their thoughts and emotions. In Podcast 2B, co-researchers shared that they value flexibility and understanding, such that their day-to-day mood, apathy, and ability to interact will shift and change. In the subtext, or what is not said, I perceive emotions such as sadness, anger, and frustration when it comes to tensions that develop in what were trusted relationships with people, once a diagnosis is shared. Lastly, I felt the group really came together in their discussions about shifting relationships. While I was there and engaged, the co-researchers were able to connect on these experiences in a way that I was not able to completely relate to. It was clear that co-researchers value relationships in their lives, and have had to find ways to navigate different perspectives and responses to a diagnosis of dementia, shift with changing relationships, and grieve family and friends who have walked away.

The impact of changing relationships following a dementia diagnosis is not well documented. Most of the research available "is dyadic in focus; has predominantly considered spousal relationships; has rarely extended to other family members or the potential impact of dementia upon the wider family and has not always included the perspective of the person with dementia" (La Fontaine & Oyebode, 2014, p. 1244). Beyond the family, there is little research that demonstrates how persons with dementia navigate existing friendships and relationships beyond the care context, with most of the focus being on how to develop new relationships and peer support (Ward et al., 2011), as well as on the quantity not the quality of the relationships (Harris, 2013). Additionally, Harris (2013) indicated that the sparse research on friendship and dementia typically falls within three categories, which are, “1. The impact of friends on the dementia experience; 2. The presences of friends as a preventative factor against the risk of developing dementia; and 3. The development of friendships in long-term care facilities” (p.143). What the literature does indicate is that “dementia takes its toll on social relationships and many friends withdraw and ‘disappear’” (Harris, 2013, p. 143), particularly in instances when it becomes difficult to interact and communicate. Factors that appear to play important roles in the maintenance of friendships after a diagnosis of dementia are, “the importance of the friendships, factors affecting the quality of the relationships, mutually beneficial relationships, core values, acceptance and disclosure, and recognition of strengths and understanding of limitations” (Harris, 2011, p. 305). More research is needed to explore the preservation and importance of friendships for persons with dementia, as well as to better understand the experiences and impact of grieving those who have walked away; these are particularly under-researched areas specifically within the YOD context.

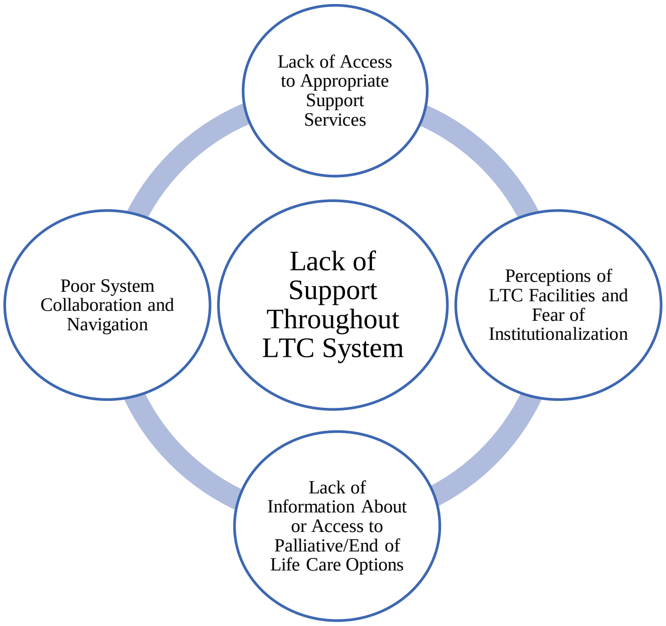
The literature has documented the ways with which harmful dominant discourses impact the stigmatization of and discriminatory practices towards persons with LOD (Dobbs et al., 2008; Dupuis et al., 2012a; Mitchell et al., 2013, 2020). While such theorization did not necessarily exclude persons living with YOD, there is no research that I could find focused solely around understanding such injustices from the perspectives of younger persons with dementia. The contributions that this work has made to better understanding the unique ways that dominant discourses and systemic structures marginalize and oppress younger persons with dementia will be further discussed in the implications and learnings section.

Theoretical Reflections: Learning from Past and Present

Learning from Past and Present: Overview of Key Messages

Core Challenges Identified by Co-Researchers

Discrimination and Marginalization



Possible Action Items:

Supporting Full Citizenship and Human Rights

Ensuring Access to Appropriate Support Services:

- Removal of stringent and exclusionary eligibility criteria
- Development of more relevant and desired programming (to satisfy demand and reduce waitlists)
- Increased information about existing relevant programs
- Increased information and support in accessing other relevant opportunities (e.g., learning new skills/interests, volunteering, rehabilitation programs, meaningful recreation and leisure, etc.)
- Development of s specialized YOD training for healthcare professionals (such as program staff)
- Provision of government subsidies to afford programming
- Further research and development into potential of virtual programming in the YOD context

Improving System Collaboration and Navigation

- Development of an environmental scan of support service provision across geographic locations, and identification of gaps
- Increased education and training for healthcare professionals about helpful referrals pre- and post-diagnosis
- Advocacy efforts to initiate system collaborations, and policy changes that reward integration, such as financial incentives

Supporting LTC Culture Change and Alternative Approaches to LTC

- Implementation of culture change initiatives and policy changes to improve standards of living and resident quality of life (e.g., removal of locked units, reduction of psychotropic medications, opportunities for meaningful recreation and leisure)
- Increased financial support for individuals utilizing LTC facilities
- **Suggested shifts:**
  - Consideration of YOD specific spaces
  - Financial and other necessary supports to enable individuals to live in their own homes for longer
  - Improved information and access to support service for individuals living with YOD and care partners

Providing equitable Access to Humane Palliative and End of Life Care

- Increased research around this topic in the YOD context, including the development of helpful resources, supports, and reformed palliative and end of life care options
- Increased education and training for healthcare professionals (e.g., dementia as a terminal illness, available options, etc.)
- Increased understanding of existing options such as MAID

Figure 5: *Learning from Past and Present - Overview of Key Messages*

In this section, we begin to see how dominant discourses and associated systemic injustices become apparent in the provision (or lack thereof) of appropriate care and support options for younger persons with dementia. The intersections of temporality, sociality, and spatiality was particularly interesting in discussions around community-based supports. Having a support network, in any capacity, seemed to be of the utmost importance to co-researchers, and finding ways to achieve fulfillment in this area amid the pandemic proved difficult.

The literature demonstrates that there is a lack of appropriate support services for persons with YOD (Alzheimer's Association, 2006; ASC, 2016; Oyebode, 2015), with some programs excluding individuals who are under the age of 65 (Shnall, 2009; van Vliet, 2012). But what does 'appropriate services' mean? After talking with co-researchers, I found this means a variety of things. Co-researchers valued giving back by volunteering in advocacy and research efforts that would improve the system of care for persons with dementia in some capacity. Co-researchers also highly valued socialization and forming true relationships, even intergenerational ones. That being said, most co-researchers spoke to the benefits of support groups that were comprised of individuals in a similar age group because of the opportunity to bond over like-experiences, and the ability to engage in activities that reflected their abilities and generational interests.

What the co-researchers did not like, is the assumption that they would fit in with programming designed for persons with LOD, with the largest factor being a lack of engagement in meaningful activity to the extent where it was perceived as disrespectful. In Podcast 3A, Mary Beth shared stories of not being accepted into programs due to the age restriction of 65+, as well as instances where she was placed in programs that were inappropriate for her leisure and social preferences, and her level of physical ability. John echoed this experience, noting that he had also experienced being put in programs designed for individuals with LOD, where he had a difficult time relating to the activities that were provided. This reflects moving from the idea of occupation towards one of purpose that Bartlett and O'Connor (2010) discussed in their framework towards social citizenship. Here, it is recognized that historically, 'occupation' within the context of support services is used for its "psychosocial or therapeutic value" (p. 42), where often the focus should be on providing purpose or meaning. In the context of this research, it is clear from the stories shared that when the support services are not relevant or appropriate, there is a lack of meaning and engagement. The shift should therefore be focused on the ways through which services can better support younger persons with dementia in finding purpose and meaning.

In discussions about system navigation, there were clear inconsistencies that existed in the provision of and access to support services depending on where one lived. While some co-researchers described being referred to the Alzheimer's Society early after diagnosis, other co-researchers described being left to fend for themselves, unsure of where to go or who to talk to. This brings us back to the discussion about the power healthcare professionals have in shaping the experiences of younger persons with dementia. Co-researchers should not be leaving the doctor's office after being diagnosed and not knowing what to do next or where to turn for support. In response to this, co-researchers called for more educated healthcare professionals, as well as better system navigation. In Paul's experience, where there were no referrals or guidance, he describes six years of staying in his home in social isolation. Why is there so much inconsistency? This question is reflected on in the following paragraph.

In Podcast 3A when Rose began discussing the lack of collaboration across organizations within the healthcare system across Ontario, I again came back to the tensions we know exist between the systems word and the lifeworld (Edgar, 2006). What I had not yet thought of was the tensions that also exist between various components of the systems world, and the strategic power that comes from working in a siloed fashion. Where Rose is proposing for systems to work together to create communicative action (the use of action towards reaching a shared understanding), healthcare systems and organizations are instead working within a strategic action framework that leads to organizations “directing, manipulating and controlling situations” (Jones & Delany, 2014, p. 3). It has been proposed that one such reason for why the healthcare industry so often engages in strategic actions is due to the impact of power and financial pressures (Jones & Delany, 2014). After reflecting further, I feel that organizations that have taken time and effort to create knowledge and develop support services and access to information, do not want to share or collaborate with what should be considered other healthcare allies, because of the capitalist perception that time is money. Why share something that they have invested to create, that makes them unique, and that makes them in high demand? Part of this stems from the competition between organizations to access funding. In Canada key dilemmas have been documented to include “intergovernmental disputes between federal and provincial levels of government and determining how to organize care, what to pay for (comprehensiveness), and what incentive structures to put in place for payment” (Deber, 2003, p. 20), as well as the use of bundled versus integrated payment models (Sutherland & Hellsten, 2017).

I think the siloed nature of the healthcare system is one reason that there are inconsistencies in services provision between regions within Ontario. Within this fragmentation of services, Dupuis and Smale (2004) identified a lack of sharing and resources between service providers and the need for interagency collaboration, difficulties navigating the system post-diagnosis and the need for better system navigation, and geographic disparities in availability and access to support services between urban and rural locations that needs to be addressed. For example, as we saw in Rose’s story above, spatiality and sociality bring attention to the impact of where one lives on who they come in contact with (e.g., healthcare professionals), as well as access and availability to support services. For example, Dave and Kathleen reside in Kitchener-Waterloo region, where they both had positive experiences being immediately referred to their local Alzheimer’s Society and able to access specific programming for younger persons with dementia. That being said, co-researchers described the long waiting lists that are often present when trying to access specific supports for younger persons with dementia, which I attribute to the lack of support services of this nature that are available. Within various geographical locations, sociality brings attention to the importance of who an individual comes in contact with in the system, as the healthcare professional that provides the diagnosis is the one who will be responsible for referring younger persons with dementia to their Local Health Integration Network, local Alzheimer’s Society, and so on. Based on the discussions, there is a great need to educate healthcare professionals about YOD, and for there to be a greater level of awareness about supports and resources available in the community for referrals and references, as some co-researchers described this as a missing component at time of diagnosis. This was also recognized by Dupuis and Smale (2004) in the broader dementia context, however this discussion should highlight the importance of specialized training in dementia and dementia care to also include specific guidelines for working with and supporting younger persons with dementia.

The lack of appropriate programming available for younger persons with dementia contributes to the lack of opportunity there is for engaging in meaningful recreation and leisure. Support services are often subsidized in some capacity by the government. For example, the

Young Onset Dementia Association was initiated in August 2014, and at the time was funded through the Sunnyside Foundation although it has now obtained permanent funding through the Waterloo-Wellington Local Health Integration Network. As such, the program comes at a cost of $17.50 per day (11:00am to 4:00pm), and covers meals, activities, and outings (including transportation). Such a cost is still burdensome to many individuals living with YOD, due to the array of financial challenges discussed earlier. Without subsidized programming in place, persons living with YOD and their families would have to pay out of pocket for expenses relating to recreation and leisure activities. Based on the discussions had about financial challenges, I anticipate that many persons with YOD often sacrifice their recreation and leisure activities in lieu of basic necessities needed to live.

The lack of access to meaningful opportunities and social connections was exacerbated with the onset of the COVID-19 pandemic. Co-researchers described inconsistent access to support services (including age-appropriate services), and a lack of access to meaningful recreation and leisure opportunities in the community during the extended lockdown period. One such consequence of the restriction of support services and access to the community has been social isolation. Some co-researchers, like Rose and John in Podcast 3A, described their social nature and the difficulty they have been having maintaining social contact in the time of COVID, including through programming. Dave also described the impact of the pandemic on the programs he was participating in and contributing to, and explained his excitement for the chance to share in the programs with others again, and to further regain his advocacy efforts. One unanticipated benefit of the pandemic has been the uptake of programming through virtual platforms such as Zoom, which co-researchers described as being important for maintaining some level of socialization, the continuation of their advocacy efforts, and participation in different projects, such as this one. John described the benefit of having access to virtual programs for “apathy days” when he doesn’t feel like going out. That being said, while grateful for the benefits of virtual programming, he did note that it could not replace social contact.

While it is anticipated that a lack of appropriate support services can contribute the early institutionalization of persons living with YOD (Carter et al., 2018), little is known about the perceptions that younger persons with dementia hold about LTC facilities. In discussion with co-researchers in Podcast 3B a number of perceptions emerged. The consensus amongst co-researchers was that going into a LTC facility was a last resort, and for some, not an option at all. Although a couple of co-researchers described changes that would help LTC facilities be a more appealing choice, the primary focus of the discussion was on various concerns that have been raised and been exacerbated because of the pandemic. Changes to LTC facilities described by a couple co-researchers included but was not limited to: the removal of locked units and stringent schedules, having freedom of choice and movement, being surrounding by individuals of a similar age and level of ability, well educated and informed staff, an environment that reflects home-like touches, in addition to the embracement of other best practices.

At the foundation of concern for co-researchers with regards to LTC facilities is the violation of human rights. First, one co-researcher explained the crippling financial costs, even in rooms where four people are sharing. In Ontario, the monthly rates to live in a LTC home range depending on if you select basic, semi-private, or private accommodation, and range from $1,891-$2,701 (Government of Ontario, 2021). Trying to afford such accommodation (and having qualify for financial support through a government subsidy for basic accommodation), plus the cost of living of the care partner, in addition to the various financial obligations discussed above, seems impossible. In connection to this idea, co-researchers also had concerns about being separated from their partners and expressed the desire to continue being able to live with their partner. Although, co-researchers would like for this to take place in their own homes, the discussions indicated that this would take away some of the financial challenges of having to move into a LTC facility, and make the transition easier as they would not have to separate from their partner.

Second, co-researchers described the overuse of medication in LTC. In Podcast 3B, Mary Beth described the increase in use of medications during the pandemic, noting that doctors who had spoken with Dementia Advocacy Canada have recognized this as an increasing concern. Literature had previously recognized the excessive use of psychotropic drugs, particularly among the YOD population in LTC (Mulders et al., 2016). Since the pandemic, more recent literature has found a “statistically significant increase in the use of antipsychotics, benzodiazepines, antidepressants, anticonvulsants, and opioids” (Campitelli et al., 2021, p. 1) among nursing home residents in Ontario.

Third, we can see how the impact that a lack of age-appropriate programming for individuals living with YOD in the community is exacerbated in LTC facilities. In Podcast 3B, co-researchers spoke about how difficult they found it to imagine themselves in LTC. John and Dave both spoke specifically to how it must feel to be in your 50s and be living with people in their 70s and 80s. Co-researchers made it clear that such age discrepancies were bothersome because of concerns with social connection, sense of belonging, and appropriateness of the environment and supports available (Oyebode, 2015; Theurer, 2015). Additionally, what is often seen in LTC settings is the use of therapeutic interventions that are guised as recreation and leisure, turning something that is supposed to be meaningful into a tool to control or ‘improve functioning’ (Mitchell et al., 2020). Between the lack of meaningful social and recreational stimulation provided and the often high levels of physical and verbal ability, it can be seen that the social and environmental factors of LTC facilities are responsible for creating an inhumane living situation, contributing to embodied expressions of frustration and confusion (Theurer et al., 2015).

Lastly, the COVID-19 pandemic furthered negative perceptions of LTC facilities. Discussions brought attention to concerns regarding the spread of disease or infection, being locked in your room like you're in jail, infectious control procedures taking away time from resident care, the overuse of medications and sedatives, and above all, the incomprehensible number of deaths that were documented. Such a disregard for human life shows the extent with which the systems world has control over the lifeworld (Edgar, 2006); a control that can decide life or death. Residents had little access to the outside world, as access to technology is not a guaranteed privilege, despite the human rights concerns this creates. In particular, Paul expressed the need to improve access to technology in LTC homes, including making Wi-Fi available. Why wasn't more done to protect the lives of residents? Has the impact of dominant narratives really resulted in disregard for human life of individuals deemed 'problematically different'? It appears that the construct of citizenship shifts upon entering LTC, whereby its power is stripped away by the forceful pressure of systemic structures that paralyzes one's ability to act, to have a voice. I can say with certainty that no one in society would have freely chosen to undergo the inhumane treatment and isolation that occurred throughout the pandemic.

It is well documented that Canadian nursing homes have long been recognized as having "unacceptable and sometimes scandalous conditions" (Estabrooks et al., 2020, p. 652). COVID-19 has shone a very bright light on this fractured system, and demonstrated the extent of ageism that must exist in our society to have allowed residents to suffer physically, mentally, and emotionally, and for Canada to have the highest rates of nursing home deaths (Estabrooks, et al., 2020; Hsu et al., 2020). In Podcast 3B, co-researchers made statements such as "We are doing it all wrong," "they turn long-term care into a factory," "you'd be crazy to want to go there." How do we restore trust in the system? Is it even possible? Some might be reluctant to think so, however, Estabrooks and colleagues (2020) have made clear that it is a choice to be made. Research has shown promising practices in the LTC sector, as well as potential 'solutions' (Estabrooks et al., 2020; MacCourt et al., 2020). Through using existing and ongoing research, and gaining insight from diverse models nationally and internationally, Estabrooks and colleagues (2020) have hope for systemic reform *if* and *when* our society "consciously and deliberately decides as a country to act" (p. 654).

Podcast 3C, about palliative and end of life care options and considerations, was added by co-researchers during our story revision meetings. When asking about alternatives to LTC facilities, it was acknowledged by co-researchers that there were not many other options for palliative care. Some co-researchers had accepted that they would likely end up in a LTC facility. Other co-researchers explained that if they were no longer able to stay in their own home, that they would want, and in some cases have already signed up for, Medical Assistance in Dying (MAID). Factors such as a lack of appropriate support services, and the (lack of) affordability of existing options, played a role in this decision. Co-researchers were right to advocate for the inclusion of this topic, as there is virtually nothing presented in the literature about the palliative and end of life care experience for younger persons with dementia (Koopmans et al., 2015). Of the few articles available, there is little research that includes the voices of younger persons with dementia, or LOD for that matter, and instead relies heavily on the opinions of healthcare professionals (physicians, psychologists, nurse practitioners, and registered nurses), care partners, and researcher perceptions (Koopmans et a., 2015; Koopmans et al., 2021; Sellars et al., 2019). Research that has explored palliative and end-of-life care for persons living with dementia has deemed such care inadequate, due to such factors as "overly aggressive treatments, low rates of palliative care referrals, and poor pain and symptom management" (Sellars et al., 2019, p. 274). It has also been recognized that persons with dementia are often viewed as *not* having a terminal illness (Godwin & Waters, 2009), which could also be contributing to the lack of understanding and research about the "views, wishes, and preferences" (Poole et al., 2018, p. 631) of persons with dementia and their care partners/family regarding this topic.

Through these discussions we have learned that there are few palliative care options for younger persons with dementia beyond LTC facilities, and that some co-researchers have therefore planned to access MAID as an end-of-life care option when the time comes (based on parameters that individuals have decided upon with their families). As a newly explored option, some co-researchers in the group had questions about the planning and processes that must take place, indicating a lack of access to information. Information about available palliative and end-of-life care options and supports should be available and shared by healthcare professionals (i.e., the diagnosing physician), as well as easily accessible through organizations such as the Alzheimer's Society, and governing bodies such as the LHINs. To the proponents of MAID in the group, I asked whether their decision to use this end-of-life care option would change if the system better supported persons with YOD in living well. Mary Beth responded to me and indicated that the ways through which the current system is reinforcing existing practices, such as with the continued funding of LTC facilities, leads her to feel that the question I posed is not even fathomable.

Theoretical Reflections: Looking to the Future

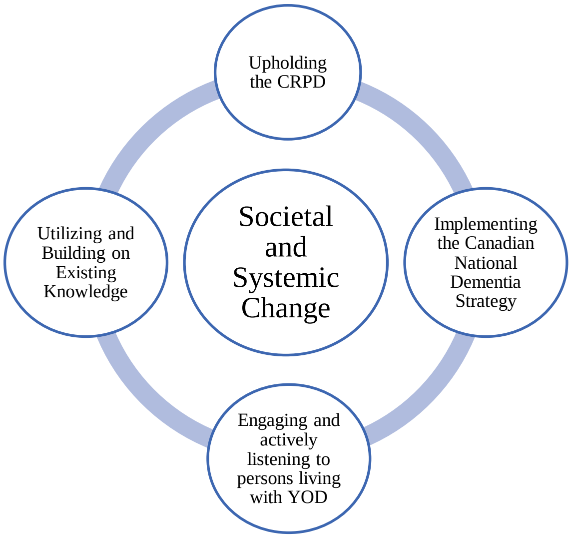
Research question addressed in the following sections: What do persons with YOD need to live well that needs to be considered in a re-imagination of caring for persons with YOD?

Looking to the Future: Overview of Key Messages

Personal Aspirations

Co-Researchers Aspirations for the Future of Care

Discrimination and Marginalization



Possible Action Items to Support Personal and Care Aspirations:

Supporting Full Citizenship and Human Rights

In addition to the action items outlined in figures 3, 4, and 5, co-researchers identified the following:

Promoting Advocacy, Inclusion, and Collaboration:

- Raising awareness of prevalent issues in the YOD context
- Collaborating with governments, organizations, policy makers, etc. to bring about change
- Expanding advocacy efforts to include a greater range of people impacted by YOD and LOD
- Joining forces with other movements (e.g., the Disability Movement)

Being Inspired and Taking Action:

- Being inspired by and learning from other countries and the initiatives they have put in place
- Utilizing existing knowledge and continuing with research efforts
- Implementing existing frameworks and strategies (e.g., the Canadian National Dementia Strategy)
- Addressing and acting on well-known systemic issues (e.g., diagnostic processes, service provision, supports for home care)
- Improving information about and access to Assistive Technologies
- Improving system navigation (e.g., implementation of system navigators and/or independent facilitation)

Figure 6: *Looking to the Future - Overview of Key Messages*

In the last sections of the podcasts, we explored co-researchers' hopes and aspirations for the future. What became quickly apparent, and resulted in the creation Podcasts 4A and 4B, was that these hopes and aspirations existed on both a personal level, as well as a systemic level, and that the stories not only reflected what co-researchers' want in the future, but also what they want to avoid (e.g., poor physical and mental health, being forced to live in a LTC facility, being a burden to family). Through stories shared about what co-researchers' did not want to experience in the future, came the juxtaposition of imagining what could be. On a personal level, co-researchers expressed the desire to remain healthy and autonomous (Smebye et al., 2012; Wolfe et al., 2020), be a good family member (La Fontaine & Oyebode, 2014), contribute to society and find purpose (especially through advocacy) (Bartlett & O'Connor, 2010; Seetharaman & Chadbury, 2020), continue to engage in meaningful recreation and leisure (e.g., photography, art, exercise, and travel) (Bartlett & O'Connor, 2015; Novec & Menec, 2019; Oyebode, 2015; Roach & Drummond, 2014), live well in place at home (Hansen et al., 2017; Jennings et al., 2017), and of course, live to be 100 years of age. What much of the associated research was missing with regards to many of these topics, was the perspectives of persons with YOD (and often LOD as well).

The stories shared by the co-researchers in my study provide some examples from the perspectives of people with YOD. These include but are not limited to: what does it mean to be healthy and autonomous from the perspective of younger persons with dementia? *Being physically able and strong, financially independent, having a voice and being heard, active participation and being in the community, continuing with 'normal life', having dignity*. What does it mean to be a good family member, particularly beyond one's partner? *To be a good grandma, to be supportive, to be 'plugged in', to be fun, to love, to be memorable, to aspire to be* *the best person every day, to go on family trips, to have pets.* What does living-well at home look like? *To live obstacle free, to be with loved ones, to have an accessibility-friendly home, to feel safe and invigorated, to have care and support (for the care partner as well), to be supported by the community.* Ideas about how to make some of these aspirations a reality are provided in the discussions about re-imaging the future of care.

The personal aspirations co-researchers shared in Podcast 4A, demonstrated a willingness and motivation to be active citizens in society in a way that counteracts biomedical reductionist perceptions of dementia through the presentation of capacity and desire for growth (Bartlett, 2015). So, what do persons with YOD need to support them in fulfilling their personal hopes and aspirations? Probably quite a bit more than this dissertation can shed light on. But, the conversations with the people with YOD in this study provide a starting point in beginning to identify changes that might be needed to better support people with YOD. Action needs to be taken by government, policy makers, and healthcare professionals to not just acknowledge, but *act* to remove the societal and cultural limitations that further the gap between the 'problematically different' and the 'status quo', as explained by the social relational model of disability. This means upholding the articles of the CRPD. This means *acting on* and *implementing* aspects of the Canadian National Dementia strategy, including guidance to provinces and regions about expectations and timelines. This means continuing to *engage* younger persons with dementia in conversation and *actively listening* and including their voices in decisions around policy and support service provision. This means having zero tolerance for the discrimination of younger persons with dementia based on age, diagnosis, or disability. Setting a precedent by righting the wrongs (such as by improving the diagnostic process and access to support services and financial supports), would begin to allow persons with YOD the freedom they are entitled to, to continue to live well, and reduce the fear they have about their future lives.

In our discussions about reimaging what the future of care and support could look like in Podcast 4B, many of the actions just described as needing to take place were indicated as imperative in the change process. Mary Beth began by acknowledging the development of the Canadian National Dementia Strategy entitled, *Together We Aspire*, through which she aspired that dementia truly become a national priority, that our country become better educated, and that a human rights lens be embraced. Kathleen supported these reflections, and highlighted the importance of humanity throughout the care trajectory. John and Rose raised the concern that although the government released the Canadian National Dementia Strategy in 2018, nothing has been done to ensure its implementation, leaving co-researchers feeling a lack of trust in promises made for reformation. In response to this, Paul and Rose began a discussion about the advocacy efforts needed to keep the government and associated systems accountable, including the use of the media to raise awareness and educate the public.

Co-researchers gained hope from knowing that better models of care exist in other countries, with particular reference to the dementia villages in the Netherlands. In discussing other models of care, it became apparent that co-researchers believed Canada was lagging behind in the availability of and access to a relevant and desired system of care, one that might look different than what we currently have. Co-researchers moved into discussion about support options they felt are more feasible in the Canadian context, through which there was a desire to improve the financial and support services to better support persons with YOD staying in their home. One specific area of services mentioned to support this desire is the improvement of rehabilitation options. Mary Beth indicated that rehabilitation has been a largely closed of resource, due to the stigma and associated discriminatory practices that are occurring driven by biomedical discourses. For instance, in Podcast 4B Mary Beth described being discounted before even receiving a service, including through statements made by healthcare professionals that persons with dementia “can’t remember the directions”. Connecting back to the difficulties co-researchers experienced in forced transitions out of employment, one can postulate about the positive impact rehabilitation could have on helping younger persons reintegrate into the workforce if desired, also helping to alleviate some of the financial strain. Research supports the vocational rehabilitation of younger persons with dementia (McCulloch et al., 2016), as well as disabled people (Bjelland et al., 2010; Campolieti et al., 2014; Stucki et al., 2015), in recognition of the implications at the individual, societal, and economic levels. Stucki and colleagues (2015) outline these implications by explaining that disabled people “have the right to full and effective participation and inclusion in the society”, that “society has the ethical and legal obligation to include them in all aspects of life”, and that “society is interested that persons with disabilities contribute to the community either in the form of tangible or intangible productivity” (p. 3).

When discussing other supports that might be helpful for younger persons with dementia in Podcast 4B, Dave and Paul highlighted the importance of technology. They spoke to the use of technology applications that would: support people when engaging with persons with dementia who may no longer be verbally communicative, help in instances of getting lost (such as GPS tracking), and provide access to information and connection to the outside world. There is a growing body of research that supports the use of assistive technologies for persons with dementia and their care partners (e.g., Bharucha et al., 2009; Cahill et al., 2007; Carswell et al., 2009; Gibson et al., 2015, 2016). What needs further investigation is how to make sure assistive technologies are known about, accessible, and affordable.

In addition to improved access to supports for younger persons with dementia and their care partners, one particular area of focus was the need for better system navigation. The existing use of Care Coordinators from the LHINs has been brought into question in these discussions, through their lack of accessibility and insufficient support. It is suggested that the liaison role of a Care Coordinator shifts to a more comprehensive system navigation role, where persons with YOD and their care partner are fully supported from point of diagnosis all the way through to end-of-life care. Other co-researchers agreed that having system navigators would alleviate some of the worry and uncertainty. What is exciting is that in a search of the literature, I found a toolkit that was released this year, and developed by researchers at the University of New Brunswick (UNB) and the Centre for Research in Integrated Care. This toolkit provides a comprehensive framework for how to develop and implement a navigation program to support persons with dementia, and reflects the desires discussed by co-researchers (Doucet et al., 2021). Another opportunity that could be used to better support persons with YOD, stems from the disability world and the use of independent facilitation. What this approach recommends is that people who receive funds for disability supports should also be provided with a facilitator, who would help in the "development of goals and support plans, as well as how people might actually spend the money to support those goals" (Lord, 2008, p. 2). This could be complimentary to, or apart of a move towards system navigators, where part of the role would be to help allocate financial supports in a way that would best support the individual and their care partner/family beyond just a focus on medical needs.

In addition to the use of system navigators, a 1-800 24/7 support telephone line was also suggested, and perhaps could be used in conjunction with system navigation teams. Through a search I discovered that different provinces do provide access to dementia helplines. For example, the Alzheimer's Society of British Columbia provides access to *First Link Dementia Helpline* that covers an array of topics, however, it is unknown the extent with which operators are familiar with the realities experienced by individuals with YOD, and these lines are only available during certain times of the day. The Alzheimer's Society of Ontario provides access to a Telehealth Ontario number, where persons with dementia or a care partner can get in touch with a Registered Nurse 24/7. Again, the extent of knowledge about YOD may vary across healthcare professionals.

Summary of Reflections

When looking at theoretical applications, we can see the interconnectedness of co-researchers' experiences. These stories reflect the biomedical and dementia as tragedy discourses that lead to the production and reproduction of harmful stigmatizations and discriminatory practices. From point of diagnosis, persons with YOD are being told statements such as "you're going to be useless" and to "get your affairs in order" reflecting such discourses; the individual is reduced to their disease, and essentially told that their life as they know it is over. This reflects Swaffer's (2015) Prescribed Dis-engagement$^{\text{TM}}$, whereby the individual is told to plan for their demise, which can be detrimental to the person if internalized as it may cause them to "become depressed, experience poorer function and self-confidence, have decreased social interaction, and lowered self-esteem" (Dobbs et al., 2008, p. 518). These discourses lead to discriminatory practices, in that the person is automatically treated differently, such as through the prioritization of planning of 'management' strategies for their disease over the consideration of dementia as a new journey whereby the individual can live and thrive in new and different ways. One of the co-researchers, Paul, backed this notion with a powerful statement in Podcast 2A when he said, "We're not the walking dead. We're alive. We still can contribute. We have feelings, and we have a voice."

Implications and Learnings

This research demonstrated the ways through which CG and CDS frameworks can provide a comprehensive lens when brought together and the strengths that such collaboration can create compared to a siloed approach. By fusing CG and CDS, this research was able to interrogate the marginalization and discrimination of persons living with YOD based on their age and problematizing ageism (Baars et al., 2006), *in addition to* bringing into question the systemic and social relationships that fuel such inequities and urge for a shift to understandings that stem from a social relational model of disability (Thomas, 2004); that is one where the systems world and society take accountability for the construction of the 'problematically different', and move to instead embrace a politics of difference (Jones, 2006). Also, the collaboration of the two disciplines speaks to the overlapping nature of the discrimination and marginalization experienced by individuals and groups who are deemed "problematically different", through which we as a people can unite to challenge. This means, for example, that the knowledge produced from this research can link to and support the interest of other movements, such as the Disability Movement (i.e. providing an understanding of the connections between dementia and disability, as well as the creation and impact of the CRPD for human rights), and the Feminist Movement (i.e. demonstrating the impact feminists have had in advocating for more inclusive notions of citizenship and access to human rights, as well as bringing light to the intersection of women's experiences in the dementia context and added discrimination this can create).

Although qualitative research with persons living with YOD has been increasing over the past five years, there is still uncertainty and much more to be learned about appropriate methods and ways of engaging younger persons with dementia in research (Bell & Leong, 2019). To date, little research has been conducted that solely focuses on the perspectives of persons with YOD, particularly in the narrative space. This project, therefore, has provided an opportunity to explore the ways through which younger persons with dementia can reclaim their narrative agency, and through this, citizenship. More specifically, this project has demonstrated the use of virtual communicative spaces, and how such spaces can be used by co-researchers to connect and collaborate in dialogue. By incorporating flexibility into this project, co-researchers were able to not only engage in narrative agency through sharing their stories (Baldwin, 2008), but also by taking a key role in guiding the emergent processes, such as deciding on what topics to explore, helping in the analysis process, identifying how stories should be shared and disseminated, and creating the stories to be shared. As noted previously, such processes provide opportunities for the reclamation of citizenship through action, by engaging persons with YOD on the quest for justice (Bartlett & O’Connor, 2007) through an exploration of personal, inter-personal and institutional/structural factors (Baldwin, 2008). Additionally, by creating a collaborative project through the use of storytelling workshops, this project has further demonstrated relational notions of citizenship by showing the power of relationships and collaboration in accessing shared experiences and mutual support (Baldwin, 2008; Kontos et al., 2017).

By using innovative methods, as scholars such have Dupuis and colleagues (2016) have done through the use of critical arts-based approaches with persons with dementia, this research has demonstrated the use of CNI for understanding how the stories of persons with YOD reflect and challenge dominant biomedical and dementia as tragedy discourses. While the work of scholars has demonstrated the ways through which dominant discourses impact persons with dementia (see Dupuis et al., 2012a; Mitchell et al., 2013; Mitchell et al., 2020), little research has been done to identify the ways through which these experiences are the same or different in the experiences of younger persons with dementia. For example, this research has demonstrated the impact of such discourses on contributing to the difficult and lengthy diagnostic process, in the lack of appropriate support services (i.e., developed for or exclusive to individuals 65+ years of age), and through the exacerbated marginalization of persons with YOD in LTC settings, to name a few.

This project has provided insight into the application of narrative analysis, using a braided narrative technique for persons with YOD. As mentioned, little research has been conducted that solely focuses on the perspectives of persons with YOD, particularly in the narrative space. The use of storytelling workshops was decided on through their likeness to focus groups - which have the ability to provide feelings of mutual support, an opportunity for shared experiences to trigger thoughts and memories, as well as to alleviate the immediate pressure to respond (Bamford and Bruce, 2000) - in addition to emphasizing the co-researchers' active role in guiding emergent processes (Abma, 2003). As I learned through my master's work, alternatives to solely discussion-based focus groups are helpful for engaging younger persons with dementia who prefer to communicate in other ways (Main, 2016). While this research started off with the intent to support diverse communication preferences, co-researchers were all highly verbally communicative, resulting in a shift to focusing on the discussions and stories shared. That being said, myself along with co-researchers acknowledge the benefits of using multiple mediums for accessing diverse groups, which led to the creation of the Podcast Series and our plans to incorporate such mediums in our interactive e-flipbook representation beyond this research.

As mentioned, co-researchers and I decided on using conversation pieces around topics identified as particularly important to the group, which then developed into the idea of turning the conversations into podcasts scripts. This allowed for the individual journeys of co-researchers to be followed, while also showing how the stories interacted and held tension with other narratives in the group. I believe this will allow audiences to become invested in the different journeys shared, and help the stories not just be heard but listened to. From here, I have made a commitment to co-researchers to continue to work collaboratively on a representation that also weaves in other mediums and creative contributions (i.e., photos, videos, audio, poems, etc.) in addition to the podcast scripts.

The creation of podcast scripts that reflect the ways through which persons with YOD experience and challenge marginalization and oppression in the healthcare system can be shared as an educational tool to better inform healthcare professionals, policy makers, and government officials about these realities. Through a continued commitment to further knowledge translation opportunities in the form of an interactive e-flipbook, it is the hope of myself and the co-researchers that we can widely disseminate our work, particularly in educational settings. Of particular importance is the insight gained to actionable items and desired ways forward. For example, the reformation of diagnostic processes for YOD, the development of appropriate and relevant support services including vocation rehabilitation, and the use of system navigators and educational tools to better support persons with YOD and their care partners through the trajectory of their journey. This research has also highlighted areas that require deeper investigation, including gaining insight on the experiences of diverse individuals and groups that live with YOD.

Limitations

At the time this project was taking place, our society was deep in challenging and navigating the devastating racism that exists in our society, through the Black Lives Matter movement, trying to overcome the Xenophobia that was illuminated amidst the COVID-19 pandemic, and the devastating uncovering of the residential school murders and the impact on our Indigenous communities. I would have loved for this project to be more culturally diverse and completely recognize this as a limitation of this research. Recruitment was a challenging process during the pandemic, yet I could have utilized different approaches to try and access individuals who are experiencing different intersections of marginalization not represented in this work. Myself as the researcher, as well as the co-researchers of this project, recognize this limitation and at minimum would like to state our support for the groups impacted.

In connection to this, all co-researchers in this research are active advocates in the dementia community, which might explain part of the reason as to why the co-researchers were accessible and willing to participate during such challenging times. Through the extensive knowledge this group of co-researchers have as advocates, I believe we were able to learn a lot from their experiences and stories. That being said, the experiences of a broader range of individuals needs to be explored; in addition to various intersections of marginalization, this also includes individuals living with YOD who are at different stages in their dementia journey. Part of the inability to do so in this project resulted from another limitation. Due to the geographic spread of the co-researchers and the restriction in place during COVID, our group was only able to meet and connect virtually. Being able to hold face-to-face meetings might have supported the inclusion of diverse groups, including people living with YOD later in the disease progression, as I could have integrated the use of arts-based approaches (Bennet et al., 2019; Boydell et al., 2012; Dupuis et al., 2016b).

Opportunities for Future Research

This research represents at a starting point. Future research should begin by addressing the limitations of the research. As previously stated, the findings of this work are acknowledged as a starting point for understanding the experiences of persons with YOD and addressing recognized systemic gaps and inequities. From here, research is needed to explore the extent to which the experiences shared in this research hold true, and in what ways they differ for individuals who have different intersecting marginalization's. In addition to discrimination based on age and disability, other marginalized intersections may include but are not limited to race, gender identity, sexual orientation, cultural minorities, and Indigenous populations.

Other areas of research that require deeper exploration, largely lie with the podcast sections *Learning from Past and Present*, and *Looking to the Future*. Some questions that require attention include but are not limited to:

- What can be done to improve information about, and access to appropriate support services for youngers persons with dementia? Their care partners?
    - What resources or opportunities are available to persons with YOD for meaningful recreation and leisure in community settings? How can access and affordability be improved?

    - In what ways can virtual programming be used in a post-pandemic world to alleviate social isolation and increase accessibility?
    - What rehabilitation models exist that would support persons with YOD? And more specifically, what vocational rehabilitation models would help persons with YOD re-integrate into the workforce if desired?
    - How can employers better support people with YOD who desire to remain in their jobs?
    - What supports from the disability community are available and accessible to persons with YOD?
- How can consistency within and between provinces be improved with regards to knowledge about YOD, programming, and system navigation?
    - How can consistency within and between provinces be created with regards to education about YOD?
    - How can Canada move towards the use of system navigators? What would it take to implement the framework put forward by UNB?
    - What are the possibilities of independent facilitation in the context of dementia?
    - What are the next steps for acting on the guidelines set forth by the Canadian National Dementia Strategy?
- What are the experiences of persons with YOD in LTC facilities?
    - What do we know about existing palliative and end-of-life care options for younger persons with dementia? Where do we go from here, what is needed?
    - What else can be done to support persons with YOD in living longer in their homes?
    - What alternative housing options might better support people living with YOD?

In future research, the use of participatory and emergent processes is recommended to foster agency and allow for flexibility in methodological processes. Providing communicative spaces for persons with YOD through research opens opportunities for persons with YOD to reclaim citizenship through action (Bartlett, 2014).

Similar to I’m sure many other critical scholars, I have hopes and aspirations of my research making impactful change in the dementia care space by providing insights into how we can re-imagine dementia care so that it better supports people with YOD in the ways they want to be and deserve to be supported. Persons with YOD have been long overlooked and have experienced injustices for far to long. There is an urgent call for systemic change, and this research hopes to “hammer home” the message that this is a call that cannot be ignored. The time for change is now.

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Appendix A: Information Letter

The Time for Change is Now: Using Narrative Inquiry to Envision Possibilities for a New Model of Care from the Perspectives of Persons with Young Onset Dementia

[Date]

Dear [participant's name]

My name is Sarah Main and I am conducting a study as part of my doctorate degree in the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Dr. Sherry L. Dupuis. This letter provides detailed information about this project and will help you to make an informed decision regarding your participation.

What is this study about?

- Individuals with young onset dementia (YOD) have unique experiences that may not be supported by the healthcare/long-term care system.
- **I am interested in hearing and sharing the stories of younger persons with dementia about their care journey so far and to explore with them what ideal care and support might look like in the future.**
- **The purposes of this project are**:
    - To open spaces for group discussions and reflections.
    - To understand how younger persons with dementia describe their experiences of the long-term care system.
    - To re-imagine what ideal care and support might look like in the future.
    - To develop a collaborative representation that provides clear paths for positive change in dementia care to better support younger persons with dementia.

What does participation involve?

- You will first be asked to take part in a one-on-one conversation via video-call where I will explain the study. Should you wish to take part in the study, this meeting will also be used to obtain your consent to participate. I would also like to get to know you a bit more during this session by asking you a few brief questions about yourself (e.g., age, gender, current living arrangements, official diagnosis etc.).
- You will be asked to take part in a minimum of two group video-calls, although there may be as many as five depending on the preferences of all participants, taking approximately one-hour each.

  - The first small group video-call will be used to gain an understanding of participants' stories and experiences with the healthcare/long-term care system so far.
  - The second small group video-call will be used to re-imagine what ideal care and support might look like for people with young onset dementia in the future.
  - Any additional group video-calls will be determined based on the information shared in the first two video-calls and will be decided upon by the group. These group calls will be used to reflect and discuss on the stories shared, and to collectively decide how the group would like these stories to be brought together and shared with others.
  - Extra one-on-one conversations or small group video-calls can occur at the request of the participants. Participants may use these conversations to raise any questions or concerns they have, or, to share any additional information they have relating to this project.

(Optional) – In addition, I invite you to share with me any photographs or other creative submissions (poems, songs, other written pieces etc.) that you feel reflect your stories and experiences about living with YOD. I will include these items in the analysis to gain a more in-depth understanding of your stories about living with YOD and the experiences you have had with the healthcare/long-term care system. These items can be sent to me directly through email at semain@uwaterloo.ca. If the photos contain images of other people, you will need to get their permission prior to sending the photos to me.

Who may participate in the study?

- Participants must have a diagnosis of young onset dementia, that is, individuals must have been diagnosed with a dementia before the age of 65 and must be under the age of 70 at the time of the study.
- Participants must have some level of ability to participate, or availability to someone (a care partner) who can support their participation.
- Participants must have access to some form of communicative device (e.g., phone, email, IPad, computer, other video-chat options), as well as any electronic and digital devices they wish to use for this project.
- Participants must be able to provide recorded verbal consent to participate, then recorded verbal agreement regularly throughout the research process and at the beginning of each meeting. If you are not able to provide your own consent and wish to participate, I will require written consent from a substitute decision maker (care partner, family member, or Power of Attorney).

Is participation in the study voluntary?

- Participation in this research project is completely voluntary.
- Should you choose to participate, you will need to provide recorded verbal consent, or if needed, your substitute decision maker will be asked to sign a formal letter of consent stating your consent to participate.

- You may decline to answer any of the questions asked during the video-calls and throughout this research project.
- You may decide to exit the individual or small group video-calls at any time without any consequence.
- Please note that the video-calls will be audio- and video-recorded. The audio portion will be transcribed and all recorded material (audio and video) will be used to help the analysis process.

What are the potential benefits of the study?

- Participation in this study may not offer personal benefits to you. However, it is my hope that this study will be an enjoyable and empowering experience for participants as they offer their expertise and valuable insights about experiences with the current healthcare/long-term care system and the possibilities for the future of care and support for people with young onset dementia.
- The results of this research will hopefully inform individuals and groups (e.g., policy makers, advocate groups, organizations, etc.), about factors that can lead to individuals with young onset dementia feeling marginalized in the care system, as well as how the system can and needs to be changed, from the perspectives of younger persons with dementia.
- It is also hoped that the stories shared and represented in this study will challenge dominant stigmas and discourses around aging and dementia.
- This research has implications for the academic community regarding the ways through which the virtual world and multiple methods can be used to engage persons with young onset dementia in this type of research project. Through this, insight may also be provided into the effectiveness of the virtual world in supporting the rights and citizenship of people with young onset dementia.

What are the possible risks of the study?

- Given that the study focuses on participants’ experiences living with YOD, it is possible that some of the discussion may be emotional for you. Please remember that participation is voluntary and you do not have to answer any questions you do not want to answer.
- If any participant experiences emotional stress, with their permission, I will connect them with the local Alzheimer Society family support persons.
- Please note that whenever information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). In addition, this risk is also associated with any internet use (e.g., e-mails etc.). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.

Will my information be kept confidential?

- Identifying information will be removed from the data that is collected and will be stored separately. If you do not wish to be identified in study results, your name will not appear in any paper or publication resulting from this study, however, with your permission quotations may be used with a pseudonym in place of your real name. Alternatively, you may decide to be identified by name and have your quotations directly attributed to you in study results. Additionally, you can decide to allow the creative submissions and photographs from your participation to be used in papers and publications to help illustrate study findings. Similarly, you may decide to have these attributed directly to you, or if you prefer, a pseudonym will be used.

- Collected data will be securely stored for a minimum of 7 years in an encrypted folder on a password protected computer and in a locked office. Any physical artifacts, written pieces, or other creative submissions that may have been mailed to the researcher, will be stored in a locked cabinet. Only myself and my advisor will have access to your information and photographs, unless you provide consent to use all or some of them in the representations created that will be shared more widely.
- You can withdraw your consent and request that your data (including photographs and creative submissions etc.) be removed from the study by contacting the researchers up until the completion of the final thesis submission (Summer 2021). Please note that due to the group format of the conversations, it may not be possible to remove all data associated with you. Additionally, it is not possible to remove data once study results have been submitted for publication.
- We will ask all participants to keep in confidence information that identifies or could potentially identify another participant and/or their comments, however we cannot guarantee that everyone will honour this request.

Has the study received ethics clearance?

- I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

What if you have questions?

- **If you have any questions regarding this study**, or would like additional information to assist you in reaching a decision about participation, please contact me by email at semain@uwaterloo.ca.
- You can also contact my supervisor, Professor Sherry L. Dupuis at 519-888-4567 ext. 46188 or by email at sldupuis@uwaterloo.ca.

Thank you for your interest and considering participating in this project!

Sincerely,

Sarah Main, PhD Candidate
Department of Recreation & Leisure Studies
Research Assistant | Partnerships in Dementia Care Alliance | Faculty of Applied Health Sciences
University of Waterloo | 200 University Avenue West, Waterloo, ON, N2L 3G1
semain@uwaterloo.ca | uwaterloo.ca/pidc | @pidcalliance

Appendix B: Third Party Consent Form

Declaration of Informed Consent Form: Third Party Consent

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal or professional responsibilities.

I have read the information presented in the information letter about the study being conducted by Sarah Main of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional information I requested. I am aware that assent will be obtained from my relative throughout the project.

I am aware that I or my relative may withdraw from the study without penalty by advising Sarah Main or her advisor, Dr. Sherry Dupuis, of my decision.

I understand that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755). If I have questions for the Committee, I can contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca.

For any other questions, I have been told I may contact Sarah Main by email at semain@uwaterloo.ca . You may also contact Dr. Sherry L. Dupuis at 519-888-4567 ext. 46188 or by email at sldupuis@uwaterloo.ca

I consent to the following:

With full knowledge of all foregoing, I agree, of my own free will, that my relative can participate in this study.

☐ YES ☐ NO

I am aware that my relative will be audio/video-recorded during **all discussions to ensure accurate transcription and analysis of the data.**

☐ YES ☐ NO

In papers, presentations and collective representations resulting from this study:

I give permission for the use of my relative’s quotations with the understanding that a pseudonym will be used in place of their real name (e.g., Jane Doe).

☐ YES ☐ NO

I give permission for the use of my relative’s quotations with the understanding that they will be directly attributed to my relative (e.g., they will be identified by name).

☐ YES ☐ NO

I give permission for the use of any physical artifacts, written pieces, photos, or creative submissions made by relative.

☐ YES ☐ NO
(Please note that if any of these items include images or other identifiable information about people who are not a part of this study, permission must be granted from those individuals to use the items in the research and any resulting publication/presentation/representation.)

I give permission for my relative’s physical artifacts, written pieces, photos and creatives submissions to be attributed to them.

☐ YES (they will be identified by name) ☐ NO (a pseudonym will be used)

____
Participant’s name

____
Participant’s substitute decision maker’s name

____ __________________
Signature of participant’s substitute decision maker Date

____
Researcher’s/ Witness’ name

____ __________________
Witness signature Date

Appendix C: Protocol for Attaining Assent Throughout the Project

PROTOCOL FOR OBTAINING ASSENT TO PARTICIPATE IN THE STUDY FROM PERSONS WITH DEMENTIA

The following assent protocol will be completed for persons with dementia participating in the study:

1. Initial assent will be performed by going through the study information letter, then going through the following points verbally with the individual with dementia:

- ☐ **I have read the project information letter or had the opportunity to go through it with Sarah.**
- ☐ **I have asked questions that I have about the project.**
- ☐ **I understand that meetings will be audio and video-recorded and I will be asked for my consent at the beginning of each meeting.**
- ☐ **I know that my contributions in the group discussions, as well as any creative submissions I send, may be used in this project.**
- ☐ **I know that I can stop participating at any time.**
- ☐ **I know that I can call someone if I have any questions about my participation.**

2. Researcher to complete the assent form demonstrating that assent was obtained and continually confirmed prior to and during the data collection. Verbal consent will be captured in audio and video recordings, and other forms of consent will be documented in the researcher's notes.

Participant Assent to Participate Process – Documentation Form

Participant assent was gained from ________________________ (Name of Participant) on
___________________________(date) by __________________________________(Researcher).

Assent was expressed in the following ways:

____
____
____
____
____

Printed name of researcher	Signature	Date

Appendix D: Email Script for Contacting Agencies

Dear [name of agency contact],

My name is Sarah Main, and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I am currently conducting research under the supervision of Dr. Sherry Dupuis on understanding the lived experiences of persons with young onset dementia (YOD) in the healthcare/long-term care system, as well as exploring how individuals with YOD might re-imagine care and support in the future. I will be asking participants to engage in small group video-conversations, as well as inviting participants to send along any creative submissions they feel will help express their story (e.g., photographs, poems, written stories, etc.). I have attached a letter of information developed for potential participants with YOD that provides more details about the study.

I would like to set up a meeting with you so I can tell you more about the study and discuss with you how you might help me recruit potential participants. If you are willing to meet with me by phone or videoconferencing, simply respond to this email and let me know what dates and times would be most convenient for you in the next two weeks.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755).

Thank you in advance for helping me recruit participants for my study. I look forward to hearing from you.

Sincerely,

Sarah Main, PhD Candidate
Department of Recreation & Leisure Studies
Research Assistant | Partnerships in Dementia Care Alliance| Faculty of Applied Health Sciences
University of Waterloo | 200 University Avenue West, Waterloo, ON, N2L 3G1
semain@uwaterloo.ca | uwaterloo.ca/pidc | @pidcalliance

Appendix E: Email Script for Agencies to Contact Participants

Dear [name of potential participant],

Our organization was reached out by a student at the University of Waterloo regarding a study that you might be interested in participating in. Please read her message below and the information letter attached. If this is something you are interested it, please reach out to her directly (see contact information below or in the information letter).

My name is Sarah Main, and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I am currently conducting research under the supervision of Dr. Sherry Dupuis on understanding the lived experiences of care and support for persons with young onset dementia (YOD), especially in terms of their experiences in the healthcare/LTC system. I am also interested in working with persons with YOD to re-imagine what ideal care and support might look like for YOU in the future. I will be asking participants to engage in small group video-conversations, as well as inviting participants to send along any creative submissions they feel will help express their story (e.g., photographs, poems, written stories, etc.). I have attached a letter of information developed for potential participants with YOD that provides more details about the study. Please read through the information letter, and if you are interested in participating or would like to hear more about the project, simply email me at semain@uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755).

Thank you in advance and I look forward to hearing from you.

Sincerely,

Sarah Main, PhD Candidate
Department of Recreation & Leisure Studies
Research Assistant | Partnerships in Dementia Care Alliance| Faculty of Applied Health Sciences
University of Waterloo | 200 University Avenue West, Waterloo, ON, N2L 3G1
semain@uwaterloo.ca | uwaterloo.ca/pidc | @pidcalliance

Appendix F: Script for One-On-One Information Session

Researcher (R): Hi (name), thank you for taking the time to chat with me today. My name is Sarah and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. Today I would like to provide you an overview of the project, and get to know you a bit more by asking a few brief questions. If after I provide an overview of the project you decide you would like to participate, I will ask that we run through the eligibility criteria and if met, a verbal consent/assent process that I will record prior to continuing on with today's meeting. Does that sound okay?

Participant(s) (P): No

R: Okay, no problem. Is there a better time I can get in touch to share this information with you?

P: Yes, please contact me again on [date/time].

OR

P: No, I am no longer interested in learning about this study.

R: Okay, no problem. Thank you for your time.

OR

P: Yes

R: Okay, great! I would like to begin by talking you through the information letter.

[At this point I will go step-by-step through the information letter with the participant]

Do you have any questions about the project?

P: No

OR

P: Yes

R: Okay, what is your question?

P: Question(s)

R: Answer(s). Any other Questions?

P: No

R: Okay, great! Is this study something you would be interested in participating in?

P: No.

R: Okay, no problem. Thank you for your time today, bye!

OR

P: Yes

R: Okay, great! The study does have eligibility criteria that need to be met in order to participate so I'm just going to run through that quickly before we continue on to the consent process.

Do you have a diagnosis of young onset dementia?
P: [Response]
R: Are you currently under the age of 70?
P: [Response]

R: Are you able to participate independently, or have availability to someone (a care partner) who can support you throughout the duration of this study?

P: [Response]

R: Do you have access to some form of communicative device (e.g., phone, email, IPad, computer, other video-chat options), or any other electronic and digital devices you may wish to use?

P: [Response]

[If any of the responses to these questions are ‘no’ then the researcher will say: “Thank you for your time and interest in participating in this study. While I'm sure you have many valuable and important experiences to share, this study requires participants to meet the eligibility criteria just discussed, of which you mentioned you do not meet [explain specific criteria]. Thank you again for your time, and feel free to reach out if you have any further questions or concerns.”]

[If all responses to these questions are ‘yes’, then I will proceed to obtain consent/assent. At this time I will have a good idea whether or not the participant is able to provide their own **consent**. If they are, I will continue with this script. If I have concerns, I will move to the **Protocol for Attaining Assent** and reach out to the substitute decision maker for written consent and to confirm the participant meets the eligibility criteria]

R: Okay, great. In order to participate in this study I will need to turn the recorder on and ask you a few consent questions, is that okay?

P: No

R: Okay, no problem. I will be in touch with you over the next couple of days to see if you would still like to participate in this study and to pick a time we can go through the consent questions together. Thank you for your time today, bye!

OR

P: Yes

R: Okay, great. As a reminder, by agreeing to participate, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities. Is there someone you would like to discuss this information with before you make a decision or that you would like to involve in this decision-making process?

P: Yes

R: Okay, no problem. I will be in touch with you over the next couple of days to see if we can schedule a time to go through the consent process all together. Thank you for your time today, bye!

OR

P: No

R: Okay. I will now turn on the recorder.

R: [States date, time, and participant name]

With full knowledge of all foregoing, do you agree, of your own free will, to participate in this study?

☐ YES ☐ NO

Are you aware that the study sessions will be audio and video-recorded to ensure accurate transcription and analysis of data?

☐ YES ☐ NO

In papers, presentations and collective representations resulting from this study:

Do you agree to the use of quotations with the understanding that a pseudonym will be used in place of your real name (e.g., Jane Doe)?

☐ YES ☐ NO

Do you agree to the use of quotations directly attributed to you (e.g., you will be identified by name)?

☐ YES ☐ NO

Do you agree to the use of your physical artifacts, written pieces, or creative submissions?

☐ YES ☐ NO ☐ I would like to decide later (If any of these items include images or other identifiable information about people who are not a part of this study, permission must be granted from those individuals to use the items in the research and any resulting publication/presentation/representation.)

Would you like your physical artifacts, written pieces, or creative submissions attributed to you?

☐ YES (you will be identified by name) ☐ NO (a pseudonym will be used)

Do you agree to the use of your photos (including ones in which you appear)?

☐ YES ☐ NO

In photos in which you appear, would you like to be identified by name?

☐ YES ☐ NO

Okay, that's it! Do you have any questions for me?

P: No

OR

P: Yes

R: Okay, what is your question?

P: Question(s)

R: Answer(s). Any other Questions?

P: No

R: Okay great! Before leaving today I would like to take this opportunity to get to know you a little bit better. Is that okay?

P: No.

R: Okay, no problem. Thank you for your time today, bye!

OR

P: Yes

R: Wonderful! Tell me about yourself…

P: [Response]

[Throughout the participant's response the researcher may probe around certain areas such as: "What is your current living arrangement?" "Approximately when were you diagnosed?" "What is your official diagnosis?" "What kind of supports do you currently use?"]

R: Thank you for sharing a little bit about yourself, I look forward to getting to know you more throughout the research process. That is all for today! Do you have any questions for me?

P: No

OR

P: Yes

R: Okay, what is your question?

P: Question(s)

R: Answer(s). Any other Questions?

P: No

R: Okay great! Thank you for your time today and I look forward to seeing you in our first group session, which will be held on [date/time]. I will touch base soon with more details. Bye!

Appendix G: Script and Guiding Questions for Group Discussion 1

Researcher (R): Hi everybody, thank you for making the time to be here today. My name is Sarah and I am an PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I am excited that you all agreed to participate in my research that aims to share your experiences of living with young onset dementia (YOD), and gain an understanding of how you view the healthcare/long-term care system today, as well as how you wish it might be in the future. What we are going to do here today is not like a typical interview. It is an informal discussion where we will be collectively exploring some guiding questions and prompts around your current experiences with the healthcare/long-term care system. If you do not wish to participate verbally, you may also comment on the discussions by typing out and sending a written message to the group – or – feel free to take some time after the meeting to reflect on the questions and provide your responses at a time, and in a way that best suits you. The conversations will be audio and video recorded, and the recordings and transcriptions of the recordings will only be used for the purpose of this research project. Unless you gave permission to be named in study results, your identity will be kept confidential, with a pseudonym used in the place of your name.

A few reminders before we begin:

- Your participation in this project and in this video-call discussion is completely voluntary.
- During the discussion, you may decline to answer any questions that you prefer not to answer.
- You may choose to stop participating at any time.
- [This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755)]

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: Do you provide consent to continue with this virtual discussion?

P: Yes

R: (If everyone replies to Yes) Thank you. Okay let’s begin. I will now turn on the audio- and video- recording and give you your first guiding question.

OR

P: No

R: (If one or more participants say ‘No’ those individuals will be able to leave the group call. If everyone in the group wishes to reschedule that will be an option as well) Okay, no problem. Please feel free to exit this group chat, and I will be in touch within the next couple of days to discuss your consent to continue participating in this study. Thank you for your time today and I will talk to you soon.

Group Discussion 1 – Understanding current experiences in the healthcare/LTC

1. What do you want the world to know about you and your experience of living with YOD?

2. What has supported you on the dementia journey so far?
    a. What has been important for living well?

3. What challenges have you faced since your diagnosis?

4. What are your perceptions of long-term care (LTC) homes?
    a. To what extent do you think LTC homes could support you as a person with YOD?

5. What is a story of an experience you have had with the healthcare/LTC system?
    a. What was that experience like for you? Who was there?

6. What concerns you about the current healthcare/LTC system?

7. What concerns you about the current healthcare/LTC system based on the stories that have emerged from the COVID-19 pandemic?

8. Is there anything else you would like to share about your experiences of care and support?

Closing Script:

Thank you very much for taking the time to share your stories, your participation is greatly appreciated. I look forward to meeting again on [dated selected by group] for our next discussion where we will explore what an ideal future of care might look like. As previously mentioned, this study [has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755). If you have any comments or concerns resulting from your participation, you may contact the Office of Research ethics with your concerns. If you have any questions regarding the project itself, please contact my supervisor, Dr. Sherry L. Dupuis, or myself.

Thank you again for your participation and I will talk to you all again soon.

Appendix H: Script and Guiding Questions for Group Discussion 2

Researcher (R): Hi everybody, thank you for making the time to be here today. As a refresher, my name is Sarah and I am an PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I would like to begin by thanking you again for your time in our last meeting and for sharing your experiences with myself and the group. I am excited that you all agreed to participate in my research that aims to share your experiences of living with young onset dementia, and gain an understanding of how you view the healthcare system today, as well as how you wish it might be in the future. What we are going to do here today is not like a typical interview. It is an informal discussion where we will be collectively exploring some guiding questions and prompts to collectively re-imagine what ideal care and support would look like for persons with young onset dementia. If you do not wish to participate verbally, you may also comment on the discussions by typing out and sending a written message to the group – or – feel free to take some time after the meeting to reflect on the questions and provide your responses at a time, and in a way that best suits you. The conversations will be audio and video recorded, and the recordings and transcriptions of the recordings will only be used for the purpose of this research project. Unless you gave permission to be named in study results, your identity will be kept confidential, with a pseudonym used in the place of your name.

A few reminders before we begin:

- Your participation in this project and in this video-call discussion is completely voluntary.
- During the discussion, you may decline to answer any questions that you prefer not to answer.
- You may choose to stop participating at any time.

- [This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755)]

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: Do you provide consent to continue with this virtual discussion?

P: Yes

R: (If all participants indicate ‘Yes”) Thank you. Okay let’s begin. I will now turn on the audio- and video-recording and give you your first guiding question.

OR

P: No

R: (If one or more participants indicate ‘No” those individuals will be able to leave the group call. If everyone in the group wishes to reschedule that will be an option as well) Okay, no problem. Please feel free to exit this group chat, and I will be in touch within the next couple of days to discuss your consent to continue participating in this study. Thank you for your time today and I will talk to you soon.

Group Discussion 2 – Exploring possibilities for re-imagining and envisioning the future of healthcare/LTC

1. What aspirations and hopes do you have for the future?

2. What would you need to live well in the future?
    a. What supports would you need to live well?

3. I would like you to close your eyes and imagine what an ideal world, with no limitations, would look like for you as a person living with YOD
    a. What would you want ideal care and support to look like for you in the future? Where are you/Where is your care and support taking place? Who is there? What are you doing? What needs to be there to support you to live well? What supports do you have? How does it feel to be cared for and supported in this way?

4. What would be a good way to share this vision of care and support with others?

5. Would anyone like to meet again so that we can work on creating a representation of what this ideal world might look like?

Closing Script:

Thank you very much for taking the time to share your stories, your participation is greatly appreciated. As previously mentioned, this study [has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755). I will send you a thank you note with the contact information for the Office of Research Ethics at the University of Waterloo, as well as mine and my supervisor’s. If you have any comments or concerns resulting from your participation, you may contact the Office of Research ethics with your concerns. If you have any questions regarding the project itself, please contact my supervisor, Dr. Sherry L. Dupuis, or myself.

Thank you again for your participation.

Appendix I: Information Letter for Photos

My name is Sarah Main, and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I am currently conducting research under the supervision of Dr. Sherry Dupuis on understanding the lived experiences of persons with young onset dementia (YOD) in the healthcare/long-term care system, as well as exploring how individuals with YOD might re-imagine care and support in the future.

As a part of this process, I will be asking participants to email me any creative contributions that reflect their stories and experiences of young onset dementia (e.g., photographs, poems, written stories, etc.). The creative contributions shared may include pictures/images of individuals other than the participants (i.e., an image of yourself). With your permission, the image will be used in analysis and/or reproduced in papers, presentations and representations resulting from the research. In these, your name will not be used, however your face will be visible. If you prefer, your image can be obscured/blurred. If you prefer that the pictures/images not be used in reports or presentations, I will respect that as well.

A reminder that collected data will be securely stored for a minimum of 7 years in an encrypted folder on a password protected computer and in a locked office. Any physical artifacts, written pieces, or other creative submissions that may have been emailed to the researcher, will be stored in a locked cabinet. Only myself and my advisor will have access to your information and photographs, unless you provide consent to use all or some of them in the representations created that will be shared more widely.

Also, you can withdraw your consent and request that your data (including photographs and creative submissions etc.) be removed from the study by contacting the researchers up until the completion of the final thesis submission (Summer 2021). Additionally, it is not possible to remove data once study results have been submitted for publication.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me by email at semain@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519-888-4567 ext. 46188 or by email at sldupuis@uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

Thank you for helping me and the research participants in this study.

Sincerely,

Sarah Main,

PhD Candidate, University of Waterloo

Appendix J: Informed Consent for Photos

I agree to allow Sarah Main of the Department of Recreation and Leisure Studies at the University of Waterloo to use any pictures or images that I am in and that I submit for the purposes of this research project. I have made this decision based upon the information I received in the Information Letter, have had the opportunity to view the photos/images that may be used, and have received any additional details I have wanted about the study. By allowing the participants to use my pictures/images, I understand that it may be used for the study and for use in research papers, presentations and representations that arise from the study. I am also aware that I have the option to blur my face in an image to help protect my identity. I understand that this project has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42755) and that I may contact this office if I have any concerns or questions about the use of my pictures/images in this study.

I agree to the use of my photos in research reports, presentations, and representations that come out of this study with the understanding that my face will be visible but I will not be identified by name.

☐ YES ☐ NO

I agree to the use of my photos in research reports, presentations, and representations that come out of this study providing that my face is blurred in the images used.

☐ YES ☐ NO

Participant’s name: ___________________________

Participant’s signature: ________________________

Date: ______________________________________

Appendix K: Feedback and Thank You Letter

University of Waterloo

[date]

Dear [Participant's name]:

I would like to thank you for participating in this study. The purpose of this research is to understand how people with young onset dementia envision the future of their care journey, and what ideal care and support might look like.

The data collected during the small group discussions will contribute to a better understanding of how younger persons with dementia describe their experiences of the long-term care system, as well as in identifying paths for positive change in dementia care.

I will be sending out a summary of the findings of the research for your interest once the study is completed, likely sometime in Summer 2021.

I hope you will get in touch with me if you have any further comments or questions about our conversations or about the study in general. I can be reached at semain@uwaterloo.ca. I would also like to remind you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42755). If you have any questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. Thank you again for your participation in the project.

Sincerely,

Sarah Main, PhD Candidate
Department of Recreation & Leisure Studies
Research Assistant | Partnerships in Dementia Care Alliance | Faculty of Applied Health Sciences
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