Exploring student discourses:

Would intergenerational cohousing be possible?

by

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A thesis

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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

Intergenerational cohousing programs are arrangements which promote contact between younger and older adults through living together, including within retirement and long-term care homes (LTCHs). These cohousing opportunities have several important benefits for younger and older people, yet the stigma associated with LTCHs, exacerbated by the pandemic, is threatening these cohousing possibilities in the future. This narrative research explored three related puzzles: (1) How do students story the experience of life and leisure in LTCHs; (2) What dominant discourses pervade their stories; and (3) What does this suggest about future participation in intergenerational cohousing programs and how does it expand the intergenerational contact model? Narrative interviews were conducted with undergraduate students at the University of Waterloo. Participants included students with experience working and volunteering in LTCHs, as well as students who have only visited to see family members. Three discourses were interpreted from the data: the discourse on The Transition(ed), the discourse on (Mis)Management, and the discourse on (Re)Valuing. These discourses, along with an exercise in narrative futuring, were used to construct and explore four vignettes of a narrative future in which intergenerational cohousing within LTCHs is an established practice. This study suggests that intergenerational cohousing in a LTCH may be possible in the future, however significant changes must be made in order to realize that future; changes that are likely to improve the quality of life for all residents, young and old. This study also suggests that discourse is an important social condition that must be considered as part of the intergenerational contact model when developing intergenerational experiences, especially cohousing.

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#### Acknowledgements

From the onset of this work, I have related the research process to building and navigating a large ship. However, it would be remiss to think that I could crew such a ship on my own. There are countless people who have contributed to the production of this work along the way, and I am incredibly grateful to have had them as part of my team.

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For Lloyd,

help is on the way.

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This thesis is like a large ship. I once thought about installing an engine but chose a set of sails instead. As such, I will go where the wind takes me. What lies beyond the horizon remains unknown to me, accessible only through this craft. I know hurricanes will surely assault its hull. If it is built well, I will be carried forward into new knowledge. If it is built poorly, I may rightly sink beneath the crashing waves. And if the wind fails to blow at all, I have packed an oar.

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-the author

# Prologue

In February of 2009, I found myself sitting in the shallow, dusty-pink padding of a rigid, waiting room chair with the smell of dinner wafting through the hallways. I was mid-way through ninth grade and heard about a quick way to get all 40 hours of required volunteer service for my high school diploma. I would be lying if I said that my motivations to start helping in long-term care settings were purely altruistic, however, it did seem like an excellent fit for me as well. I still had all four of my grandparents to whom I was very close. I also got along well with the older adults in my church community. I simply enjoyed the company of older souls and they seemed to enjoy mine.

An opportunity was presented to my class by our math teacher to volunteer at the Lodge, a small long-term care home half a kilometre from my high school. We would be asked to give two hours a week after school assisting with crafts, teaching computer skills, folding laundry, or whatever else might be needed for that day. It seemed like an easy enough way to get my volunteer hours early in my high school career and so it was that I found myself in that stiff waiting room chair on a cold, dark, winter afternoon.

While I waited for the volunteer coordinator to arrive with my assignment, my eyes drifted around the room. They settled on a wheelchair-bound resident, not far from my seat. He was hunched forward with hands settled crookedly in his lap, staring blankly ahead with sleepy eyes. Since we both appeared to be doing nothing, I decided to say hello. He did not respond immediately. I waved towards him, saying hello once more, and his gaze slowly shifted towards me, eyes straining to see if I was really speaking to him. He responded with a weak hello and smiled briefly before staring back into the void. I continued the conversation by asking how he was doing and was met with some hesitation before he started to speak again. He explained that

he was tired and sore and upset. I wasn't entirely prepared for that kind of response, but I pressed into it, asking more questions and waiting in silence for short answers.

As we conversed, the volunteer coordinator, Judy, arrived and asked if we could speak for a moment. I said goodbye to my new acquaintance and followed her behind the nurse's station. Judy had noticed that the man and I were chatting and asked how the conversation had gone. I responded that he seemed pleasant enough although he was not entirely happy. She then explained to me that his name was Lloyd and he was what they referred to as a "yeller". He would often be heard yelling "Help! Help!" wherever he was, though he never mentioned what he needed when a staff member responded. Besides calling out for help, he did not say much else to anyone. Further, Judy explained that Lloyd didn't receive many visitors, perhaps only a few per year. Since she had seen us talking together, Judy asked if I would be comfortable visiting with Lloyd once a week as my volunteer placement. Really? Just visiting someone would count towards my volunteer hours? That sounded great to me!

That was how I met Lloyd. Visiting him every Friday after school for two hours was something I looked forward to each week. This volunteer experience became a primary leisure space for me that year, and I might well assume the same for Lloyd. Although I cannot speak entirely on his behalf, I do know that our meeting was one of the few moments that he looked forward to each week. I would push him around the grounds in his wheelchair as we swapped stories about our lives: he explained what life was like on his farm while I compared it to life on my parents' farm; he told me stories of his childhood while I shared my hopes of becoming an astronaut. As our relationship grew, Lloyd began to confide in me about his fears and his dreams. Some nights he would see things in his room that he knew were not real. He had hope for another life after this one, where his body would not limit him as it did now. I also shared with Lloyd

what I was worried about: grades, friendships, aspirations, etc. Occasionally he would still cry out for help, even when I was with him, but he seemed to become more at ease as our friendship deepened. It began to feel more natural for me, like spending time with any other close friend; I was hanging out with my buddy.

Lloyd graduated from this life, with honours, only a few years after I met him, but that short time was powerful. Throughout high school, my aspirations shifted from the stars of the sky to the souls of the Earth. I began to pursue other opportunities for building into the lives of the people around me, especially older adults.

This watershed relationship in my developing years was possible only because of the intergenerational contact that was made available to both Lloyd and me. Our relationship was built on shared goals and expectations. Although it was a volunteer opportunity that got me through the front door, it was the relationship building that kept me coming back and Lloyd ready to receive me. We spent two hours, weekly, for nearly a year pouring into each other's lives as equals and friends. The time span, frequency, and power dynamics were all set up to have a successful contact experience. According to the intergenerational contact model put forward by Fox and Giles (1993), each of these components is required for a high-quality interaction, although I had no notion of theory at the time.

In recent years, I came across a newspaper article (Jansen, 2015) that outlined a program in which university students were welcomed to live in long-term care settings, free of charge, in the Netherlands. Was this for real? Since my time meeting Lloyd, I had visited or volunteered in several other settings that housed and cared for older adults. Not once had I considered that I might move in during my 20s. Yet, now I wanted to. One conversation led to another and as I concluded my undergraduate career, I found myself entering graduate school to explore the lived

experiences of people participating in a similar program in Canada. Unfortunately, the global pandemic of COVID-19 derailed that direction of inquiry since most long-term care settings had more pressing matters at hand. In its place a new idea emerged: as stories of tragedy swept through the long-term care sector within Canada, how would they impact young adults' stories of long-term care? Would they even be willing to try intergenerational cohousing in these settings after the pandemic was over?

Stories are powerful things. Stories, lived and told, played a role in every step that led me to the Lodge that winter afternoon. Stories, lived and told, before, during, and after my time with Lloyd had life-changing impacts on the characters who danced in and out of them. Stories, lived and told, of life in the Lodge for other residents, had impacts on characters I never even knew until long after, as you will read in the end.

This study is a story about Lloyd. It is a story about every resident, family member, staff, and volunteer at the Lodge. It is a story about my high school classmates, the ones who chose to volunteer and the ones who did not. Even though none of these people or places will form the bulk of this narrative inquiry, their stories are part of the historical and sociocultural backdrop for the stories that I did explore. It is their stories, and others like them, which form society's dominant discourse on ageing and long-term care. If, in this work, you and I will have only listened to the stories of lived experience that are told, we will have met the bar. If we do something about them, even better.

I do not want my children to grow up in an isolated neighbourhood, knowing neither the realities of old age nor the meaning of racial heterogeneity. Age, race, and social class discrimination are clearly inimical to the developing human community. . .

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(Butler, 1969, p.246)

# **Chapter 1: Concerning Ageing**

People, for the most part, need to go through life in community with others. This drive to stay connected with one another has hardly been more obvious than through the recent COVID-19 pandemic which forced many of us to segregate ourselves from one another. Yet prior to stay-at-home orders and physical distancing mandates, many people in Canada were *already* segregated at institutional, spatial, and cultural levels according to their age (Hagestad & Uhlenberg, 2005).

From our first foray into the coliseum of kindergarten to our final days on Earth, Canadians are systematically divided according to how much time has passed since their birth. Of course, in sharp contrast to the stay-at-home orders of a global pandemic, we are *permitted* to break through those age-related boundaries to interact. Yet, how often do we choose to do so?

This project explores the stories that young adults tell about life and leisure in long-term care settings. How do they understand life in those settings, and can they see themselves taking part in it? It is my hope that by the end, you and I, together, will learn something from their stories and the discourses shaping those stories that can inform intergenerational programs, particularly ones involving cohousing arrangements.

## **An Ageing Population**

It is no secret that Canada's population is ageing. In fact, older adults (often recognized as individuals 65 years of age and older) are the most rapidly growing age population in Canada (Sibley et al., 2016). In 2016, persons at least 65 years of age accounted for 16.5% of the population, compared to 16.1% for children between 0 and 14 years of age (Statistics Canada, 2016). Astonishingly, this was the first instance in Canadian history where older adults comprised a greater proportion of the population than children (Statistics Canada, 2016). Today, Statistics Canada (2019b) claims the proportion of older adults has grown to 17.5% while the

proportion of children remained mostly unchanged (about 16.0%). The trend towards an older population is further accentuated when you consider that in 1986, only 30 years prior, there were twice as many children than older adults in Canada (Statistics Canada, 2019c).

Though not solely responsible for the trend, the 'Baby Boomer' generation is contributing greatly to the rise in Canada's median age, from 30.6 years to 40.8 years since 1984 (Statistics Canada, 2019a). In 2016, 'Baby Boomers', a term attributed to those born between 1946 and 1965, made up only 35.7% of older adults (Statistics Canada, 2016). Today, over half (51.1%) of all persons at least 65 years old are from the 'Baby Boomer' generation (Statistics Canada, 2019b). Their longevity has been attributed to factors including being generally healthier and having more active lifestyles as well as increased financial stability and independence (Sibley et al., 2016). However, they are not the only ones benefitting. The oldest among us are also benefitting from advanced healthcare and better lifestyle choices. In 2019, there were 10,795 centenarians across the country, triple the number since 2001 (Statistics Canada, 2019b). Localized Ageing and 'The Ghetto'

Canada is not alone in this. Nations all around the world are experiencing rapid ageing for various reasons (Novak et al., 2014). Shifts in population age have been attributed to population booms, institutional population control, the spread of disease (e.g., HIV/AIDS in sub-Saharan Africa) and conversely increased progress in medicine, and urbanization/globalization (Novak et al., 2014). Localized regions also experience rapidly ageing populations due to economic migration that facilitates the separation of families, with older, immobile adults forced to live in poverty or seclusion while their younger family members go looking for better opportunities (Novak et al., 2014). In other cases, mobile older adults choose to self-segregate into specific regions, such as Miami Beach in Florida, which contributes to the perceived ageing of those regions as well (Revell, 2018).

Regional shifts towards ageing populations have attracted products, services, and policies that focus primarily on serving the real and perceived needs of older adults (Revell, 2018). Although this centralization of goods, services, and policies can strive to serve an aged population more efficiently, it may also inadvertently inhibit the geographical mobility of older persons, as well as their access to younger generations (O'Dare et al., 2019). Having quick and convenient access to everything they 'need' within their neighbourhood not only decreases the perception that they could move away if they wanted to, but it also makes the space attractive for other older adults to move there (or in some cases for children to send their parents there) (Chen, 2015). While some older adults may actually prefer convenient access to the products and services they need in a place populated entirely by their peers (it doesn't sound that bad to me either, to be honest), for others it has been identified as "age-homogenous ghettos" (O'Dare et al., 2019, p.11), "geriatric ghettos" (Portacolone & Halpern, 2016, p.849), and "grey ghettos" (Wild et al., 2018, p.259) (which seems to sound a whole lot worse). Robert Butler (1975) recognized this association with ghettos in some styles of retirement communities in his seminal work Why Survive?

The term ghetto has a very long and storied history, beginning with Jewish segregation in Middle-Age Venice, resurrected by Germany and Italy during the second world war, and entrenched in North American society as a term for poor city areas, usually populated disproportionately by African-Americans (Haynes & Hutchison, 2008). While its most popular usage in North America has been in reference to racialized and poor urban centers, it finds its roots in the idea of voluntary or involuntary segregated living more generally and thus has been attributed to the phenomenon of age-segregated living conditions. It is my opinion that this

ghettoization of space according to chronological age, whether natural or contrived, is no clearer than in the dominant North American concept of long-term care.

#### A Moment to Process

This is a strong claim, no doubt. And as I process the implications of such a claim, I am profoundly aware of the harm it may cause. Racialized ghettos were not formed through care and compassion for a vulnerable group. Sure, there is money to be made in the industry of elder care, but don't most carers enter this field for the right reasons? How can I relate the structural violence experienced by racialized people today, and historically, to that which is experienced by older adults in long-term care settings? Do I minimize or overshadow the harm of racialized people by stating this case? Or overstate the harm against older adults? Am I capitalizing on current trends and issues to push my own agenda? Do I contribute to the stigmatization of long-term care and older adults by saying 'Yes, it is this bad!'? I am actively struggling with this issue of language, systems, and their implications.

My comments are not meant to focus on the shortcomings of any particular residence for older adults, nor to call into question the ethics of those who operate such establishments. My intent is to address a system that has made total institutionalization the de facto method for *dealing* with an ageing population, in both the minds of the young and the old. Couldn't there be an entirely different approach to supporting our older adults?

It is my hope that as you and I proceed to follow this line of inquiry together, we can find a way through that both uplifts and enlightens for the benefit of all. To find our way forward, we should start by figuring out where we are now. Our first stop is a brief look at what long-term care options currently exist in Ontario's healthcare system.

#### **Current Options in Long-Term Care**

Long-Term Care (LTC) may evoke different ideas for different people. Some may immediately associate the term with long-term care homes or nursing homes, which are residential institutions that provide care to older adults. Others may associate it with Continuing Care Retirement Communities (CCRCs) that offer varying degrees of support and independence depending on individual needs. In fact, LTC is a very broad umbrella term that covers everything from home care and day programs to hospitalization and end-of-life care (Dupuis et al., 2012). As of writing, in Ontario there are three levels of LTC that have been established. They are home care, retirement homes, and long-term care homes.

*Home care* is the first option that most older adults will encounter if they need additional support personally or in the home. It is the most likely option for older adults who wish to remain independent in their homes and do not require 24-hour nursing care. Services provided may include physiotherapy, nursing, personal support, or daily tasks such as laundry and washing dishes, among others (Ontario Ministry of Health, 2019a). In the province of Ontario, most home care is covered, in part or in full, when accessed through the Local Health Integration Network (LHIN). However, private options are available for services not covered by the province or if an individual would like to select a specific home care provider. Due to the shortage of space in other forms of residential LTC, home care has become an essential part of the continuum of care for older adults.

*Retirement homes* are the second option available to older adults in Ontario. These are privately owned homes where older adults who wish to live independently may rent accommodations at their own expense, while also having convenient access to goods, services, and limited care options (Ontario Ministry of Health, 2019b). Some retirement homes are part of larger CCRCs and form the bridge between independent homes and long-term care homes.

Retirement homes come in four flavours: *Independent supported living* – usually an apartment or communal housing arrangement with optional care services available at an additional expense; *Assisted living* – an apartment or communal housing arrangement with some care included in the fees (e.g., dressing, bathing, etc. . .); *Specialized dementia or memory care* – a shared home specifically geared to supporting persons living with dementia; and *Short-term stays* – a room for individuals wanting to try retirement homes or people recently discharged from hospitals who are unable to go home because of limited support options (Ontario Retirement Communities Association, 2019). All these living arrangements may exist within the same building or separately, depending on the offerings of the specific retirement home.

*Long-term care homes* (LTCHs), sometimes called nursing homes, are the third option. At the time of writing, LTCHs are only accessible in Ontario through the LHINs, with an application process and, often, a waitlist. Residents of LTCHs are typically older adults who need assistance with their activities of daily living (ADLs) as well as 24-hour nursing care (Ontario Ministry of Health, 2019c). These homes are primarily occupied by people where care is not adequately supported through community-based services and/or by family. Personal care is covered by the province in Ontario; however, accommodation and food are often not, though this extra expense may be subsidized when necessary.

Although these three LTC options are available to all Ontarians, and in fact to most Canadians through their own provincial programs, they do not appear to be adequate for meeting the needs that exist. Demand for beds in LTCHs is rising in Canada, with nearly 14% of hospital beds being occupied by older adults who require LTCH support but cannot find an opening (Gibbard, 2017). In 2015, over 26,000 people were on a waitlist for accessing LTCH beds, including older adults who were already receiving home care and people who anticipated

needing additional care later but not immediately (Gibbard, 2017). It is not only LTCHs that are facing this demand. According to the Canada Mortgage and Housing Corporation (CMHC), the 2016 vacancy rate for standard rooms in retirement homes was 7.4% with the national average rent sitting at \$2,210. Ontario had the highest average rent at \$2,978 for standard retirement home rooms (CHMC, 2016). Low vacancies with high rent show an increasing push for older adults trying to access retirement housing. What this data does not show is *why* older adults are trying to access these types of residential care and the actual experience of living there; that topic will be covered in the next chapter. For now, it should suffice to say that older adults are increasingly moving towards age-segregated housing even though there is not enough to go around.

#### Ageism

Robert Butler coined the term 'ageism' in 1969 in an attempt to describe the contempt he found his neighbours express for older adults (Butler, 1969a). The idea was born out of a housing crisis that had developed in the United States through the early 1960s. My understanding of the context which precipitated this response comes from a collection of news articles published in 1969 in the Washington Post, among other newspapers (see the following articles for more details on the case: "Apartment Opponents Turn Noisy," 1969; "Regency House Vote Set for Tonight," 1969; "Regency Sale Is Completed For \$2.4 Million," 1969; "The Battle of Chevy Chase," 1969; C. Bernstein, 1969; Butler, 1969b; Saunders, 1969).

To stagnate the growth of racialized, poor, and ageing neighbourhoods, a plan for integrating these populations into established neighbourhoods across Washington DC was adopted by the National Capital Housing Authority (NCHA). In the case of Butler's neighbourhood, Chevy Chase, Maryland, an apartment building was selected for housing the poor elderly, many of whom were also Black people. This building, the Regency House at 5201 Connecticut Avenue,

was considered to be a luxury apartment complete with indoor parking, a pool, air conditioning, and a recreation room. Chevy Chase was a primarily white, upper-middle-class neighbourhood. A very noisy minority of residents in this neighbourhood were appalled at the idea that this apartment would be used to house 'such people'. Their primary concern? The occupants' ages.

While race and socioeconomic status undoubtedly played a role in their distaste for the idea, Butler noted that the primary concern was that older adults were not wanted in that neighbourhood. He found the same opposition to this housing plan in predominantly Black neighbourhoods (Butler, 1969a). The argument was never that older adults did not need housing, access to appropriate services, or even that they did not like older adults. The residents of Chevy Chase offered up several suggestions for alternative locations in the city for such a building. The issue was they did not want the older adults in *their* neighbourhood. They did not want to see them. Since that time, the literature has exploded on the concept of ageism, attempting to describe the stigma that older adults, and more recently, young people, face because of their chronological age.

Ageism exists in Canada, even in areas that appear to be trying to help. While Canada adopts the World Health Organization's (WHO) mandate that promotes Age-Friendly Cities and Ageing-In-Place initiatives (Bigonnesse et al., 2014; Hartt & Biglieri, 2018), they are born out of the assumption that institutionalization is inevitable and older adults must be kept in the community for as long as possible to ease the 'burden' they present. In fact, the UN actually states in the universal declaration of human rights:

"Everyone has the right to a standard of living adequate for the health and well-being of himself [sic] and of his [sic] family, including food, clothing, housing and medical care and necessary social services, and the right to security *in the event of unemployment, sickness,* 

*disability, widowhood, old age or other lack of livelihood in circumstances beyond his* [sic] *control* [emphasis added]" (United Nations General Assembly, 1948, Article 25.1).

Old age is considered as part of a list of unfortunate occurrences in a person's life that must be accommodated if it should happen to them. Of course, unemployment, sickness, disability, and widowhood may be more likely in the life of older adults, but old age is not in and of itself an unfortunate circumstance that needs accommodating. Quite the opposite in my opinion. Although this declaration isn't a law, it is symptomatic of a system built on implicitly ageist ideas.

Before beginning this research journey, I frequently thought about the ways friends, family, and the media talked about the 'generation gap'; a seemingly irreconcilable difference in how people view the world, based on the years in which they were born. 'It's just the way they are' people would say. Our society creates labels to identify these 'others' such as Gen Z, Millennial and Baby Boomer, but they quickly devolve into tools for causing intentional harm (e.g., the dismissive phrase "Ok, Boomer" in popular culture). How did our society become so entrenched in ageism that this behaviour is considered acceptable?

One argument insists that ageism can find its roots in age-segregation (Hagestad & Uhlenberg, 2005). As society stratifies itself according to age, gaps in knowledge and experience between the generations widen, leading to ageist attitudes, beliefs, and behaviours. This ageist social condition reinforces age-segregation practices, widening the gaps further.

Various styles of intergenerational programs have been used to try and bridge the generation gaps, especially in leisure and education spaces (Ballantyne et al., 1998; Cohen, 2014; Conway & Hodgman, 2008; Dupuis, 2002; Gray & Worlledge, 2018; Jarrott & Smith, 2011; Kuehne, 2003; Kuehne & Melville, 2014). Intergenerational contact has been suggested as an effective

way to decrease stigma towards age groups, however, a specific set of conditions has been prescribed to ensure they are quality contact experiences (Christian et al., 2014; S. Fox & Giles, 1993). Education and leisure spaces might provide excellent contexts in which to host intergenerational contact for reducing stigma, but another option is emerging as well, intergenerational cohousing.

Intergenerational cohousing offers an interesting option for facilitating contact between the generations because it encourages people to <u>do life together</u> rather than formalized activities for a set time frame. Three options I will present in the following chapter are homesharing, university-based retirement communities, and live-in students at retirement settings. Each of these options is usually, but not always, facilitated through educational institutions and provides for greater and more personal flexibility on how the intergenerational relationship will develop, especially during leisure time. It evolves the contact experience to a relational experience.

The current COVID-19 pandemic makes it impossible to study existing intergenerational cohousing projects (the original purpose of this research project) due to restrictions on the activities within long-term care settings. However, a new relevant direction has emerged as a result. LTCHs across Canada have faced tragedy and fear while trying to protect their vulnerable residents. At a societal level in Canada, we were trained to avoid contact with older adults for their own protection and this is especially true in the LTC context. Media sources such as news outlets and social media continue to perpetuate this discourse of loss, tragedy, mistakes, and abuses. Headlines such as "Military mission ending in most Ontario long-term care homes" (The Canadian Press, 2020), "Military deployed to another Ontario long-term care home ravaged by COVID-19" (Aguilar, 2020), and "Canadian forces leaving GTA long-term care homes" (CityNews Toronto, 2020) suggest that long-term care settings in Canada are war zones. In other

cases, headlines read "Young people are infecting older family members in shared homes" (Bernstein, 2020), citing young people as the reason for increased COVID-19 related deaths. A report called for the federal and provincial governments to investigate LTCH practices in order to improve a broken system (Mahoney, 2020), with the Ontario Long-Term Care COVID-19 Commission completing their report in April of this year (Marrocco et al., 2021).

Though programs exist that place college and university students in both retirement and privately held homes with older adults, student's willingness to participate in such programs may be affected by this crisis and by the resulting narrative. Students who believe LTCHs in particular are dangerous or unpleasant places may be less inclined to participate in programs that require a live-in role. Conversely, the idea that young people could be harbingers of a deadly disease may cause older adults and administrative officials alike to reconsider their involvement in such programs at all. This discourse will have profound impacts on a public that has not frequently considered life in LTCHs before, especially among young adults.

#### **Theoretical Framework**

In developing my theoretical framework for this study, I began by examining the intergenerational contact model developed by Fox and Giles (1993), and based on Hewstone and Brown's (1986) intergroup contact theory. Prior to the pandemic, I had focused my work on the aspects of contact theory that prescribed the conditions under which positive and quality intergenerational contact happened. I planned on using this framework to explore the lived experiences of people participating in intergenerational contact model remains a useful framework for exploring young adults' stories of life and leisure in LTCHs, especially since it takes into account the social conditions surrounding contact experiences (Fox & Giles, 1993).

I support the tenets of the intergenerational contact model; however, I believe that its recognition of social conditions does not go far enough. For this reason, the current project aimed to explore dominant discourses as another social condition that the intergenerational contact model must consider in its framework. This exploration of those dominant discourses has relied considerably on narrative inquiry. What follows is a brief outline of these two theoretical frameworks, the intergenerational contact model and narrative inquiry, which are covered in greater detail in chapters two and three, respectively.

#### Intergenerational Contact Model

Fox and Giles (1993) suggested that an intergroup theory is needed in intergenerational research since the salience of age may lead participants in intergenerational programs to "view the other generation as a different social group" (p.433). A contact theory is one in which the necessary conditions to produce a positive shift in attitude between two or more groups is prescribed (Fox & Giles, 1993). The intergenerational contact model applies this thinking to ageist views between generations. Their model for intergenerational contact considers individual traits, goals, communication styles, expectations of participants, social conditions in society, the nature of the contact experience itself, and participant reflections afterward. You will find a thorough overview of these ideas in the second chapter.

Talk of models and outgroups with prescribed conditions have a thoroughly postpositivist flavour, but both intergroup contact theory and the intergenerational contact model rely on two key components that are the focus of this interpretive research project; a social context beyond the contact experience and communication.

The intergenerational contact model requires that wider social conditions existing within society be considered when structuring a positive interaction between generations (Fox & Giles, 1993). When Fox and Giles talk about social conditions (or factors as they put it), they are

specifically talking about how increased longevity affects housing, status, and political influence. Perceptions of their own and each other's position in this social structure will affect how young adults and older adults relate to one another (Fox & Giles, 1993), but the authors give no concrete direction on how to explore that idea. I have suggested that the wider social conditions should include both the public and private discourses that relate to ageing, as these stories not only influence how we think about and story ageing in our own lives but also think about and story our own intergenerational contact experiences. While other augmenting factors such as time span, frequency, power, and territory can be adjusted and modified according to program design, social conditions (i.e., dominant discourses) exist beyond the control of such designs. I believe even if all other aspects of the model were executed perfectly, these dominant discourses that surround such contact will still have a profound impact on the participants before, during, and afterwards as they reflect on and share about their contact experience. It is especially important to understand how discourse shapes a person's reflection on and sharing of stories. One way to begin this exploration of stories and discourse is through narrative inquiry. Narrative Inquiry

Narrative inquiry offers one approach to exploring discourse in society. Clandinin and Connelly (2000) say that "humans are storytelling organisms who, individually and socially, lead storied lives" (p.2). Stories are an integral part of how humans share and understand their life experiences. And yet, the relationship between human and story has also been described as symbiotic (Frank, 2012). Stories possess a life of their own. While my storied experience may be uniquely mine, I use narrative components, such as character archetypes and plotlines, that exist externally to me in order to make sense of it for myself and others. Since people tend to borrow from a finite culturally-relevant pool of narrative components when storying experience, taking a closer look at the narrative components chosen for specific discourses by people as individuals

can provide suggestions about what is going on in the larger social discourse beyond them (Frank, 2012; Riessman, 2008). Chapter three will dig deeper into the minutiae of this particular approach to narrative inquiry, known as dialogical narrative analysis.

Part of doing narrative inquiry well is learning to think narratively (Clandinin & Connelly, 2000). This means becoming aware of how I story my own lived experiences and remaining conscious of that throughout the research process. Part of doing this involves taking readers back in time and space to share the stories that I feel have guided me this far. It involves interjecting expressions or metaphors into my writing which help to story my thought processes. It also requires that I always remain aware that my story, and that of my participants, is not yet finished and will be further altered by engaging in this research (Clandinin & Connelly, 2000; Frank, 2012; Riessman, 2008).

Taken together, the intergenerational contact model and narrative inquiry will be the primary theoretical frameworks that guide my work. The intergenerational contact model is made stronger through narrative inquiry.

#### **Purpose and Research Puzzles**

The purpose of this narrative inquiry is to explore university-aged students' stories of life and leisure in Canadian LTCHs, identify dominant discourses shaping those stories, and examine the student's role in them. This study also attempts to enhance the intergenerational contact model by broadening what is considered to be the wider social conditions of a contact experience.

In this study, I am presenting the exploration I undertook in the form of research puzzles. The shift from research questions to research puzzles is part of learning to think narratively. Using puzzles rather than questions implies a continual searching that is essential to narrative

inquiry rather than defining precise answers (Clandinin, 2016). In this study I will present possible solutions to these puzzles. Three research puzzles will guide this narrative inquiry:

- How do students story the experience of life and leisure in a LTCH and how, if at all, do they see themselves in those stories?
- 2. What dominant discourses are present in the stories of LTCHs?
- 3. What does the emerging dialogue suggest about future student participation in intergenerational cohousing programs and how does it expand the current intergenerational contact model?

The information gathered through this narrative inquiry will be used to envision what would be necessary for intergenerational cohousing in a LTCH to work for young adults. Further research will be needed to explore what would be necessary for older adults to thrive under this same system although suggestions made in this study may prove to be beneficial and helpful clues to that end.

#### Significance and Implications

This research project stands as an early dive into the new world of post-pandemic discourse among young adults that could affect the stigma already surrounding LTCHs and older adults generally. If intergenerational contact reduces ageism and the stigma that surrounds ageing and ageing communities, intentionally avoiding intergenerational contact, even for medical reasons, may increase ageism and ageist ideals. This study is initiating the conversation on how intergenerational cohousing projects should be structured and marketed moving forward so that young people might be willing to go through the front door and experience the positive and potentially life-changing aspects of intergenerational relationships, the way I did with Lloyd.

This research is particularly necessary if we are to re-enter discussions about intergenerational cohousing programs post-pandemic.

Second, this project has narrative implications. As stated earlier, participants in this study, myself included, will not depart from this work unchanged. The act of engaging in conversation can stir people to think differently about topics they previously held as given (Clandinin & Connelly, 2000). While I hope for culture change in the way we talk about age or structure intergenerational contact, I am aware that changes at the personal level are also very important. I am not suggesting that everyone who participated in this study has suddenly become 'champions of the cause', however I do expect that at least some of them have begun to think in new ways about how age and age-segregation affect their lives. For myself, I have begun to think about research itself in new ways by engaging with this study in a narrative fashion. My own views about long-term care and young people's understanding of the system were challenged by the stories participants told. As much as my interview guide attempted to predict important stories I wanted to hear, participants often had fresh and surprising stories that needed further digging at the expense of the guide. Moving forward, I wonder how much more my own stories will be affected by the way participants shared theirs?

Third, this study took aim at what the intergenerational contact model classifies as social conditions and expanded the definition to include discourse. There are several other social conditions which could be considered including cultural expectations, institutional and historical paradigms, language (beyond stories and discourse), personal experience, and so on. Some of these are taken up by Hewstone and Brown (1986) in their original contact theory but are not discussed of expanded on in Fox and Giles (1993) model. Through this study, I have tried to open the possibilities about which social contexts should be considered when thinking about

intergenerational relationships. To be clear, the intergenerational contact model does imply that a person's personal and social context, as well as their perceptions of that context, are important, but it doesn't give sufficient names to the possible contexts. Future research will do well to keep exploring this list of contexts or social conditions that must be accounted for in the model.

Finally, future research in this vein could be used to challenge and critique dominant discourses that promote and protect ageism, setting us up for a new path forward in the care of older adults in Canada – a path that has intergenerational relationships at its core.

#### Where Do We Go From Here?

Tragedy within LTC settings globally have led to a call for the re-evaluation of LTC practices (Mahoney, 2020; Marrocco et al., 2021; Phillipson, 2020). The dominant discourses on life and leisure within a LTCH will dictate how Canada moves forward in the following years. Thus, it is important that we explore, understand, and critique those discourses and understand how they may impact generational relations moving forward.

As a contribution to that end, this narrative inquiry begins by exploring the dominant discourses among young people, particularly university students, that shape how they story life and leisure in a LTCH and their place in it.

The next chapter will provide greater detail on the current literature regarding the academic conversation on ageism, age-segregation, and their effects, followed by a discussion on the work being done on the intergenerational front. Chapter three will discuss how I explored these topics through narrative inquiry, more specifically dialogical narrative analysis and creative analytic practice. Chapter four will take us through a discussion of research puzzles (1) and (2), exploring how participants storied their experiences and perceptions of LTCHs along with the underpinning discourses. In chapter five, I will present to you four narrative futures in which students are actively living within an intergenerational cohousing community, based on a

narrative futuring exercise conducted with each study participant. Finally, chapter six will bring it all together, discussing the narrative futures and responding to research puzzle (3). Let's go!

This area is ripe for future research and our attempt to integrate past knowledge with present and future concerns should motivate useful discussion and revisions...

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(Fox & Giles, 1993, p.447)

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# **Chapter 2: Generational Gaps**

Much work has been done in the past to make strides towards a more equitable life for all people. In this chapter, I will discuss how the work to include people of all ages came about in the late 60's, born from the work to include people of different races in the United States of America. While efforts were being made to increase racial integration across the US, age-segregation was also increasing in the form of more homes for the aged, inadvertently contributing to ageism, stigma, social isolation, and loneliness. The current academic discourse related to age-segregated housing often points towards deinstitutionalization and reaffirming the personhood of those who occupy such housing. I believe one way to reaffirm their personhood is to work towards reconnection with the broader community.

To conclude this chapter, I will look at a new concept for cohousing young adults and older adults, reimagining long-term care homes into long-term communities. Although at its core this chapter is an academic literature review, it is also a story about us, what we have lost, and one way we might get it back. It begins and ends with community.

#### Ageism and Age-Segregation

Butler (1969a) originally coined the term ageism, defining it as "prejudice by one age group toward other age groups" (p. 243). As discussed previously, this term was born out of Butler's frustration with the public's negative response to a government initiative that would see a large number of poor, elderly, and Black people move into an apartment building within an affluent neighbourhood of Washington D.C. (Butler, 1969a). Many of the comments that Butler recounts from the impassioned public hearings, prior to the purchase of the building, invoked advanced age as a point of contention. For example, one community member stated, "Who wants all those old people around." (p. 243). As stated earlier, Butler also found that the response against elderly people moving into new public housing was the same in "a predominantly black [sic] section of

Washington" (p. 244). Butler's point was not to minimize the obvious prejudice of others based on class and race that was also noticed during this debacle. Rather, his point was to shed light on prejudice that most continued to accept as being normal and appropriate.

Butler's rallying cry against ageism did not fall on deaf ears. The study of ageism grew over the decades to become a prominent subject within psychology, gerontology, and other social sciences (Hagestad & Uhlenberg, 2005). For example, research into our implicit attitudes, beliefs, and behaviours on a myriad of subjects, especially prejudice, stereotyping, and discrimination eventually found its way to confront the issue of ageism. Levy and Banaji (2002) first discussed implicit ageism as consisting of two components, implicit age stereotypes and implicit age attitudes.

*Implicit age stereotypes* are conceptualized as "thoughts about the attributes and behaviours of the elderly that exist and operate without conscious awareness, intention, or control" (Levy & Banaji, 2002). Likewise, *implicit age attitudes* are conceptualized as "feelings towards the elderly that exist and operate without conscious awareness, intention, or control" (Levy & Banaji, 2002). Taken together, Levy and Banaji (2002) posit implicit ageism as an unconscious change in thoughts, feelings, and behaviours towards a person or group, based on their perceived age. They note that what makes ageism so distinct from other forms of prejudice is the lack of formalized, explicit hate groups or movements directed against specific age groups. Instead, it is socially acceptable, even praised and considered funny, to express negativity towards people based upon their age in fully conscious and intentional ways. Implicit acceptance makes explicit action possible. Although like Butler, Levy and Banaji admit ageism can be directed towards any age group, they primarily concern themselves with the plight of the aged (Levy & Banaji, 2002).

Building further on this idea that ageism begets ageism, Hagestad and Uhlenberg (2005) suggest that the roots of this cycle lie in age-segregation, the very notion that spurred Butler on to sound the alarm. Age-segregation is the grading and positioning of one's role in society based on chronological or perceived age (Hagestad & Uhlenberg, 2005). It isn't new to our society, nor is it unique. Some level of stratification based on the perceived chronological age of people has been used throughout the world (Hagestad & Uhlenberg, 2006). In their typology of age-segregation, Hagestad and Uhlenberg (2005) distinguished three forms: institutional, spatial, and cultural.

*Institutional age-segregation* is perhaps the most visible type suggested. It manifests as the opportunities and constraints applied to people according to their chronological age (Hagestad & Uhlenberg, 2005). Examples of these stratified structures include the education system, the workplace, and many housing institutions. Other conceptual structures include: the 'age of majority'; legal ages to drink, drive, and vote; the age of retirement or to access retirement funds; and so on.

*Spatial age-segregation* happens when individuals with different ages do not coexist within the same physical space (Hagestad & Uhlenberg, 2005). This limits the number of face-to-face encounters that people can have with different generations, a necessary component for meaningful intergenerational relationships (Fox & Giles, 1993). Spatial age-segregation tends to happen in three contexts. They are the home, the neighbourhood, and areas of regular, day-to-day activities like work, shops, recreation, and education (Hagestad & Uhlenberg, 2005). Older adult retirement lifestyle communities are a specific example of this.

Some studies (Glass & Vander Platts, 2013; Moorman et al., 2017; Revell, 2018) perpetuate the idea that spatial age-segregation is a positive experience for older adults. Revell (2018)

argued for policies that would promote the success of self-segregating older adults in retirement lifestyle communities. Although I agree that older adults who choose to self-segregate should be allowed the opportunity to do so, and thus communities that promote this should be supported, Revell cites "reducing their involvement with a society that seems overly preoccupied with the desirability of youth, the rewards of employment, and the joys of child-raising." (p.73) as a positive outcome of this spatial separation, as though older adults have nothing to contribute to those spaces. Hiding 'less desirable' people from public view for their own protection is the sort of discourse that justifies oppression and yet it persists unhindered towards older adults. Revell notes that arguments against age-segregated communities point out that these communities are often poorer, less physically healthy, more isolated, and experience more ill-will on the part of younger community members. He points this out when quoting 1960s publicist, Hal Cohen, by saying "No one here has anything against old people individually. It's just that they create problems collectively." (p.73). Revell's point is that poverty, declining health, isolation, and other such issues perceived in age-segregated communities can be solved simply through proper economic policy and planning. When executed correctly, Revell argues, we should be able to keep older adults safe, secure, and separate from the rest of us.

*Cultural age-segregation* is most apparent in the language that we use. The language used to address people of particular age groups (i.e., elderly, youthful, etc.) further cements the idea that their identities are not compatible and, in fact, are opposites (Hagestad & Uhlenberg, 2005). The language used in media, birthday cards, and colloquial speech reflect the qualities we attribute to certain age groups. For example, 'You're having a senior's moment' is a common phrase offered when a middle-aged or older adult has a moment of forgetfulness, reflecting the common stereotype that older people are very forgetful or that cognitive deterioration is a normal part of

ageing. Other examples include birthday cards that make use of chronic ailments to reflect ageing or depict older adults engaging in "youthful activities" to create comedic dissonance. Furthermore, dominant discourses within a culture or society, as I will soon discuss, play a role in promoting both spatial and institutional segregation.

Hagestad and Uhlenberg (2005) note that the differences between groups we attribute to chronological age are most often rooted in historical contexts. The historical periods, cultures, and circumstances that shape an older adult's life story and personal preferences can be so vastly different from those of a younger adult. For example, all older adults do not necessarily prefer to play bingo, as the stereotype might suggest. Rather, at one point in history, bingo was a major event for socialization and enjoyment, with dedicated bingo halls similar to gyms or arenas. The older adults who prefer to engage in bingo today likely preferred to engage in bingo when they were younger. The continuity theory of ageing (Atchley, 1989) further expounds on this idea that our leisure pursuits might remain constant more often than not throughout the life course. I am not saying that young people can't enjoy engaging in bingo. In fact, I used to play bingo every other Wednesday in my apartment building's recreation room, but my friends jokingly referred to me as 'grandpa' for doing so. This joke, if one should call it that, only makes any sense because the game is culturally linked to an older population. Further, to my friend's point about my 'grandpa-ness', the five other regular participants at Wednesday night bingo were aged 50 to 95 (the 95-year-old regularly took the stairs to her 14<sup>th</sup>-floor apartment after our games). Culturally and historically linked concepts, such as specific leisure pursuits, can serve to widen the generation gap. In my case, I closed the gap by ignoring the association between 'bingo' and 'old' to enjoy an evening with my neighbours.

Hagestad and Uhlenberg (2005) conclude their discussion on age-segregation and ageism by positing a cyclical nature between them. Institutional, spatial, and cultural segregation according to chronological age fosters the development of ageist stereotypes, prejudices and discrimination and creates 'safe spaces' in which to express those views explicitly. Ageist positions, even well-intentioned ones, reinforce segregation and prevent positive intergenerational interactions. The cycle repeats.

Where does this leave us then? A degree of age-segregation in living arrangements has been shown to produce positive results among older adults (Glass & Vander Platts, 2013; Moorman et al., 2017; Revell, 2018). Even Butler (1969a; 1975) makes the argument for giving older adults more choice in living arrangements as they age. However, a high degree of age-segregation has also been linked to negative outcomes such as increased ageism, social isolation, and loneliness (Gardiner et al., 2018; Gray & Worlledge, 2018; Sibley et al., 2016). Age-inclusivity has the potential to address the negative implications of age-segregation, including the mental health concerns among both the young and old, as well as address practical concerns such as housing costs and personal support.

#### Social Isolation and Loneliness

Though these concepts are often coupled together, social isolation and loneliness are not the same things and in fact have a weak relationship despite being conceptually related (Shankar et al., 2011). Loneliness is a subjective experience, a feeling, rooted in one's perception of the quality of their social relationships and general contact with people (de Jong Gierveld & Havens, 2004; Gardiner et al., 2018). The opposite of feeling lonely is feeling a sense of belonging (de Jong Gierveld & Havens, 2004). In contrast, social isolation is an "objective absence or paucity of contacts and interactions between a person and a social network" (Gardiner et al., 2018, p.148). When someone is socially isolated, they tend to have very few social relationships.

Both young adults and older adults are at a greater risk of becoming socially isolated and/or experiencing loneliness. In the UK, a study was conducted to evaluate the prevalence of loneliness in the general public (Victor & Yang, 2012). The researchers reported that participants under the age of 25 and over the age of 65 were most likely to report feeling lonely. Social engagement was found to be very important in protecting against loneliness, however, it manifested in different ways for the young and the old. For participants under the age of 25, the *quantity* of social relationships was more important whereas for participants over 65 the perceived *quality* of those relationships was more important (Victor & Yang, 2012). de Jong Gierveld and Havens (2004) would argue the young adults in this study were more at risk of becoming lonely when socially isolated. The older adults seemed to be more shielded from the effects of social isolation than young adults but still experienced loneliness if the few relationships they had were not meaningful. Regardless, both groups reported their experience as being lonely.

In a similar study from Norway, the same pattern of loneliness for young adults under 29 and older adults over 65 was shown (Nicolaisen & Thorsen, 2014). Similar to the UK study, these authors concluded that the quality of relationships trumped quantity for older adults and the reverse was true for young adults (Nicolaisen & Thorsen, 2014). Again, much like the UK study, these authors concluded that older adults over 65 were at the greatest risk for experiencing both loneliness and social isolation likely due to retirement, widowhood, chronic illnesses, loss of friends or close relationships, and shrinking social network (Nicolaisen & Thorsen, 2014; Victor & Yang, 2012).

Older adults encounter significant changes in lifestyle and relationships that are uncommon among younger age groups. For example, retirement is a significant transition for most people

and represents an adjustment to their place in society (Raman et al., 2012). The freedom from workplace obligations is often accompanied by a loss of comfortable, important relationships as well as the social interaction and engagement that accompanies a regular work routine (Raman et al., 2012). Older adults are also more likely to experience loss of relationships through death (Nicolaisen & Thorsen, 2014; Victor & Yang, 2012). Most older adults who live until late life will have already lost many, if not all, of their older family and friends. Slowly, they begin to lose their contemporary relationships as well. For many, the loss of a spouse is one of the worst experiences they will go through, contributing to loneliness in a significant way (Nicolaisen & Thorsen, 2014; Raman et al., 2012; Sibley et al., 2016; Victor & Yang, 2012).

In a profile on the state of social isolation in Canada (Keefe et al., 2006), low levels of education, urban living, chronic illnesses, and cultural expectations all contributed to an older adult's vulnerability to becoming socially isolated. In the case of chronic illness, it was declining functional capacity and frailty that impacted a person's ability to maintain involvement with programs and people they care about. This leads to fewer social interactions outside the home, usually translating to fewer social interactions overall (Nicolaisen & Thorsen, 2014). Additionally, there is a psychological component.

Falling is a major concern for older adults as it is the first critical step towards disability, dependency, and, ultimately, death (Hull et al., 2013). The fear of falling, whether a major fall has been experienced or not, is a significant factor in an older adult's experience with social isolation and loneliness (Hull et al., 2013). The fear of falling and other psychological factors act as constraints, preventing older adults from engaging in activities inside and outside the home. Interestingly, these psychological factors correlate with an increased risk of falling (Hull et al., 2013). Older adults who fall often sustain an injury that prevents them from attending social

engagements. Psychologically, when older adults experience a fall, their fears are validated and they will be less likely to participate in social engagements even after recovery (Hull et al., 2013).

Although the factors that contribute to a person's experience with loneliness and social isolation are numerous, I would suggest that age-segregation has amplified their effects. Each of the factors listed above (i.e., retirement, loss of loved ones, chronic illness and decreased functional capacity, a fear of falling) leads to a reduced social network. Not only are the quantity of relationships diminished but the quality ones are lost too. In the past, a close-knit, intergenerational community, such as the traditional idea of a rural village, may have helped to fill the void created by loss in later life. For the young adults who yearn to be well connected, age-inclusive communities would broaden the opportunity for multiple consistent relationships as well. However, it is not as simple as forcing the young and old to cohabitate. The nature of their relationship is just as important (Fox & Giles, 1993; North & Fiske, 2012; Sánchez et al., 2011).

## **Age-Segregated Housing**

Last year, Stats Canada published its analysis on what it is like to live alone in Canada (Tang et al., 2019). Along with the historical statistic that more Canadians were now over the age of 65 than under the age of 14, a second incredible point came out of the 2016 census data; one-person households were the most common living arrangement in the country (Tang et al., 2019). Over 4 million people lived alone in 2016, representing 14% of the population older than 14 years (Tang et al., 2019). Interestingly the distribution reflecting people who live alone in Canada shares the same U-shape that loneliness does, with nearly 20% of young adults living alone until they are 30 years old and 26% of people over 65 living alone (Tang et al., 2019). The percentage of Canadians living alone increases dramatically with chronological age after 55 years. Nearly half

of the young adults living solo found that the cost of living, particularly the cost of shelter, was too high accounting for more than 30% of their monthly income (Tang et al., 2019). Meanwhile, older adults (39%) were still occupying single detached homes after the loss of a spouse (Tang et al., 2019).

This report reveals fascinating information on the state of housing arrangements across the country. While young adults are living alone in small condo's they cannot afford, older adults are living in detached houses that are much too big to manage though they desire to 'age in place' (Tang et al., 2019). This report also makes clear the extent to which spatial age-segregation manifests in Canada. The old and the young are not overlapping by much in their living arrangements. Though the report does not draw any distinct conclusions regarding living alone and social isolation, it is interesting that the age groups most likely to live alone are also most likely to self-report feeling lonely.

As I discussed in the first chapter, age-segregated housing is not only a phenomenon in the community; it is also a Canadian institution. Institutionalizing people because of stigma, feelings of burden, or believing it to be the 'right course of action' is nothing new. In fact, Ontario is still reeling from the institutional and personal abuses that occurred in their regional centres for people with intellectual disabilities (Rossiter & Clarkson, 2013). Although the specific harms of the regional centers may be distinct from the on-goings of LTCHs and age-segregated housing generally, Goffman (1961) supplies us with the terminology that can be applied to both: total institutions.

Total institutions are designed to meet all needs for their residents in a single place, requiring nothing from outside the confines of the institution (Dupuis et al., 2005). Though a very convenient system in practical and administrative terms, total institutions inevitably lead to a

reduction in autonomy, restriction of available services, and fewer communal ties (Dupuis et al., 2005). As described earlier, these qualities are hallmarks of age-segregated housing.

Specific care practices, such as 24-hour nursing care, as well as goods and services directed towards older adults, may be required for a holistic approach to caring for older adults who do need those supports. Convenient and accessible locations for these supports are also necessary for age-inclusive designs. But if the system facilitates convenient physical care while creating inconvenient social care, it is not a truly holistic system. Lacking sufficient social care has a profound impact on the residents of these institutions, especially feelings of loneliness and social isolation.

# Life in Age-Segregated Housing

Transitioning to life in age-segregated housing, such as retirement homes and LTCHs, is viewed as both significant and inevitable for many older adults (Portacolone & Halpern, 2016). For some, moving to a retirement community is a positive change. Portacolone and Halpern (2016) stated that some older adults who moved into retirement communities were met with an expanded opportunity for making new friends. They were bound with a sense of togetherness and "being in the same boat" (p.843). Even though some of their participants described a sense of unity and solidarity, others found themselves isolated due to language barriers, distrust, and personal insecurities. One participant who loved to dance became isolated after having a stroke. He recounted that despite his desire to dance and his enjoyment in the community room, he was embarrassed by his reduced fine motor control. While leisure opportunities were present to facilitate camaraderie, and others could take advantage of this, his stroke formed a constraint that he felt was insurmountable.

The reality is older adults living in LTCHs, a nexus of institutional, spatial, and cultural agesegregation, are more likely to self-report being lonely or isolated than community-dwelling

older adults for a multitude of reasons (Gray & Worlledge, 2018). William Thomas introduced the Eden Alternative in the mid-90s, when he identified the three plagues of LTC: loneliness, helplessness, and boredom (Thomas, 1994). Yet in the intervening decades since, these plagues have remained a concern among older adults in LTCHs.

In a Norwegian study of 30 LTCHs, it was found that 56% of all residents identified as feeling lonely (Drageset et al., 2011). Notably, contact with care staff and friends outside of the LTCH did not help to alleviate these feelings (Drageset et al., 2011). In another study, feelings of loneliness were found to be more extreme when residents felt helpless or had a lack of autonomy in their everyday life (Andrew & Meeks, 2018). In this case, the biggest concern residents had about their autonomy was a lack of choice in their activities, schedule, and social interactions (Andrew & Meeks, 2018). Limited options in how their leisure time was spent led to feelings of helplessness, loneliness, and low life satisfaction. Ironically, individuals who choose to move into a retirement community, as opposed to people who are forced into them, are typically looking for neighbourly interactions and a close community (Gray & Worlledge, 2018), but that isn't always what they get.

In their analysis of loneliness and isolation in retirement housing, Gray and Worlledge (2018) found the most common approaches for mitigating perceptions of being alone are peer-topeer support programs, health promotion, supporting participation among the frail, outreach programs connected with schools or community initiatives, and teen volunteers within the retirement home. Increased autonomy and choice do not appear to make the list of interventions.

The situation is no different in Canada. In their study on Quality of Life (QoL) in Canadian LTCHs, Kehyayan and colleagues (2015) evaluated how well age-segregated housing was moving away from being institutions to person-directed homes. Using the interRAI Self-Report

Nursing Home Quality of Life Survey instrument, the authors found persons living in LTCHs were often very satisfied with privacy, safety, and respect from the staff. Even so, they felt their autonomy was not respected in the course of receiving care from staff (Kehyayan et al., 2015). The lowest scores were related to forming personal relationships with staff and neighbours, noting that only 39% of participants felt that the staff knew their stories (Kehyayan et al., 2015). Only 59% of participants felt that LTCHs were actually *homes* (Kehyayan et al., 2015), which is a chilling thought when you remember they will likely have to live in that space for the remainder of their life. As far as mental health was concerned, 1 in 4 participants showed signs of mild to severe depression and 23% showed signs of 'aggressive behaviour' towards others (Kehyayan et al., 2015). While 72% said they enjoyed mealtime, 44% said they rarely received their favourite foods and 51% could not eat whenever they wanted (Kehyayan et al., 2015).

These statistics paint a staggering image of the way older adults living in LTCHs view their experience. In particular, the low score of personal relationships cannot be ignored. Researchers have proposed the need for a social revolution that rejects superficial programming efforts in residential care, replacing it with much more meaningful engagement opportunities (Theurer et al., 2015). If care staff are unable to meet the social demands of residents, perhaps other residents would be better suited to fulfill the role.

The social revolution put forward centers on the development of social identities through peer support and social productivity (Theurer et al., 2015). Social identity is described as a way of seeing oneself in relation to the larger group with whom they associate (Theurer et al., 2015). Social productivity eliminates feelings of loneliness and enhances connectedness through reciprocal exchanges in relationships (Theurer et al., 2015). Said another way, to be socially productive means to build new, or enhance existing, connections through mutually beneficial

exchanges. Going to your neighbour for help builds a stronger sense of togetherness than receiving help from the powers-that-be in your neighbourhood. It also provides the opportunity for friendship (Theurer et al., 2015).

If a social revolution of this kind is effective at building a sense of connectedness between existing residents of age-segregated housing, how might it affect the relational gaps imposed by ageism when this approach is expanded intergenerationally? Can a social revolution that promotes socially productive relationships between generations effectively address ageism? I believe it could. I also believe this could be realized through age-inclusive housing more effectively than other intergenerational programs.

Despite the fractured foundation of the LTC system that COVID-19 and our response to it has exposed, LTCHs do not completely fail to meet the needs of their residents. To their credit, a certain minimum level of medical and personal care is required by law in Ontario (Roblin et al., 2019) and many more attempts have been made to push LTC settings out of the institutional model of care and to promote relational caring (Dupuis et al., 2016; Kehyayan et al., 2015; Mitchell et al., 2020; Rockwell, 2012; Theurer et al., 2015). That reality has not yet fully materialized, but I expect change is coming!

#### Stigmatizing Age-Segregated Housing

Stigma is linked to both age and age-segregated housing (Hagestad & Uhlenberg, 2005; North & Fiske, 2012; O'Dare et al., 2019; Smith et al., 2014). Goffman (1963) defined stigma as an "attribute that is deeply discrediting" (p.3). Stigmas tend to isolate people who possess these attributes from individuals who do not, through social rejection, institutional practices, and societal norms (O'Dare et al., 2019). Age itself has been stigmatized, with ageism and agesegregation following as products. As such, living in age-segregated housing is stigmatized by

nature of its purpose: to care for older adults experiencing functional decline and who need additional supports not readily available in the community.

In Portacolone and Halpern's study (2016), a participant described their reluctance to move into age-segregated housing because she associated the place with "disabled or elderly people" stating that it was "also a little depressing" (p.842). Despite being 81 years old herself, she just could not associate herself with 'those people', saying "I prefer to be with … younger and healthy people, you know... I have a tendency to get depressed when I'm with older people or people who are sick" (p.842). However, this participant also interpreted her own desires as selfish and that the right thing to do would be to move into age-segregated housing. This is just one example of how the stigma towards age manifests itself as stigma towards age-segregated housing.

Discourse can play a significant role in both creating and perpetuating stigma. An example of the current discourse related to age-segregated communities in literature is the concept of the ghetto. Referring to age-segregated communities of any type as a ghetto is a particularly popular choice (Butler, 1975; O'Dare et al., 2019; Portacolone & Halpern, 2016; Wild et al., 2018). In Portacolone and Halpern's case (2016), using 'ghetto' to refer to age-segregated housing was primarily coming out of the quotes from their participants, showing that the term was not only found throughout the literature but exists in the community as well.

Language with as contentious a history as the word ghetto evokes powerful imagery in our minds, based on the stories that we have heard, told, and lived. These images go on to form the basis for our new stories, further solidifying the idea that ghettos and age-segregated housing are one and the same. Eventually, the ideas of age-segregated housing and ghettos become

inextricably linked, institutionalizing the idea that these two spaces are the same, with real implications for both spaces.

Recent tragedies in Canadian LTCHs during the pandemic have further accentuated the stigma surrounding these places. As mentioned in the first chapter, recent media headlines include: "Military mission ending in most Ontario long-term care homes" (The Canadian Press, 2020), "Military deployed to another Ontario long-term care home ravaged by COVID-19" (Aguilar, 2020), and "Canadian forces leaving GTA long-term care homes" (CityNews Toronto, 2020). These types of headlines would normally apply to war-torn nations or international disaster relief efforts. They evoke terrifying images of death and destruction. And to a certain extent, this is all very true. Medical units from the Canadian military were called in to aid certain struggling Ontario and Quebec LTCHs.

Citing a report by the military personnel who tended to these homes, media outlets described the conditions of specific LTCHs as infested by bugs, abusive, negligent, and that residents would be "left crying for help for hours" (The Canadian Press, 2020). One story recounted how a resident had passed away from a "lack of nourishment", despite being free of the coronavirus (Aguilar, 2020). According to these news outlets, not only are LTCHs particularly susceptible to COVID-19, but you or your loved one may actually die due to neglect and the quality of the care available. These stories do not instill confidence in the broader system.

Despite the stigma, older adults often feel pressured to make the decision to move into agesegregated housing out of a sense of duty to their families or communities (Chen, 2015; Portacolone & Halpern, 2016). In the above example from Portacolone and Halpern's (2016) study, the participant felt it would be selfish not to move into age-segregated housing, despite the fact that she didn't want to move. Moving into age-segregated housing would be "proper

behaviour" (p.842). Other times they feel forced out of their homes because of how their neighbours, children, and landlords treat them (Portacolone & Halpern, 2016). Poor co-residence conditions or perceptions of those conditions in multigenerational homes often leave older adults feeling like it is time for them to go because they are a burden (Chen, 2015).

As mentioned, social discourse plays a role in contributing to the dominant ideas about LTC. I believe that discourse can play a significant role in reshaping ideas and eliminating stigma. To get there, we should understand a little more about what discourse is and how it relates to agesegregated housing.

# Dominant Discourse on Age-Segregated Housing

Discourse is a "complex web of both subtle and explicit communication providing information about a particular subject" (Rose, 2015, p.147). In this study, I understand discourse as a broad, ethereal conversation amongst members and institutions within a society, composed of the stories we hear, tell, and live. Some stories shared between members of society reach a state of saturation which privileges them over other stories. They become institutionalized and hegemonic (Crotty, 1998).

When stories become institutions, they form the lens that similar stories are experienced through. This cycle is what makes it seem natural to send older adults into LTC institutions despite that not being the case for thousands of years.

Media, such as newspapers and books, have previously been used to explore how older adults shape their social identities (Hubble & Tew, 2013). Today, thanks to widespread access to the internet, the sources of media we can potentially consume has exploded beyond books and newspapers. We now have access to more voices than ever before but that doesn't mean that all voices are necessarily heard or privileged.

Hubble and Tew (2013) agree with the founders of Britain by Mass-Observation (MO), a large social science organization in the UK, that opinions develop through two ways; a person's judgement when presented with 'the facts', and a person's reaction to the opinions of others. Quoting the founders of MO, the authors write:

"Few are so confident of their own judgement... as to be uninfluenced by knowing what other people are thinking. It is here that the newspaper plays an important role... [when they] state *their* version of the facts – they also state *their* version of the public opinion of the moment [emphasis included in original]" (p.12).

I would argue that online news platforms, social media, and internet culture fulfill the same 'important role' today as newspapers did at the founding of MO in 1937. As I explained earlier, these media sources have already begun to influence the existing stigma surrounding LTCHs.

Media has also perpetuated the idea that COVID-19 related deaths are caused by young adults. One outlet commented that "as the death toll escalates in coronavirus hot spots, evidence is growing that young people who work outside the home, or who surged into bars and restaurants... are infecting their more vulnerable elders" (Bernstein, 2020). Statements like this at the beginning of news articles allow the reader to draw a direct relationship between irresponsible young adults and the death of older adults, even though later sentences suggest that "people can become infected in a variety of ways" and "discussion of intergenerational transmission involves some speculation" (Bernstein, 2020). But that isn't the story being told.

One of their sources is a Facebook post in which a woman from Florida believes her stepson infected their family after spending time with friends while not wearing a mask (Bernstein, 2020). In this case, the discourse taking place on social media influenced the discourse in news

media and presented a story that did not align with the fact that it involved speculation and "research on household transmission is mixed" (Bernstein, 2020).

No matter how real or not, stories that are lived and told go on to shape future stories that are relived and retold (Clandinin & Connelly, 2000). In a personal example, while writing the proposal for this study, my maternal grandmother was placed onto a crisis list for a room in a LTCH, due to her physical condition. For some time she had difficultly living in her own home, even with family and community support. In the last two years, my mother has often tried to help her apply for a LTCH despite my grandmother's opposition to the idea. However, the prospect of actually moving was now terrifying to my parents since the LTCHs in her area were hit particularly hard by the coronavirus. Should they really send their own mother to a place described as neglectful and a war zone? Their stories of life in LTCHs have already been reshaped and retold by the dominant discourse presented in the media. How might the very prominent discourse of LTCHs be shaping the perceptions, understandings, and stories of younger people who might not have previously given LTCHs much thought?

## Young Adults and Age-Segregated Housing

At my current stage of life as a person in their late-20s, I can sometimes feel invincible. Generally speaking, I take care of myself physically and mentally while preparing for a future career. I think about the future but often envision myself looking and acting the same as I do now. There is a continuity to my imagined future self that ignores any physical changes or life events that come with the passing of time. In a way, I imagine myself to be immortal. Despite being actively engaged in gerontology and having several positive intergenerational relationships, my own mortality has little to do with my day-to-day life. I just don't think about getting older. If it wasn't for my specific interest in reimagining LTCHs, I might not think about my future with age-segregated housing at all. And I'm not alone.

Members of the Millennial and Gen Z generations are excited to retire and expect it to be a life of leisure, including hobbies, shopping, golfing, and travel while still holding negative views of being old (Anderson & Gettings, 2020). Anderson and Gettings (2020) suggest that for young adults today, ageing 'successfully' means not ageing at all. When asked to draw images of old age, the images presented typical stereotypes of an aged person without any consideration of place. But when asked about retirement, young adults often spoke about moving to warm places or buying a nice house (Anderson & Gettings, 2020). There was a complete lack of consideration that they may one day find themselves in a LTCH, while still acknowledging their concepts of old as frail and isolated.

In another study specifically asking Chinese Millennials about their intentions to use LTCHs later in life, they found the young adults were ambiguous in their response (Hsiao et al., 2018). The young adults neither agreed nor disagreed that they wished to live in a LTCH in later life. Their attitudes towards LTCHs were also neutral. Neutrality on the subject of LTCHs for Chinese young adults was significant as they were historically expected to take care of their aged parents themselves. Access to discourse regarding LTCHs from other cultures appeared to change that (Hsiao et al., 2018). This was contrasted with a US study in which college students were more likely to have a slightly negative view of LTCHs despite growing up with them as part of the social norm (French & Mosher-Ashley, 2000).

If we are to break the cycle of ageism and age-segregation, thus reducing the stigma associated with age, we need to rethink the institutions that are currently fulfilling support roles for older adults. One of the ways for reducing stigma towards age is intergenerational programs (Ballantyne et al., 1998; Cohen, 2014; Conway & Hodgman, 2008; Gray & Worlledge, 2018; Jarrott & Smith, 2011; Kuehne, 2003; Kuehne & Melville, 2014; Statham, 2009). In particular,

intergenerational programs that are guided by a contact theory should be considered for this purpose as they have strong potential for reducing stigma (Fox & Giles, 1993; Jarrott & Smith, 2011).

No intergenerational program will be successful in their own goals, nor in reducing stigma towards ageing generally, if they cannot get participants through the front door. What participants think about an intergenerational cohousing program will be influenced by how they process their experiences and stories with LTCHs before, during, and after taking part in such a program. Thus, exploring the dominant discourses that young people are engaging with today surrounding older adults and LTCHs helps to inform how intergenerational cohousing programs should unfold in the future.

#### Intergenerational Programs

Intergenerational programs are social initiatives that attempt to bridge the generation gap between the young and old. Programs of this nature arise for several reasons but are especially useful for addressing a need within the community (Gray & Worlledge, 2018; Kuehne, 2003) or improving social cohesion (Statham, 2009). Examples of such programs include childcare centres within LTCHs or adult day program centres (Jarrott & Smith, 2011), music and choir participation (Cohen, 2014; Conway & Hodgman, 2008), older adults volunteering in schools (Ballantyne et al., 1998; Dupuis, 2002), teens volunteering in retirement/LTC communities (Gray & Worlledge, 2018), and mentorship programs (Kuehne, 2003).

For older adults, intergenerational programs have become a source of personal reward and feelings of making positive contributions to the next generation (Dupuis, 2002). Intergenerational programs involving children were particularly successful for persons living with dementia (Galbraith et al., 2015). In their review, Galbraith and colleagues (2015) found that persons living with dementia were happier, much more engaged in their activities, and experienced an

improved sense of self when children were involved. Although many studies will often talk about how much young people have learned from their interactions with older adults (Dupuis, 2002; Gray & Worlledge, 2018; Kuehne, 2003), there is also evidence that young people can teach and influence older adults a considerable amount when the program supplies an opportunity to exchange information, skills, and experiences reciprocally (Ballantyne et al., 1998). For both young adults and children, the opportunity to work with and hear from older adults broke down some of their stereotypes about later life, noting that the older adults were quite fun to be around (Dupuis, 2002; Galbraith et al., 2015).

Initiatives that bring people together in typically segregated spaces sound like a great idea but a frequent criticism of such programs is their lack of theoretically grounded implementation or evaluation (Statham, 2009). Kuehne agrees but provides two decades worth of examples where intergenerational programs were based on or evaluated using theoretical and conceptual frameworks (Kuehne, 2003; Kuehne & Melville, 2014). Kuehne collected a list of 15 theoretical approaches in her first review of the literature and several more in her second review with Melville in the proceeding decade, which they found to be significantly more grounded in theory.

Some examples of theories that were found included: *social identity theory*, which examines how our identities are shaped in the context of a social group; *generativity*, which understands the role of older generations as nurturing the next generation; *activity theory*, which suggests that older adults are able to maximize their well-being, sense of self, and life satisfaction by shedding old roles and taking on new ones; and *intergenerational contact theory*, which relates intergenerational contact to intercultural exchanges and borrows from cross-cultural frameworks to build programs that are more effective at addressing social issues (Kuehne, 2003).

Kuehne's intention was to provide a list of available theories and concepts that researchers and programmers could draw on when developing and evaluating their intergenerational programs. However, she ends the second review with a call for theories that would dive narrower and deeper into the intergenerational relationships that formed.

While Hagestad and Uhlenberg (2005) describe a need for intergenerational interventions to go beyond the superficial one-offs of common programming, they also argue that it is the role of systematic longitudinal research to establish the best practices. Longitudinal research with the aim of understanding causal relationships between intergenerational experiences and ageist attitudes, beliefs, and behaviours, both implicit and explicit, is a necessary piece of the discussion. However, I would argue that it is not uniquely positioned for diving deeper into what makes an intergenerational experience meaningful for the participants, nor is it the only source for useful insight in developing effective future programs. On the contrary to Hagestad and Uhlenberg's point, Kuehne and Melville (2014) make the following call:

"A fourth theoretical path forward emanates from important observations about increasing mutuality in intergenerational programs, questions about the meaning of these mutual experiences for participants... theories typically applied to intergenerational practice do not provide adequate insight into the depths of relationships that may yield more profound, fundamental understanding of what each participant brings to an intergenerational program experience and why they do so" (p. 335).

As has been expressed, I initially intended to answer this call through a phenomenological study into the lived experiences of participants in an intergenerational cohousing program. This deep and narrow look at a few lives would have responded to the call for a new direction in program evaluation related to intergenerational programs. However, given the change in scope

for this study, that exploration will have to wait. This is truly a rich area of research for future scholars.

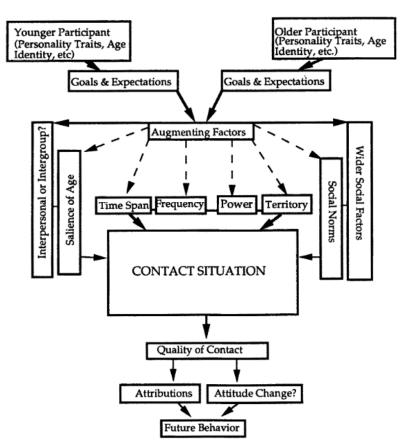
Among the initial set of theories discussed by Kuehne in her 2003 review are contact theory and the intergenerational contact model. It is my opinion that contact theory provides one of the most robust models for developing and implementing intergenerational programs while narrative inquiry provides an excellent conceptual and methodological framework for exploring the stories that surround them.

#### Intergenerational Contact Model

The intergenerational contact model was developed by Fox and Giles (1993) after being discouraged by their discovery that most studies of intergenerational contact lacked any theories of contact in their analysis. A contact theory is one in which the necessary conditions to produce a positive shift in attitude between two or more groups is prescribed (Fox & Giles, 1993). Fox and Giles built upon the existing intergroup contact perspective of Hewstone and Brown's model, developed several years prior. Hewstone and Brown posited that intergroup contact consists of the following elements: social factors of the two groups, the contact situation, factors affecting the contact situation, the perception of the contact as interpersonal vs. intergroup by participants, the two groups cognitive processes during the contact, and similarities or differences in their attitudes (Fox & Giles, 1993).

Fox and Giles began to unpack Hewstone and Brown's intergroup contact model as it would apply to intergenerational relationships. They found that when intergenerational contact was developed using Hewstone and Brown's model and involved getting to know someone on a personal level, attitudes towards the other person became positive but there was no change in attitudes towards the general group (Fox & Giles, 1993). A young person may describe their older friend very positively while still having a negative attitude towards older adults in general.

Proposing that intergenerational contact situations were similar to intercultural contact situations, Fox and Giles drew on the work of Bochner's typology of cross-cultural contact. In Bochner's contact model, the most important variables included: the location/territory, duration, purpose, type of involvement, frequency of contact, intimacy/social distance, status and power, and the proportions of people representing each group (Fox & Giles, 1993). With Bochner's variables added to Hewstone and Brown's framework for intergroup contact, Fox and Giles produced their own model for intergenerational contact.



*Figure 1: Intergenerational Contact Model (Fox & Giles, 1993, p.440)* 

In their model for intergenerational contact, Fox and Giles (1993) begin with the knowledge that each participant, young and old, enters into the contact situation with their own personalities, experiences, identities, goals, and expectations. These, along with wider social conditions and the

salience of age, form the background in which the contact takes place (Fox & Giles, 1993). Augmenting factors such as duration, frequency, power hierarchies, and territory will affect the contact situation in controllable ways and so can be adjusted to fit the goal of the contact experience (Fox & Giles, 1993). For example, contact that takes place in a retirement home (a traditionally 'old' territory) may result in a different contact situation than if it had taken place at a mall or a park, all other factors remaining the same. This is because a retirement home is typically situated as a space belonging to the old that the young are temporarily invited into. The theory posits the more neutral the location and power dynamics are, the more positive the experience will be for both groups (Fox & Giles, 1993). Intergenerational cohousing programs are one way that the issue of age-segregated 'territories' are being neutralized. The actual outcomes of the intergenerational contact are mediated by the communication processes that occur during contact.

Final judgement on the quality of the contact is passed by the participants based on whether or not their goals were attained, expectations were confirmed or denied, and the interaction's intimacy. Attitudes toward another generation may be adjusted if participants view their contact as involving a typical member of that different generation rather than a special case or a close friend (Fox & Giles, 1993). Put another way, although each participant in an intergenerational contact situation has their own unique qualities that distinguish them from the stereotypes of their generation, unless they are considered to be like a typical member of their generation, attitudes toward the entire generation broadly will remain unaffected.

This model does not end with the contact experience itself though. Fox and Giles (1993) apply communication accommodation theory (CAT) to discuss how communication styles and discourse that take place during contact are just as important as location, time span, frequency

and so on (Fox & Giles, 1993). I would posit that communication styles and discourse taking place outside of the contact experience are equally important.

In particular, Fox and Giles discuss how convergence and divergence in communication play a direct role in the outcomes of intergenerational contact. *Convergence* is conceptualized as "a strategy whereby individuals adapt to each other's communicative behaviours in terms of a wide range of linguistic/prosodic/non-vocal features" (Fox & Giles, 1993, p.442). These features could include the rate of speech, pauses, facial expressions, gazes, etc. *Divergence* is "the accentuation of these communicative differences between individuals" (Fox & Giles, 1993, p.442). Interlocutors who converge will begin to match their communication styles. Conversely, interlocutors who diverge will make the differences in their communication styles more pronounced. Intergenerational contact in which speakers attune their communication styles to one another will lead to more satisfaction and understanding between the generations than situations in which that does not happen (Fox & Giles, 1993). This contributes to an overall successful contact experience.

The intergenerational contact model has been promoted as a robust starting point from which to develop intergenerational programs that are effective at changing ageist attitudes between generations (Kuehne, 2003; Sánchez et al., 2011; Statham, 2009). Still, others have gone back to the roots of contact theory and tried to build new understandings of how it may impact intergenerational contact (Jarrott & Smith, 2011).

What is most fascinating to me is how similar Fox and Giles model for intergenerational contact is to that of organic contact which occurs within small communities or neighbourhoods. Communities and neighbourhoods exist within the confines of wider social conditions and the interactions that take place within them are still influenced by duration, frequency, hierarchies,

and territory. The salience of age remains ever-present in these 'natural' environments. Fox and Gile's model was developed to consider how 'manufactured' contact within programs might influence the attitudes of individuals in the dominant group towards individuals who may be marginalized because of negative discourse and stereotypes. An interesting puzzle for me is how might the intergenerational contact model play out in the context of intergenerational cohabitation, particularly in a LTCH, if that cohabitation became a natural experience?

Although they are still 'manufactured' programs, at least currently, systems of intergenerational cohousing that have begun to spring up around the world may be the closest controlled approximation we have to naturally age-inclusive communities, that is communities that have organically grown to be intergenerational. I would suggest that by examining such programs of intergenerational cohousing, we will learn how to encourage and support the natural growth of these communities beyond the confines of a program or institution. If spatial agesegregation has led to a cycle of ageism and more segregation, perhaps spatial age-inclusion will help to reverse the cycle. How young people perceive these settings will shape, in important ways, whether or not intergenerational cohousing is a real possibility post-pandemic. Whatever the case, more research needs to be done.

#### Intergenerational Cohousing

As we saw earlier, a significant proportion of Canadians live alone, either by choice or by circumstances. Most young adults who live alone say they have no intention of remaining that way forever and older adults are looking for ways to age in place after the loss of a loved one (Tang et al., 2019). Combine the rising cost of shelter expenses with a high risk of social isolation or loneliness among both groups and you'll find a looming crisis for the bookend generations. However, new and creative ways have begun to emerge to address both of these issues. Though it goes by several names such as co-residence or cohabitation (Sánchez et al.,

<sup>52</sup> 

2011), intergenerational cohousing refers to any program which matches up young adults, often university or college students, with older adults in symbiotic living arrangements. Three examples of this have begun to emerge including homesharing, university-based retirement communities (UBRC), and live-in students at retirement homes.

#### Homesharing

Homesharing is a form of cohousing in which a householder, often the owner of the home, provides free or low-cost accommodation to a homeseeker in exchange for support around the house (Homeshare International, n.d.-a). Although this mode of cohousing may have existed informally throughout much of the world before (Fox, 2010), professional homeshare organizations have been matching householders with homeseekers since 1972 (Homeshare International, n.d.-b). According to Homeshare International, a network of national-level homeshare associations, the first programs began in the USA before moving to the UK in the 1980s. Spain independently conceived of their homeshare program in 1991. Following their success, homeshare organizations took off, with national networks existing in Australia, Canada, France, Germany, Spain, the UK, and the USA. Most recently, Japan began to pilot their own Homeshare program in 2013. Often, these programs begin in response to student housing shortfalls (Homeshare International, n.d.-b). Interestingly, all of these countries are experiencing an ageing population, with the UK, France, Germany, and Japan all having greater than 17% of their populations over the age of 65 (Statistics Canada, 2019a).

Homesharing can be an experience as unique as the people participating in it. It most often takes the form of an older adult offering residence to a young adult or student in exchange for assistance or companionship (Allen, 2017; Fox, 2010; Howe, 1985; Sánchez et al., 2011; Suen, 2012; Ward, 2004). For older adults who wish to remain in their own homes, even with declining functional capacity, a homeshare is ideal for retaining their sense of independence and supporting

them to age in place. Occasionally, similar programs also support persons living with mental illness (Rhoades & McFarland, 1999) or physical and intellectual disabilities (Stevens, 2017). This economic exchange of services constructs the backbone of the experience and is the most cited justification for beginning such a project (Sánchez et al., 2011).

Sanchez and colleagues (2011) challenged economics as the sole justification for homesharing by investigating the relational outcomes of intergenerational co-residence. Using Silverstein and Bengtson's solidarity model, they investigated three dimensions of solidarity; associational (frequency of contact), affectual (intergroup sentiments), and functional (support given and received) (Sánchez et al., 2011). Sanchez and colleagues concluded that, regardless of how long participants were involved in homesharing, both older adults and students experienced significantly greater levels of intergroup contact, understanding, and improved relationships. This was significant because previous studies using the solidarity model had focused primarily on familial relationships (Sánchez et al., 2011). Non-familial intergenerational homesharing was shown to positively complement familial relationships since familial contact was often less frequent and over the phone, rather than face-to-face (Sánchez et al., 2011). In many cases, the student was either the first or second source of support to the householding older adult. This was the case regardless of whether the older adults were married or widowed (Sánchez et al., 2011).

The possible implications of an intergenerational homesharing program beyond economics are interesting and yet very little has been written on the subject (Altus & Mathews, 2000). Most literature points towards instructions on how to establish and maintain a homeshare program, based on the economic exchange, with little regard for relational outcomes.

However, that is beginning to change. Suen (2012) wrote about their own personal experience living in a homeshare. Suen found the program while looking for an affordable

housing solution in the UK during their Ph.D. Based on a thematic analysis of their journal reflections written during the stay, Suen arrives at a description of what their relationship was like with their host, including mutual emotional support (Suen, 2012). Though it represents a very brief insight into one person's lived experience of a homeshare program, it also begins to shape a new direction for exploring and evaluating such programs.

In Canada, studies have been conducted to explore the "phenomenon of home" in a homeshare focused around intellectual disability in Vancouver (Stevens, 2017) and to evaluate an intergenerational homeshare in St. John's based on participant experiences with ageing in place, social inclusion, and learning (Legge, 2014). In the study on homeshare for people living with intellectual disability (Stevens, 2017), one of the main themes that kept returning was the sense of safety, security, and belonging that was associated with the participants' sense of home. The participants in each household knew they were 'home' because of the comfort that living together brought them (Stevens, 2017).

In the case of intergenerational homesharing (Legge, 2014), the author found homeowners were more willing to leave their homes to attend social engagements because they were confident that issues related to their pets or homes could be handled by the homeshare partner living there. Interestingly, they did not attribute their social inclusion to engagement with the homeshare partner directly. Rather, because someone was always home, they could go out more (Legge, 2014). Homeowners also reported feeling less lonely because they could have conversations more often than before the homeshare partner moved in (Legge, 2014).

Homeshare programs are a rich source of new knowledge that should be explored. There is enormous potential for more work to be done on intergenerational relationships, social isolation

and inclusion, and the phenomena of place, being, time, and relationship in the context of a homeshare housing model.

#### University-Based Retirement Communities

The University-Based Retirement Community (UBRC) is another popular housing solution. A UBRC is a retirement community that develops with close connections to a post-secondary institution. The concept of a UBRC is not a new one; universities have been welcoming older adults through their doors for decades (Carle, 2006; Smith et al., 2014). In 2006, Carle set out five conditions that a UBRC must meet in order to be successful: (1) be located within a mile of the core campus amenities, (2) pursue formal integration between generations through programming, (3) include a full suite of services that older adults may need access to, (4) establish a clear financial relationship between the university and housing providers, and (5) ensure at least 10% of residents had some affiliation with the institution. These five conditions became the criteria by which UBRCs are planned and evaluated today (Smith et al., 2014).

In an early study on older adults' interest in moving onto university campuses (Ward et al., 2005), the authors found that people with more education, smaller households, and no local family showed more interest in living at a UBRC. Of those surveyed, 23% indicated they would be much more interested in living at a UBRC if it meant proximity to graduate student families (9% indicated this made them less interested) (Ward et al., 2005). The aspects of a UBRC that respondents looked forward to the most were cultural and age diversity, shared meals, mentoring and learning, and involvement with children (Ward et al., 2005). Already living near the university was one of the strongest predictors of interest, indicating that ageing in place was possibly still very important to survey respondents (Ward et al., 2005).

Despite the fact that many older adults would rather choose to age in place, research has shown that living in an a residential setting like UBRCs correlates with a boost in resident health

and well-being beyond that of their community-dwelling peers (Montepare et al., 2019). Many UBRCs fully embrace the Continuing Care Retirement Community model and offer residents options that include independent living, assisted living, and nursing accommodations (Smith et al., 2014). This is consistent with Carle's third criteria for successful UBRCs.

Although these sorts of programs have been gaining popularity across the United States for over thirty years (Smith et al., 2014), there is little in the way of evaluating them academically (Lewis, 2011). Even in the decade since Lewis's dissertation on university-linked retirement communities, little progress has been made in this academic space. As you will continue to see, alternative housing options for older adults need more exploration.

#### Live-In Students

Another form of intergenerational housing that is growing in popularity is the student live-in program. Popular examples of these programs exist in the Netherlands, the United States, and Canada (Jansen, 2015). These sorts of programs distinguish themselves from UBRCs and homesharing in that they welcome upper-year and graduate students to move into existing retirement homes in the community, rather than on university campuses or in private homes. These homes are explicitly designed for older adults in terms of services and amenities, which makes them different from community dwellings and university campuses. Many older adults move into retirement communities, by choice or not, with the expectation that they will be surrounded by people like themselves. The presence of students living in retirement homes likely creates a cognitive dissonance among the older adults living there. Unfortunately, there is very little in terms of literature that describes this experience for older adults. Similarly, research on the experience of young adults and staff members in these programs is almost nonexistent. At this time the current literature on this arrangement is limited to a student thesis (Allen, 2017), not unlike the present study.

Allen (2017) describes the most famous example of this living arrangement, Humanitas Retirement Home in Deventer, Netherlands. Humanitas offers independent and assisted living to older adults while also welcoming a handful of university students to live in their facility for free, in exchange for spending at least 30 hours per month 'being a good neighbour' and helping out with dinner on a weekly basis (Allen, 2017). Similar programs have begun to launch including a program entitled Musicians-in-Residence at Oakcrossing Retirement Living, a retirement community in London, Ontario. Here, three upper-year and/or graduate music students from the University of Western Ontario are provided with the opportunity to live in the facilities completely free in exchange for sharing their music with the other residents, participating in meals, and, once again, being a good neighbour (*Musician in Residence Program*, 2017).

Living arrangements such as this provide a fascinating new space for research to explore the meaning of intergenerational relationships in a space initially intended exclusively for older adults. Though not based on the intergenerational contact model from its inception, *doing life together* as neighbours on a regular basis provides an excellent example of the ideal model proposed for influencing intergroup attitudes. Exploring the lived experiences of participants in such a unique program has the potential for incredibly rich and important findings that have been largely untapped (Allen, 2017). Living arrangements between young adults and older adults may not be for everyone, however, if they are to be an option, we should seek to make them better.

## A Return to the Village

While taking a brief look at any list of age-segregated housing models, be it university dorms or older adult housing, you will find the word 'village' strewn throughout. At the University of Waterloo, nearly every residence on the main campus carries the title of 'village'. Within the City of Waterloo, you will find several older adult residences titled 'village'. The

most interesting point to note here is that none of these examples constitute a complete village. Though they may be presented to look like a traditional, European concept of the village and have all the amenities and events one would expect, or at least most of them, they tend to lack an aspect of community that adds to the vibrancy of village life, namely diversity of people across age.

If this new conceptualization of intergenerational cohousing is to be realized, how are we to get there in an ageist system that prefers to segregate? Healthy young adults having an opportunity to, and indeed choosing to, live in a retirement or care setting is definitely going against the dominant systems of the day. But with the recent tragedy of death and disease outbreaks across Canada's LTCH system during the global pandemic, will young people be willing to continue entering, let alone living in, those spaces? The question now has shifted from "What is this new system like for older and younger adults?" to "What do young people think this new system will be, or should be, like in the future?". It is truly a step backwards and yet perhaps it was necessary all along.

Stigma and negative discourse related to retirement homes and LTCHs are not new. Perhaps, and regrettably through tragedy, I have arrived at the question that should have been asked first all along. If intergenerational cohousing is to break the cycle of systemic ageism in Canada, how do we get people through the front door? This study aims to explore this question through the discourses on life and leisure in LTCHs that might be shaping young people's own stories of these settings and their place within them.

"Whenever you say something explicitly to anyone, you also say something else implicitly, namely, that you think you are the guy [sic] to say it."

 $\sim$ 

 $\sim$ 

(Alan Gregg, quoted in Crichton, 1970, p.xiii)

# **Chapter 3: Storied Lives**

In the beginning, I told you a story. It was only one story, a snapshot from one period in my life. One relationship. One point of view. Yet that story holds significant meaning for me and how I conceptualize the world and my place in it. No doubt my relationship with Lloyd sparked something within me that changed the course of my life. The story that I continue to tell myself and others about that relationship is what carries me forward when momentum is lacking. In fact, upon further reflection of this one story, several more stories surfaced which remind me of how I got to where I am, how I think the world is, and how I think it should be.

My story of friendship with Lloyd has a special meaning for me that is nearly as special as the friendship itself. If I had the opportunity to ask Lloyd today, he may construct different meanings from our friendship, from our story of friendship, and he would probably remember events differently than I do. His story might be very different. From the perspective of some, including myself years ago, the academic significance of such stories would be low. Stories might hold some anecdotal relevance or add a human touch to an otherwise impersonal study, but it wouldn't be considered a primary data point. After all, you can't generalize one person's story! But what if that wasn't the point?

Embedded within my story are multiple voices from characters and institutions, a sociocultural and historical backdrop, the genre of an unlikely friendship, and, I hope, your imagination allows you to walk the halls of the Lodge with Lloyd and me, joining in our friendship. That telling of the story is uniquely mine, but the story itself is not unique to me. Without exhausting the academic literature, you may be able to recall stories of intergenerational friendship in your own life or the lives of people you know. Recalling those stories allows you to respond to my story in ways that are personal to you, thus adding your voice to a growing

discourse of intergenerational friendship in our historical, cultural, and social context. With so much richness bubbling up from the stream of human experience as expressed through stories, a way to explore them further must be pursued.

#### **Enter Narrative Inquiry**

Narrative inquiry is a methodology that has been extensively described over the last three decades (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2019; Connelly & Clandinin, 1990; Riessman, 2008). In their landmark paper, Connelly and Clandinin (1990) pinned narrative inquiry on the concept that "humans are storytelling organisms who, individually and socially, lead storied lives" (p.2). The authors go on to make the case for using stories as a way to study human experiences in the world. Although they are slow to set specific rules or definitions for the boundaries of narrative inquiry, Connelly and Clandinin (1990) suggest that an important distinction exists between a story and a narrative: a story is a phenomenon, a lived experience, and the data source for inquiry; a narrative is a construction that inquirers give shape to by collecting and describing these stories. Geertz refers to this narrative construction as "lumbering, shaky, and badly formed; a grand contraption" (Clandinin & Connelly, 2000, p.6), on the basis that any narrative constructed is the result of the inquirer's interpretation which may be very different from another inquirer's interpretation. Interpretations from the same inquirer may also shift as the story is reread, retold, or relived as the case may be.

In their follow-up book, *Narrative Inquiry*, Clandinin and Connelly (2000) make a point about the variety and complexity in both theory and methods as they pertain to this type of study. In fact, the authors specifically mention that "although it may be interesting, we do not think it is very helpful to begin with a search in which we sort and place theoretical methods beside one another" (p.128). Immediately after this statement, they discourage blossoming narrative inquirers from worrying too much about building a robust argument for the methodology,

especially since narrative inquiry tends to skirt the boundaries of formalistic research processes (Clandinin & Connelly, 2000). For this reason, remaining true to the spirit of the methodology as set out by Clandinin and Connelly, this chapter will progress by descriptions of my methodological choices and the underpinning philosophy which guided each choice.

# **Philosophical Considerations**

My philosophy regarding narrative inquiry is largely based on the work of Clandinin and Connelly, who in turn base their philosophies on the work of John Dewey regarding human experience (Clandinin & Connelly, 2000). For Dewey, human experiences have two main attributes: they are temporal and relational (Clandinin & Connelly, 2000). The temporality, or continuity as Clandinin and Connelly prefer, is important because human experiences are never fixed in time. Every experience, every story, has a past that led to it and a future to which it leads. Experiences beget experiences (Clandinin & Connelly, 2000).

The continuous nature of human experiences makes me wonder how meaning can be ascribed to a single event in a single life without broader considerations of the continuum in which it sits. It is like saying light only comes in seven discreet colours (red, orange, yellow, green, blue, indigo, and violet) without consideration for the spectrum of colours that exist between them and beyond the spectrum of light visible to the human eye. Meaning must be constructed with continuity in mind.

Dewey also held that experience happens in relationships, either *personally* or *socially* (Clandinin & Connelly, 2000). While each person is in fact an individual and it is helpful to understand them as such, they are also part of a community. Each individual is intricately woven into their social context which further shapes and forms them, and their stories, across time. The interaction is reciprocal as the individual shapes and forms their social context too. Relationships with people, institutions, and stories, among other things, contribute to this weave. Returning to

the metaphor of light, it has a dual nature that continues to perplex physicists. In many instances, it is helpful to understand light as a particle with mass, a photon. In others, it is more useful to understand it as a wave of energy without any mass at all. Even so, neither expression of light is considered complete without the other. Similarly, human experience exists as a duality between the personal and social, two concepts which appear to be incongruent and yet are necessary to understand the whole.

Recognizing the continual and contextual attributes of human experience, Clandinin and Connelly (2000) devised a three-dimensional approach to narrative inquiry. In their threedimensional approach, one must consider *interactions, continuity*, and *situations*. *Interactions* include the personal and social dimension of a human experience, where the personal directs you to consider feelings, hopes, and reactions while the social directs you to consider the larger relational context in which experience happens or a story is told (Clandinin & Connelly, 2000). *Continuity* includes the past, present, and future of the experience (Clandinin & Connelly, 2000). Where did it come from and where is it going? In my understanding, rather than drawing causal links between experiences, continuity deals more with the interconnections and implications of those temporal experiences. Finally, *situation* includes the "concrete physical and topological boundaries of inquiry landscapes" (Clandinin & Connelly, 2000, p.51). Situation asks where an experience takes place or a story is told and what role the space has in shaping it.

The three-dimensional approach to narrative inquiry reminds me as an inquirer to not ignore the context in which stories exist, at the interactional, continual, and situational level. The intergenerational contact model also reminds me that context plays a significant role in how the intergenerational contact is experienced, both the immediate context of the interaction (time

span, frequency, etc.) and the wider social conditions that surround it. As I worked through this study, I made sure to keep context at the forefront during interviews and analysis.

## My Role as a Narrative Inquirer

One more philosophical consideration is my role as a narrative inquirer in this study. Clandinin (2016) talks about the relational position of an inquirer alongside their participants. At one point she writes that "narrative inquiry is people in relation studying people in relation" (Clandinin, 2016, p.23). By this, she means that each of us, both inquirer and participant, are recognized as people who exist in relationship with the world, time, people, institutions, language, culture, and so the list goes (Clandinin, 2016). Inquirer and participant also enter into a new relationship with each other. We become a part of each other's stories and the stories that we tell each other exist because of our relationship. In many of Clandinin's example studies, the narrative inquiry proceeds by entering into a specific, geographical place where people live and work. She becomes a student, a teacher, a co-worker, and a friend (Clandinin, 2016; Clandinin & Connelly, 2000).

In the case of my research, I did not come alongside my participants in the same specific sense of place as Clandinin had suggested. However, I did enter into the inquiry as a university student who is living in the same broad sociocultural, historical, and health-related experience as my participants. I recognize this to be an enormous assumption. Do not confuse it by thinking I believe my participants and I have all experienced the COVID-19 pandemic, intergenerational relationships, or media consumption in identical ways. But our experiences are intertwined in that we are all going through this pandemic together in a time when discourse represented through news and social media make up a significant part of how we make sense of our experiences and our identities at this moment. In this way, I have positioned myself in relationship with the participants.

Through narrative interviews, described in-depth later in this chapter, stories were shared and constructed between myself and participants, together. I recognize that in the research process, participants may have initially viewed our relationship in the traditional researcher-toresearched paradigm. I intended to address this relationship by using narrative interviews that followed a much more conversational approach with turn-taking, meandering between topics, and insertion of my own voice. Although this method risks creating a lengthy interview that does not entirely address the substantive topic of the research (and in some cases, that was exactly what happened), following the conversational path redistributes power in our research relationship (Riessman, 2008). No longer am I set above the research participant, drawing information out of them like a pail of water from a well. That said, I used an interview guide to help direct the conversation towards the topic of LTCHs (see Appendix G), effectively retaining some degree of authority over the process. However, I believe that using a conversational approach brought us closer to an equal status. Rich and genuine stories can be told more easily when the barriers of a power-relation are dismantled (Riessman, 2008).

Furthermore, I did not walk away from this research experience unchanged. Clandinin (2016) says that participants and inquirers "meet in the midst... and leave in the midst" (p.51) of our lives and participating in the inquiry space will have an effect on who we are. For myself, at least, this is exactly what happened.

It is easy, especially while conducting a literature review during stay-at-home orders, to get stuck inside one's own head. For me, reading about LTCHs, the history of the literature on ageism, and all the while hearing about the atrocities and deaths inside of Ontario LTCHs, it was easy to become hopeless, angry, and maybe a little cynical. However, listening to the stories that other young adults participating in this study had to share about their loved ones at home and in

LTCHs, as well as those who worked in LTCHs before and during the pandemic, it refreshed my own ideas of what life and leisure could be like for older adults living in LTCHs. Definitely, you will see in my discussion of the discourses interpreted from this work that there are multiple stories of abuse, loneliness, loss, and anxiety about growing older. There were also stories of hope, strong and beautiful relationships, laughter, and looking forward. The stories reflect the complexity of experiences. My own stories of life and leisure in LTCHs now include excerpts from the ones shared with me. And I am reminded of the moments and conversations at LTCHs I have had in the past that sounded similar to those expressed by the study participants. If nothing else comes of this research, the discourses that I engage in now have been significantly influenced by the conversations that were had. These will continue to influence me going forward.

## Five Commitments in Narrative Inquiry

Narrative inquiry, especially approaches which focus on stories as dialogue, exists in a tension between talking *about* a study participant and talking *with* them (Frank, 2012). While analysis often tries to pull some finding out of the process to arrive at a conclusion about the substantive topic, in the approach I've chosen, concrete findings are less important than the conversation that is constructed from the process. To ensure that I respected the storytellers and the story's they tell, I aligned myself with Frank's (2012) five commitments for narrative inquirers:

First, I "recognize that any individual voice is actually a dialogue between voices" (Frank, 2012, p.34). Although my own voice has been, and will continue to be, present throughout the research process, helping to co-construct meaning along the way, I also recognize that there is a plurality of voices in both my voice and that of the participants. Frank (2012) describes these voices as being polyphonic and heteroglossic. Polyphony refers to the people who storytellers

bring in or anticipate responding to through their stories (Frank, 2012). This might be friends, family, professionals, or people with whom they identify. Heteroglossia refers to the language codes or genres that are selected to help tell the story (Frank, 2012). Jargon, emotional expressions, and deciding whether a situation should be humorous, sad, exciting, or scary are all part of heteroglossia. The codes of language and genre used will often reflect the voice of some general "speech community" that the storyteller associates with rather than a concrete person (Frank, 2012).

Second, I have avoided constructing a monologue of meaning from the stories that I collected. Each story that I was told, and now retell in this work, will be brought together to form a dialogue that has not necessarily, but could have, taken place in person between participants (Frank, 2012). I am a witness and participant in this dialogue, helping to give it shape, and acknowledging that I do not have a final say on its form, but rather that position is taken up by you, the reader.

Third, I recognize that stories exist in a symbiotic relationship with people; each is independent yet required to sustain the other (Frank, 2012). The author describes this relationship by saying that "stories need humans in order to be told, and humans need stories in order to represent experiences that remain inchoate until they can be given narrative form" (Frank, p.36). As I expressed at the beginning, a story told by me is uniquely mine, yet every part of the story is borrowed from an existing library of narrative components such as plots, genres, characters, settings, language codes, and so on. Any participant may have shared similar stories to that of other participants by using the same components, but they are still uniquely theirs because of the experience they are relating through the story. In this way, the story components exist independent of us but require our experiences to exist at all.

Fourth, stories of life and leisure that were collected through this study are understood as still under construction. Participants and their stories should not be construed as fixed or completed during the interview and analysis process (Frank, 2012). A specific experience may have been initially lived at a fixed time and location but the story and person are not "finalized" yet (Frank, 2012). Since the person and their story are not yet in a finalized state, the finer details of analysis should focus on the narrative components that I listed earlier (i.e., characters, genres, plots, etc.) since these exist in much more concrete and depersonalized ways.

Finally, representation of this research has not culminated in a list of findings but rather an expression of conversation that demands a response from the reader (Frank, 2012). Although I am exploring the research puzzles listed in the first chapter and hope that new insights on them will make a difference, the final authority on this work does not rest with me. It is an invitation for you, the reader, to join a dialogue that did not necessarily exist before inquiring and should not end with the conclusion of this work. To these five positions, I was committed as I explored the ways young adults story life and leisure in LTC settings in Canada.

## **Narrative Methods**

One aspect of this research that makes it particularly unique from other types of narrative inquiry is that I am asking participants to imagine stories as well as remember them. Participants were asked to draw on past experiences with older adults, LTCHs, and the stories they have heard about them in order to construct an imagined future story about what life and leisure in LTCHs could look like, and whether or not they can see themselves in those stories. To arrive at this imagined story, I conducted hour-long recorded narrative interviews to generate conversations between myself and the participants. Following interviews, recordings were transcribed for dialogical narrative analysis, identification of discourses at play, and representation through narrative futures.

#### Participant Recruitment and Selection

Participant recruitment took the form of advertisements through undergraduate courses at the University of Waterloo (UW) during the Winter 2021 term. Currently, the only live-in student program at a Canadian retirement home takes upper year and graduate students from a university music program. For my research, I intended to target the broad range of student's who would potentially qualify for such a program, regardless of their academic fields or level of university education.

I began by contacting instructors at UW to ask if they would be willing to post an advertisement through their online teaching platform (Desire2Learn) since this was the only direct-access avenue to students that existed while the university weathered the pandemic (see Appendix A). Advertisements included a video message from myself (see transcript provided in Appendix B), as well as a traditional research poster (see Appendix C). Interested students were asked to contact me directly via email and those who did received an information letter outlining the details of the study (see Appendix D) and a consent form they were asked to sign and return if they agreed to participate in the research (see Appendix E). I used convenience sampling through programs related to recreation and leisure, as well as aging, since this is the population of university students I had easiest access to and, as far as I knew, their experiences with older adults and LTCHs would be as diverse as any other randomly selected group of people.

Sample size is a tricky thing to determine in qualitative research because 'validity' of the research is not determined by how many participants are in your study, as is often the case with quantitative work (Patton, 2002). Some narrative inquiry studies have used between four and ten participants (Ho, 2010; Johnstone, 2017), while others are determined by the number of people they engage with through ethnographic practices (Clandinin & Connelly, 2000). In some cases, such as in the use of autoethnography, the only participant is the researcher themself (Clandinin

& Connelly, 2000). Patton (2002) recommends starting with a small target size and increasing it as necessary until the researcher feels that a sufficient number of stories have been collected. In the method of narrative inquiry I have chosen, the unit of analysis is stories rather than people (Riessman, 2008) and so recruiting more participants is really dependant on the number of stories I collected. For the purposes of my study, I sought out a minimum of six individuals, which was successfully attained.

## Participants

Six participants reached out to participate in this study; Betty, Olive, Phoenix, Millie, Kat, and Kelly. Of those six, Betty, Olive, and Millie had previously worked in some capacity in a LTC setting, in both fulltime co-op and part-time positions. All six participants were undergraduate students at varying stages in their degree completion and had visited a family member in a LTCH at some point, except for Millie who was currently working part-time at a LCTH's front desk. Interestingly, Phoenix, the oldest participant in his mid-thirties, was working on his third undergraduate degree while also working in supportive housing for people living with addictions and mental illness. All participants were studying therapeutic recreation, despite best efforts to reach out to courses that included students from multiple disciplines. In terms of culture, two identified themselves as Chinese, one as Portuguese, one as Mennonite, and one as Italian with a mix of several other European groups. One did not associate themselves with any cultural identity through the course of the interview.

# Narrative Interviews

Although authors regularly state that ethnographic approaches are preferred in narrative inquiry (Clandinin & Connelly, 2000; Riessman, 2008), the interview still holds its place as a suitable technique for elucidating human experience through stories. Riessman (2008) describes the narrative interview as a departure from the structured and semi-structured interviews

common to social science. These unstructured, conversational interviews may contain generative questions or artifacts to spark the conversation within the realm of the substantive topic, but the inquirer should limit the power of their position to guide the conversation, especially if it seems to be tracking away from the initial discussion (Riessman, 2008). The inquirer must share power with the storyteller by becoming an active participant in the conversation instead of its director. One story may lead to another and the inquirer should not dismiss these as digressions but instead follow their trails (Riessman, 2008).

Participants should have the opportunity to speak for as long as needed to tell their stories, even if it is longer than normal for day-to-day speak or traditional interviews (Riessman, 2008). Generative questions were used in addition to probes that encouraged the storyteller to share more. For example, I asked participants if they have ever been to a LTCH and to describe what the experience was like. As necessary, I probed further with follow-up questions such as: why were you there; who did you see; why does this story stand out; etc. To gain a better understanding of the voices at work in their stories, I asked about stories they had heard and where they had heard them, especially if they had never engaged with LTCH settings before. Questions were open, brief, and allowed the storyteller to express their story in whatever way they found meaningful (Riessman, 2008). At times, I interjected with my own stories and experiences as they became relevant, lending to the conversational nature of the interview. In one case, the participant frequently circled back to a story I shared about my grandmother's experience living in a LTCH in order to develop their own thoughts and discuss their own story. The unpredictability of a conversational format makes it difficult to consider all possible probes and lines of questioning but the guide I used can be found in Appendix G.

# Narrative Futuring

At the end of our conversations, I asked participants to imagine what it would be like for them to live in a LTCH. This process of storying imagined experiences comes from narrative psychology which recognizes storytelling as necessary for human thought, action, identity, and meaning (Sools & Mooren, 2012). Futuring is the act of imagining the future through storytelling (Sools & Mooren, 2012). The human capacity to imagine their future self is a key assumption to several psychological theories including generativity and Maslow's hierarchy, just to name a few (Sools & Mooren, 2012). Anticipating the future is also a key component in Clandinin and Connelly's three dimensional approach to narrative inquiry (Clandinin & Connelly, 2000). Continuity implies that every story has a past, a present, and a future. As Frank (2012) reminds us, stories are unfinalized constructs that will continue to be reshaped with every retelling and every anticipation of a new audience. This anticipation of the future is also a way of constructing new stories (Sools & Mooren, 2012).

In Sools' and Mooren's (2012) work, they looked at the process of futuring through letter writing. Participants were asked to write letters to themselves *from* their future selves (in contrast to common letter writing practices which direct letters *to* our future selves). This practice of letter writing from your future self forces you to imagine what the future will be like and focuses attention on what you think is important to know about it. The authors used futuring to study how it might build resilience to future challenges or traumas (Sools & Mooren, 2012).

In the course of talking with study participants, I began by asking open questions about their history with LTCHs, eventually moving to a final question about their future experiences with LTCHs. Specifically, I asked them to imagine they were living at a LTCH in the near future, during their academic studies, and describe what a day in the life would be like. Could student's actually see themselves in that kind of future and what role would they give themselves in it?

Due to the ongoing nature of the COVID-19 pandemic, interviews were conducted remotely via an online video chat software (Cisco WebEx) and audio-recorded for transcription. Following each interview, I sent participants a letter of appreciation, thanking them for the time they spent with me and the stories shared (see Appendix F). Transcriptions were recorded verbatim at first and then reorganized into discrete stories for each participant. For example, if a participant told a story about visiting their loved one in a LTCH but included various details at different points within the interview, those details were then moved next to each other to create complete stories. Narrative futures were left intact without any reorganizing and have been included in Appendix H of this thesis.

## **Dialogical Narrative Analysis**

Analysis of the stories was conducted using dialogical narrative analysis (DNA). DNA is an approach to exploring stories of lived experiences that recognizes the plurality of voices, or dialogue, that may exist within a single story told by a single storyteller (Frank, 2012). As Frank puts it, "stories are always told within dialogues: storytelling responds to others – whether actually present or imagined – and anticipates future responses, including the retelling of the story, with variations" (p.33). In this view, the purpose of the analysis does not restrict itself to a summary of findings, as if to end the conversation then and there, but rather it broadens the horizon of stories that are available to be heard and encourages response from the reader (Frank, 2012). It is as if the individual stories laid out by the storytellers converge into a dialogue among themselves and invite the reader to be part of the conversation.

This polyphonic concept of stories comes from the work of Bakhtin (Frank, 2012; Riessman, 2008). Forms and meanings found within stories arise as a result of some dialogue between the storyteller and their context (Riessman, 2008). Their socio-cultural and historical background, as well as both the real and imagined audiences of their story, create a context in which the story

can take shape and give meaning (Riessman, 2008). Using a DNA approach, "the [inquirer] can interrogate particular words, listen to voices of minor characters, [and] identify hidden discourses speakers take for granted..." (Riessman, 2008, p.107). All of this is possible because the story does not belong solely to the storyteller. Each narrative component is borrowed from somewhere and carries with it a previously agreed upon meaning which makes it useful in expressing the storyteller's experience. Of particular interest to me is the "hidden discourses speakers take for granted".

Based on the work of authors mentioned previously (i.e., Clandinin & Connelly, 2000; Frank, 2012; Riessman, 2008), I developed a line of questioning to explore the discourses and dialogue that I expected to emerge from my conversations with participants. In my analysis, I looked at the narrative components storytellers used to shape their stories and frame the discourses with which they engaged.

## Narrative Components

Stories require several components to be considered as such. For example, Labov's template, often used in structural analysis, considers a story to be full or complete when it contains an abstract, orientating details, complicating actions, evaluation, resolution, and a coda (Frank, 2012; Riessman, 2008). The simplest story consists of only a complicating action and a resolution (Riessman, 2008). While this is useful for identifying whether or not what was communicated should be considered a story, it is not as complete as Labov would suggest (Frank, 2012). A story also requires components such as characters, plotlines, genres, points of view, settings, and an audience (Frank, 2012; Riessman, 2008). I suggest that *characters, audiences, plotlines,* and *settings* are most interesting and useful for elucidating the discourses at play in student's stories. Each of these narrative components relates to the three-dimensional narrative inquiry space that I laid out earlier: characters and audience relate to the interactional

dimension; plotlines relate to the continual dimension; and settings relate to the situational dimension.

*Characters* represent the voices which contribute to the dialogue in the story. Characters may include specific people known to the storyteller, groups of people characterized with a unified voice (e.g., professionals in a field), institutions anthropomorphized, the storytellers themselves, or other such constructs. Before I conducted my interviews, I imagined that participants might draw on what they knew from media sources or family members. By analyzing the character archetypes that storytellers used to identify the voices in their story, I could begin to explore how they framed the discourses those voices represent. Was an institution represented as wise, intelligent, or authoritative? Was authority construed as a positive or negative characteristic? Were some voices given privileged positions or greater airtime while others receive lesser positions or are forsaken entirely? What character type did the storyteller choose to represent their own voice? Narrator? Hero? Bystander?

*Audiences* represent the body to which a story is directed by the storyteller. A story's audience will significantly affect the way it is told. Consider a story where the primary complicating action involves the storyteller driving 130 km/h down the freeway. The manner in which they explain this story to the police officer who pulls them over may be very different from how they explain it to a group of peers who enjoy the thrill of driving fast. Audiences can be imagined as well (Riessman, 2008). A story can often be told to multiple audiences, revised and adjusted with each retelling as a sort of response to how an audience interacted with a previous telling. The current iteration of a story might be presented anew to the current audience, such as when telling it to me as a researcher during an interview, while simultaneously representing a response to the previous audience (Riessman, 2008).

As I listened to the stories that people my own age shared regarding their experiences in LTCH settings and how they imagined life and leisure to play out in those spaces, I listened for the other voices which contributed to their stories. These voices could consist of characters within the story as well as previous audiences for whom the story had been adjusted. This interplay of representing one's self, representing others, and responding to audiences is part of the *interactional* dimension described earlier. Both the personal and social aspects of discourse rise to the surface when looking at the voices within a story. Furthermore, the stories I heard and told through the narrative interviews were similarly affected by the interview interaction itself. In one interview, I shared a story about scissors being confiscated from my grandmother that I did not share in other interviews. It was a response to the conversation and my understanding of her experience was reshaped by the response of the interview participant 'audience'. The process of sharing stories with each other requires a retelling for a new audience.

This narrative component proved to be the most difficult one to elucidate from the stories and so it is not relied on or discussed as heavily throughout the rest of the work. Future research might reconsider the value of including this narrative component or how they will specifically seek it out if it is to be included.

*Plotlines* take into account the progression of a story. The order of events (or scenes), repetition, and tenses are all components of the plotline that have the potential to carry meaning. For example, repeated lines or themes tend to signify an important point to the story (Riessman, 2008). Shifting between past, present, and future tenses guide the listener on the same journey that the storyteller is taking, showing where they have been, where they find themselves now, and where they expect to go (Riessman, 2008).

The plotlines of stories are strung together with scenes that the storyteller believes are important for sharing (Maple & Edwards, 2014). Sometimes storytellers will specifically leave scenes out because of unsettling emotions attached to them or because they believe it to be irrelevant to the conversation (Maple & Edwards, 2009). The order of the scenes is not always linear; a storyteller might begin at one point, take you further back in time to explain something else, pop briefly into the present to share some insight, then dive back in or even move into a future scene (Riessman, 2008). Each participant was asked to share or imagine stories about similar experiences and they each chose to compose their stories according to plotlines that converged at times and diverged at others. How participants chose to construct their plotlines indicates what moments they think are important, what they expect for the future, and how they position themselves in all of it. This recognizes the continuity of both the story they tell and their identity in it.

Settings represent the spaces in which stories are lived and told. Setting the stage for your audience grabs their imagination and focuses their attention on the features of the story you think are important. When participants shared stories about their experiences with older adults, in LTCHs, and imagined living there, what settings did their stories focus on? Does the story mainly take place in private apartments, common spaces, dining areas, outside the home, or within the community? Which spaces were important to describe and which were not for the listener to fully grasp what the storyteller was trying to convey? As the storyteller guided a tour of the imagined space within their mind, what features did they point out? Or did they set the stage much at all? What spaces were left out, missing?

Exploring the settings that student's select for framing their stories relates to the *situational* dimension discussed earlier. How does situating their stories in the dining room of the LTCH

shape the meaning of the story versus situating it in the common rooms or outside on a bench? How might where they situate their stories express the boundaries (or possibilities) they expected older adults to encounter. Situation also covers the context of the narrative interview, in this case online over a video chat. How did sharing stories across this digital medium, as a conversational research interview, shape the stories that were told?

Taken together, the characters, audiences, plotlines, and settings for each story provided more clues to explore the discourses students are engaged in on the topic of life and leisure in LTCHs. The voices they chose to represent, and the characteristics of those voices, says a lot about the sources of information students value. The way the stories were structured along their plotlines draws attention to the significant ideas and concepts that students draw on when conceptualizing life in LTCHs. Finally, the settings in which the stories were framed speak to the boundaries that students believe exist in the experience of life and leisure in LTCHs. All of this taken together can be used to construct an idea of the overarching discourse, or multiple discourses, that students are currently engaged in.

As I mentioned earlier in this chapter, the point is not to arrive at certain findings but to establish a dialogue that demands response from the reader and remains open to reinterpretation. However, to arrive at a place where a coherent dialogue can be synthesized, I agree with Frank (2012) that constructing a provisional typology of discourse from the analysis of narrative components is a necessary step towards that dialogue.

## Typology of Discourse

Although the final representation of this work should be a dialogue that is not yet finished and demands a response from the reader, one approach to DNA recommends that analysis should involve a typology of stories based on the narrative components (Frank, 2012). Creating typologies of stories, or discourses in my case, maintains the storyteller's state of being

'unfinalized'. The storyteller can continue to grow and shift how they present their identities and stories, while the narrative components they used are left for analysis (Frank, 2012). However, I recognize as well that typologies are not without their dangers (Frank, 2012).

A term like typology carries with it connotations that are 'finalizable' and 'categorical'. At first glance, using typologies as a form of representation flies in the face of how I have positioned myself and this research project. However, it is not, in fact, the representation but rather another step in analysis. Crafting a typology of the discourses that emerged from participant stories is a way of acknowledging the broader social conditions in which the stories take place. Rather than looking at each participant's story as representative of them personally, DNA focuses on the social dialogue that contributes to the shape and form of those stories. By grouping certain voices, audiences, plotlines, and settings into types of discourse, it makes a tangible starting point from which to explore the conversations going on between and beyond the stories within society. I am not creating "descriptions of personalities or dispositional structures" (Frank, 2012, p.47) that will trap people in boxes, finalizing them in my work and shutting the door on further conversation. These are not final, nor absolute, types from which to make administrative decisions or to classify certain people as belonging to certain discourses. I'll admit there is the risk that results of this research could be used as such, but it shouldn't preclude me from using this method of analysis (Frank, 2012).

People tell stories using the narrative components to which they have access (Frank, 2012). A person will not use a metaphor, genre, character type, or trope with which they are unfamiliar or that they do not believe fits their story (Frank, 2012). For example, at the beginning of this thesis, I used the metaphor of shipbuilding. I did not invent the metaphor although I shaped it to meet my needs. I am probably not the only person to ever discuss writing as an act of creation or

a journey. At some forgotten time in my life, I learned 'the journey' was an appropriate way to talk about my way of going through life. Someone else might not use 'the journey' to describe their life and work but perhaps will describe it as 'finding/creating one's self', 'a climb', 'a wisp in the wind', or something else entirely. Exploring narrative components in this way helps inquirers to see what components people choose and prompts questions about what constrains access to some but not others (Frank, 2012). It allows for broader questions about the way stories are constructed across cultures (Riessman, 2008) and, I believe, generations as well.

## Constructing a Typology

To construct this typology of discourse, I followed Kluge's (2000) method for empirically grounded type construction. Kluge goes through four stages to construct a typology: (1) developing relevant dimensions, (2) grouping cases, (3) type construction, and (4) characterisation of types. Consistent with the recursive nature of this work, Kluge encourages researchers to cycle between stages (1) through (3) to find the best dimensions for construction. For this study, I used the narrative components of voice, audience, plotline, and setting as my relevant dimensions and the actual identities or characteristics under each narrative component was interpreted inductively from the stories that were shared. Thus, identifying new voices, audiences, plotlines, and settings was a recursive and inductive process guided by stages (1), (2), and (3).

Stage (1) involved developing the relevant dimensions for the typology. As, stated above, the voices, audiences, plotlines, and settings were drawn from the stories through several readings of the transcripts. As I was able to identify these components, they were recorded for quick reference. Below is an example of how that looked for one excerpt from Betty's interview:

Well as I said before, one of my grandmas, in the last couple years of her life, she got switched between a couple different long-term care homes. I was only like 12 at the time so it was kind of this scary, weird experience of 'oh, like, grandma's not living in her

house anymore.' And we'll go visit her at this one long-term care home. But now she's changed to a different one so then we visit her at that one... Seeing her in her final long-term care home, I saw the one that she sticked with... I saw it really positively in a sense. It had a much better vibe and everything... I think a huge piece of it was that she was more comfortable there. Because I remember my dad just talking about how, at the last home, she was super distraught, and like, you could equate that to her dementia diagnosis or anything like that.

Orange indicates the characters in the story, with her dad and the dementia diagnosis both representing characters with a voice, while her grandma is a character without a voice. 12-yearold Betty plays both the role of a character with a voice and an audience member or observer to the events of the story. Red indicates the settings or qualities of the settings that were used to set up the story. Green indicates the significant moments and movements in the story's plotline.

In stage (2), as the components became available, I started to group them accordingly. Grandma or great-aunt became Primary Older Adult; dad or mom became Parental Figure; and so on. They were then connected to other narrative components that existed in the same stories. Which voices are speaking to which audiences, in which settings, and following which plotlines? To do these groupings, I used a method learned from experience with solving complex puzzles in my elementary school years, the matrix. The matrix is a system of boxes which allows one to quickly compare and relate multiple dimensions quickly. My matrices contained large boxes with the headings *voice, audience, plotline,* and *setting.* Within each box there were several rows and columns that contained the attributes that were inductively gathered through reading the transcripts in stage (1). The boxes were arranged into a grid that allowed for the relationships between attributes to be explored. X's placed within the grid indicated where relationships between narrative components existed. Below is an example of what the matrices looked like:

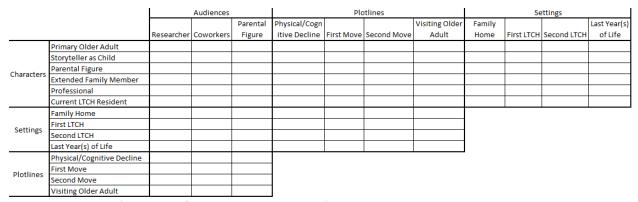


Figure 2: Example Matrix for Constructing Typologies

Once a matrix was established, I began stage (3), constructing types of discourse from the relationships that emerged. I then returned to the transcripts to see if the constructed types of discourse reflected what I had interpreted from the stories. This process continued cyclically until I was satisfied that sincere types of discourses had been identified.

Once satisfied with the types I constructed, I characterized the types (stage (4), drawing on examples from the transcripts that lent themselves to those types. This type construction is taken up thoroughly throughout chapter four.

Crafting several types of discourse allowed me to explore the complexity of stories about LTCHs among young people and address my second research puzzle. It also added depth to the dialogue and plurality of voices expressed in the final representation, presented in chapter five.

Again, I will acknowledge that these are 'shaky constructs' that make themselves available to reinterpretation by the reader, and by myself throughout the research process. Yet the value of the process has become apparent as the types of discourse become embodied through fictional characters and situations in the last stage of representation.

## **Representation Through Dialogue**

The final research puzzle outlined in chapter one is pragmatic and reflects my heart in this research project. The research puzzle asks what inferences can be made about student interest in

intergenerational cohousing programs. Through the first and second puzzles, I explored the stories and discourses that student's engage with on the topic of life and leisure in LTCHs, however, in order to consider this final puzzle, I needed to put it all together. When I say 'put it all together' I am talking about synthesizing something of a dialogue between study participants that includes the types of discourse I explained earlier. A conversation of conversations that invites the reader to take part.

Following Berbary's (2019) considerations for Creative Analytic Practice (CAP), I represented the outcomes of this work as a collection of narrative futures that were based on the narrative futures imagined by study participants. The narrative futures that participants created provided the voices, settings, and plotlines that contributed to the presented narrative futures written and imagined by me.

My work was well situated to apply CAP in its representation because it collected in-depth stories of experience and imagination which are understood as part of a collective discourse. CAP is often applied to work that begins with narrative data that informs larger concepts (Berbary, 2019). The stories constructed through this research are personal, and other approaches to narrative inquiry may do well to remain at the personal level, but this work is much more focused on the societal implications of the dialogue that emerges. A visionary narrative future speaking within that dialogue is an excellent way to represent the outcomes of the research while respecting the unfinalized personalities that contributed to it.

Further, my purpose in representing the data this way is to encourage stakeholders in the sector to think differently about LTCHs, even more so than they have already been asked to do. Intergenerational cohousing will go beyond an idea in the mind of an idealist, or a program in

some far away country that 'wouldn't work here', to an actual decision being made by the characters in the narrative future. It makes the possibility of such a program come to life.

Additionally, representing the reasons potential program participants have for joining such a cohousing model should help stakeholders planning intergenerational programs. When using the intergenerational contact model, as it stands today, to organize effective and meaningful programs, stakeholders may miss the rich discourse that takes place before participants even get started. Reading through a vision of the future based on discourses today could actually force these stakeholders to consider more deeply the social conditions in which the program exists and start making more accommodations towards that direction. Again, it brings life to an otherwise ignorable idea.

## Summary

In summary, this work has sought to explore the stories of life and leisure in LTCHs as lived and told by university students and develop a collection of discourse types based on the narrative components of those stories. The discourses are used to provide a glance at how participants story the current and historical life of residents in LTCHs. Participants were then asked to imagine a future in which the lived in a LTCH while still in their current status as a young adult in post-secondary education. The concepts from these narrative futures were then combined into four narrative futures constructed by me. The narrative futures are meant to act as a dialogue between myself, the study participants, and the reader to contribute to a new discourse on the future of LTCHs as well as intergenerational cohousing schemes. How and whether this new discourse propagates into our broader society is up to the reader.

"Since 1958, when I first began to look into commercial nursing homes, I have concluded that a nursing home is a facility that had few or no nurses and can hardly qualify as a home."

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(Butler, 1975, p.263)

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# Chapter 4: The Life (Dis)Course

Three discourse types emerged while analyzing the common narrative components that each participant used while sharing their stories. These types represent discourses on *The Transition(ed)*, *(Mis)Management*, and *(Re)Valuing*. If I am honest with myself, these are somewhat dark and foreboding discourses. Indeed, there were times during the analysis when I wondered if I was being too harsh, too critical, too unfair. Yet, for me, the participants seemed utterly dissatisfied in their perceptions of what life and leisure in Canadian long-term care homes consisted of. This was most apparent to me in the practice of narrative futuring, in which they expressed an interest in intergenerational cohousing with the caveats that the living environment would need some serious improvements.

# Perceptions of Retirement vs. Long-Term Care Homes

At the beginning of each conversation, participants were asked "When you think about retirement or long-term care homes, what do you think of?" It shouldn't have surprised me that when they responded, their descriptions were accompanied by a story to explain how they arrived at their understandings. Afterall, stories are how we "represent experiences that remain inchoate" (Frank, 2021, p.36). If a young person who I am speaking with has not previously given much thought to LTC settings, it makes sense that a story would be used to fully develop their perceptions of those settings. Indeed, that is what I saw throughout much of the interviews; participants developing and actively deciding what they thought about residential care settings as the conversation progressed. This even happened for me, someone who spends perhaps an inordinate amount of time thinking on the subject. I shared thoughts and perspectives with participants that I would need to later debrief with my partner as they were so new and fresh that they hadn't ever left my lips before the interview.

For example, while talking with Phoenix about autonomy and ownership as it relates to communal living, I shared a recent experience that my grandmother had gone through in her LTCH that I hadn't discussed with anyone since it first happened. The story centered on a pair of scissors that she allowed her roommate to borrow. They had been in her purse from the time she moved into the home until the staff realized and confiscated them from the roommate. I suppose the old adage rings true: no good deed goes unpunished. I had never discussed the implications of this event with anyone until that interview. Phoenix helped me to process the event and the example helped to further explain Phoenix's position on ownership in shared spaces.

Although the bulk of this chapter will analyze the narrative components that were used to construct each story and shed light on broader discourses, I do want to take a moment to summarize the perceptions that students entered into the conversations with regarding LTCHs and retirement homes. As you read through the stories that follow in this chapter, see if you can spot where and how these perceptions are reflected in those stories.

*Retirement homes* were described as places where you "live in your own unit and you do your own thing". They are identified as places where residents are generally wealthier, active, independent, have more functional and cognitive ability, and more autonomy or control over their own lives. It is a "nice transition living in someone's home to a retirement home" as Betty would put it. Overall, the sentiment was positive when they considered a retirement home over a long-term care home (or nursing home as many would call them).

*Long-term care homes* were associated with functional and cognitive decline, extra staff care, loneliness, lost autonomy, inability to leave, abuse, and sedentary lifestyles. Thinking about LTCHs made participants feel sad, fearful, and, in several instances, they thought about going to

work rather than going 'home'. Betty had two thoughts come to mind when asked about LTCHs: "it's a place where 1) you go to die and 2) where...like, you go to die?".

## **Conflicting Discourses in Student Stories**

Across the board, and in spite of the negative connotations associated with LTCHs, each participant seemed to echo the idea that every older adult must eventually enter a LTCH when their care becomes too demanding for the family. While that isn't so surprising, given the discussion of LTCH's purpose in chapter one, it is remarkable that a place described as lonely and abusive would also be associated with the perception that it is best equipped to care for older adults experiencing a decline in functional capacity.

As I explored the discourses that participants used to frame their stories, I began to realize that it was quite common for them to hold opposing views at the same time. The first discourse I typified was originally called 'the discourse on transition', due to the significance each story gave to the idea of changing states (ownership>shared, active>sedentary, etc.). However, as I went through the stages of developing my typology, I noticed something in stage (3). The third stage involved reviewing the narrative component relationships in my matrices, interpreting a discourse type from it, then going back to the text to see if it fit the stories well. What I noticed during this recursive process was that the discourse was much less about the transition itself and more about the one who was transitioned and the family's role in making it happen. The voice of the transitioned person was entirely absent while every decision was made on their behalf. The stories were about a main character with no lines; a prop in their own play. Their significance to the storyteller was never in question, but they were regularly silenced in favour of other authoritative voices.

In fact, each discourse seemed to exist in an oxymoronic state. Hence, each discourse type was adjusted to reflect this. The discourse on transition became a discourse on the transition(ed);

management became (mis)management; values became (re)valuing. In each case where one discourse was presented, a conflicting discourse seemed to exist just below the surface. Occasionally it was explicit, as when Phoenix responded to the first interview question with "Do you want the, like, utopian or dystopian thought pattern here?"

So how were these discourses presented in their stories? The following is my interpretation of their stories, but I welcome you, the reader, to assess these interpretations and decide if you see the same thing. Each block of text is taken directly from the transcripts and has been edited for clarity where necessary [indicated by square brackets]. Each block of stories is then followed by a discussion of the significant narrative components drawn from each story and how they were used to develop the discourse types.

## **Discourse on The Transition(ed)**

Well as I said before, one of my grandmas, in the last couple years of her life, she got switched between a couple different long-term care homes. I was only like 12 at the time so it was kind of this scary, weird experience of 'oh, like, grandma's not living in her house anymore.' And we'll go visit her at this one long-term care home. But now she's changed to a different one so then we visit her at that one... Seeing her in her final longterm care home, I saw the one that she sticked with... I saw it really positively in a sense. It had a much better vibe and everything... I think a huge piece of it was that she was more comfortable there. Because I remember my dad just talking about how, at the last home, she was super distraught, and like, you could equate that to her dementia diagnosis or anything like that. But also, I think seeing her comfortable in the final home was really nice. I knew she was comfortable by what some of my dad would say. Or like my aunts and uncles would say about her. And I remember ... I just remember being younger and seeing this Zumba class happen. And I was like 'oh my gosh. It's so cool. I

wanna do that.' So, I think it would definitely be that she felt more comfortable there. So I was like 'ok this is a good place for grandma' even though I didn't really think that much about it because I was 12. (Betty)

Whenever my aunt and uncle, who [my grandfather] lived with, went on vacation or were busy, I would sleep over at their place for weeks at a time and we would watch tv together, he'd cook, he'd show me how to cook, we'd do dishes, he'd rewash dishes I already washed... I remember [the transition] being very sad because at first, we tried, or my aunt and uncle tried to keep him home as long as possible so they hired care. And eventually he mainly just stayed in his room for fear of falling if he were to go down the stairs so that was really the moment where we decided him staying in his room all day is not that great quality of life anyway and so if we could send him to a nursing home and get the care he needs and have access to greater space and scenery then that might be a better option. (Olive)

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I'm thinking maybe it's because, like, my grandfather has always had a thing even to this day that he never wants to go into a home. So, I think it's like, kind of a cultural aspect because, like, Portuguese people, like, they want to be at home. We don't want to leave. We don't wanna have to go interact with, like, nurses and stuff like that. So I think that's kind of where it comes from. And, like, I know one family member, she had to go into a home in Portugal and, like, I heard stories from there and I was like, okay, like, she had like, a really hard time adjusting... But I feel like maybe it was like, a lot of like a social

aspect, which was what kind of made it hard because she... we all knew she didn't want to be there. She'd rather be at home. (Millie)

My grandfather was going to be put into a long-term care home but my grandma was very, very, very specific about what she would accept and what she wouldn't accept. Which resulted in him not being in one. Then there came a time in which the ambulance was called almost every day to their house cause he would fall and she couldn't get him up. Which at this point everyone was like '[Grandma] you gotta put him in a home, you can't do this, you're sucking up resources. Let the man go somewhere where he can be properly taken care of.' But he got accepted in the geriatric clinic thing. And the hope with that was by him going there, she would be able to get him into [one of] the three acceptable long-term care homes. (Kat)

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I did have my mom explain this to me when I got older. Basically, it was that my [greataunt's], like her children didn't... the wife of her son didn't want to live with them anymore. And they had to decide just to put [her] in the nursing home and then after they did put [her] in the home they visited not very often. And I think since my grandparents passed away early, my mom and her siblings felt more of a connection toward her cause she was sisters to my grandmother. So, I think that they just had a negative feeling about her own children, so it was like throwing shade... I did hear when my [great-]aunt moved to the other home where she had to be taken care of, they did switch her to a new home entirely and for budgetary reasons I guess. I think they wanted to save money. They put her in not as renowned of a place as she was in before. And then it was just the fact that she was elderly and she had limited English. So, they put her in a nursing home that was no longer predominantly Asians, because apparently those ones were too expensive, and she had a hard time finding friends. And then she didn't really enjoy the food that they had there. They had things that she wasn't used to eating so her appetite significantly decreased. And then I think that... I think that maybe some of my mom and her siblings blamed the fact that was such a big change for her, and it was kinda traumatic. That contributed to why she passed so early. And so much faster and sooner than she had expected. Or like everyone. Like the doctor had told her. (Kelly)

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It wasn't an immediate transition. Initially, [my uncle] had a house built for him and his wife and they made an in-law suite in it. So, they moved [my grandmother] out of the family home into the in-law suite in their house. That lasted for like a year or two. But then, that was under the pretense that 'we will be around so if something happens, we are here.' So, you got your family around. But then they decided they wanted to up and move somewhere. 'So, we're going to sell the house and now you don't have your own house. So, the next best thing is to move you into one of these retirement community things' and did not last long. There was no reason for her to move in the first place, but it was like, 'We as a family are worried about your health and safety now that you're getting up there in years so maybe you should move in with us' but then 'oh, we want to go do other things'. It's like when you have a toy that gets old and you leave it behind. There's a little bit of negative feelings towards my great-uncle right now in terms of the management of

that situation. You don't wanna blame someone for the death of your grandmother when she was around 100. But still there was a noticeable difference there. (Phoenix)

## Narrative Components for *The Transition(ed)*

The first discourse that emerged was on *The Transition(ed)*. When asked where their perceptions of LTCHs came from, each participant shared about the transition that an older family member made into a LTCH. The main characters in these stories usually consisted of the participant as a child (although Phoenix was nearly 30 years old in his), parents, aunts, and uncles, in addition to an older family member who was transitioning into a LTCH. These stories were also told by making reference to secondary characters within the care system such as home care nurses or LTCH staff.

Each of the stories also draws from a similar selection of settings. Their stories tend to begin either in the family home or living with family in an in-law-suite type situation. From there the story moves to a LTCH setting. In some stories there is another move to a second LTCH setting. This change in setting reflects a decision that was made on behalf of the primary older adult through language such as "put into", "had to", "send to", "got switched" and so on. This is all language that points to something happening to its object, beyond its control.

With each change in setting, a new tone was set. Mood was directly attached to the setting that was described. A happy kitchen scene with grandparent and grandchild cooking together. The confusion of a 12-year-old trying to understand where they would see grandma this time. The in-law suite associated with familial duty. Phoenix perhaps displayed this best when describing the first time he went to see his grandmother in the LTCH:

For me, the contrast of seeing my grandmother in this large, open space house with sunlight and plants and making her gnocchi in the kitchen, you know, from scratch as she was known to do, or just riding her bike out in the sunlight. I would always stop and see my grandma on her bike and be like, 'Grandma, it's 5 kilometres to town. You're 95. What's going on? This is a highway. I realize it was a one lane street back 50 years ago but we're up to 4 lanes now.' But that always made me laugh and bring joy to me to see my grandmother out there and it was a source of pride for me to tell people... The first time I saw her in a long-term care facility... tiny room, one window, little tv, La-Z-Boy chair, a bed and a bathroom. Just sitting in her chair. Not mobile. Not up and about doing things. Just uninterested in participating in the things that were going on within the facility... 'Oh, we're going to go and have a karaoke thing in the lounge now' and she was like 'I don't wanna do karaoke. I wanna ride my bike and I wanna garden' but they didn't have a garden. She had no where to ride her bike to because she was already in town. She didn't have a bike because there was nowhere to store a bike. All of the things that had made me proud of my grandmother, she had lost the passion for them and the ability to participate in them. And it felt like someone had stolen my grandmother from *me. (Phoenix)* 

A large, open, sunny home where grandma could be active in the kitchen was contrasted with a small, one-windowed room catered to sedentary living. A home filled with plants became a gardenless residence. Bike rides to town on a busy street were replaced with a La-Z-Boy chair and a TV. In Phoenix's story, his grandmother's voice is heard but not listened to. From the family home to the in-law suite to the one-windowed room, the setting tells the story of the one

who was transitioned; in being transitioned the essence of the person "is stolen", not just from the older adult being transitioned but from the storyteller as well.

Finally, if you could not tell yet, the plots for each of these stories was very similar. One of the things I noticed from my matrices was that once you had the voices and settings worked out, the plots became very predictable. An older adult living in a failing body with increasing care needs being transitioned out of their home through authoritative voices that were not their own because there was no other reasonable choice, culminating in their final, uncontrolled transition from life to death. They are stories in which the only constant is to be transitioned.

The participants did not share whether or not they had told this story to anyone in the past. In cases where the participant only heard about the transition, they would have constituted at least one audience to the story. In their retelling of the story through our interview, I constituted another audience.

The specific circumstances, settings, and characters are unique to each story. The common plot I suggested above does not perfectly map onto each story that was presented in the discourse on *The Transition(ed)*. However, the narrative components are so similar that it indicated to me their stories were part of a larger societal discourse. That discourse is dominated by a couple of key voices: familial authority and professionalized/medicalized care. Ultimately, these voices carry the message that a lose of autonomy for older adults appears inevitable.

## Familial Authority

There was something about directly witnessing or hearing from other family members about the move that made the concept of LTCHs more real in the participants' minds. Phoenix recalled that before his grandmother moved, he thought that "this is just how these people live", in reference to the sedentary lifestyle of LTCH residents in general. But afterwards he thought "this is a pretty stark contrast to what I'm used to seeing my grandmother doing." Similarly, Olive said

that although it wasn't her first exposure to a "nursing home... I experienced it in a way I hadn't prior. When my grandpa was there himself."

I heard this again when Kelly explained what she heard from her mom about the story of her own grandmother's multiple moves. As a 12-year-old, Kelly remembers the transitions being "scary" and "weird". Although she didn't think about it much, something was awoken within her which left an impression about how she perceived LTCHs.

At its most surface level, I thought that perhaps this first discourse would be about the transition itself. The experience of witnessing or hearing about a significant change in the life of an important person for each of these storytellers led them to certain conclusions about life and leisure in LTCHs. And perhaps this has merit. However, exploring the narrative components brought me to the conclusion that the stories were not about the *act of transitioning* so much as they were about *the one who was transitioned* and the family's role in making it happen.

Did you miss it on the first reading of each of the stories above? I did. Following Franks steps for developing a typology of discourse, re-enter stage (3) and re-experience the stories presented at the start of this section. What do you notice on this second reading? Whose voice is not present in most of them?

The most absent voice in each story is that of the one who moved while the loudest voice is that of a family member (usually a parental figure, aunt, or uncle) who is making decisions on behalf of the older adult experiencing the transition. Often the storyteller will align their own voice with those family members by using language such as "we decided", "we all knew", "we as a family", and "everyone was like..." followed by a performance of what 'everyone' said. Power was held by the voice of the family (and by extension, the storyteller as well) who would

make the 'best decision possible' for the future of the older adult, although the decisions did not always prove to be the best in the end.

The voice of the family possessed an authority that was especially powerful in influencing how the participants perceived the transition when they were children. Phoenix, on the other hand, was quite willing to express his discontent and oppose the family's decision to move his grandmother during his retelling of the story. Phoenix is distinct because he was nearly 30 years old when the transition story took place, 4 years from the time of our interview. He not only expressed his disappointment in the decision but also gave voice to his grandmother by saying that she was resistant to the idea that her brother should make all the family decisions. In this story, I hear a resistance to accept the voice of familial authority, even if it ultimately spoke the loudest.

The voice of familial authority was not the only voice contributing to the discourse on *the transition(ed)*. While in the family home, whether it was a second-floor bedroom, in-law suite, or shared accommodations with their children, the voice of the family was dominant. But it carried with it echoes of another voice which would gain more authority in the LTCH setting.

## Professionalized/Medicalized Care

The voice of professionalized/medicalized care is another dominant voice contributing to this discourse as it speaks in concert with the voice of familial authority. In some ways, the voice of the family seems to gain its authority by referencing professional or medical care as a rationale for moving in the first place.

When the tone steers towards professionalized care, this voice says that if family caregiving or cohousing become unmanageable, professional care is the best option. For example, Kat explains that her grandmother was willing to pay whatever it took to keep her grandfather at home, including home care. However, when the ambulance was called regularly to help pick him

up after falling down, the family relied on professional care as the reason he needed to move out of the home. Kat recalled that "everyone was like '[Grandma] you gotta put him in a home, you can't do this, you're sucking up resources. Let the man go somewhere where he can be properly taken care of."

When this voice takes on a medicalized tone, the older adult's condition speaks in place of themself. In Betty's story, as an example, it was a dementia diagnosis that spoke on behalf of her grandmother, through her father. This was how Betty, and her family, knew "she was super distraught" in the first LTCH. Her grandma's experience is made known by equating emotion with diagnosis.

When families experience burnout as informal caregivers, should they not have access to additional resources that will support them as well as their loved one receiving the care? If an older adult is living with a disease that impacts their quality of life, shouldn't they have access to treatment or management plans? And if those additional resources or treatments include people, should they not be well trained and properly valued to do the task before them? What I understand the voice of professionalized/medicalized care to be saying in this discourse is, yes, struggling caregivers and older adults living with disease do deserve to have access to supportive resources and those resources coalesce at the LTCH. Even home care is not seen as a viable option for Kat's family at a certain point because her grandmother is still "sucking up resources" through additional ambulance visits.

When the voice of professionalized/medicalized care points only towards settings such as LTCHs, it gives authority to the concept that the primary older adult from each story *should* move into a LTCH. In Olive's story, she explains her family's opinion that "if we could send him to a nursing home and get the care he needs and have access to greater space and scenery then

that might be a better option." Millie says that her family didn't "*wanna have to go interact with, like, nurses and stuff like that*", however it was decided that her family member "had to go into a home" anyway. Kelly explained that her family blamed the death of her great-aunt on the trauma from a negative move between LTC settings. The idea that the death was premature was given authority by what "the doctor has told her" at the LTCH. The discourse that access to professionalized/medicalized care necessitates a move into a LTCH holds more authority than the older adult's own voice, like Millie's family member in Portugal.

'Lose my older adulthood.'

The discourse of *The Transition(ed)* is one that speaks to the eventual and inevitable loss of autonomy for the older adult. A phrase that continues to haunt me was spoken by Kelly when asked if she had any other memories about nursing homes that were significant to her:

There's one time when my mom told me, she was like 'did you know there's 50-somethingyear-olds that live in the nursing home.' And I'm like 'no I didn't know that. Aren't they too young?' 'No. You have to take care of yourself or else your body will fail and then you'll have to do that.' I think she was just trying to get me to stay healthy, but I think about that a lot actually. It would be really unfortunate if something happened and then I just lose my older adulthood. (Kelly)

Kelly carries with her a very real worry that something might happen to her that would cause her to lose her older adulthood. When I probed further into this, it was tied specifically to a worry about becoming quadriplegic and requiring a significant amount of care including showering and feeding her. She was clear that moving into a LTCH setting would not constitute a loss of her older adulthood but that a loss of autonomy would. Meanwhile, the hallmark of the discourse of *The Transitioned* is exactly that, a loss of autonomy, particularly when older adults are excluded from the decision surrounding their move. Kelly does not directly link moving into a LTCH as a loss of autonomy in this instance, but it is reflected throughout her stories and others.

Similarly, during the narrative futuring exercise, Millie continually put herself into the home as someone who would experience the same kinds of strict scheduling and physical or verbal abuse that she witnessed in the home where she worked.

...like one minute, I'm eating dinner for example, and then the next minute I'm supposed to go take a shower. There's no flexibility there... I'm already uncomfortable because I work in a place like that. But I feel like living with that would just make it worse. It opens up the opportunity for not only people that I know and love to be treated [poorly], but for myself to be treated like that too. (Millie)

For Millie, moving into a LTCH meant a loss of autonomy as well as a loss of safety. For Phoenix, the contrast between his grandmother living in her LTCH and back in her lifelong home was so striking that "it felt like someone had stolen my grandmother from me."

The discourse on *The Transition(ed)* is a covert realization that we may one day have our autonomy and thus our older adulthood stolen from us, either by tragedy, professional opinion, or family.

# Discourse on (Mis)Management

I was really excited. I knew I was going to be working during the pandemic but I had prepared myself to do so. And I was like really pumped to get exposure in that type of setting. And I remember looking at their reviews online for the home. And they were all pretty old but they were so bad. And I was just like, 'Oh my gosh I don't wanna go into this place and then it like ruins my dreams of working in this field. What if I hate it?' And

it really freaked me out. There was just stuff on the Google reviews that was like, 'Don't take your family members here.' 'Really high staff turnover.' Stuff like that. So, I was really nervous... [However] there was a lot of wonderful times. Specific to the residents. And I love most of the employees. Some were really difficult to interact with just because it was like [this home] had a history of resident abuse. So, within the past two years they got a completely new administrator and they switched up a lot of their policies and everything. While I was there, there was one PSW who was like there for a little bit and then gone. And a lot of the PSWs there were like... you would just hear... there would be chats among staff members... [Then] I had been called in for a resident assistant shift and I had assumed that I would get training for it or something like that. I checked in with the nursing station. And I also started on a holiday, so all the administrative staff were gone. So, I asked the nurses, 'I'm not really sure what to do. What is this?' And they were just like 'Oh I don't know, maybe check with this one PSW who had worked as a resident assistant before.' And I got to know her. She is super nice. So, she literally told me in 5 minutes what to do. And she had this sheet that she wrote out about what she would do for her job, like when she was a resident assistant, because that was what she started as. So, she gave me this sheet that was like an itinerary kind of thing. So, then I just followed that... [There were] like 10 residents per PSW. The policy was that you always had to do toileting, do transfers, do all that stuff with two people. Actually, I think it was just two people with transfers. But bedtime was all transfers because you know... and its hard. It takes a lot of effort. So anyhow on my first resident assistant shift I was like, 'Ok, I'm going to help wherever is needed.' So, I helped a couple PSWs just with getting people ready for bed. It wasn't like direct care. It was like the second person to that person

providing the direct care. But I found, like, I wasn't trained at all. Like at all. And I got trained after I had already done some of these things which made me second guess like 'Oh, should I have asked for it or something?' (Betty)

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So, on my physical support unit, I've heard of individuals who really appreciate being in long-term care especially with all the attention and care that's immediately available around the clock. With a good ratio between nurses and the number of residents they attend to. And I've heard they appreciate that it's all veterans, which is a unique experience to me, and there's a bond. They appreciate that their loved ones can have peace of mind knowing that they're safe and they're cared for. I know a lot of residents were impressed with the rec therapy department. They often thought 'How do we get to go to the art gallery? How are we going here and there? How are you bringing in pet therapy? How are you hosting a kids day event or there's vendors of cotton candy or ice cream, etc. 'So, I think they really appreciate the rec therapy team, and how it wasn't bingo and crosswords. But it was meaningful, and it fostered social connection... So, yea I think a lot [of] residents enjoyed all the activities that were available. As well as staff members respecting if they ever wanted their alone time. It was never forced upon them to engage in a way they didn't want to... [In contrast] I've heard more individuals on the locked cognitive support or dementia care unit express displeasure with living in longterm care. I've had individuals who charged at the door with their Rollator saying 'I wanna get out. Why am I locked in. Get me outta here.' You'd have to redirect that or you'd have to distract or ensure their safety as well as others in that situation. It's especially challenging for dementia care residents who don't understand why they're in...

That was often on my mind; with whom do I remind 'Oh no. You're actually here now' and with whom do I redirect and not be explicit that these are the circumstances right now. So, I think it's just kinda disheartening; I wish it weren't so. I wish I could be honest and be clear about what the circumstance is while ensuring their safety. But sometimes it felt like I had to choose between one or the other. (Olive)

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But when I think about going to work and seeing the residents and stuff it's kind of crazy because there's a part of me that doesn't like being there just because of the way that people are treated. But then I like also going to work because I love the residents. I just love being around them, right? And then, sometimes, I think about... I kind of feel sad for them, because a lot of them are not very happy unfortunately living there. They miss their families, especially right now. And, like, just like... this sounds terrible but abuse. Like, it's not okay. And maybe like, it's very dark and I know it and I hate to say it, but it's like, I don't like to talk about it, but I have to. Because like, for example, I feel like it's a perspective that I have because it's something that I'm exposed to every day and, like, sometimes, for example, the staff members are not treated very greatly at the home. We're very understaffed and we're very overworked, and sometimes it's accidental that force or, like, rude words come out at a resident. And that's not the way that it should be because even though the staff are tired and overworked, like, it can't be justified. You have to end the problem at its root, which is management and the government and stuff like that... [I talk to my coworkers about this] just because they're really the only people that I can share to without getting in trouble because they know it already. They know what's going on. And we talk about, you know, what's happening and how curable it is, and what we

can do and stuff like that. So, that's definitely a good outlet because I know that I'm definitely not the only person there that feels this way... [Also] I have family members that work in other homes and stuff. You kind of hear the exchange between what's happening. (Millie)

I think that's something that I really saw through my grandma. That there were a lot of like decent long-term care homes that she turned down. And like she was thinking of hiring their own PSW to have them come in [the] home because she's like 'I don't wanna pay for lack lustre stuff etc etc.' Money wasn't an [issue] for her. She wanted the best. And then she was going to get it. And she was going to get it and make sure that she would pay for it... From my grandmothers very heightened refusal to put grandpa in a home, because he was going to get sick and so basically grandma's stuff isn't factual. It's a rough, rough time. But I do know that a lot of PSWs were not... a typical thing for PSWs is they don't get paid very well and they don't necessarily get very good hours so a lot of them are having to work at 2+ homes. And they would essentially... if you get COVID you're bringing it into two homes. It sucks butt. And then you're really spreading it to a very [vulnerable] population. And I remember the government being like 'how could this happen?' And you're like 'how could this happen? You did this!' (Kat)

And my mom was visiting her [at the second home] and they noticed when they took her clothing to be laundered, it'd come back with things missing and my mom would be like 'Oh I'm not familiar [with] this.' You're supposed to label. You're supposed to separate

loads or whatever and clearly something was going wrong. Or whatever they were doing was really disorganized. So that was upsetting and I guess... I don't know if its justifiable that just cause you're paying less that you get your clothes missing. It kinda irked me. (Kelly)

Now, in the current setting, long-term care homes are awful. You know it's like great we have these awesome places however nobody wants to stick in to do the proper work and care that we need to do in this pandemic response situation that we've got, and the places are just falling apart and they are actually becoming a detriment to peoples health. If they aren't managed properly and they're restrictive, it becomes an issue... I think there's a certain consideration that needs to be put into what these spaces are that we're creating. Are they more akin to a home community where you can be your best self and explore new things in your upper years or is it like prison with face paint on? (Phoenix)

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# Narrative Components for (Mis)Management

The second discourse that emerged was on (Mis)Management. When I asked study participants whether they had worked, volunteered, or visited at a LTCH, I was met with stories that tended to focus on the working and living conditions of the homes in terms of the management practices they perceived. The characters I associated with this discourse from participant stories were the undervalued, overworked, and untrained staff member, the agitated or unhelped resident, and the absent administration or management staff. In some stories of mismanaged care, like Kelly's, their loved one was present. For others, such as Betty and Olive,

the mismanagement of care was disconnected from the experience of their loved ones. Additionally, the government appeared as a character in Kat's story as the one who was primarily responsible for the pandemic crises in LTCHs.

As for settings, it was clear to me that the participants with experience working in LTCHs associated them with workplaces and clinical settings rather than with homes where people live. When asked what comes to mind when she thinks about LTCHs, Millie responded, "...I think about work. I think about going to work." Participants who hadn't worked in LTCHs still understood them as a place of work but wished they could be more like homes and less like hospitals. It was Phoenix who said, "if I'm walking into someone's house, I don't wanna see hospital people all the time." The sentiment that LTCHs are perceived negatively when overly medicalized is not a new concept (French & Mosher-Ashley, 2000).

As for plotlines, there were two major directions for these stories. For participants who had worked in a LTCH, the plot began with considering their career path and deciding that therapeutic recreation in a LTCH was the way for them. The highlight of their work was spending time with the residents, learning their life histories and doing activities together. The worst parts of their job involved feeling uncertain or helpless in their role and witnessing or hearing about abuse towards residents. For participants who visited a loved one in a LTCH, the plot involved a visit which exposed the inadequacies or inconsistencies in care that was received.

Once again, audiences for these stories were rather limited. In some situations where the participants only heard about the (mis)management, such as Kelly in her story about clothes going missing, they were the audience to these stories and retelling them to me as another audience member. Interestingly, both Millie and Betty mentioned that they could only talk about issues of abuse towards both the staff and the residents amongst their coworkers. Millie

mentioned she only wanted to share the positive stories with people outside of the LTCH because "I don't like all the abuse stuff. I try not to talk about it. Just because A) I'm not supposed to. And B) some specific stories make people sad and that's not what I'm trying to do." Later, Millie goes on to say that she and her coworkers talk about "what's happening and how curable it is, and what we can do and stuff like that. So that's definitely a good outlet because I know that I'm definitely not the only person there that feels this way." To me, it appears there is a silencing, whether internal or external, that prevents this story from gaining greater audiences. As a researcher, it is a privilege to be an audience member to stories held so close.

For the most part, the participants' language regularly pointed towards policy and economics as driving forces that shaped the atmosphere in the homes, the roles of staff, (dis)organization of administrative bodies, and the residents as passive recipients of the end product of this work. Three important voices enter the conversation through this discourse: the voice of policy, the voice of economics, and the voice of the powerless staff member. Ultimately, through this discourse, participants seem to recognize inconsistencies and inadequacies amongst LTCHs. Policy

The voice of policy was significant in stories for participants in their roles as staff members and/or family members when discussing LTCHs. In Betty's story of beginning to work as a resident assistant, she talked about how her LTCH has a "history of resident abuse". Google reviews from long before she worked there mentioned "high staff turnover" and generally discouraged anybody from moving in. As a result, the administration was overhauled in recognition that "the root of the issue" was in management and policy, as Millie would put it in her own story. However, in Betty's time working there, issues of abuse persisted, presumably resulting in at least one PSW no longer working there. Clearly whatever issues they had sought

to prevent with an administrative change persisted, to the point where Betty was placed in a role she had very little training for.

Similarly, Millie pointed to issues of understaffing and overworking as being the result of poor policy work at the level of management as well as the government. Kat echoed this sentiment when she talked about the failure in LTCHs throughout the pandemic: "And I remember the government being like 'how could this happen?' And you're like 'how could this happen? You did this!""

Meanwhile, Phoenix offers a different approach. In his experience visiting his grandmother in the LTCH, he was overwhelmed by the number of "healthcare staff" that he saw in the building:

I just remember that it felt like the constant presence of healthcare staff. So, like, people in smocks walking around delivering pills. Doing whatever. It just had this very hospital presence to it. And it was like, if I'm walking into someone's house, I don't wanna see hospital people all the time. I want them to come out once a day. I want them to be stored upstairs in the attic so I can't see them when I'm visiting my grandma in her home. Then at medication time a pleasant alarm sound comes and the hospital staff are released and then they have to get everything done in like 30 minutes then they have to be unseen afterwards. I want them to be in a visiting context. They come by the house to do the thing they need to do and then they are gone to do something else. (Phoenix)

To some, his solution may sound a bit harsh towards the healthcare providers themselves. However, the issue was once again a matter of policy which led to the medicalization of a space that he expected to have a more home-feel. Managing the staff routines in such a way that limited their presence and increased the home-feel of the residence was at top of mind for him.

For Phoenix, it was the difference between living in a home versus living in a "prison with face paint on". He was quick to follow up that position by asserting that:

...having to work with these people as staff, and someone who is intending to be staff, there is a lot of... it almost feels detrimental to be there sometimes. I don't wanna say that like what we do isn't important, but it can get to a point where residents start to take advantage of the services you provide, and they start to expect that you'll do everything for them. They stop trying to make their own food, they stop trying to go the store. It becomes a fight to go out and do regular things, they don't wanna do their laundry; they want you to do it for them. That is not behaviour that I want to support. (Phoenix)

To be clear, in Phoenix's case above, he was referring to his role working in group homes for people living with mental illness and addictions. However, he drew comparisons between the two congregational living schemes by noting that older adults can still benefit from the autonomy to do things on their own, receiving support when it was requested rather than thrust upon them. In this view, policy that promotes excessive support appears to fall under detrimental management. A hands-off policy, Phoenix suggests, would improve the autonomy of older adults who could still reasonably do things such as laundry.

Finally, the voice of policy appeared to lead to confusion or uncomfortable moments for some participants in their role as staff. It also led to inconsistent care for residents. In Olive's story, how older adults in the physical support unit experienced the LTCH was different from how older adults in the cognitive support unit experienced it. While there are likely to be multiple and individual reasons for those differences, it is in Olive's story of the cognitive support unit that we find policies such as locked doors and "reality orientation" that ultimately lead Olive to second-guess whether she should prioritize honesty and clarity or safety. When new

COVID-related restrictions came into the home, Olive was left with a dilemma between prioritizing mental health and physical health by saying "maybe rules need to be broken... I remember thinking like 'I wish things were clearer' or I wish I could just act one way and think 'I've decided I'm going to break it. It is what it is.'"

Betty experienced this second-guessing when she wasn't trained properly to do her job as a resident assistant. Within the discourse of (Mis)Management, the voice of policy weighs heavy on the staff and families. Again, because the voice of the resident is often missing in the stories, we can only imagine how the voice of policy also weighs on the people living there. Certainly, some of the stories shared provided glimpses into this reality.

#### Economics

The voice of economics enters this discourse in a significant way. In this case, excellent care is associated with higher costs while poor care is associated with lower costs. Kat explains that her grandmother rejected LTCHs as a viable option of care and would prefer to pay for the very best care on her own in the form of home care. Her grandmother's argument was that only three LTCHs in the region were "acceptable" and even then, she would prefer not to use them. In another place, Kat discussed a retirement village that her grandmother's cousin lived in and described it as "amazing" and "phenomenal" but qualified the statements by saying "I think that is partially dictated by cost. Who can really afford to live there? Typically, it's higher income white folks." In one of Olive's stories, she related the high level of satisfaction among residents in her LTCH to the "larger amount of funding for recreation therapy than other settings…"

In contrast, Kelly describes that her great-aunt had to move for "budgetary reasons" and that paying less for care means there's a chance that your stuff can be lost: "I don't know if it's justifiable that just cause you're paying less that you get your clothes missing." Interestingly, she also associates this scenario with management practices by adding "…whatever they were doing

was really disorganized." The high cost of quality care associated with the voice of economics tended to influence how the participants described acceptable expectations for the living conditions that their loved ones would experience.

There is a second component to this voice of economics, and it ties into the final voice of the powerless staff member. Butler (1975), quoting a TIME magazine article from 1969, describes it in such a way that you might be forgiven for thinking it was written last year. The piece quotes a man named Richard Rynd, who owned a nursing home in Baltimore. Butler quotes the following: "President Richard Rynd, 38, a onetime scrap metal dealer, openly scoffs at a competing home that employs registered nurses rather than aides. 'No wonder it loses money,' says Rynd." (p.266).

The issue of paying fair wages to the staff of LTCHs is not new and, 50 years later, continues to pervade the discourse of (mis)management heard in young people through this study. From her introduction, Kat expressed that she had no interest in pursuing a career with older adults. She felt she was much better suited to working with children. However, she made several points about the pay staff in LTCHs made, as well as the funding they generally received:

I do know that a typical thing for PSWs is they don't get paid very well and they don't necessarily get very good hours so a lot of them are having to work at 2+ homes... I knew that there's a lot of money currently to be made by people who are not PSWs in long-term care... I know that before the pandemic, long-term care was kind of like a decently hot topic of like, 'We're not funding it enough but there are no problems right now. It'll be fine.' And then we have a massive problem and that wasn't fine. (Kat)

Someone who had no interest in pursuing a career in the field was actively thinking about the difficult economic proposition being made to those who did want to work in the field. A lot

of this information came from friends of Kat who did want to work in LTCHs. What this tells me is that the discourse that Kat engages in separate from her own interests included the voice of economics in the LTCH sector. Kat wasn't the only one who mentioned this topic in their stories. Betty also talked about the low wages for a PSW.

Because I had really considered staying on for a couple shifts a week while I was doing school. Just because for me as a student, the pay was really good. But for like PSWs who aren't students, who have whole families, the pay was horrible. The difference between our pay was like \$0.17... maybe I was looking at the starting pay. For co-op students it was \$19.50. Something like that. Around that range, and for me I was like, 'That's so good. I've never made anything above minimum wage.' I was like, 'Ahh yeah! I'm in a professional job.' And PSWs made like \$19.70. It's definitely not a job that I would want to pursue for my job in the future. (Betty)

Betty wants to work in LTCHs as a recreation therapist but a PSW is "is definitely not a job that [she] would want..." It isn't even really about the work being done because she was willing to continue assisting PSWs in their work after her co-op work term was completed. It was the pay that bothered her.

The voice of economics contributes to the discourse on *(Mis)Management* by saying that good care in LTCHs is associated with a higher amount of funding going towards those homes, all while wages for the staff performing essential care has remained low. However, low wages are not the only issue for staff members presented in these stories.

## **Powerless Staff Members**

One final voice that was present throughout the stories was that of *the powerless staff member*. Their voice was restricted to conversation among themselves. Discussion of harms and

abuses could not be talked about beyond their circles, as in Millie's situation. Despite not talking about it to other people, Millie would have exchanges that indicated people were becoming aware of those abuses during the pandemic:

A lot of people I find that talk to me, they're like, 'Oh, you work in a home?' And I'm like 'Yea'. And they're like, 'Oh, that must be so terrible.' Meanwhile, six months ago, sorry, not six months ago. A year ago, they would be, 'Oh, you're working in a home? That's so awesome!' The perception has just shifted entirely. (Millie)

Betty described this same situation in her home as well. In each of these stories, care staff are passive recipients of instruction and policy from management and going against it to provide what they see as better care is discouraged. As one more example, read this story from Betty about a resident for whom she cared:

There was this one night that I was [resident assistant] and there was this one resident who gets super agitated at night. Like we would call [it] sundowning. Anyways so she had completely peed her pants and there was no PSW on this side of the hall. I wasn't sure what to do so I just asked the nurse, and they were like 'The PSW should be down the hall.' But there was no one. So, I just sat with this woman but it's like you can't even... like I think a lot of people would be like 'Oh, they blame it on the PSWs.' That PSW who wasn't there ... it wasn't like the whole hall was empty with no staff. There was a nurse and a PSW for 40 people or 50... That PSW who I knew, she was overdue on her break, and she hadn't had dinner yet. You know? Cause she had assisted with the other people's care and continually pushed off her break. (Betty)

Betty, the untrained resident assistant, was left to sit with an agitated older woman lying in her own urine because the PSW hadn't been able to get a break in yet and it wasn't the job of the other care workers to help her. Betty was powerless and so was the woman who was left to sit in her soaked bed. The administrators and policymakers were taking the holiday off while the care workers were left to provide insufficient care according to policies and funding decisions by those same administrators.

The underpaid and overworked care worker plot is recognized by storytellers with and without experience working in these settings. Kat, who has no interest in working with older adults at all, draws on the experience of her friends who have had co-ops working in LTCHs to discuss what she knows about the state of healthcare workers in that sector. The discourse on (Mis)Management seems to indicate that better management is needed within the LTCH sector, which also includes hiring more trained workers who are paid better wages. Policy and economics have consequently formed a culture that creates the powerless staff member. One way forward would be to change policy to give more power back to the staff member who feels undervalued and insecure in their place of work. A parallel policy change could be to broaden the community of people who live in LTCHs and lean on a non-professionalized, multigenerational community of support, such as neighbours and peers. This would be another way to relieve the tensions that care workers face while also reducing costs to the institutions. This would be congruent with Phoenix's vision for a home in which the care staff take on a visiting role as well as the social revolution (Theurer et al., 2015) discussed earlier. It places the older adult at the center of the LTCH, transforming the establishment to a home rather than a workplace. It does not prevent staff from having the fulfilling relationship with residents that these participants

enjoy in their work. Rather it gives them the freedom to do so knowing that they alone are not responsible for complete social care in addition to physical care.

The discourse on *(Mis)Management* is a recognition that something is fundamentally broken about the system of care that older adults have access to today in LTCHs, while believing there might be a way to fix it through policy, economics, and empowerment.

### Discourse on (Re)Valuing

I think given my Chinese culture, there is a huge emphasis on respecting your elders and having that relationship with them... I just want to get to know people who are older, who have life experiences to share. And my grandpa was actually a pretty quiet guy so often when I would hear friends of different cultures who shared how personable their grandparents were, how detailed they were in life events, I didn't really have that. And partly my Cantonese is lacking so it was limited communication. But I think there was an appeal of just intimately being involved in someone's life that was interesting to me. And when I was in hospital with my grandpa, the few times he was hospitalised. I remember thinking if I wasn't there, I'd be really sad about him not being able to communicate or him being misunderstood. And of course that's with a language barrier and there can be English speaking people here who wouldn't have that specific barrier but I just had the thought that if there's an elderly [person] living in a facility where they're not being treated well or they're not being heard or have opportunity to communicate then that was very compelling for me to pursue that setting so that I could do my role, or could not have what I felt sometimes happened to my grandpa, where he received less than ideal care in the hospital, at a long-term care or nursing home setting. (Olive)

It's kind of interesting, too, the way my culture impacts what I'm studying. Cause back in Portugal, [recreation therapy] isn't a thing. Right? And like, if it is, it's just becoming a thing. And then even seeing, because the home I work at, there's lots of Portuguese residents, and just seeing their cultural perceptions towards recreation, as opposed to some of the other people that are there, it's kind of interesting... So, I think it's like, kind of a cultural aspect because Portuguese people, like, they want to be at home, we don't want to leave. We don't wanna have to go interact with, like, nurses and stuff like that. So, I think that's kind of where it comes from... Regarding the transition of my one family member in Portugal... it was still kind of perceived as a negative thing. Maybe it's because I'm thinking that in our culture people don't like to ask for help. It's more of like a, 'I'll do it by myself kind' of thing. Maybe the help being accessed in homes is what's negatively looked upon? I don't know. (Millie)

Part of what I really have drawn from being Mennonite and growing up and kind of having those beliefs around is just the sense of family and the sense of community. And I see it interestingly enough with the two sides of my family. So, one of them is Mennonite. The other one is not. My dad's side is Mennonite but my mom's side isn't. My mom's side is a lot different in the way we've dealt with family members getting older and general care and even the practitioners they see. So, they'll see doctors, they'll see gerontologist. As opposed to the Mennonite side where my great-aunt, who was just called my aunt, had ALS but she didn't go to get diagnosed because there's kinda like a distrust of the medical community there ... Not putting my [maternal] grandpa in care was more so because they could afford it outside. On my dad's side it's been more of, 'We take care of our family

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instead of putting them in a home...' Situations have worked out well enough that there haven't been any instances that people have really needed to be in homes. Like my greataunt had ALS. They just took care of her at home. My grandma's doing fine. My grandpa died at home. My grandpa on my dad's side died at home. It's a cultural thing of, 'We take care of our own...' I think it comes a lot from like seeing what your family has done. Like seeing what your parents did, seeing how other people have dealt with it, how much education you have. And I think just like in the Mennonite community, the Mennonite community of my grandma... [in her] time there was still much more close-knit community. So, she grew up on a homestead and all of that fun stuff that went along with it. So, they're more used to going through dramatic things together and health things together. Like my [paternal] grandma, when she was 12, got her tonsils out at the kitchen table. My grandparents on my mom's side never had that experience. (Kat)

I guess I thought it was sad because my mom would always be like, 'Imagine raising your children and then having them kick you out for no reason.' And then use your own money to pay for it... I do believe [my great-aunt] enjoyed [the first home]. I think she just did a lot more than living in a hostile home where your daughter-in-law... it's odd when they don't like you and your presence in the home causes your son and his wife to bicker. I feel like it was probably better for her to be living [at the LTCH]... me and my cousins have brought it up before when we were just, like, chatting but not with anybody outside of my family. Just cause I feel like nobody really talks abut this topic often... We'd be like, 'Oh, did you see this' or like 'she tried to give us this, this, this,' and then our parents would talk about it and I guess we would have our own conversations about it but it was never

super deep... I don't think that I really talked about it much with anyone. No one really brings it up and I think a lot of my friends that I've heard them talk about their grandparents, they live at home as long as possible. So, it wouldn't really involve a longterm care home... It's really common for Asian families to live with their families as they got older. So that they can help take care of the parents and the parents can kinda help take care of the kids. So it's like really normal to hear that your grandparents live with you. (Kelly)

Italian family. So, the boys make the rules apparently. In the old school Italian world, which was always a point of contention because my grandmother, not my great-uncle but his sister, you know, firmly was against this as a way to go with things. But as the daughter in the family no one listened to her. My great-uncle made all the decisions. (Phoenix)

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I think as a person... or as a kid who had never ever seen something like [a LTCH], I was just weirded out by the fact that, 'Oh this is where you go at the end of your life' sort of thing. Which that might not even be true. There are lots of different hospice or palliative care services that actually assist with your end-of-life process. As a kid who didn't know any of that, I was just like, 'Oh so these people go to these homes where they are just in really large groups and then you just position yourself in front of the TV for like multiple hours.' So that was how I thought. Yeah so, I definitely saw it as a bizarre thing. But I would also equate it to being younger and not really being exposed or having open

conversations about the end-of-life process. I just didn't know. I'm not sure if it was like, 'Oh I didn't know because it wasn't something that was talked about a lot'... it was a really meaningful moment to be there. Like moments before her death. Because I was there when that happened. (Betty)

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# Narrative Components for (Re) Valuing

The third discourse to emerge was on (Re)Valuing. I asked study participants about where they thought their perceptions of LTCHs came from. Throughout the interviews, they shared with me multiple stories that would frame what they know about LTCHs in terms of their cultural identity and family stories. Five of the six participants connected their perceptions of LTCHs to their culture. Two connected themselves to Asian culture, one to Portuguese culture, one to Italian culture, and one to Mennonite culture. I did not explicitly ask them about the role their cultural identities played in shaping their perceptions. At the beginning of each conversational interview, I did introduce myself by associating myself with Mennonite heritage, which prompted a quick game of Mennonite bingo with Kat, however I did not draw connections between that and my perceptions of aging or LTC. In one sense, I suppose sharing my own cultural identity served to invite them to discuss their own.

These cultural voices comprised a significant character in their stories and their larger discourse. Other main characters in these stories were loved ones living in LTCHs, parental figures, and extended family (aunts, uncles, and cousins). Secondary characters sometimes included friends, the residents of LTCHs in general, and faith communities. Much like the discourse on *The Transition(ed)*, the settings for these stories included the family home as well as a care setting such as LTCH or hospital. This discourse followed similar themes in terms of

changing from one state to another however it was distinct from the first discourse. In the discourse on *(Re)Valuing*, storytellers were actually talking about a shift or development in their own perceptions of LTCHs, end-of-life, and relationships with older adults. Following their plots, participants would begin their development by associating with a particular culture or family stories. Throughout the course of their interviews, they would explain how they developed or adapted the understandings rooted in their cultural and family values to something they were more comfortable with. Rather than outright rejection, participants engaged in an act of reassessing their values; what I call (re)valuing.

The audiences to these stories included myself as the researcher and the storyteller as the one being developed and redeveloped by their retelling. Within one of the stories, a faith community played audience to the participant's development. Largely, it seems that few are audience to the stories of (re)valuing as it appears to be an incredibly personal process for the participant. Meanwhile, there is concurrently a dominant discourse between their stories that includes a conversation about shifting values. The key voices contributing to this discourse include cultural identity and family stories.

### Cultural Identity

The most striking concept I heard from each participant who connected their culture to understandings of LTCHs said such similar things: My culture or family recognizes the value of caring for our older adults. Traditionally, value of caring was supposed to result in older adults living with family. For some participants, interaction with a LTCH and its residents, through work or visiting, was the trigger for (re)valuing.

Cultural identity speaks into this story through the participants themselves or members of their family. In some cases, it is affinity towards the cultural identity that led the participant to pursue a career in LTCHs. Olive mentions that in Chinese culture "there is a huge emphasis on

respecting your elders and having that relationship with them." Despite this value, she finds that she never really had the deep conversations with her own grandfather that she had heard about from people of other cultures. This drives her to work in a space where she can pursue the relationships that she was unable to have in her own family.

Furthermore, in Olive's story the cultural value that promotes older adults living with family is incredibly strong. Her story about her grandfather's transition into a LTCH begins with this contextualization:

... I couldn't really process much about what it meant when [my grandma] passed away, but I remember not going over to my aunt and uncle's house as often anymore because she had passed on. And my grandpa is the husband of my grandma. Though they had separated, they still lived together. It was civil. (Olive)

For myself, it seems odd to me that Olive's grandparents would continue living under the same roof, their children's roof, after a separation. I did not probe the subject any further during our interview and so I am left to interpret what this living situation meant to the family in my own shaky way. Kelly shared that "it's really common for Asian families to live with their families as they got older." I see this in my own life where my wife's Vietnamese Ama (grandmother) continues to live in her family home with some of her children.

For Olive's family, the desire to keep the family together and at home remains strong until they finally decided that the quality of life for her grandfather being left in his second-storey room was not good enough. It appears to me that since living in a LTCH was an option, (re)valuing allowed for the family to maintain their significant connection to their older family member while also pursuing the care they perceived that he needed. LTCHs made it possible for

both Olive and her family to engage in (re)valuing that would both support and expand their own cultural value to respect their elders and have relationships with them.

"Imagine raising your children and then having them kick you out for no reason" says Kelly's mother. As I mentioned above, Kelly connects her Asian culture to living with your grandparents. It isn't odd to hear about friends who live with their grandparents, she says. While holding this view, she mentions how much better it was for her great-aunt to live in a LTCH rather than the hostile environment of her son and daughter-in-law's home. While this might suggest that living with family is only preferred when that living environment is a positive one, it also shows evidence of Kelly's family having negative feelings about needing to resort to a LTCH instead. It was counter to their cultural expectations of the family and so the move out of the family home into a LTCH was viewed as negative. That said, Kelly came to (re)value what it meant for her great-aunt to live in a LTCH:

"...they actually get activities. She gets to come downstairs. Every single day there's different activities all day long and she gets to choose whether or not she participates.' So I thought that was kinda nice. I felt that long-term care homes were sad before that. Cause I... I don't know if it was the way my family made it sound but it kinda just sounded like they... stick them there because they didn't want them to live with them anymore. And then I was, in my head, I always thought that it was a sad place or they weren't the happiest to be there but that moment stuck out to me cause I was probably thinking that this may be a good option for them.

Millie also connects the idea of living in a LTCH as counter cultural to the Portuguese values she grew up with. Despite the negative connotations of asking for and receiving care in these settings, she finds herself, as well as other family members, wanting to work in LTCHs. And if

medical care is unwanted, recreation therapy is apparently unheard-of and novel to the Portuguese people she interacts with. While owning her Portuguese-ness with pride by mentioning how every meal has "bread and potatoes", she (re)values the part of her culture that is resistant to the idea of receiving care by training to become a care provider herself.

The voice of cultural identity was seen as incredibly significant and core to how most of the participants understood the experiences of life and leisure in LTCHs. Meanwhile, each story presented a moment where justification was offered to break from the traditional and accept that LTCHs were a necessary step in the life of the older adult. Even Phoenix, who offered the strongest rejection of LTCHs as a necessary step in the life of his grandmother ("there was no reason for her to move in the first place"), thought that the idea of a community of peers offered a reasonable socialization opportunity for older adults:

[So] from a strictly socialization standpoint and creating a community of people who have lived through the same things as you and have experienced the same sort of stuff, I think it's a good idea to have community living centers.

When the setting was connected to their cultural identity (e.g., making gnocchi from scratch in the kitchen, receiving gifts from the Chinese dollar store, playing Mahjong in the predominantly Asian LTCH, getting your tonsils out on the Mennonite homestead, etc.) it was seen as a positive setting. When they were absent, the setting was seen as detrimental (e.g., language barriers, the wrong kinds of food, asking for unwanted help, etc.).

A major setting that most of these stories took place in was Canada. Being in the Canadian context likely played a significant role in the stories of how participants and their families (re)valued their positions. How would these stories have been different had they not taken place in Canada? It's possible that nothing would have changed for them. Researchers in Taiwan have

previously shown that Chinese Millennials are increasingly becoming more open to the idea of their family members going to LTCHs (Hsiao et al., 2018). But does living in Canada make this decision easier? Unfortunately, I do not have an answer for that but it would be an interesting direction for future research.

#### Family Stories

Family stories have been understood as a generative activity, one which helps guide and develop the next generation (Green, 2013). They have been described as serving to explain origin myths, real-life histories, and cautionary tales (Green, 2013). Through these interviews, I heard several family stories which led participants to certain understandings of life and leisure in LTCHs. In some cases, participants were inclined to challenge those stories by engaging in (re)valuing. In other cases, such as Betty's, the lack of any family stories led her to conclusions that were challenged as soon as she had a new experience that would become something of a family story to fill the void

Kat had several family stories that were tied to her Mennonite culture, and they had an influence on her understandings of LTCHs. However, when I asked how she would describe herself, she said:

You know that's a pretty hard question because I'm still kinda figuring that out. Part of what I really have drawn from being Mennonite and growing up and kind of having those beliefs around is just the sense of family and the sense of community. And I see it interestingly enough with the two sides of my family. (Kat)

Kat went on to describe those differences between the two sides of her family. It was clear from our 'Mennonite bingo' exchange that she associated strongly with that community but not completely. Her Mennonite side had some distrust of the medical community and preferred to

take care of their own at home, viewing LTCHs as a place for older adults who expressed a "tendency to have violence." On her mother's side, the ethnic or cultural identity was not described but she said they were very much in favour or engaging with the medical community (aside from her grandmother's hesitation with LTCHs). Kat grounded her own position by saying, "I think it comes a lot from, like, seeing what your family has done. Like seeing what your parents did, seeing how other people have dealt with it, how much education you have."

At the time of our interview, Kat was actively engaged in her own process of (re)valuing and deciding where she stood on the two seemingly opposing positions that her family aligned themselves with. She told stories about how her great-grandparents would have medical procedures done at home or consume whiskey to help with period cramps. These family stories, as entertaining as they were, also had to be (re)valued in the context of the healthcare world that she and her friends were trying to enter into. Kat will, presumably, continue in the act of (re)valuing based on the family stories that she engaged with that had not been shared with me.

Betty had a different story from the rest when it came to (re)valuing. Betty never connected her perceptions of LTCHs to her cultural identity. In fact, she never mentioned her cultural identity at all. However, Betty did share that her family influenced her understanding of end-oflife matters by not discussing it. Whether or not this topic was perceived as taboo was never mentioned. Betty described her initial understandings of LTCHs as a place you go to die. Now she understands that there are several more options, such as palliative care, but it wasn't part of the conversation when she was younger. How many of us have walked into a LTCH or retirement home and seen a number of older adults blankly staring at a TV screen or asleep in their chairs? Betty had.

I just remember in one seeing a lot of people sleeping. And I just remember being kind of weirded out by that when I was younger... There are lots of different hospice or palliative care services that actually assist with your end-of-life process. As a kid who didn't know any of that, I was just like, 'Oh, so these people go to these homes where they are just in really large groups and then you just position yourself in front of the TV for like multiple hours.' I definitely saw it as a bizarre thing. But I would also equate it to being younger and not really being exposed or having open conversations about the end-of-life process. I'm not sure if it was, like, I didn't know because it wasn't something that was talked about a lot. (Betty)

To 12-year-old Betty, this was how you prepared to die. You found a comfortable spot and waited. Betty gave no indication that this idea was ever challenged while growing up and it worried her.

But when the time came for Betty's grandmother to pass away, she shared that it was really special to be part of that moment. It wasn't wrapped in fear but rather in comfort. Death was not a part of the family conversation and so Betty had to fill in the blanks herself and it had worried her as a child. Being part of the process when her grandmother died redeemed it for her so that it was no longer scary but rather special. Betty wasn't raised to talk about dying but she was willing to offer up the discussion on her own as part of our conversation because it was important to her. Her understanding of LTCHs and their association with death had been (re)valued by living a new family story about death that could fill in the void of stories that existed before it happened.

Kelly engaged in (re)valuing when she told her story of retirement expectations. Kelly's mom "always said that when I went off to university that she would just retire and then go

travelling and that's when her life begins again." Kelly used this story to explain that she had thought of LTCHs as a place you only went to after you were "well seasoned into your retirement". Kelly thought that she might do something similar when she retired:

If I ever have children and they're out of the nest then I'd be able to re-explore my passions and maybe pickup new skills and hobbies. Travelling the world is my mom's dream but my dream is... I wanna make puzzles. You know like different ideas of building skills or pursing new passions. Mine are a lot more domestic.

Kelly had heard the stories of what retirement would be like from her mother and they involved seeing the world. But Kelly didn't see it that way in her own story of retirement. She wanted to make crafts and do puzzles. Kelly was engaged in (re)valuing the retirement lifestyle based on her mother's stories of what it would be like. For this reason, Kelly actually saw LTCHs as something that wouldn't necessarily be that bad if she was able to still do her crafts and puzzles.

Family stories, though they may occasionally be connected to our cultural identities, influence how we engage with and make sense of the world. However, they are not set in stone. Several participants challenged and re-assessed their values in light of how they understood LTCHs. In turn, those values and (re)values also influences how they understood life and leisure in LTCHs.

The discourse on *(Re)Valuing* recognises how cultural and/or family values shape our sense of self and inform what we believe about how we should treat older adults while also reevaluating those positions in light of more dominant and shifting cultural identities, family stories, and experiences.

# Summary

In summary, the three discourses that emerged in the stories shared by the participants were the discourse on *The Transition(ed)*, on *(Mis)Management*, and on *(Re)Valuing*. The discourse on *The Transition(ed)* is a covert realization that we may one day have our autonomy and thus our older adulthood stolen from us, either by tragedy, professional opinion, or family. The discourse on *(Mis)Management* is a recognition that something is fundamentally broken about the system of care that older adults have access to today in LTCHs, while believing there might be a way to fix it through policy, economics, and empowerment. Residents living in these spaces and staff working in them are both harmed by this oppressive mismanagement. The discourse on *(Re)Valuing* recognises how cultural and/or family values shape our sense of self and inform what we believe about how we should treat older adults while also re-evaluating those positions in light of more dominant and shifting cultural identities, family stories, and experiences.

Taken together, these three intersecting discourses shape how students understand and construct the stories of life and leisure in LTCHs. They also come together to influence how young people see themselves, and their relationships with the older residents, in those settings and provide important clues on what would need to change for them to want to live as young people in these settings. I turn to that next.

"What Dad didn't understand was that no matter how much he hated or feared the future, it was coming, and there was only one way to deal with it: by climbing aboard."

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(Walls, 2009, p.68)

# **Chapter 5: Welcome to Civitas**

This chapter contains a collection of short narratives, based on the narrative futures described by this study's participants. Additionally, it draws on aspects of LTCHs which the participants shared at earlier points in the interviews as well as my own voice to construct the world in which these narratives take place. To establish their narrative futures, participants were provided the following scenario:

You have been given the opportunity to have a free room and meals in a LTCH near your school. The LTCH is within walking distance and a bus stop is just outside as well if needed. In exchange for the free accommodations, you must make an effort to spend some time with your new older adult neighbours.

Follow up questions were used to help probe their stories (see Appendix G). Participants were asked to describe a typical day in this environment for them, who they would meet, what they would do, and so on. Rather than expressing each of their own constructed narrative futures as independent stories, I have consolidated their ideas to create new narratives that express their ideas in concert with one another, using dialogue as a tool to represent discourse. The concepts I drew on from each interview have been provided in Appendix I and will be discussed in greater detail through the final chapter of this work.

There are four narratives in this chapter: Moving In, Knowledge Exchange, Handling Challenges, and Moving On. Each one follows a young adult who has chosen to live in an intentional and intergenerational community called Civitas, a name that reminds us of the intricate linkage between the built environment and its habitants. Civitas is a Latin word that refers "simultaneously [to] the city and its citizen community" (Wallace-Hadrill, 2020, p.18),

where each member of the community is recognized as a sovereign participant in the direction of that city, a value that was persistent across the participant's narrative futures.

These new narratives below are set at least 50 years into the future and as such contain elements of science fiction or futurism but don't let that dismay you to believe they are unrealistic or simply concocted fantasy. The year was intentionally selected since that is approximately when the typical undergraduate student today would start to become eligible for living in LTCHs as they exist today. The main ideas expressed through each narrative are an evolution of what this study's participant storytellers said would be necessary for them to live in a long-term care home today. If that is true today, it is reasonable to assume that would be true in 50 years, especially when it comes to topics of autonomy, privacy, friendship, family, learning new things, etc.

# Moving In (Saturday, September 6, 2070)

The autonobus silently purred up to it's stop, right outside the Civitas Intentional Community. Alaric grabbed his duffle bag from the overhead storage bay and slung it on his back before exiting through the rear door. Alaric had dreamed of living at Civitas ever since his older brother had lived there three years earlier. Alaric was now entering his second year of undergraduate studies in therapeutic recreation, a bit unlike his family, who were mostly historians. His older brother, Eno, always raved about living at Civitas because it brought history to life! Eno would return to the family home on holidays and retell his neighbours' stories about the Lost Years of the '20s, the economic hardships, and the subsequent boom which led to the Migratory '40s, in which people from across the country uprooted their lives in a collective effort to reorganize as intentional communities. Eno was obsessed with that time period and the efforts made to avoid other pandemics and epidemics, both viral and social. Alaric, on the other hand,

was less interested in those years. He was more enamoured by the idea that he could make a difference today by fighting for wellbeing through meaningful social connections, space, and activities. As an added bonus, his favourite TwitchVR duo lived there; Fred and Tony of the Frony Show.

Alaric entered through the main doors as the autonobus purred away behind him. It was even more spectacular than he imagined. He had walked through images before on their InstaReal stories, but they didn't quite do it justice. The main room was enormous, with tall, vaulted ceilings and large windows across the entire back wall. Looking to the left, Alaric saw a café and patio-like space which advertised an oatmeal and fruit breakfast, followed by a dim sum lunch. The smell of baking wafted out from the café and Alaric wondered if they made their own bread and pastries. He heard that Civitas operated on the concept of shared responsibility, so the bakers, cooks, and servers at the café were all likely to be residents.

"Hello? Can I help you?" called a friendly voice from behind. Alaric turned to see the kind face of a woman, contoured by the passage of time, laughter, and grief, in a pale blue pantsuit with ruffled collar and hems. The crest of Civitas on her left lapel indicated she worked in the community's hospitality department.

"Yes," replied Alaric. "I'm here to move in as part of the university's Cooperative Community Placement Program with Civitas."

"Excellent! You can drop your things off behind the front desk here and I will get you started with the tour."

The tour guide's name was Rhiannon Walsh. As they walked together, Rhiannon explained that she had a long history with the community at Civitas, even before it existed as it did today. She explained that 40 years ago, just before the migratory years, she was responsible for

managing her parents' affairs while they moved into this community. At the time, it had been called Sunny Glen Village. It was an institution where only older adults lived, called a long-term care home. It had changed several times to include a community daycare and other types of intergenerational programs, but during the Lost Years of the '20s, much of that had stopped while the community was isolated from the world for it's own protection. By the '30s, when Rhiannon was helping her parents to move, the echo pandemic of loneliness was fully established in Sunny Glen Village. However, what drew Rhiannon and her parents to this particular home was their attempt to combat the echo pandemic by introducing an intentional, intergenerational community model which invited local university students to live at Sunny Glen. It was bumpy at first, with a lack of interest from students. But as Sunny Glen learned what the community needed to thrive, students began to apply in droves.

"My parents were avid cyclists, even into their 90s," explained Rhiannon. "When Sunny Glen introduced bike storage and bike lanes directly to the university for the student residents, my parents were thrilled that they could use those facilities as well. Students wanted to be able to cook for themselves, the ability to start book clubs and knitting circles, and have lockable doors for their units. Introducing changes like these helped Sunny Glen to realize that giving their older residents the same access to freedom and privacy that students wanted was beneficial for the entire community. Of course, emergency overrides were available to unlock unit doors in case of emergency but there were strict policies about when it could be used. Small changes evolved into bigger ones and when the great migration into Intentional Communities was underway, Sunny Glen evolved once more into the Civitas you see today. An intentional community for all people, 'Doing Life Together', as our motto says."

Rhiannon showed Alaric the central courtyard, around which the community was built. It was filled with pathways and benches under large, sprawling trees. What Alaric noticed the most was the raised community gardens that filled a quarter of the courtyard, residents of all ages and abilities tending to the plants and harvesting some of its produce, together.

"These are only some of the gardens," said Rhiannon. "We placed them in the courtyard to allow for people with various constraints to be able to participate if they wanted to. There is much more out back. Obviously, we aren't able to produce enough food to feed all of us yearround; what's why we partner with local Intentional AgriCorps for much of our food. But nothing beats the satisfaction of digging out your own potatoes for dinner one night! In Autumn, many of our residents will harvest and can the produce so we can enjoy it through the winter as well. Sharing what they produce is a great source of meaning and pride for our community."

The tour concluded at Alaric's new apartment. Although single rooms were available at Civitas, Alaric opted for one of the shared apartments that came with a roommate. There were also 3 and 4 person apartments available, as well as family units. Alaric settled into his room which provided a single bed, desk and reading lamp, some shelving, and a large window which let in plenty of sunlight. His things had already arrived in the room, presumably brought in by a member of hospitality. Rhiannon had reminded him that orientation would begin for new residents on Monday, but until then there were plenty of activities to investigate, clubs to join, and tasks to complete that weekend if he wanted.

As he unpacked, two men walked past the apartment's open door, talking about something highly technical sounding. One looked much older, with slicked back silver hair, a green sweater vest, and spoke with a thick Italian accent. The other was probably half his age, with messy black hair and a sports jacket over a band t-shirt. His voice growled deeply like one of those ancient

internal combustion engines. Alaric stepped out into the hall to get a better look, but he could already tell who was living on his floor. It was Fred and Tony from the Frony show on TwitchVR.

Awesome! This was going to be a great year.

## Knowledge Exchange (Tuesday, November 18, 2070)

Cassian wasn't the greatest baker before moving into Civitas Intentional Community. In fact, when they first moved in, they did so with the understanding that they would contribute to the community through music. Cassian was a fantastic pianist who was working towards a Bachelor's of Music, focusing on the classical pieces of the early 21<sup>st</sup> century, such as *Mr*. *Brightside* by The Killers or *Hey Ya!* by Outkast.

And Cassian certainly did make the halls of Civitas ring with excitement when they tickled the ivory keys of the classical piano that was set up in one of the communal living rooms. Hammering away to their own renditions of music by Taylor Swift, Lady Gaga, and Drake, the floor would become electric with excitement while audience members would belt out the lyrics, "You used to call me on my cellphone", a concept entirely foreign to Cassian.

However, Cassian had other interests too. For as long as they could remember, Cassian wanted to learn how to bake. There hadn't been much opportunity back when they lived at home with their parents. Cassian's parents were experts in ordering food for delivery, using their kitchen for nothing more than decoration. Although playing music for the crowds was fun, it often felt like doing homework. For sure, Cassian needed to practice for upcoming tests, and this provided a fantastic outlet for that practice. Still, Cassian would smell the incredible foods coming out of the communal kitchens or cafés and wish that was something they could make.

On this morning, Cassian was sitting at the piano, humming half-heartedly and scribbling some notes on their smartpad, occasionally striking a single note or two. Carolina Santos, one of

the resident bakers, came into the room with a fresh batch of croissants, offering them to whoever was sitting in the living room. Carolina had owned a bakery for 35 years before moving into Civitas 10 years ago. Now she was using those skills to ensure everyone at Civitas was intaking exactly the amount of butter and carbs that doctors regularly advised against. It was her public joy and private rebellion. Carolina approached Cassian at the piano and asked if they wanted a croissant.

"Oh yes please!" said Cassian. "Thanks so much, this is really making my morning."

"You're very welcome, Cassian," replied Carolina. "You know, you make my day every single time you sit down to play the piano. Even when you don't play the piano, I can see you working the notes out in your head, writing music that only you can hear. It is a beautiful talent that you have. Sometimes, I really envy your abilities."

"Really? Thanks Carolina. Have you ever played an instrument before?"

"Not since I was very young," replied Carolina. "They used to hand out recorders to each of us in elementary school. I could never figure out what to do with my fingers. And it was a relief every time that class was over. But you have a real gift for this."

"If you'd like, you can join me and I'll teach you how to play something," suggested Cassian.

Delighted, Carolina set down the plate of croissants on the coffee table and Cassian shoved the bench aside so Carolina could maneuver her wheelchair next to it. Cassian guided Carolina's fingers over the keys, indicating which notes to press and when to do it. Cassian showed Carolina the melody a couple of times and Carolina would try to replicate it, clumsily at first, then confidently as they practiced. Before long, Carolina was tapping out a very staccato *Chopsticks* in treble while Cassian improvised an elaborate riff in the bass. An audience slowly

gathered as neighbours from down the hall joined to watch the show. Cassian would play a little faster and Carolina would try to keep up until finally they broke out into laughter and could not keep it going. The room was buzzing with excitement.

"Wow, that sounded good!" exclaimed Carolina, between wheezing breathes and giggles. "I never would have thought I'd have that much fun with an instrument."

"You did great," said Cassian. "If you want to learn how to play more, I would love to teach you. And to be honest, I have really admired how well you bake. I never learned how to use a kitchen growing up. Maybe I can trade some piano lessons for baking lessons?"

"You never learned how to use a kitchen?" said Carolina, utterly shocked. "This evening, you come up to the kitchen on the third floor after dinner, and we will make the best focaccia bread of your life. I've already got some dough prepping in the fridge, but we can make more if you want to learn from scratch."

Cassian excitedly accepted the offer and looked forward to it for the rest of the day. Sure enough, that evening they made the best focaccia bread the community had ever tried. Cassian drowned theirs in olive oil and enjoyed the fruit of their labour. Next week, Cassian thought, they would invite Carolina to try playing Canon in D, and in return, perhaps they might make white chocolate, macadamia nut cookies, a Carolina classic!

Booyah! This was going to be a good week.

## Handling Challenges (Friday, March 20, 2071)

"That's it! I'm leaving!"

Falynn slammed the door to her bedroom, shaking the digital PhotoFrames hanging on her walls. Things had been difficult ever since her new roommate, Meagan Dennis, had moved in. Falynn tried to tell herself that she should be patient, that Meagan was just having a difficult time adjusting to her new normal. Afterall, Falynn thought, what if I had been thrown off the back of a

horse only days after retiring from my career of 43 years and became paraplegic. Falynn tried to be empathetic to Meagan's situation, but she was dealing with her own crises too and just couldn't take it anymore.

Falynn had moved into Civitas as a part of the university's Cooperative Community Placement Program. Originally, she had been excited for the opportunity. Her passion was to be a community manager one day and that required she spend at least a year in placement with a local intentional community. She chose Civitas because it had one of the better reputations. Since September last year, she had been fully engaged in the community running book clubs, organizing field trips to a neighbouring community's art gallery, and, most recently, starting a Zumba class on Friday mornings. But these weren't just activities for padding a resumé; for Falynn, they were some of the most meaningful moments she spent with her neighbours.

However, there were other demands pulling at Falynn's time as well. She was involved with intramural sports at school, was behind on three projects (all of which had extensions coming due), and was starting to look for work after graduation this year. Organizing her schedule and life patterns to fit the communal routines of Civitas was a challenge all on its own. Her 'Type A' personality had gotten her this far but now it was starting to feel as if everything was crumbling. To top it off, Falynn hadn't been able to sleep well for the last three weeks. She could hear Meagan at night through their shared wall. Sometimes it was gentle crying, other times it was loud sobbing or screams from night terrors. During the day, Meagan wouldn't leave the apartment and watched the same couple of movies over and over.

Falynn had tried to approach Meagan but she wouldn't have it.

"How could you have any idea what losing the independence of your older adulthood is like?!" shouted Meagan between tears of anger and sadness.

Losing *your* older adulthood? What about *my* younger adulthood, thought Falynn. She would regularly video-chat with her friends who lived outside of Civitas in the student-only sector of town. At first, it wasn't a big deal to hear about the 'wild world' her friends were living in. Occasionally she would still head out to join them or she would host a party at Civitas. She really hadn't felt like she was missing out on the 'quintessential student experience' until the last three weeks.

This morning was the last straw. She had been late to her own Zumba class by 20 minutes because she slept through all three of her alarms. Meagan had been having one of her fits all night again. Falynn was exhausted and embarrassed and finished with Civitas.

"Community is hard," she thought. "Maybe I'm not fit to be a community manager. I need a drink."

She went down to the Kegger, Civitas's bar, which was right beside the MainStream, a portion of the rec hall dedicated to video games and VR experiences. She noticed Tony Romano was inside, alone, playing a game on one of the large projector screens. Maybe she would stop by and chat with him; Tony was always good for a talk.

Falynn grabbed a sour mead with blueberry twists from the bar, her favourite comfort drink, and wandered into the MainStream.

"Hey Tony," said Falynn.

"Falynn! Good to see you!" said Tony, without taking an eye off the screen. "One second, I'm almost finished this race. Fred's ahead of me but I've been holding a secret weapon."

Falynn grabbed a seat next to him on the couch and watched as what looked like a blue turtle shell launch from Tony's racing cart and plow through another cart ahead of him,

presumably Fred's. Upon impact, she heard a voice yell something like 'duck in fell' through the earpiece that Tony was wearing, as he laughed and drove across the finish line.

"Good race, Fred," said Tony. "Maybe next time. I gotta go; Falynn is here. Lick your wounds and I'll beat you again tomorrow." Tony tapped the smooth surface of his earpiece and looked at Falynn. "How you doing?"

Tony was an Italian man in his late 70s who had helped to pioneer the MainStream in its early days. He wore an iconic green, knit sweater vest almost everyday and reminded Falynn of one the characters from a turn-of-the-century New York sitcom that was always playing on the classic television streams.

"Honestly, it's been a really hard day. I think I'm ready to quit Civitas and move back into the student-only sector. I'm behind in everything, Meagan keeps giving me grief, and Clarence on the fourth floor keeps talking about the same stuff again and again. Still believes his Dogecoin will 'moon' after all these years. I just can't take it anymore."

"Sounds tough," said Tony. "You know, people are pretty difficult to live with sometimes. But difficult things aren't always bad; their just, you know, difficult."

"Does it get any easier?" asked Falynn.

"Oh my, not at all," laughed Tony. "We're all just doing our best to figure things out as we go along. And once you think you have it figured out, life throws another curve at you. I spent years trying to figure out what I wanted to do with my life. I found and lost at least 3 'life callings', or whatever you want to call them, before I got here. And I still don't know what I wanna do tomorrow. I learned not to take life too seriously."

"I guess. But it's still hard not to feel like my life is crumbling around me. I thought I wanted to do community management but how am I supposed to do that if I can't even manage

my own life. I get that the idea of this place is that we should be 'Doing Life Together' or whatever but sometimes stuff comes up and I just feel a lot of pressure to always be on. I wish I could have just done it differently."

"Civitas is about living not performing. It's a lifestyle, not a job. Perhaps those two functions get muddled a bunch around here but that's the fluidness of life. If you really feel this isn't for you, that's fine. It isn't for everyone. But maybe it's just a bad day and there will be better ones. No use in making life-changing decisions because of a couple bad days. As for your roommate issues, talk to Hospitality about it. Sounds like you and Meagan need more support than you can offer each other. Maybe they can work out a better situation for each of you."

Falynn stirred the remaining fruit pieces around the bottom of her glass and considered what Tony had said. After a few moments of silence, he tossed her one of the game controllers and asked, "You wanna play?", as his iconic half-smile spread across his cheek.

"Sure," she said, cracking a smile as well.

Falynn didn't know if she agreed with Tony's philosophy or not, but it was something to think about. She finished her sour mead and set it aside, taking up the game controller. Maybe it was just a bad couple of weeks and there would be better ones. There certainly had been in the past. She would talk it through with Hospitality and see what her options were. Maybe Meagan should be part of the discussion too, she thought.

Ugh. This was going to be a hard conversation.

## Moving On (Friday, April 28, 2073)

The autonobus silently purred up to it's stop, right outside the Civitas Intentional Community. Alaric grabbed his duffle bag from the ground and stepped in through its front doors. He had graduated from school and was leaving the intentional community although he

didn't have to leave upon graduation. In fact, many people did choose to stay at Civitas longterm after completing the Cooperative Community Placement Program.

In Alaric's case, it had been a remarkable experience. For years after he would tell people that the experience he actually gained living in that community environment was more important to him than his degree ever was. This was why he was leaving.

Alaric's parents had sold the family home and were moving across the country. After years of listening to their kids rave about Civitas, they decided it was time to retire from their careers and move into an intentional community closer to their families. They had originally moved cross-country for work, leaving family and friends behind, but now they wanted to return to somewhere familiar. Fortunately, there was an intentional community in their old hometown and a few friends had already moved in so it would make for an easier transition into communal life. Alaric had decided to join them in moving back across the country and settling in their new community. He had other incentives too.

Cassian stuffed their bag into the overhead compartment and dropped down into the seat next to Alaric.

"You are going to love the ocean," said Cassian. They had grown up on the coast in the same hometown as Alaric's parents but moved for university in 2070. Cassian had decided they would move back home and live in one of the intentional communities there. This might have been Alaric's additional incentive. He liked his family and all but there was something special about Cassian that he enjoyed and he wanted to stay close by. Three years at Civitas together had made them close friends and Alaric wasn't about to let that go so easily.

"Alright, let's get this show on the road!" Tony loaded all three of his bags into the undercarriage of the autonobus and gave it a slap as he boarded. "This thing won't drive itself you know."

"Actually, it will," joked Cassian. The autonobus started moving forward, throwing Tony back against the seats in front of Cassian and Alaric.

"Wow. This thing has more get-up-and-go than Ethel Franklin, God bless her," said Tony.

"Aren't you going to miss doing the Frony Show with Fred?" asked Alaric.

"Ah, sure. But I'm going to equally enjoy watching him work with this new squirt who can run circles around him in Battle Chess. Fred has no idea what's coming. Ha!" Tony settled into his seat and quickly went to sleep. He was also moving to the coast to help setup a partner streaming platform at a new intentional community. He might be 81 but he was still considered the best.

"I'm going to miss living at Civitas," said Cassian as they settled their head on Alaric's shoulder. "It was so much fun to learn about so many different perspectives and life experiences. I think I will be taking what I learned with me for the rest of my life."

"Oh, for sure," said Alaric, being very careful not to move his body so that it wouldn't disturb Cassian. "It was routine and comfortable and I like that about a place. I mean, there was room to be spontaneous too and it wasn't too tightly scheduled. It was just, you know, comfortable. I could organize my day around my various commitments and schoolwork, and still know that I was coming home to a place where people felt like family and we could watch a movie or something. That's a good feeling."

"Do you think it'll be hard to start that over again in a new place? I mean, I guess we know some people and I heard Falynn was hired as a community manager there, which will definitely help, but there will still be a lot to learn."

"I guess so. The nice thing is that everyone who chooses to live there does so intentionally, with the purpose of doing life together. I expect there will be a lot of new ideas, perspectives, and life experiences that shape the community, but I don't think we will have trouble moving in. We get to hang out with all sorts of people, have our independence and privacy when we want it, meals and housing are taken care of, there is ample opportunity for meaningful connections and activity, and, with time, it will be filled with people we know and care about. Like a family. Wherever we go, that sounds like the kind of long-term home I want to live in."

Alaric stopped and looked down, noticing that Cassian's eyes had shut, with a small drop of drool pooling on his shoulder. The people I know and care about, he thought. Yeah, this is my kind of long-term home. As the autonobus silently carried them away, Alaric closed his own eyes and dreamed of the future that was ahead of them.

Oh yeah, this was going to be a good life.

"But I spoke hastily. We must not be hasty. I have become too hot. I must cool myself and think; for it is easier to shout stop! than to do it.

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(Tolkien, 1977b, p.77)

## Chapter 6: So, What Then of the Future?

In this final chapter, I will discuss the narrative futures from chapter five, seeking a possible solution to my third research puzzle: What does the emerging dialogue suggest about future participation in cohousing programs? As well, I will speak to it's implications for the intergenerational contact model and research in this area moving forward.

## A Discussion of Moving In

In this first narrative future, *Moving In*, the stage is set and we meet a second year Therapeutic Recreation student named Alaric. Alaric has moved into the Civitas Intentional Community as a part of the university's Cooperative Community Placement Program. The suggestion is that this program might operate similarly to a work cooperative placement program but for the purpose of building community-related skills and networks rather than work-related skills and networks.

The idea that an intergenerational cohousing program might operate in this way comes from the way the participants considered this scenario. For them, moving into a LTC community under the conditions of the scenario presented (you will receive accommodations in exchange for community engagement) was seen as a regulated and supervised program that they would take part in, as opposed to a lifestyle choice. For example, when presented with the scenario, Olive asked questions such as "Is there a certain hours per week?", "Do I have a couple that I am assigned to?", "...to whom am I accountable?", etc. Initially, Betty expressed some hesitation at the idea of living where she worked, implying that she saw this as a work opportunity that would be relevant to her future career endeavours in LTCHs. Phoenix said that "it's still a business and there's probably going to be some kind of contract here that dictates a weekly allotment of time spent..." running community-building programs. Kat suggested that the program might be more

similar to L'ARCHE Canada, a program which matches up live-in and live-out assistants with a home for persons living with intellectual disabilities (L'Arche Canada, n.d.).

This shouldn't be surprising on the one hand as I myself have often thought about intergenerational cohousing as something similar to a Residence Life Don in university residences, except without the power dynamic inherent in that role. In fact, several participants made exactly this same connection to a Residence Life Don. On the other hand, I have increasingly come to think of intergenerational cohousing as something that could or should be more akin to a lifestyle choice. I relayed this sentiment through Tony Romano's voice in the narrative future entitled *Handling Challenges*, "It's a lifestyle, not a job. Perhaps those two functions get muddled a bunch around here..."

Based on the interviews in this study, it would make sense to offer an intergenerational cohousing program in a LTCH with a contract for the young adults that clearly outlines the expectations of their time spent in the home. In fact, it is my understanding that this is already how similar cohousing programs are operated (Allen, 2017; Fox, 2010; Howe, 1985; Sánchez et al., 2011; Suen, 2012; Ward, 2004). In my experience living and working as a Residence Life Don at the University of Waterloo, it began with a contract and training to do the job that was required but quickly became a lifestyle in which I was choosing to do life with this group of (typically) younger people moving away from home for the first time. I suspect that something similar may occur for young adults who choose to participate in an intergenerational cohousing program at a LTCH for an extended time. The two functions (life and job) may become muddled.

Through *Moving In*, we are also introduced to the setting in which Civitas exists. The most positive descriptions of existing and imagined LTCHs from participants often included large windows, sunlight, open space, access to air/outdoors, and so on. The 'old, hospital smell'

attributed to LTCHs was replaced with more welcoming scents such as freshly baked bread of a nearby café. A variety of foods mentioned in the interviews were placed in Civitas to show the significance that food played on making a space feel like home.

Each resident's door could be locked since access to privacy was a deal breaker for many of the participants, as well as a complaint for many older adults residing in LTCHs that they knew about. Millie, in particular, said that she would have no interest in living in an intergenerational cohousing program if she could not lock her doors, citing an example of privacy intrusion experienced by a resident she worked with at a LTCH. Provision was provided to unlock doors according to strict policies so that emergency or auxiliary services could be provided when needed.

Access to the world outside of Civitas needed to be easily obtained and encouraged for all residents in order to avoid becoming a total institution (Dupuis et al., 2005). Again, Millie highlighted the importance of having access to the outside world via taxis and buses so that residents could maintain a level of independence. Thus, access to public transit, bike trails and storage, and walkways needed to be available to all members of the community. For the participants of this study, LTCHs have to make significant upgrades to how they build their home environments in order to become more habitable, access to privacy and space being the two most significant factors. I believe that taking that into consideration will not only make homes more attractive and habitable to young people but for older residents as well.

In their study of college students' perceptions and attitudes regarding residential care institutions, French and Mosher-Ashley (2000) argue that the highest rated positive features for a LTCH were it's pleasant décor, home-like atmosphere, and friendliness of staff members towards residents. Décor and aesthetic became a negative when it reflected a sterile, hospital appearance.

Participants in their study were much more detailed in their descriptions of the negative attributes of the LTCH that they toured, including: increasing resident privacy, increasing resident interaction with the outside world, increasing the number of staff, needing better food options, doing away with an unpleasant odour, and so on. There were a total of 25 recommended changes compared to 7 positive aspects. It has been twenty years since that study took place in central Massachusetts. The perceptions of college students touring LTCHs in the year 2000 have not changed significantly when compared to the perceptions of similarly aged Canadian students in 2021. Furthermore, the study concluded that these particular negative perceptions of LTCHs, or equivalent residential institutions, hadn't changed in 30 years prior to the study. That indicates that these perceptions of have persisted in some form for at least the last 50 years.

In his 1975 work, *Why Survive? Being Old in America*, Butler describes "Houses of Death", that being nursing homes, in this way:

Often there is a pervasive, permeating odor of urinary and fecal incontinence... food costs are kept down to the point of malnourishment... Occasionally, there are books, shops, and beauty parlors. Ironically, barbers and beauticians may have more professional training than either nursing aides or ambulance drivers... How often can the resident of a home go out freely and buy a hamburger or have a cocktail?... Why [can't they have] one's own furniture and some familiar personal possessions instead of institutional furnishings? What about privacy for sexual activities? (p.265-266)

Half a century of talking about the same stuff over and over and over. When Kat mentions the "manufactured" appearance of the downtown village in a LTCH or Phoenix brings up the "generic soap opera set" of a recreation living room, these are observations that have been made in only the last four years. Kehyayan et al. (2015) reinforce some of these points in their study of

self-reported quality of life for LTCH residents. Only 62% indicated that they could control who accessed their room and 59% reported a home-feel to the facility (Kehyayan et al., 2015). Low scores were given to food options and mealtimes, which the authors suggested could lead to malnutrition, depression, and mortality (Kehyayan et al., 2015). This reminds me of Kelly's great-aunt's experience when she moved into the less-expensive, non-Asian LTCH.

The environment that is described in Civitas attempts to address these issues, based on the participants' narrative futures. Participants were able to imagine a world that was better than what we have offered for the last 50 years. I am left to wonder why it has not yet materialized.

On one final note, Alaric is introduced to multiple opportunities for meaningful activities and social connections. Among meaningful activities mentioned by the study participants were clubs for reading, kitting, crafting, etc. as well as puzzles, games, cooking/baking, and socialization. Access to outdoor recreation such as gardening, walking, and cycling were important to some of the participants and their loved ones and so it was included in Civitas. Both Phoenix and Kelly mentioned the importance of still being able to do things for themselves and as they got older and so a significance was placed on giving residents of Civitas the opportunity to "share what they produce..."

## A Discussion of Knowledge Exchange

The second narrative future, *Knowledge Exchange*, introduces us to Cassian, a music student studying "classical" music from the start of the 21<sup>st</sup> century. They enjoy what they do but feel like they are somewhat stuck in their role as a pianist at Civitas. Meanwhile, Carolina Santos, a retired career baker, who has continued in that role while living at Civitas, has been watching and listening to Cassian all this time, secretly wishing that she could have the same skills. Through this narrative future we see that intergenerational cohousing programs are useful in facilitating and reinforcing knowledge exchange between the generations. This scene is based on

a portion of Phoenix's narrative future in which he learns how to play chopsticks from one of the older adults who hears him hammering away poorly on a piano.

The idea that an intergenerational cohousing program would be a source of knowledge exchange was common among the narrative futures that participants shared with me. In Phoenix's narrative future, he met two characters with whom he engaged in mutual knowledge exchange. One was a lady named Ethel with whom he did laundry, ate meals, and discussed dating. The other was a man named Fred who was a war veteran that became his computer gaming partner. (In some way, a nod was given to both Ethel and Fred through the character Tony of the Frony Show duo.) For Phoenix, the idea that knowledge exchange could be "bidirectional" across the generations came out of his experience living with people younger than him in university residences as well as with older adults through his time working for the railroad. In a very succinct summary, he said "…there are things to be learned and things to be taught in a bidirectional sort of sense… we each have things we can give to each other."

Olive arrived at a similar position of mutual knowledge exchange through her experience working in a LTCH and then in her narrative future. Like each of the participants who had worked in a LTCH, Olive said that she learned so much from her relationships with the older adult residents that were under her care. In her narrative future, she talked about learning how to crochet or knit from her neighbours. She also suggested that "[older adults] appreciate learning new things and seeing new things..." and that she would try to discuss new ideas or concepts with them.

Hearing this from the participants reminded me of the work done by Ballantyne et al. (1998) in which intergenerational influence was used as a means to expand the reach of learnings related to environmental issues. They argued against the unidirectional process of learning, that children

are primarily receivers of learning from older generations, and instead adopted an interactionist approach in which learning and influence could be bidirectional under the proper conditions. This challenges cultural age-segregation that is on display within our society through phrases such as "you can't teach an old dog new tricks." What the participants were sharing with me is that they are actually willing to challenge the notion that older adults are "stubborn" or "set in their ways" and instead are willing, if not actually seeking, to learn new things, whether concepts or skills.

Ho (2010) also examined knowledge exchange in what they called "intergenerational learning". Ho studied this in the context of the family home and looked at the process of exchanging ideas between children, parents, and grandparents. The author noted that in Cantonese, the concept of 'teaching-learning' was primarily applied in a unidirectional way that implied a hierarchy of old on top and young below. When discussing knowledge exchange in the context of different generations, they preferred to use the term 'share'. The study found that particularly technical knowledge might only flow in one direction, such as computer skills, but values and interests could more easily flow back and forth between the generations. Ho suggests that if young people are instilled with a culture of bidirectional knowledge exchange from an early age, they will maintain that position as they grow up.

Intergenerational cohousing in a place such as Civitas not only provides space for organic knowledge exchange to occur, such as the unplanned experience that Cassian and Carolina had in the normal course of their days, but it was also relatively easy to reinforce those learnings. Carolina could spontaneously invite Cassian to the kitchen after dinner and Cassian could easily accept it because barriers related to distance, access, visiting hour policies, and strict scheduling were removed. If Cassian had the free time that evening and wanted to use it to go bake focaccia

bread with Carolina, there wasn't anything to stop them. Meanwhile, as things stand today in Ontario, kitchen access, meal preparation, tight schedules, and food management practices are all incredibly strict and would not necessarily permit this kind of event (Lowndes et al., 2015).

When Kelly shared her narrative future, she said that the people she would most likely spend her time with are the ones who lived around her, indicating that the convenient proximity of her neighbours would be a driving force behind relationship building. Betty imagined a similar situation in which rooms would alternate between young adult and older adult to help mix it up. Olive suggested that she might live in an all-female hall and would get close to the women who lived there with her. Proximity is clearly an important condition to facilitate relationship building through knowledge exchange. And we see a similar situation with Falynn in *Handling Challenges*.

## A Discussion of Handling Challenges

In this third narrative future, we find ourselves entering into the midst of a crisis for Falynn, a soon-to-be graduating student who is questioning her decision to live at Civitas and her future career prospects. Catalysing her doubts is a difficult relationship with her roommate, Meagan, who is struggling to adjust to a new normal of her own. Frustrated, Falynn heads down to the Kegger for a drink and decides to strike up a conversation about her struggles with Tony Romano, one half of the legendary Frony Show duo.

As it was mentioned above, the proximity that Civitas offers as an intergenerational cohousing community facilitates the conversation that Falynn and Tony are able to have. While Falynn's purpose in heading down to the Kegger was to find a glass of her favourite comfort drink, she notices Tony in the other room and decides to talk with him about her struggles. In this case, rather than knowledge exchange, the happenstance meeting is able to propel Falynn towards a possible solution to her concerns. The idea that living with older adults would help

young adults to process their concerns about the future was a common concept discussed by the study participants. I suspect that the informal support system that is made available through a cohousing model such as Civitas would be beneficial for both older and younger adults, "bidirectionally" as Phoenix would suggest.

Kat notes that a benefit to intergenerational cohousing is that "you are hanging out with people who are not all stressed and angry at the same time..." about the same things. She says that if students are worried about midterms or the job market, having a different set of perspectives from the traditional student perspective would be helpful in mitigating some of their stress.

Informal support networks have been considered a major tool in creating age-inclusive neighbourhoods (Yamaski, 2009) as well as in homeshare programs (Legge, 2014). In Legge's study (2014) in particular, the student home sharer was the only informal support that the older adult had access to. According to Yamaski (2009), socialization with next door neighbours is a major source of informal support for older adults as well as young families:

Conversations over coffee and treats are a popular way for most of the participants to spend time with neighbors. These gatherings are usually impromptu, as are the spontaneous interactions occurring between individuals working in their gardens or walking through the neighborhood. (p.76)

A place such as Civitas brings together the benefits of both the concept of homesharing, in which intentional space is made for informal support networks to function, and age-inclusive neighbourhoods, that allow for the more random and dynamic aspects of informal support networks to be played out.

The issues that Falynn faced were based on concerns about living in LTCHs that the participants brought up through their narrative futures and earlier parts of their interviews. Olive, Kat, and Kelly were all concerned about whether or not they would be able to meet the vague demands of 'being in the community' along with their responsibilities and interests as students and young people. They maintained that connection to students living outside of the LTCH would be critical for them, that spontaneous plans would need to be possible, and that the "quintessential student experience", as Kat put it, would potentially be missed by anyone living in a LTCH.

For the participants, we see that the idea of living in what they have unknowingly characterized as a total institution is not desirable. The feeling of being cut off from friends, communities, and lifestyles that exist outside of the LTCH would be a significant barrier to participation in this type of cohousing program if access to the outside was not available and encouraged.

As has been discussed several times earlier, access to the outside world is a significant factor in how life in LTCHs is perceived (Butler, 1975; Dupuis et al., 2005; French & Mosher-Ashley, 2000). Maintaining connections to our communities, neighbours, and leisure spaces is a major factor when it comes to evaluating our quality of life (Yamaski, 2009). Olive refers to staying in his room all day as not a good quality of life for her grandfather. To some extent, LTCHs have been described as having a similar attribute to that second-storey bedroom; it constrains access to the rest of life beyond just surviving.

Falynn also felt that her academics were slipping and that she was unable to fulfill the challenges of being a student and member of Civitas. In her narrative future, Kat said that it would be a challenge to hang out with fellow residents while balancing "a full-time course load

on top of literally just being a young adult and figuring out how to live life..." Olive wondered "if it was a challenge to meet my academic demands..." living at a LTCH. When asked where she would spend much of her time at the LTCH, Millie said she "would probably be in my room by myself doing homework. Just because right now I'm a student. That's the priority I have right now." Millie was also concerned that strict scheduling would not help her to manage her multiple priorities well.

Finally, a major contribution to Falynn's crisis was her relationship with Meagan, an older adult who had recently become paraplegic through an accident shortly after retirement. This idea was drawn directly from the fears that Kelly had expressed in her interview about "losing her older adulthood" through personal injury which would leave her paralyzed or in a vegetative state.

At first, one might wonder if it is reasonable to assume that Falynn and Meagan would actually be roommates in a LTCH environment, and that this scenario would not be plausible. However, when discussing her experience working in a LTCH, Betty made reference to a 60year-old man who was living with MS at her LTCH. She said that "he hated" living at the LTCH because "his two roommates had dementia." She followed up his story with this: "I just imagine myself as the man who was middle-aged with two roommates with dementia who would say the same things all the time. They would scream and everything. I think I would just feel really stuck." At one point Betty asked the home if the first floor was primarily for the "less cognitive patients" and they responded that if it seemed that way, it hadn't been intentional at all. According to Betty's story, there was no intentional placement of people within the home environment so when she imagined her narrative future of living in a LTCH, she specifically

asked if the layout was a mix of students and older adults in alternating rooms. Intentional placement mattered to Betty but apparently not every LTCH engages in this practice.

In contrast to Betty's story, Olive explains that the home she worked in had specific halls for people who would fall into similar categories as defined by the home (i.e. veteran's hall, cognitive support hall, etc.). So, it is possible to design spaces with intentionality in mind. However, that does not preclude the issue of roommate concerns. When Phoenix tells his story, he asks about recourse available for someone who is having an issue with a roommate or neighbour. This is clearly a subject that matters to these potential program participants.

*Handling Challenges* should remind us of the challenges that any intergenerational cohousing program at a LTCH may face. In particular, access to the broader community for all residents, balancing social and academic expectations, intentional environmental designs, and resident placement are at the forefront of this discussion for young people. These are by no means prohibitive barriers to the possibility of intergenerational cohousing, but they would need to be addressed.

## A Discussion of Moving On

This fourth and final narrative future brings convergence and closure to the story of Civitas and its residents. Alaric, Cassian, and Tony are each moving away from Civitas for their own reasons although they are still tied together in some way. Falynn has already moved away from Civitas and is now living her dream as a community manager at the new intentional community that they are moving to on the coast. However, its only purpose isn't to wrap up this narrative with a nice bow. Rather, embedded in this story is a collection of the values that the participants held by the end of their narrative futures.

Like most people who engage in narrative work, each character does not leave Civitas unchanged. Alaric's retelling of his time at Civitas had inspired his parents to move back to the

home of their youth and to live in an intentional community themselves. For himself, Alaric entered Civitas expecting that he would use his academic training to help improve the wellbeing of the other residents there. While this may have happened during his stay, he also found something deeper that went beyond his career aspirations. Alaric's desire to keep living in community echoes Phoenix's final words in his narrative future:

And that was one of the main draws for me to live in residence... I always say the experience I actually gained in those four years was working and living in residence and supporting that community sort of living environment and it was more important to me than my degree ever was. (Phoenix)

Formal education might prepare students for field-specific careers and workplace co-ops might prepare students for workplace environments, but both Alaric and Phoenix found that communal living in intergenerational spaces prepared them for the side of life that those two areas miss; personal and empowering friendships in the midst of doing life's ordinary, necessary, and leisurely stuff. That stuff that makes up the rest of life, outside of work or studious obligations, is where both Alaric and Phoenix have been able to grow the most in their intergenerational cohousing arrangements.

Cassian reminisces about the new perspectives and life experiences that they were able relive with their friends and neighbours at Civitas. "It was so much fun to learn about so many different perspectives and life experiences," they said as they settled into their seat on the autonobus. At the end of her narrative future, Kat said "it's basically the greatest thing ever. You're hanging out with people who you want to hang out with... and having those different experiences is useful and good." Kelly ended her narrative future with "I would enjoy it. I'd be

pretty content and mostly just find it fascinating. It would have a lot of different experiences and perspectives and things to share."

The participants would appreciate the experience because of the vast wealth of experiences that they would be exposed to by living intergenerationally. Like Millie said earlier in her interview, "It's where the world comes to one place." That level of diversity may not be present in each and every LTCH but there is the recognition that these settings are capable of being that world nexus where younger and older people can be exposed to new and different ideas from many different walks of life. It is an idea that excites them about living in a LTCH.

Alaric remembers that at a certain point, the residents and neighbours at Civitas started to feel like family. Betty experienced this transformation in the midst of the telling of her narrative future. During her narrative future, she referred to the other folks living at the LTCH with her as "residents", "table members", and "people" until she reprised an earlier story about her positive relationship with an older neighbour when she was young. After that point in her narrative future, she began referring to the other residents as family and friends. Having this example of a positive relationship in her life helped her to see these imagined participants in her narrative future as someone more personal than 'other residents'. And this is how Alaric thinks about the imagined people they will meet at the new intentional community. At this point in time, they are unknown strangers, but he has no difficulty relating to them as "a family" while he reflects on the people he knew back at Civitas.

Fox and Giles (1993) explained that positive intergenerational contact situations that resulted in one participant viewing another older/younger participant as representative of their entire generation facilitated a decrease in ageist attitudes. In Betty's narrative future, I see this happening when she momentarily relives her visits with the older neighbour when she was a

child. Suddenly she can imagine the people she might live with in a LTCH as like that neighbour. She can now call them family and friends, rather than residents and table members. Alaric and Cassian experienced something similar in their time at Civitas. And I believe we can do that too.

## Extending the Intergenerational Contact Model

Fox and Giles (1993) suggest that we need prescribed intergenerational contact that follows their model in order to facilitate a reduction in ageism and bridge generational gaps. In this final section, we will explore what this study has to offer on that matter.

In their intergenerational contact model, Fox and Giles focus on a handful of wider social factors (or social conditions as I will refer to them) that should be considered when creating and evaluating an intergenerational contact experience: housing, status, and political influence. Social conditions are "influences which are beyond the immediate control of the contact situation. The contact theory they draw on for their model (Hewstone & Brown, 1986) also considers history, law, politics, demographics, status, wealth, power, and tolerance as influences over a contact situation. Furthermore, Fox and Giles suggest that a contact participant's *perception* of these social conditions is more important than the actual objective measure of those conditions. In particular, how someone perceives their own generation versus another generation within a social structure will influence the intergenerational contact experience they share.

I am suggesting that this model be extended in its classification of social conditions to include discourse as it has been understood within this study. I will reiterate that I am using discourse to describe a broad, social conversation that is being had implicitly and explicitly among members of our society. In my opinion, I agree that the objective, measurable social conditions, as well as our perceptions of them, are important considerations to understand when designing and evaluating an intergenerational contact experience. However, if we want to get at

the heart of people's perceptions of those social conditions, we need to listen to their stories and listen for the discourses which underpin them.

Earlier in this study, I interpreted three discourses that seemed to be engaged by my study participants in the area of LTCHs. They are the discourse on *The Transition(ed)*, the discourse on *(Mis)Management*, and the discourse on *(Re)valuing*. Associated with these discourses was participants' perception of LTCHs as a locus of loss. Even the one's who suggested that moving into a LTCH was going to yield the best outcomes for their loved one expressed a feeling of loss. For example, Olive was unable to maintain the significant activities and visits with her grandpa due to decreased access to him. Her role became that of an occasional support within hospital settings. After processing his death, she decided to enter the field of healthcare in order to circumvent the limits that barred a deeper relationship with her grandpa and to fulfill her cultural values of respect and relationship with older adults. Here it is in her own words:

...we decided him staying in his room all day is not that great quality of life anyway and so if we could send him to a nursing home and get the care he needs and have access to greater space and scenery then that might be a better option... It happened to coincide with a summer when I went back to school. So, it was especially hard to see him as regularly as I did because I think it was my grade 11 year and things were picking up and the nursing home was further, like not within bussing distance, so I had to wait for my parents to drive and they had to be off work and at that point it was his dinner time, and it was challenging to make that work... I think given my Chinese culture, there is a huge emphasis on respecting your elders and having that relationship with them. So, I think partly that played a role in [choosing a career in healthcare]. I just want to get to know people who are older, who have life experiences to share. My grandpa was actually a

pretty quiet guy. So, often when I would hear friends of different cultures who shared how personable their grandparents were, how detailed they were in life events, I didn't really have that. And partly my Cantonese is lacking so it was limited communication, but I think there was an appeal of just intimately being involved in someone's life that was interesting to me. And when I was in hospital with my grandpa, the few times he was hospitalised, I remember thinking if I wasn't there, I'd be really sad about him not being able to communicate or him being misunderstood. And of course that's with a language barrier and there can be English speaking people here who wouldn't have that specific barrier but I just had the thought that if there's an elderly [person] living in a facility where they're not being treated well or they're not being heard or have opportunity to communicate then that was very compelling for me to pursue that setting so that I could do my role or could not have what I felt sometimes happened to my grandpa where he received less than ideal care in the hospital, at a long-term care or nursing home setting. (Olive)

In this example, there are a few perceptions that can be interpreted. First, the transition is seen as a decision that is made by the family, although not by the older adult who is to be moved. Second, the LTCH or nursing home setting is a place that offers necessary access to care and quality of life but is difficult to access for a young grandchild who wishes to visit. Third, despite replacing the role of familial responsibility in elder care, LTCHs provide an opportunity to regain connection to those same cultural values through employment. Finally, LTCHs are a place where older adults are vulnerable to losing their ability or opportunity to communicate with the people who are there to support them. There are worries about facilities where residents are "not being treated well", "not being heard", and "received less than ideal care".

These are only four perceptions regarding LTCHs that I interpreted from Olive's story. Perhaps you are able to see more or different ones that I have presented here. Each of these four perceptions, which are rooted in some unique lived experience, actually contribute a voice to the larger discourses going on in society regarding LTCHs. I have only drawn on Olive's experience in this example, but the unique lived experiences of the other participants contribute their own unique perceptions. Some perceptions are similar and others are different. But they are all influenced by and contributing voices to these three interpreted discourses.

Fox and Giles used a young person's perception of how many older adults live in a "longstay institution" (Fox & Giles, 1993, p.436) as an example of where perceptions can differ from reality. In this example, young people perceived that about 1 in 10 older adults lived in a LTCH or equivalent institution when in fact the number at the time was 1 in 20 (Fox & Giles, 1993). However, the question they did not address was *why* young people perceived this to be true. What lived experience and discourses led them to this conclusion? I submit that this is an important consideration for extending the intergenerational contact model. In this study, I have provided an example of how narrative inquiry could be used to explore perception and discourse, especially as it relates to intergenerational relationships, contact, and the possibility of cohousing. Future research in the field of intergenerational relationships, contact, and cohousing would do well to keep exploring these connections.

## Conclusion

So, what then of the future? In this study I set out to explore and propose solutions to three research puzzles:

- How do students story the experience of life and leisure in a LTCH and how, if at all, do they see themselves in those stories?
- 2. What dominant discourses are present in the stories of LTCHs?

3. What does the emerging dialogue suggest about future student participation in intergenerational cohousing programs and how does it expand the current intergenerational contact model?

I propose that students story the experience of life and leisure in a LTCH through three dominant discourses: discourse on *the Transition(ed)*, *(Mis)management*, and *(Re)Valuing*. Students largely engage in these three discourses by hearing the stories of parental figures, extended family members, and friends, witnessing the activities of life and leisure for themselves, and accepting the normalization of professionalized clinical care as the 'best' option for managing aging and failing bodies. At times they see themselves as witnesses or bystanders to the stories that take place within LTCHs. Other times they are active participants in creating those stories through significant relationships with the residents of LTCHs. Sometimes these residents are family and sometimes they are not. Students are also capable of imagining a future in which they could live in a LTCH however the conditions must be right. In particular, participants suggested that they would need to maintain privacy, autonomy, access to the larger community, clear expectations of their purpose, and the opportunity to continue engaging in the activities they enjoy today. They see the potential for LTCHs to be places of continual learning and growing, both educationally and relationally.

This study has also provided an example for how discourse might be explored and considered when constructing intergenerational cohousing programs using the intergenerational contact model. If you want to understand the sources of a person's perceptions on matters relevant to society, the dominant discourse in which they engage cannot be ignored. If those discourses prove to be counter to the direction in which society as a whole wished to go then discourses must be altered. More specifically, if the intergenerational contact model intends to

address the issue of ageism in society, it must add discourse to the list of social conditions for consideration.

## Limitations

The possible solutions to these research puzzles I have presented here are significant but not without their limitations. For one, the entire participant pool consisted of students within the Therapeutic Recreation discipline at the University of Waterloo. These students may already be well attuned to the successes and deficiencies of the LTCHs in Ontario since that is a major market for their future careers. Topics of autonomy and activity are already significant in the education they receive. Future research should seek to draw from a more diverse pool of disciplines and fields to get a broader sense of the discourses going on across this current generation of young adults.

An additional limitation to this study was that it only included young adults. Future research should consider performing a similar study tailored to older adults who are currently living in LTCHs. A major puzzle that was missing from this study is the question of whether or not they even want young people to be living in that space with them and what they imagine such a lifestyle to be like. How do they story the experience of life and leisure in a LTCH, for themselves as well as potential young adults?

## **Final Thoughts**

It is my hope that the narrative futures presented in this work make this research accessible to stakeholders within the LTCH sector as well as to the general public. Engaging in a narrative inquiry, especially one which strives towards a more creative mode of representation, is truly a departure from my comfort zone in research. Narrative interviews with limited structure, interpretive analysis, and creative representation were all quite foreign to me in my previous scientific training. However, I believe that I have since come to understand a broader approach to

knowledge and inquiry. If I can learn to appreciate this mode of research and find value in its results, I expect that the general public can as well. In the very least, I hope they are able to find a story that resonates and engages them in the conversation as well.

Ultimately, through whatever mode of research and inquiry, I hope that the world continues towards age-inclusivity, not only in official designation by the powers-that-be, but in very real personal and relational ways as well. As for myself, I am committed to that conversation.

"The Road goes ever on and on, Down from the door where it began. Now far ahead the Road has gone, And I must follow, if I can, Pursuing it with eager feet, Until it joins some larger way Where many paths and errands meet. And whither then? I cannot say."

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(Tolkien, 1977a, p.44)

# Epilogue

Visiting with Lloyd was one of the most meaningful experiences I had while volunteering at the Lodge but it wasn't the only one. Although, I was primarily there to visit Lloyd, I was given other tasks to do as needed. Occasionally, I would spend the first hour visiting with Lloyd and the second working on some other tasks such as writing email correspondence between residents and their families. One email stands out among the rest, although it didn't at the time it was written.

A resident at the lodge had passed away and the care staff asked if I could find photos of her on their computer and send them to the family. I had met her once or twice previously and so I knew who I was looking for. As I sorted through the photos, I was reminded of certain activities I had been able to take part in. For example, one time I had participated in a group that was threading beads onto string to make necklaces and bracelets. A very chatty resident was so happy to be making the jewelry with us, but she was also very insistent that she needed to go home soon. She told us about how her mom had broken her leg and needed extra help in the kitchen that night. Puzzled by this, I learned later there was no mother to go home to, but she was always insistent it was time to leave. It was the first time I could remember interacting with a person living with dementia.

I found photos of birthday parties, special meals, arts and crafts, and other candid moments of life in the Lodge. It was strangely nostalgic for me, despite my short tenure at the Lodge and the fact that I was not involved in many of the events photographed. I selected several photos of the resident who had passed away and sent them to the family with a brief message of condolence and appreciation for the opportunity to meet their mother. I never saw a reply.

Fast forward several months and I was no longer volunteering at the Lodge although I would still stop in to visit Lloyd. As was often the case on Saturdays, I could be found in the basement of my friend Eric, playing Xbox with our group of friends. Eric's mother also ran a hair salon out of their basement, and it wasn't uncommon for us to see people coming in for a haircut. On this particular Saturday morning, a man came in for his haircut who was known to Eric and his mother. We were introduced and upon learning my name his eyes brightened and he asked if I had ever worked at the Lodge (remember I am from a very small town). I told him that I did volunteer there the year before but didn't any longer.

Still baffling to me to this day, he remembered my name from the email that was sent with the photographs of his mother. He immediately began to thank me for the photos and the message that I had sent. For him, the photos brought back several memories that he was quick to share with us. His eyes welled up as he told us her stories; his stories of her. He was never quite sure if he did the right thing, placing her into the Lodge when he did. The photos, and subsequent memories that accompanied them, brought him peace in that decision. He was comforted by the fact that people, like myself, were there to care for his mom (despite the fact I had little to do with her direct care).

Stories are powerful things. Stories, both lived and told, are imbued with meaning constructed by those who share in them. Stories, both lived and told, have histories, presents, and futures that shape us even while we are shaping them. Stories, both lived and told, need to be heard. This narrative inquiry has heard them, has been shaped by them, and constructed meaning collaboratively with participant storytellers. If, as a society, we are going to move forward in addressing ageism, age-segregation, and institutionalization, we need to hear more stories.

Are we ready to listen?

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# **Appendix A: Email Script for Contacting Instructors**

## Dear [instructor's name],

My name is Ben Smith and I am a Master's student in the Department of Recreation and Leisure Studies here at the University of Waterloo, conducting research with Dr. Sherry Dupuis. I am interested in intergenerational cohousing, particularly in retirement home settings, and how young adult's perceptions of life and leisure in Canadian retirement and long-term care homes might shape young people's decisions about living in such a setting. This research is more important now than ever before because of the stigma associated with retirement and long-term care homes and with new calls to reassess the Canadian long-term care system in the midst of the coronavirus pandemic.

I will be asking students to participate in narrative interviews through videocalls where participants will be encouraged to share stories about their perceptions and experiences with retirement and long-term care homes or stories they have heard from others. Participants will also be asked to imagine a new story about what it would be like for them to live in a long-term care home as students rather than as older adults in later life. Interviews should last approximately 60 minutes.

I would like to advertise this study to your students in [*insert course code*] for participant recruitment. I have prepared both a recruitment video and a poster, either of which can be uploaded to your class LEARN sites or included in lecture slides. Potential participants would be instructed to get in contact with me directly if they are interested.

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 #42581].

If you have any questions or would like to know more about the study, please let me know. Thank you in advance and I look forward to your response.

Sincerely,

Ben Smith MA Candidate, University of Waterloo Department of Recreation and Leisure Studies Faculty of Health bj3smith@uwaterloo.ca

# Appendix B: Student Recruitment Video Script

Hello. My name is Ben Smith and I am a Master's student in the Department of Recreation and Leisure Studies here at the University of Waterloo, conducting research with Dr. Sherry Dupuis. I am studying young adult's perceptions of life and leisure in Canadian retirement and long-term care homes. This research is more important now than ever before with new calls to reassess the Canadian long-term care system in the midst of the coronavirus pandemic.

I'm looking for people who are interested in building intergenerational relationships. If you volunteer as a participant in this study, you will be asked to join me for a 60 minute videocall to share stories about your perceptions of and experiences with retirement and long-term care or the stories you have heard from others. You will also be asked to imagine a new story about what it would be like to live in a retirement or long-term care home as a student like you are today rather than as an older adult in later life.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation is yours. [*include ORE # on the screen*]

If you are interested in participating, please send me an email and I will get in touch with more information. [*include contact information on the screen*]

Thank you.

# **Appendix C: Participant Recruitment Poster**

# Department of Recreation and Leisure Studies University of Waterloo

# PARTICIPANTS NEEDED FOR RESEARCH INTO YOUNG ADULT'S PERCEPTIONS OF RETIREMENT AND LONG-TERM CARE HOMES

We are looking for undergraduate or graduate students with an interest in building intergenerational relationships to share their stories.

As a participant in this study, you would be asked to share and imagine stories about life and leisure in Canadian long-term care homes or other retirement residentials settings (i.e. retirement/nursing home communities).

> Your participation would involve one videocall interview, which is approximately 60 minutes.

For more information or to volunteer for this study, please contact:

Ben Smith Department of Recreation and Leisure Studies Email: bj3smith@uwaterloo.ca

This study has been reviewed by, and received ethics clearance through, a University of Waterloo Research Ethics Committee [ORE#42581].

# **Appendix D: Participant Information Email**

## Dear [insert potential participant name],

My name is Ben Smith and I am conducting a study as part of my Master's degree in the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Dr. Sherry Dupuis. I want to invite you to participate in a study titled "Exploring student discourses: Would intergenerational cohousing be possible?" I am hoping to learn how students understand life and leisure in retirement and long-term care homes and whether or not they can see themselves living in these settings. Additionally, this study will culminate in a visionary, evidence-based, fictional story about a world in which young adults are invited to live in these settings. This story will be used to help long-term care administrators and young people alike decide if this is a future they wish to pursue.

You will be asked to join me for a 60 minute conversational interview over videocall where I will ask you to share stories about your perceptions of and experiences with retirement and long-term care homes, or about stories you have heard from other sources. The interview will be audio-recorded in order to facilitate the collection of information and transcription for analysis. A link to participate in the interview will be sent to you once we agree on a mutually suitable date and time.

Your participation is completely voluntary and you may choose not to participate. If you do participate, you may choose not to respond to questions you do not wish to answer, and you may choose to end the interview at any time by notifying me of this decision.

Your participation will be considered confidential. Identifying information will be removed from the data that is collected and stored separately. 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. Collected data will be securely stored for a minimum of one year on a password protected computer. You may withdraw your consent and request your data be removed from the study by contacting me within this time period. Please note that it will not be possible to remove your data once results have been submitted for publication.

When 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). 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.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee [ORE #42581]. 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.

If you have any questions regarding this study or would like additional information before deciding to participate or not, please contact me by email at <u>bj3smith@uwaterloo.ca</u>. You can

also contact my supervisor, Dr. Sherry Dupuis at 519-888-4567 ext. 46188 or by email at <u>sldupuis@uwaterloo.ca</u>.

Thank you for your interest and considering participating in my study.

Sincerely,

Ben Smith MA Candidate, University of Waterloo Department of Recreation and Leisure Studies Faculty of Health bj3smith@uwaterloo.ca

# **Appendix E: Declaration of Informed 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 and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Ben Smith 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 details I wanted.

I am aware the interview will be audio-recorded for the purpose of ensuring my responses are accurately transcribed and analyzed.

I am aware that with my permission, excerpts from the interview may be included in the thesis, publications, and presentations to come from this research, with the understanding that a pseudonym will be used in place of my real name.

I am also aware that I may withdraw from the study without penalty by advising Ben Smith or his advisor, Dr. Sherry Dupuis, of the decision.

I understand that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42581). If you have questions for the Committee, contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or <u>ore-ceo@uwaterloo.ca</u>.

I am aware that I can contact Ben Smith, at <u>bj3smith@uwaterloo.ca</u> should I have additional questions. I can also contact Ben's supervisor, Dr. Sherry Dupuis at 519- 888-4567 ext. 46188 or by email at <u>sldupuis@uwaterloo.ca</u>.

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

 $\Box$  YES  $\Box$  NO

I am aware the interview will be audio-recorded.

 $\Box$  YES  $\Box$  NO

I agree to the use of quotations in any thesis, publication, or presentation that comes of this research with the understanding that a pseudonym will be used in place of my real name (e.g. Jane Doe).

 $\Box$  YES  $\Box$  NO

[] Verbal consent obtained.
Participant name:
Participant Signature:
Researcher Signature:
Date:

# **Appendix F: Participant Appreciation Letter**

## Dear [Participant's Name],

I would like to thank you for your participation in my study titled "Exploring student discourses: Would intergenerational cohousing be possible?". As a reminder, the purpose of this study is to explore young adults' stories of life and leisure in Canadian retirement and long-term care homes. The stories you shared will contribute to a new understanding of the discourses that are ongoing among young people with regards to retirement and long-term care homes and how the discourses might be shaping young people's understandings of these settings and their potential willingness to live in one of these settings as a student. This is especially important as we begin to reassess the Canadian long-term care system in the midst of the coronavirus pandemic.

Additionally, I want to thank you for contributing to a visionary, evidence-based, fictional story in which young adults are invited to live in retirement and long-term care settings. This story will be used to help long-term care administrators and young people alike decide if this is a future they wish to pursue.

Please remember that your participation will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or would like a summary of the results, please provide your email address, and when the study is completed, anticipated by August 2021, I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email as noted below.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#42581). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or <u>ore-ceo@uwaterloo.ca</u>.

For all other questions contact myself, Ben Smith, at <u>bj3smith@uwaterloo.ca</u>. You can also contact my supervisor, Dr. Sherry Dupuis at 519- 888-4567 ext. 46188 or by email at <u>sldupuis@uwaterloo.ca</u>.

Ben Smith MA Candidate, University of Waterloo Department of Recreation and Leisure Studies Faculty of Health bj3smith@uwaterloo.ca

# **Appendix G: Narrative Interview Guide**

**Introduction:** Hi, my name is Ben Smith and I'm a Master's student in the Department of Recreation and Leisure Studies at the University of Waterloo. I'm interested in hearing stories about what students believe it is like to live in retirement and long-term care homes in Canada. Thank you for agreeing to share your stories with me today.

Before we begin, we should get to know one another a bit more. I've already told you a bit about myself but what you probably don't know is that I studied Biomedical Science during my undergrad, with minors in French and Gerontology. My heritage is Mennonite although my family is far removed from the old order Mennonites you typically see around Waterloo region today. My interest in older adults and intergenerational relationships stems from relationships with my grandparents and volunteering in long-term care settings. That's me!

1. Could you tell me a bit about yourself and what's important to you? How would you

describe yourself to others?

- 2. When you think about retirement or long-term care homes, what do you think of?
  - a. Where do you think your perceptions of LTCHs come from?
  - b. Did you ever work/volunteer in a long-term care setting?

### If YES:

- i. When did this happen? How old were you then?
- ii. What was your role in the home?
- iii. What was that experience like?
- iv. What did you take away from that experience about what it is like to live in LTCHs?

### If NO

- c. Have you had an opportunity to visit a LTCH or know someone that has? If so, tell me about a time you visited a LTCH or about what you heard from others about their visit to a LTCH.
  - i. What makes this experience stand out for you?

- ii. When were you/other person there? How old were you?
- iii. Why were you/other person there?
- iv. Who did you/other person see/interact with during the visit?
- v. What was happening while you/other person were there?
- vi. How did it feel to be in this setting?
- vii. Have you ever shared this story before? With whom?
- viii. How did these experiences influence your perceptions and ideas of LTCHs?
- 3. Have you heard/read/seen any stories about what it's like to live in a LTCH?
  - b. Where did you hear/read/see this story? When?
  - c. Why does it stand out for you?
  - d. Have you ever shared this story before? With whom?
  - e. How might these stories have influenced how you think about LTCHs and life within those settings?
- 4. Let's explore a potential day in the life at a LTCH. Scenario: You have been given the opportunity to have a free room and meals in a LTCH near your school. The LTCH is within walking distance and a bus stop is just outside as well if needed. In exchange for the free accommodations, you must make an effort to spend some time with your new older adult neighbours.
  - f. Would you choose this opportunity? Why? Why not?
  - g. What would a typical weekday look like for you living there?
    - i. Who do you interact with?
    - ii. Where do you spend your time during the day?

- iii. What would you do with your new neighbours?
- iv. How does it feel to live there?

**Conclusion:** That's all the questions I have for you today. Do you have any questions for me? (*If yes, respond accordingly. If no, continue*) Thank you for your time and for sharing your stories with me. If after this interview you have any follow up questions about this research project, you are welcome to contact me or my supervisor, Dr. Sherry Dupuis. Take care and have a good day.

# **Appendix H: Participant Narrative Futures**

In contrast to the narrative futures constructed in chapter five of this thesis, the following appendix includes the narrative futures that were described by the study participants during their interviews. While my reasoning behind the constructed narrative futures has been described at length in previous chapters, I also believe that the participant's direct voice should be heard on this subject. It is for that reason I have include their narrative futures below, verbatim and with my own voice removed. This is how they imagined intergenerational cohousing and their place in it.

#### **Betty's Narrative Future**

Oh, I don't know. I think I would. But the reason why I wouldn't is because I'm going to be a Don and I wanted to do that for a while. So, I'll tell you the reasons why I would and wouldn't. I would because, like, free room and board for sure. But also, I think it would be nice just to connect with these people. But on the other hand, maybe not. I would be maybe worried that it would impact my job. Like if I were to want to work in long-term care in the future, I wouldn't want to live at my job. If that makes sense. And I would want to make sure that I could still have connections with my friends, if that makes sense. I think I would be more inclined to live there if I knew that my immediate friendship circle was also there. Instead of how I first imagined it would be. Just, like, me there and having to go to all my friends who would be somewhere else. If that makes sense. But I definitely think it would be a really cool opportunity. It be it would be like resident's room, a student's room, resident's room, student's room, something like that. I think in a typical day I would waking up. If it was non-COVID times, definitely go to school and spend probably a fat chunk of the day on campus going to classes and then maybe at the library. But then I can really see it coming back to like the long-term care home and like I just imagine myself talking about what I learn in class with the residents. That's just something I would imagine. So, like as that type of typical day. You come and you'd reunite with these people that I feel like it's kinda similar to living in a family. If that makes sense. I feel like you would come home, and I would assume that meals would be at the same time. I imagine coming back to the home and having, I don't know, table members or something like that. And then I also think, because honestly when I was first thinking of this, I was like, 'Oh I don't wanna have to like force relationships with people'. But then thinking more and more about it I was like, 'But what if it went well?' I don't know. My neighbour who lived down the street, who I chatted with occasionally when I was younger, like that was such a fun relationship. So, if it went well, you would come home and vou would have these friends vou know. Of course, with different life experiences than you just because of generations and like different things that happened. Anyhow, I can just see it going interestingly. But in a nice way. I feel like [relationships] would happen naturally. Like I think when I was first thinking about it, I was like, 'I don't know, I don't

really love the activities or like things where it's like please become friends with this person.' And who I would become friends with? Knowing myself, I think I could become friends with the louder residents. But specifically knowing me I think I would seek out connections with the quieter ones and ones where more wanting to stay secluded within their rooms. Which is just like a me thing, I think. I really appreciate making connections with people who aren't the ones that stand out the most in the group. So I can imagine creating connections with my neighbour, someone who is on the quieter side but I can also imagine just like leaving the building and then there's like a group of people playing or watching tv or something and you just say 'bye' to all these people who are like at a completely stage of life than you. As I like form relationships with them, I really think I would have a lot in common. Because even bringing it back to like my experience in long-term care, there are so many residents who I was like, 'Oh my gosh you did this? I'm interested in that!' You know. I think I would have things in common with them, but it would just be something that would have to be uncovered as like you got closer or something like that. I think it would feel very routine, but in a good way. I honestly think I could link it to like a feeling of living in a residence. Like a university residence or something like that. It's not like, 'Oh you have to become close with everyone.' You're kind and pleasant to everyone. But you have specific connections with specific people. And yeah, I think it would be really comfortable. Routine and comfortable. I could just imagine organizing my day on campus based off of coming back to the home and like having a movie night with a couple of people. Something like that.

#### Kat's Narrative Future

Personally, I would probably not [live in a long-term care home as a student] just based on my general interest. I do think for a lot of people the free accommodations, close to the bus stop, close to school, would be very enticing. I do think there's a large level of importance in intergenerational housing. Think there is a large importance in learning from our elders and being respectful of our elders and making sure they feel engaged and involved. I also know that would not be the right fit for me. So I would definitely encourage other people to do it and I would come visit. I tend to get overwhelmed with a lot of things and I have ADHD and living in a busy place with lots of people... I try not to live in apartment buildings because I find them overwhelming. It would not be a great fit for me.

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I believe it would depend on what kind of arrangement had been set up by you and the facility. Assuming that based on the fact that you are getting free room and board, they would have a clear exchange of what they expected. Like you know what they do at L'ARCHE. You're on for these hours at this time and then you get the rest of the time off. I assume it would be some sort of set up like that. So, it would depend on that setup. But I know there was generally communal eating areas, so you'd probably get up and go downstairs, have breakfast with people. Kind of like talk, visit, etc. Very much enmeshed in the community at that point, I hope. And I know at long-term care homes they usually have a set routine, especially because a lot of the workers are only there from nine to five. A lot of the people would be up before nine so your typical student rhythm of sleeping until 1pm isn't necessarily going to work if you have these agreements that kind of need to be filled. So, there probably won't be elderly [people] hanging out until 3 in the morning just in the common areas. A change in typical schedule would be required. I have to take my meds in the morning so I'm up anyway. I'm lucky to be in a house that has students that do get up and do their work. But one of my roommates' boyfriends, his apartment, they do not awake during the day and they're only up at night, gaming and doing work. It's horrifying and I think they're vampires. So, it depends on the students, and I think what ever students you get are going to be the ones who are going to be ok being up during daylight hours.

Well at school. Let's pretend the pandemic's not around. So, at school doing lectures, working with groups and such on campus. Usually I'm in one intramural team. So, I have my ultimate frisbee at least once a week and I do other volunteering so I'm not available Monday and Wednesday evenings. And typically, I do not study well when other people are around or there is generally noise. And when you're in a communal living situation, it does not bode well for me studying and that why I would probably be in my room while studying. And of course one of the challenges that many ADHD folks have is that we don't necessarily do our work until the last moment so there's always something to do. So, you're always kind of running around like a chicken with your head cut off cause the deadlines tomorrow. 'Ahhhh!' So, it makes it difficult to do that. And I think one of the big challenges in the, like, having room and board in exchange for hanging out with people is just the full-time course load on top of literally just being a young adult and figuring out how to live life and then also having these extra responsibility on top. It would be absolutely amazing for somebody who is really interested in this. Like it's basically the greatest thing ever. You're hanging out with people you want to hang out with. You're doing exactly what you wanna do. It's gonna be great on a resume. So absolutely phenomenal. But you gotta get the right people first.

I think it would be kinda fun to live there. It would be because basically you are hanging out with people who are not all stressed and angry at the same time and a lot of times your worries are not the same as other people worries. So, like, you're worried about midterms. They're not worried about that which is nice. Or if you're worried about what the job market is going to be like after graduation, they can be like, 'Ok this is what I did.' And having those different experiences is useful and good. And then I did have another thought. I'm not sure how impactful this would be on many people who would consider this as a great option but we live in Waterloo. I'm imagining a Laurier student who is mostly in school to party. That's not going to vibe super well with the typical views of alcohol and partying that more of the older generation have. So, there is lot a of discrepancy in what most people expect the student experience to be and all the quintessential student experiences as opposed to what would kinda be possible or expected if you're living in a long-term care home. That being said, I am approaching living in a long-term care home more as what a Don would be than just like being a student who lives there and maybe showed up three or four times a week. But then again, old people love hanging out with young people so chances are they'll probably seek you out. They know where you are and they will be there too.

## Kelly's Narrative Future

I feel like, if I was going to live alone, if I was gonna find a place to live by myself then I would consider that but a lot of my plans for housing in the future involved my friends. So, if we were all given this deal and could all live in the same building and we could all be friends with the residents there, then I would consider it. I just need to have one or two of my friends with me. I

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think we'd consider that. Cause we have been struggling to find places that we like that are walking distance to school, or a decent, like, reasonable walking distance at least. And I feel like that's important to us because even if we have cars, you can't find parking on campus anyways. You can find parking but you have to pay for parking separately again which is a little silly in my opinion. If I could bring just one of my friends, I would do it.

I think [I'd] wake up. Hopefully I have classes in the morning and then go to class. Maybe eat lunch on campus. Maybe come back to eat lunch depending on how I'm feeling. Cause I have had nursing home food and I quite enjoy it because I like soft foods so that is not one of my concerns. And probably just do work. And then I don't know, I'd probably just work most of the time. Cause that's what I do now. I don't think my life would change a lot. Maybe I FaceTime my friends. In the evening I would have dinner with the residents and some of my other friends. *Elderly friends. And then, I like to play cards so if they wanna play cards with me I could do that.* All of this would be with my friend accompanying me though. I guess when I'm thinking about this from the perspective of just starting to live there, but if I've already established other friends other than my own friend I came in with, I could do it alone. But if I was just being introduced to them then I would probably be more scared. I understand that they eat dinner really early but that's ok because I could do that. I don't have a particular time. Just evening cause I enjoy being alone for the most part so I do spend a majority of my time alone. And then I'll socialize in the evening. I guess it'd be convenient to meet the people who live next to me. I'd probably interact with them the most; you see them most in the crossing. I wouldn't mind meeting other people, people with the same interests as me. I hope that this home would have a knitting club or a crocheting club. Just mostly people who have the same interests as me because I do feel like I have a lot of interests that they could share with me. I think I would get along with most people. So just anyone who's nice I wouldn't mind interacting with and probably just someone who wants to have a conversation. Or someone who can carry a conversation. Or if they wanted, I could just do all the talking. I have a thing about being interrupted so if I could tell stories then I would totally do that. Don't really have many expectations.

I think it would feel cool because personally, I would like to work with the more mature age group in my career. So I feel like I'd be gaining a lot of insight on like their day to day life, their mindsets. I think for me I'd mostly find it interesting. I would enjoy it. I'd be pretty content and mostly just find it fascinating. It would have a lot of different experiences and perspectives and things to share.

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### Millie's Narrative Future

I'm thinking two sides right now. My brain is kind of split in half because one part of me, I would like to because free food, free bed and plus I get to speak with old people, like, sign me up. And it's right next to the school. But then like, another part of me knows that you don't have as much independence and privacy when you're there. So, I feel like I would kind of not be happy with that. Like, I like to lock my door and I also like to do my own thing without someone bothering me all the time. So, I feel like I'm kinda on the fence. Probably more so towards the 'I don't want to be bothered' because, okay, it's free and I got to talk to the other people, but my independence is very important to me. And especially, I know some residents that are still able-bodied, they're

very cognitive, right? They just have some health issues, right? And even like, when they're living at the home, same kind of thing, like, they kind of like get in the taxi and just go places right? I'm like, I could get on the bus and go wherever right but it's still like. Okay, you can be independent in that sense. But the whole, like, someone constantly coming into my room. I know for us our rooms don't have locks. If someone's constantly coming and waking me up and, like, being on a strict schedule, I feel like that's the part that I would be kinda iffy about.

I would get up at 8 in the morning and eat breakfast. And then I go to school do my thing. Then it would be kind of weird because I would go back to the home, but then like, how to do I do my homework? Like that part of it would be kind of weird because I would have constant obligations to fill because it has such a strict schedule there. That maybe I won't have all the time in the world to pursue my own needs as a student. I would have, like, many obligations or whatever. I would have such a strict schedule that like one minute, I'm eating dinner for example, and then the next minute I'm supposed to go take a shower. There's no flexibility there. If I was doing homework, for example, it would be chopped up into really weird time frames. But then, at that point, because I'm going out and I'm doing all these different things, I don't have time to have downtime, particularly with programs. Whereas me, right now, I kind of like to go with the flow. If I want to get up early and have breakfast, I can, but if I want to sleep in and then do my schoolwork, I can also do that. I would have to negotiate flexibility. Because I know for our home, if you missed dinner or whatever, like they'll save you dinner or whatever, but like, it's always cold or not fresh or something. It would just be more of a hassle than anything. Even the whole, like, losing my independence, people walking in all the time, and just doing things in my room and touching my stuff. That would kind of set me off. And then I get distracted from my homework and then I talk. I would talk to my neighbour and I feel like that would be a lot. I could probably manage if I really tried. The staff are definitely closer to my age but I personally love interacting with residents and I feel like maybe that's just because I've had such a positive experience. And maybe because I'm an old lady at heart. I don't know. But like I just love talking to the residents and we always have so much fun. We have good conversations sometimes. I'm grateful and you get to learn a lot. It makes you kinda understand where people come from. What people do. And how other people look at things. A different point of view. [We would talk about] how dinner tasted. Definitely be like a common occurrence. [Other conversations] would have to depend on similar interests or something like that. If I had someone who was like super talkative and liked to do things and, like, talk about themselves, I feel like it would be a lot easier. But then if it was someone grumpy who didn't like to talk or didn't like to do things, I'd probably just turn the tv on. I feel like it would differ depending on the person. If I had free time, I would be at every program in the world. Just because I love to be active, and I love to be busy and stuff like that. [Other times, I] would probably be in my room by myself doing homework. Just because right now I'm a student. That's the priority that I have. We would definitely do puzzles because I know that I love puzzles and a lot of my residents love puzzles so maybe that's a good general thing. Or like knitting or something like that? I know roommates that literally, if they get along, they will go walk levels together. Like do laps around the halls and they'll push each other, and they try to find different things and that just sounds like an awesome time. Just like anything to really get me active but mostly like puzzles and crosswords and stuff like that. I feel like I would be a little bit tired just because of the negotiation of time and stuff like that. I'm still kind of angry about the no privacy thing but I'll get over it eventually.

I feel like it would be more of a positive experience if I were to learn how to manage and deal with the schedule. I feel like right now, I'm already uncomfortable because I work in a place like that. But I feel like living with that would just make it worse. It opens up the opportunity for not only people that I know and love to be treated [poorly], but for myself to be treated like that too. 'You shouldn't treat the residents like that' becomes 'I don't want to be treated like that.' I know that a lot of the residents are not capable to stand up for themselves and say 'Hey that's not right' because people think that since some people are cognitively impaired that you can take advantage of them and you can get away with stuff like that. But like knowing if I was to live there in a home, I would know that's not right. 'Please don't touch me.' I know there's one lady who comes and she talks to me all the time. And it makes her so angry that someone can walk into her room at any time. I'm like I get that. I don't want that. And I know that nobody there wants that. Especially this lady who literally came up to ask me if I had a lock for her door. And I was like, 'No I don't.' Sometimes its unfortunate that's the way that it is. If there was just free rent, and we got to hang out with the residents, but like at the same time I could have my independence and my privacy and I knew that people were going to treat me right, then yeah 100% sign me up. When am I moving in? But under very specific conditions. And like good conditions. Because no one deserves to be treated badly.

### **Olive's Narrative Future**

There are some factors that I would consider prior to making that decision. Instinctively, I think I would definitely entertain it. It's appealing to have very real stresses addressed like living and food and the costs involved. What are the expectations around engaging the older adults? Is there a certain time frame or is there a certain hour per week? Is it generally everyone? Do I have a couple that I'm assigned to? And then what kind of supports are available, or to whom am I accountable to? Based on what I know, I think that I would be open to it. I think I'd feel especially confident or comfortable if I knew the commitment. Is it bad to say if I could try it out or if I could see whether it works for like a week or two or if I could visit and see what it's like? That would, I think, be very telling. But yea from what I know, I think it would be appealing.

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I wake up, I brush my teeth. My sleep schedule as a student is pretty... atypical. So now I go to sleep at like 2am, 3am, waking up 8am if I have a 9am meeting or as late as noon if I don't have a morning meeting. So, on days where I have a morning meeting, I would brush my teeth, try to make breakfast, eat something and then do my meeting. And then do work, eat lunch, maybe go on a walk. Maybe invite the residents with me on a walk if they'd like to go. I enjoy cooking... oh wait food is provided. So I'd eat dinner with the residents. I think that's probably the meal I'd be around the most. I think I'd be sad not to have access to an elaborate kitchen. I'd hope to be able to bake or cook or even work on recipes or meals that the residents would want to eat or that would be nostalgic to them. And then I'd imagine I'd do more work. I might videocall a friend. Have whatever personal commitments or meetings that I go to. I think I'd prefer if it weren't coed. Let's say I was on a floor with just ladies. Let's say there's eight on my floor. I think I'd make an effort to get to know them, especially in my initial weeks and see who is more receptive, who is less receptive to doing things together, whether they are interested in doing scheduled activities together, who's more content or who prefers to have their alone time more and then who's more social and then I might gravitate towards those who are more social and want that

interaction more. And then with individuals who prefer more so their alone time I might ask 'Would you like it if I came in every so often and we did something together?' And then hopefully I'd still have access to the residents on other floors so I could meet all the male residents and I could get to know them as well. And then ideally there'd be spaces where all residents could comingle and have that space and opportunity to interact with each other. I imagine if I had great academic demand, I would be in my room studying and then if I weren't studying, I would be maybe in the lounge, like in the common space where the kitchenette was, if we were eating dinner there. If there was an activity room, or like a living room of sorts, I think that's were I might be. And then maybe outdoors. I don't know if getting out and about, going on walks, or seeing nature is being in the community and seeing if residents want to do that as well. I would try to gauge their interest. See if there's anything they are already doing? If there's a way I can learn that or get involved in that or see if others want to get involved to make that connection. I could see myself cooking or baking, or learning to crochet, or knit. Doing trivia or playing instruments. I might initiate a book study; a bible study. Let's bring a pet in! Do something fun. I think the aspect of novelty is very important among older adults. I think they appreciate learning new things and seeing new things so I feel like as much as possible I might be like, 'Here's a new movie' or 'Here's a new idea or concept' or 'Here's what's in the news. What are your thoughts?' Puzzles. I like puzzles. We could do puzzles together!

Hypothetically, I think it would be very rewarding to have that connection and to have built these new relationships. I wonder if it was challenging to meet my academic demands or I think like am I really able to focus when at home or I wonder if more specific expectations would be helpful because definitely I recognise the idea is to live and be present when you are at home but as a student sometimes spontaneous plans come up so I would think 'Am I honouring this commitment well? Am I home enough to make the impact that I could be making? Could I be doing more?' So yes, I think I would enjoy it and I would wonder am I doing what is expected or what is good. Is it beneficial? Is it helpful? Both to the residents and to myself. I definitely think it could work. I think it could do a lot of good for both the student and the older adults. I don't know about pandemic times. I think that would factor but I think in non-pandemic times, yea it would be very interesting to me to entertain that. I think just thinking in terms of how Waterloo works, I would be confident on a term basis. If I knew the commitment was four months, I think I would definitely be open and could see myself enjoying that. And then seeing whether I'd want to return for another term.

### **Phoenix's Narrative Future**

Yes I would [live there]. Because A) school is expensive and meals can be hard to come by. But B), and I think more importantly, is that it's a community-based thing and regardless of who you are, and in my opinion, this might just be a character trait of me, but I've lived with people who are above 60. I had to teach them how to use Netflix. And once they started to use Netflix, they watched 68 straight hours of war documentaries and they blew our bandwidth. And I had to teach them what bandwidth was. And we couldn't have Netflix for the rest of the month. But it wasn't a problem and I enjoyed it and I enjoyed learning from their experiences. And I've learned hands on skills and wood working and how to fix things around the house from these people. You know when stuff breaks down and you're just like you know, we could call someone

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or we could figure this out. And their like, "Oh I've been doing this for years.' I want to just reference communal living in 100s of year past kind of stuff. Where the stories and skills and trades were passed down from elder generations, and that's the reason elders were so revered in communities because they had all this knowledge to transfer to you. And I think we've lost that. I've experienced both sides of that coin and I'm like there are things to be learned and things to be taught in a bidirectional sort of sense. Where it's like we each have things we can give to each other. I think in that setting, given that I'm meant to spend some time, and presumably with other people in the same situation, there would be some kind of setup in terms of how time was spent or how that time allotment was so that it was shared amongst people. Knowing that it's still a business and there's probably going to be some kind of contract here that dictates a weekly allotment of time spent in initiating programs or just active community activities with people. I think as the younger group of people living with this, we would begin to replace a lot of that healthcare workers or assistants that you see in a regular setting that makes it feel more hospitalized and transitions it more into that community feel.

I think I wake up in the morning. I know that my neighbours are already up because they got up at 6am. I say hello to them. Maybe we talk a little bit over some breakfast. Some good breakfast is like an oatmeal with some fruit and things. Which is much better than I would have picked up at Tim Horton's on my way to school. We have our little morning chats, they wish me a good day, and are eager to find out what I learn at the end of the day. I go do my school daily activities. Come back. Maybe, just maybe, that day I was very lucky in that in my youth I found another person in class who was interested in similar things to me and perhaps they also happened to be a pretty girl and we came back and studied together. And then Ethel, my neighbour who I shared breakfast with, asked me about class but more interestingly who the pretty young lady was that came back with me, and we have a discussion and she gives me some hot tips on how to impress her that are just like smooth 1950s stuff I wouldn't have thought of because TikTok has ruined my brain. And then you know, we do the dinner thing together. She encourages me to wash the sheets on my bed because ain't no lady going to come over if my room is looking like a mess. And I'm like, 'Ethel, this is a great idea. Let's go do laundry together.' We do laundry. We joke around a little bit. Dinner is served. There is apple pie. Just happens. And then I go back and start doing my evening activities. At which point in time maybe Fred from down the hall comes by, and he's a war vet, sees me playing some Foxhole on my computer. Asks me what that's about. Tells me some very interesting and educational stories about his experience with the war. And I try to get him to help me make some decision about what to do in the game. And we game together despite our 45-year difference in age on my super computer, where he participates in my livestream on Twitch and people love him and I suddenly go up 20 viewer count on average because the Phoenix and Fred show becomes a thing. I go to bed.

I can see the place in my mind. There are weird ferns in every corner. And there's a black piano that just sits in the living room. No one wants to play it because they are afraid to play it and it's too loud and will disrupt the residents. I would absolutely [play it]. Okay I'm bad at piano. And they'd be like, 'Oh deary let me help you with that'. And they'd slide on over. And even if they aren't as good as what they thought they should be, it'll still be better than what I played. And people are like, 'thank God she slid in on that chair because he was doing a bad job.' And maybe I learn chopsticks.

I think it's a good feeling. I think it feels meaningful. Even if I had a bad day or whatever and I had classic first/second year issues, 'Oh god I don't know if I've chosen the right career path for myself.' Here I am actually on my third degree and I'm like, 'Dammit this wasn't the right one either.' Well, we'll see. It's the pay that concerns me and the job availability. But I digress. But I feel like at the end of the day I still get to go home, and I still get to learn things. And that's always been my experience in community living settings. And that was one of the main draws for me to live in residence. And I'll always say this. My first degree I sat through for 4 years. Worked in my field for 4 months and hated it. Never worked in it again. But I always say the experience I actually gained in those four years was working and living in residence and supporting that community sort of living environment and it was more important to me than my degree ever was.

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# Appendix I: Autonomy, Activity, and Air

This is a collection of lists that contain the positive qualities of a LTCH as perceived by the study participants. I have categorized them according to how I have interpreted what they meant to the study participants. Overall, these items speak to three main concepts: Autonomy, Activity, and Air. These three concepts, along with several items from these lists, helped me to construct the narrative futures in chapter five. They are by no means exhaustive.

Scheduled Programs and Activities			Independent Programs and Activities				
_	Group activities	_	Prom/parties	_	Playing piano and	_	Riding a bike
_	Play games (Mah-	_	Zumba		other instruments	_	Watch TV
	jong, dominos,	_	Exercise classes	—	Quilting	_	Wash dishes
	cards, video games,	_	Shared meals	—	Crocheting	_	Walk the dog
	etc.)	_	Field trips (cafés,	—	Knitting	_	Go for walks
_	Performances (mu-		restaurants, deli	—	Doing own laundry	_	Go for food off-
	sicians, magicians,		shops, art galleries,	—	Tending plants /		campus
	etc.)		malls, etc.)		gardening	_	Culturally relevant
-	Ice cream, cotton	_	Optional daily	—	Free time		activities
	candy, and vendors		activity	—	Puzzles	_	Baking cookies
_	Culturally relevant		2	_	Crafts	_	Video game
	activities			-	Cook from scratch		streaming
				_	Go to grocery /	_	Access to religion
					hobby stores		on and off-campus

	Socialization		Personal Development and Opportunity
_	Know each other	-	Be your best self
_	Hangout	_	Explore new things (skills, hobbies, etc.)
_	Community of peers	_	Open minds
_	Conversation	_	Equal participants in care with staff members
-	Reconnecting with people	—	Right to say no
-	Coexist in a community	—	Free to make mistakes and learn
-	Loved ones have peace of mind	—	Cut your own nails
-	Pets	—	Play your own music / instruments
-	Children	—	Freedom to live your life and space to do it
_	Be with friends	_	Re-explore previous passions
-	Talk to friends living off-campus	—	Shared responsibilities (cooking, etc.)
_	Family and friends visit / join in field trips		

	Built Env		Staffing		
_	Houses / apartments	_	Open space / open concept / room to	-	Good resident to
_	Lawn / garden / plants /		breathe		staff ratio
	personal yard	_	Not forced to congregate in a single	_	Respect non-par-
_	Fully functional kitchen		area		ticipation
_	Comfy couch and TV	_	Open doors / lockable room doors	_	1-on-1 time with
_	Space to store / ride bikes	_	Replicate familiar spaces		staff
_	Game / activity room	_	Close to support staff	_	Option to seek
_	Café / hair salon / library /	_	Access to off-campus community		assistance with
	gym	-	Culturally relevant spaces		care
—	Big windows with sunlight	_	Sense of normalcy		