Reconceptualising relationships in the dementia context: Imagining the caring process as fertile ground for friendship between persons living with dementia and paid care partners

by

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Author's Declaration

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

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

Abstract:

Increasing concerns about the task-oriented, disease focused, and impersonal culture of Long Term Care (LTC) have led to calls for the adoption of relational caring, advocating for relationships to be at the centre of all caring. Most recently, the COVID-19 pandemic and subsequent outbreaks in LTC homes have emphasized the downfalls of the current culture of care, highlighting the need for a reimagining of the LTC system. Relational caring has the potential to rehumanize, destigmatize, and value and honour both residents with dementia and Personal Support Workers (PSWs) working in LTC homes. While existing literature on relational caring emphasizes the importance of building authentic relationships with one another, friendship remains an under-explored concept in caring contexts, especially between residents and paid care partners. Further, experiences of friendship between persons with dementia and PSWs continue to be limited by professional boundaries, misconceptions about dementia, as well as rigid, traditional notions of what friendship is.

Guided by relational cultural theory and an arts-based methodology, I collaborated with residents with dementia and PSWs living and working in an LTC home to interrogate and challenge how friendship was conceptualized in the LTC setting, prior to COVID-19. Using collaborative arts, we collectively explored understandings of and barriers to friendship in caring relationships. Through Voice-Centered Relational analysis, which captures the complexity of participants' relational stories, several patterns emerged in this data that provide a deeper understanding of how friendship is experienced in the home, and what matters most to participants in these friendships. Participants in this study identified nuanced ways in which friendship is impeded in the home and insight into how friendship might be better supported. On the other hand, participants shared several stories of friendship and spoke of three good feelings that emerged in these relationships: feeling like more than just a task, feeling remembered, and feeling loved.

This research further informs calls for relational caring and how this culture change may be facilitated in the LTC context, as well as informing new understandings of friendship between residents and paid care partners. This study also supports the use of arts-based research methodologies to conduct critical, social-justice oriented research in accessible, nuanced, and enjoyable ways. Finally, this research can contribute to a re-imagining of LTC settings as we reshape our systems after COVID-19, a future of LTC where relationships and friendship are prioritized for all persons living and working in LTC homes.

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My experience working on this thesis has exceeded every one of my expectations. Through this project I have learned to stay curious and critical, and to never stop trying my best to honour the voices and knowledge of others. I learned that my sensitivity, creativity, and passion are strengths that can help me connect with others so as to do good in the world. This project challenged me and tested my resilience, all the while expanding my world view and changing my perspective on the world. I have grown so much and have so many people to thank.

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Dedication

For my Farmor who made incredible art through her journey with Alzheimer's and whose influence continues to show itself in me the more I age, the more I explore, and the more I create.

For each and every person living and working in LTC homes before, throughout, and after the COVID-19 pandemic. You deserve more. You are not unnoticed. You are valued. Thank you.

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Foreword – Reflections in the time of COVID-19

It feels cliché now to say that I never could have imagined this, so instead I will say that it is surreal to be finishing my thesis in the midst of a global pandemic, to be defended virtually in the comfort (and safety) of my poorly lit, basement apartment. It is especially strange, while also poignant, to be doing and thinking about research in the field of Long Term Care (LTC), which has arguably been hit the hardest by the virus here in Canada. An *enormous* percentage of our COVID-19 related deaths are due to outbreaks in LTC homes, and it is only just now permeating the topics of focus in mainstream media. Most often, it is addressed in brackets, an after-thought, after presenting the total death statistics. When it is addressed, it is often rooted in problematic, biomedical discourse that further stigmatizes the individuals living and working in LTC.

While my data collection and the majority of my writing was completed before the virus prompted international lock downs, social distancing, mass lay-offs, the closure of public spaces, and devastating outbreaks in LTC homes, I believe that the findings remain relevant and important. My research addresses issues in our current cultures of caring, and in our dominant perceptions of LTC work, which are exponentially more evident as we watch this crisis unfold (Brown, 2020; Osman, 2020). Underappreciated frontline workers receive abysmal pay, do not have sufficient access to personal protective equipment, and are receiving little support from the government nor from the public as they literally put their lives on the line to care with their residents. Rampant ageism in perceptions and attitudes towards the virus are evident in how popular the belief is that it only affects the elderly so – "who cares"? Well, I care. Many of us really, *really* care. We should all care. My research explicitly challenges ageism and the stigma of care work and advocates for ideas that could make LTC a better place for residents and paid care partners, largely by looking at relational caring, which highlights the value and humanity of all individuals in the caring process.

That said, it is important to note that I designed this research project, conducted it, and analyzed the data prior to this pandemic. While I have gone back through my writing to address the pandemic and how it relates to certain aspects of the literature review, research process, and findings, this research is a snapshot in time before COVID-19, and the field will likely be forever changed by the events of this year. I hope that my research will contribute to this change, that my findings can be part of a movement that guides culture change in LTC for the better. This culture change movement, as well as an overhaul of LTC policy and legislature, are more necessary now than ever.

Chapter 1: Planting the Seeds: Why friendship?

"By being created as a human being, lies implicitly the openness and receptiveness to be affected by the other, and it is this relation that creates zest for life and courage to live."

(Sellevold et al., 2013, p.69)

1.1 Introduction

I don't think there is anyone I laughed more with at work than with my friend, Rosie[1]. At any point in time during the day, you were likely to find us shoulder to shoulder, giggling and

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[1] *name has been changed*

gossiping. Rosie had a way of whispering to you as though you were the only person in the world she wanted to share her thoughts with. She would tell me about the shenanigans of her youth, and how her husband was her best friend. We would make faces at each other from across the room, often sticking out a tongue or crossing our eyes, then bursting into laughter. She'd shake her head and say: "Oh god, we've gone *nuts!"*. We let each other be a bit nuts. She would confide in me when she was having a bad day, when she'd had a fight with someone or lost something. I would do the same with her; she had a spectacular way of comforting me. Rosie would always tell me she believed in me and that she was so, so proud of me, no matter what it was I was telling her about. Really, Rosie had a way of comforting anyone and had a strong intuition for others' feelings. If someone in the room looked sullen, Rosie would make her way over, wrap an arm around them, and ask if they were alright. If anyone new entered the space she would greet them and show them around. If someone she knew entered, she would exclaim: "Hey you! Get over here!" and embrace them in a big hug. Rosie loved birds, and dogs, and children. She loved swimming in lakes and being in nature. She hated coffee. She loved dancing and music and most of all, chocolate. If you found Rosie without a chocolate bar in her purse, it was probably because it had already been eaten. The chocolate bar served as more than just a means to satisfy Rosie's own sweet tooth. She brought it to share with her friends, to connect with others. Today, I can still hear Rosie's voice inviting me to break off a piece of chocolate, and I can still place myself right next to her, leaning against a counter or sitting and painting, both of us chewing chocolate and murmuring about how much we absolutely love chocolate. I

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treasure our memories of sitting and painting together, spontaneously singing songs from the Wizard of Oz, laughing about this or that.

When Rosie passed away, I wore purple eyeliner to her funeral after realizing I owned no clothing in her favourite colour. I went to the service with colleagues and we shared stories about our friendships with Rosie; all revolved around her sense of camaraderie, of compassion, of humour and how she connected with others. We shared squares of the chocolate bar I brought in my purse. While it is incredibly difficult to lose a friend, it helps to think that Rosie was happy with us, her friends at my workplace, during her final years. Rosie had dementia, and my colleagues and I are 'staff' at an Academy she frequented called the Dotsa Bitove Wellness Academy (DBWA) which is a space of learning for persons with dementia. My friendship with Rosie enriched my life, and though I can only speak from my perspective and through my interpretation of her feelings towards me, I hope that our friendship was just as full of joy for her as it was for me. She called us all her 'kids'; Her big smile would make an appearance when she greeted me every day, arms wide for a hug; Her last words to me after a day of drawing, writing, and laughing together were: "That was great, we should do this again some time."

The DBWA is a particularly unique setting. We engage in a philosophy that includes relational caring, which has been instrumental in creating a space where Rosie and I had the freedom to become friends. Relational caring is a philosophy of caring which stems from theories that highlight the relational and interdependent nature of human beings and address how often this nature is neglected in favour of individuality and independence (Jordan et al., 2004). Relational caring is a way to live and work in close relationship with one another, engaging in growth-promoting relationships (Jordan et al., 2004), specifically within caring contexts.

Relational theorists define a relationship that is growth-promoting as involving five good feelings for both parties: zest, clarity, creativity, worth, and a desire for further connection (Jordan, 2017). This philosophy of caring emphasizes, supports, and celebrates meaningful relationships between everyone involved in the caring process (Jordan et. al, 2004). Abma and Baur (2014) wrote a short and sweet summary of relational theory that I am rather fond of: “To put it simply: people need one another.” (p.2330).

In relational caring we are engaged in the moment in fostering relationships, caring for one another, and embracing our human interdependence (Kontos, 2017). Relational caring also considers humans as being relationally embedded in society, and that our lives are made up of complex webs of relationships and connections with other human beings and with non-human entities (Nedelsky, 2011). It is the imperative of relational caring to re-humanize our caring processes for everyone involved. You might notice that I never specify that relational caring is for ‘patients’, or individuals we ‘care for’. In fact, relational caring specifically calls for a shift towards ‘caring with’, where all care partners benefit from mutual caring in the relationship, whether they are persons with dementia, care partners who are paid or hired, family members, loved ones, etc. In this thesis I intentionally use the language of partnership when referring to caring roles, as it reflects my vision of mutual, reciprocal care arrangements wherein all parties involved are included in decision making I use the term ‘paid carer’ in lieu of ‘paid care partner’ when describing situations wherein the culture does not currently allow for reciprocity or ‘partnership’. The benefits of relational caring and culture change in long term care (LTC) are many. When relational caring is in place, individuals in the caring process experience an overall higher quality of life (Abma & Baur, 2015; Melnechenko, 2003; Rockwell, 2012; Rundqvst &

Severinsson, 1999; Scerri et al., 2015; Sellevold et al., 2013; Smith et al., 2010), an increase in recognition of personhood in older adults (Arcare, 2014; Kontos, 2017; Scerri et al., 2015; Sellevold et al., 2013), and an increase in job satisfaction among team members (Arcare, 2014; Rockwell, 2012), all of which I will explore in further detail in my literature review.

While we have been fortunate to witness some of the aforementioned benefits of relational caring at the DBWA, it is not the case for many dementia care settings, and much of the literature calls for a need for transformation within these settings and organisations (Dupuis et al., 2016b). The DBWA was founded on a philosophy of relational caring – we never needed to *change* our culture for it was engrained in us from day one (that is not to say that individuals within our walls have not had to make deep personal shifts, myself included, but that is a set of stories for another day). Other settings which have existed for years already have a culture – most likely one engrained in the biomedical approach that continues to prevail in care settings (Dupuis et al., 2016b). The biomedical approach is our dominant culture of care in Western societies (Engel, 1977). Based in 'scientific' knowledge and normative expectations of wellness and ability, the biomedical paradigm focuses deeply on disease, impairment, and pathologized behaviours (Dupuis et al., 2012; Engel, 1977; Frank, 2002; Kontos, 2005); objectifies human beings in part by diminishing them to a list of symptoms and illness; perpetuates a stigma on disease and disability; and neglects the social construction of disease and disability and the individual's social embeddedness almost entirely (Engel, 1977; Frank, 2002; Kontos, 2017; Mitchell et al., 2013). While many efforts are currently being developed and implemented with the goal of changing the culture of dementia care, these initiatives are often met with barriers in policy, budget, time constraints, and the profound stigma associated with dementia and the biomedical culture (Alzheimer's Society, 2010; Morin & Leblanc, 2005).

Stigma is an important part of the cultural issue in long term care homes and dementia care settings specifically. The stigma this research is specifically interested in includes ageism and ableism. Ageism is the prejudice and set of assumptions associated with persons of certain ages, and is particularly associated with older adults (Bytheway & Johnson, 1990). Aging is often considered synonymous with disease and disability which subsequently paints a particular picture of older adults; we fear aging, we dislike the notion of aging, and in turn these feelings extend to those we have classified as already 'aged' (Bytheway & Johnson, 1990; Estes & Binney, 1989). Ableism on the other hand paints persons with disability and illness as being inferior, wholly defined by their impairments, and otherwise useless or unable to participate in society (Friedman & Owen, 2017). Both stigmas contribute to a problematic dominant discourse about dementia. As a society we have been socialized to view, speak about, and treat persons with dementia in very particular ways based on assumptions around their loss of self, their decision making abilities, their capacities for relationships, and much more (Dupuis et al., 2016; Kontos, 2005). This is reflected in the language used when discussing persons with dementia; we call dementia a tragedy, persons with dementia ravaged and destroyed by the disease, empty shells of their former selves, and so forth (Dupuis et al., 2016a; Kontos, 2005). This dominant discourse about dementia has real consequences on peoples' experiences in dementia care and LTC (Mitchell et al., 2013). I will elaborate on these consequences, as well as the origins of the stigma about dementia in my literature review.

The deep stigma, problematic dominant discourse, policy and budget dilemmas, and other barriers listed above, are a large part of why dementia care settings - LTC homes in particular - are still viewed so unfavourably in society. “Horror stories” emerge in the news all the time about the quality (or lack thereof) of care in some LTC homes in our communities, about the seemingly perpetual wait lists, about the unwelcoming, rigid, and sterile environment. As I finish writing this thesis, new stories are emerging in light of the COVID-19 pandemic and the way it has devastated an already broken LTC system. Residents are dying at alarming rates as outbreaks overwhelm Canada’s LTC homes. Frontline LTC staff are also getting sick and dying, others are walking out and refusing to work without enough personal protective equipment in what has become a truly dangerous work place. Even prior to the pandemic, we would hear of lived experiences from persons working in dementia care settings – the violence, the task oriented attitude, the ‘grunt work’, being forced to work under-staffed and without resources necessary to care well, and the constant inputting of data for the ministry (Rockwell, 2012). Frontline staff experience burnout and stress, often due to a reported lack of social support and connection (Woodhead et al., 2016). Feelings of disconnection on the part of paid care carers contribute to and reinforce the hostile work environment and stigma mentioned previously. These numerous issues are highlighted at the time of COVID-19, but have been problems in the LTC sector for years. Yet, many LTC homes face many barriers in their attempts to change the culture within their walls, thus contributing to the wide-spread, toxic culture across many LTC and dementia care settings. With an increasing number of persons being diagnosed with dementia or memory loss every year (Alzheimer’s Society, 2010) and simply given the fact that we are all aging, it is imperative that we take action **now** to make dementia care culture within LTC one that greets people with open arms, does not instill fear in us, and does not neglect peoples' social and relational wellbeing.

The consequences of the biomedical model and current culture within long-term care settings have enormous implications for relationships in caring contexts. If we revisit the story about my friendship with Rosie, it is clear in my writing that I believe friendship between a paid care partner, like myself, and persons with dementia is enormously beneficial for both parties. Traditionally, however, and based upon the disease-focused biomedical model, we perceive caring as a unidirectional process: one person, usually a practitioner, professional, or family member is caring *for* the person who is sick or disabled (Fritsch, 2010). This is evident in the way people assume positions of power over persons with dementia, assuming their lack of ability in decision making, and in caring for themselves and others. In relational caring, similar to authentic partnerships (Dupuis et al. 2012a), we shift this perspective to a mutual caring, a caring *with*. For example, Rosie cared for me and brightened my day as much as I hope I was able to do for her. The caring between us felt very mutual. Mutual (and thus relational) caring has the potential to challenge assumptions often made in the dominant discourse about dementia, especially the perceived lack of personhood and inability to build authentic relationships (Dupuis et al. 2012a; Kontos et al., 2018). When I say mutual caring, I do not mean that persons with dementia will provide their care partners with the exact care or assistance they are themselves receiving. It is more about a flow of give and take, a bidirectional caring, which we expect out of most of our personal and intimate relationships (such as friendships) outside of caring contexts – I will touch on this notion in more detail shortly. Mutual caring has the potential to radically shift the way society constructs our perception of persons with dementia, because in viewing and embracing people’s capacity to care, we begin to view their capacities *in general*, as opposed to seeing only their diagnosis and the disease of dementia. We also begin to view the person with dementia as a full human being, not one ‘fragmented’ or ‘ravaged’ by disease (Kontos, 2005; Kontos et al., 2018). In so doing, we begin to deconstruct the ways dementia has been socially constructed and can start reimagining a new perspective on dementia as well as the care and caring arrangements within dementia care settings. It is for this reason that friendship is an intriguing concept which has potential in helping this shift in perspective.

The idea of making caring mutual through relational caring, connects this philosophy with my interest in friendship in the dementia caring context. While also being an important aspect of relational caring as described above, mutuality (or reciprocity) is one of many criteria researchers have identified as a ‘check box’ for what makes a friendship (Furman, 1996; Mendelson & Aboud, 1999). That said, later in this thesis I will challenge the notion that friendship can be defined by a check list while looking to such research in order to explore the way(s) we typically understand friendship in society, as well as how this becomes complicated in the dementia care setting.

Friendship is a concept I believe needs to be brought into the LTC culture change picture more explicitly, as it isn’t typically identified or named when discussing the relationship between paid carers and persons with dementia. For the most part, the literature on relationships between care partners and persons with disabilities (such as dementia) is rooted in the idea that the paid carer is merely a purchased service or tool for “independence”; a means through which a person with a disability can meet normative standards of participation in society (Fritsch, 2010). The relational and embodied nature of such care arrangements is largely overlooked, and so the language we use to describe the care process remains impersonal, contractual, and formal (Fritsch, 2010). In my experience and wholly from my perspective as a paid care partner, the potential for friendship clearly exists. However, most studies on friendship in the dementia context seem to focus on the friendships between persons with dementia (de Medeiros et al., 2011; Sabat & Lee, 2011; Ward et al., 2011), the friendships that do or don't last after someone is diagnosed with dementia (Harris, 2013; Roberto & Kimboko, 1989), or simply what makes a friendship (see APPENDIX A). Often, friendships between paid carers and their "clients" are discussed as risky business, as a source of fear for abuse and harm (for example, see: Allen & Ciambrone, 2003). Even in much of the literature on relational caring I've explored, which I consider the key theory that fostered my opportunity to befriend Rosie and others at the DBWA, 'friendship' is not the language most often used. For this reason, I want to interrogate and challenge current notions of friendship in the long-term care context, in what is an inherently intimate, complex relationship between paid care partners and persons with dementia. In this study, I work with both parties to reconsider or reimagine what friendship could mean in the caring process.

The shift from a biomedical culture and a problematic dominant discourse about dementia, towards relational caring, is instrumental in making the world a kinder, more compassionate and welcoming place for persons who have been or will be diagnosed with dementia (Mitchell et al., 2013). As an individual with many friends who have dementia, I personally want to strive for this better world, to make it exist for me and my friends. That being said, I do not have dementia, and my perspective is limited to my lived experience already engaging with relational caring. For this reason, I approach this research topic collectively, working directly with and being guided by persons with dementia, as well as their paid care partners in LTC. Together, **we can re-paint the landscape of dementia care**, and make it what we hope and dream it could be.

1.2 Purpose

My research has two primary objectives. First, through this research, I hope to interrogate and challenge how friendship is conceptualized in the dementia caring process. My second objective is to inspire new ways of understanding friendship in the care context. My ultimate hope is for the field of dementia care to embrace the cultural shift towards relational caring, and parallel this shift by accepting friendship as a real possibility between persons with dementia and paid care partners in the caring process. Of particular interest in this research is the relationships between persons living with dementia and the paid care partners who take the role of personal support worker (PSW) or similar roles. For the purposes of this study, PSW is the term used to describe frontline, daily care partners working in LTC. PSWs have the most frequent contact with individuals living in LTC, providing activities of daily living and the most physically intimate care. I am therefore most interested in the potential for friendship between these particular paid care partners and persons with dementia, as well as what may support or limit these relationships in the LTC setting.

Taking a critical and relational lens to this project and drawing on arts-based methodologies, I will address the objectives above by exploring the following research questions:

1.3 Research Questions

1. How are dominant discourses on friendship reflected in, negotiated, and experienced in relationships between persons with dementia and paid care partners?
2. In what ways does the current culture and structure of LTC limit and/or support constructions of friendship between persons with dementia and their paid care partners?
   a. How are the limitations/barriers negotiated by persons with dementia and paid care partners?
3. How can we collectively challenge and re-imagine friendship in the dementia caring process?
   a. How can visual arts help us collectively reconceptualize friendship?

1.4 Positionality Statement (Ontology, Epistemology, Theory, and Subjectivity)

1.4.1 Introduction to Ontology, Epistemology and Theory

If a tree falls in the forest and no one is around to hear, does it still make a sound? A common enough proverb, I like the way this question scratches the surface of ontological and epistemological inquiry. Ontology is concerned with the nature of reality and being, while epistemology looks at what Grbich (2007) calls “knowledge traditions” (p. 3): what knowledge is, how it is produced, and how it is acquired. Both ontology and epistemology have common components that are relevant to the proverbial tree question; the tree is the object, separate from (or perhaps in relation to) the human subject. The question asks us to consider the relationship between the object and the subject; without the subject present, in what way does the object exist, and does it have any meaning without a subject? The way one answers this question is a good indication of their basic ontological and epistemological beliefs, whether or not they would know to call it such. Of course, for a researcher, thinking in these terms and through these ideas is important (Crotty, 1998). Identifying one's own onto-epistemological stance requires a great deal more self-reflection and is paramount to the overall cohesion and justification of one's research design (Crotty, 1998). As I begin explaining my onto-epistemological stance here, I also begin the process of outlining my research design using Berbary and Boles' (2014) scaffolding for qualitative inquiry. This scaffolding acts as a guide for qualitative research projects while allowing for some improvisation, all the while providing a form of organization and rigour that is often expected and required of researchers in academia (Berbary & Boles, 2014). Throughout this section I will use Berbary's and Boles' (2014) eight-point scaffolding as a guide for situating myself and my research, and a way of exploring some tensions that have emerged as I engage with the various points of the scaffolding. My scaffolding work here is a beginning and I will continue to work with the remaining points of Berbary and Boles' (2014) scaffolding later in this thesis as I introduce my methodology and methods.

1.4.2 Ontology and Epistemology: Social Constructionism

In considering which onto-epistemological stance is the best fit for both my personal beliefs and my research, I start to understand what Preissle and Grant (2004) mean when they assert that epistemologies can "be considered as continua. Researchers may move back and forth along continua or take a single position in a particular study." (p.163). Preissle and Grant (2004) refer to both the realism-idealism ontological continuum, as well as the objectivist-constructionist-subjectivist epistemological continuum. The notion of a continuum appeals to me as I find myself aligning and disagreeing with various tenets of multiple epistemologies, particularly when considering my specific thesis research. Having said that, generally I feel I am in alignment with Constructionism.

To start, I will describe the epistemology of Constructionism and how I align with it. The Constructionist epistemology falls under an idealist ontology which privileges humans as the central "knowers" of our world, and emphasizes that human consciousness is how the world comes into being and has any meaning at all (Crotty, 1998). Constructionism is thus centred on the notion that meaning (knowledge) is constructed by the human subject in interaction with the object (Preissle & Grant, 2004). It encompasses two foci that make a distinction between the construction of meaning through the individual's consciousness (Constructivism), and the construction of meaning as a cultural, societal, and individual process (Social Constructionism) (Crotty, 1998). For the Constructionist, meaning and truth are conceived as subjective and multiple. However, there is perceived to be an existing, stable foundation of truth which is obscured by and perhaps impossible to reach under the net of individual and societal meanings that rest atop it (Crotty, 1998). I am intrigued by the Constructionist notion that meaning (and thus, reality) is influenced and constructed through both the personal and the social. Given that I am looking at constructions of friendship and how these constructions of friendship (and thus experiences of friendship) are influenced by broader social and cultural discourses, constructionism seems aligned with my research.

To view meaning as a construct implies that the knowing, human subject is the actor and that the object has no meaning until the subject is conscious of it and attaches meaning to it. Crotty (1998) coincidentally also uses the tree as the object in his explanations, reminding us that in constructionism “it is human beings who have construed it as a tree, given it the name, and attributed to it the associations we make with trees.” (p. 43). In Constructionism the subject is the knower-constructor, and the object is the limiting factor to the possible and multiple creative meanings the subject can ascribe to it (Crotty, 1998). This positioning of the human subject puts the individual in a position of power over the object and the meaning(s) attached to it, however the object is still of utmost importance as it is the other half of the meaning making process (Crotty, 1998). Nonetheless, the human is the central actor within the subject-object relationship, and it is only through the human engaging with an object and making sense of it, that meaning emerges from it. That being said, the social-constructionist would specifically consider how the process of construction is also informed by social contexts, histories, and ideologies. This is an important consideration in constructionism as knowledge is “always bound to a specific point in time, to a particular culture and civilization, and to their particular logics and presuppositions” (Fischer, 1997, p. 305) all of which significantly influence how different phenomena get constructed. Social constructionists recognize that we are born and subsequently live in a world of complex, pre-existing cultural meanings. These cultural understandings shape our personal thinking and actions, but also have the potential to be resisted, challenged, and re-constructed. Therefore, social-constructionist researchers approach socially-constructed knowledge critically, often with emancipatory goals, taking into consideration how societal power structures inform individual constructs (Crotty, 1998). LTC contexts are a clear example of such an influential social setting, given the numerous policies and regulations, multiple social and professional roles all under one roof, all of which are further informed by broader cultural and political contexts. My research project is aligned with social-constructionism, as in this research I am focused on interrogating the dominant discourses, culture, and power dynamics that shape individual meanings of relationships in LTC, so as to consider how friendship could be done differently in this context.

Given that Constructionist researchers are acutely aware of the power of construction and the subsequent subjectivity that exists in the meaning-making process, Constructionists position themselves very particularly and intentionally in the research process (Crotty, 1998; Preissle & Grant, 2004). The Constructionist researcher acknowledges that, while they uncover constructed meanings, they are personally engaged in a similar process of construction of knowledge. As such, researchers engage in a continual reflexive process throughout their research in order to make transparent one's perspective and evolution of perspective throughout the research (Preissle & Grant, 2004). In so doing, researchers make clear their awareness of self as being inherently and inextricably present in the research, as opposed to more traditional objectivist researchers who aim for complete objectivity (Crotty, 1998). The constructionist researcher acknowledges their subjectivities while also interpreting the lived experiences and constructed truths of their research participants. In doing so, the constructionist researcher represents their knowledge as "constructed jointly in interaction by the researcher and the researched through consensus." (Grbich, 2007, p.8). Therefore, there are no singular truths determined through a constructionist research project. There are no claims of generalizability nor validity. Instead, constructionist research is concerned with trustworthiness, credibility, and transferability

(Creswell, 2014) as well as the extent to which research leads to personal and social change, both throughout the process and through the outcomes.

As a constructionist researcher, I must consistently reflect critically on the historical, social, and political contexts of my own life, as well as my personal experiences with friendship in life and work, and acknowledge that all of this has shaped my understandings of friendship in the dementia context. These factors have also shaped how I interpret data collected throughout the research project, which I have considered and addressed throughout the process. I also acknowledge my subjectivity as a researcher attempting to understand and subsequently interrogate the meanings that my research participants construct about friendship. I realize that as a researcher I have privilege and thus a responsibility to work hard to do justice to the knowledge(s) my participants have co-constructed with me through this process.

Another important consideration in Constructionism is language. Constructionist epistemologies emphasize the importance of language as an entangled, inseparable tool of the human mind (Fischer, 1997; Miller, 2016). Miller (2016) writes that there is a plethora of potential meanings which “narrows down to one meaning when someone verbalizes a particular meaning expressed in context, thereby excluding all meaning possibilities except the one actualized by the speech act” (p. 366). That is to say that the language choices we make as humans, create particular meanings of the world and excludes others. Language is thus an organizational tool as well as a process through which humans create meaning in the world and share meanings with others (Fischer, 1997). This is particularly important to keep in mind through the research process, as language used can shape understandings and is often how the research findings are disseminated. Careful attention must thus be given to the language used by both researcher and research participants. You may notice that throughout my thesis, I often discuss the reasons for my particular choices of certain words over others. I have also approached language thoughtfully through the Voice Centred Relational (VCR) approach to analysis, which I will describe in detail in my methodology section.

1.4.2.1 Tensions

While constructionism holds great appeal and makes sense to me in the context of my study, I often struggle to reconcile my lived experiences with persons with dementia, and how constructionism might apply to research in this context. From my perspective, it seems that some of my friends with dementia at work construct and re-construct their truth(s) from moment to moment: one minute it is their father coming to pick them up; the next minute, it is their husband. Neither of these minutes is less real and truthful for the individual, in that moment. Truth and reality become fluid and therefore conducting research with persons with dementia under a constructionist epistemology might create some tensions in my research process, given that Constructionism considers there to be some form of foundational truth to begin with (Crotty, 1998). As Crotty (1998) puts it, under Constructionism objects "may be pregnant with potential meaning, but actual meaning emerges only when consciousness engages with them" (p.43). When I explore ideas on the ambiguity and paradox of reality, I begin to veer into a somewhat subjectivist epistemological stance.

In subjectivism, the relationship between objects is a dynamic, relational process wherein both subject and object remain separate as entities but are not separated by the dichotomy of subject/object as they are in Constructionism (Berbary, 2017). That being said, there is a huge variety of descriptions of what subjectivism actually is. Some describe it as a breaking down of subject/object binaries (Berbary, 2017), others as an epistemology wherein meaning is entirely imposed onto objects by the human subject (Crotty, 1998). Either way, the view of reality and truth in the subjectivist context is contingent, momentary, partial, shaped by discourse (Berbary, 2017), and entirely subjective (Crotty, 1998). For this reason, subjectivist researchers will never claim to be representing *the* Truth in their final research presentation. Instead, they offer their research as a glimpse into momentary truth(s) that challenge so-called "stable" knowledge (Berbary, 2017). Subjectivist thought is often associated with post-structural theories (Crotty, 1998), which I will touch on and describe in greater detail later in this section.

As such, an ambiguous configuration of reality and truth is much more in line with the subjectivist view of truth(s) as partial and momentary, as opposed to the Constructionist truth(s) which are multiple but foundational and, therefore, somewhat stable. That being said, the subjectivist understanding of reality is in fact aligned with certain conceptions of constructionism, for example Grbich (2007) asserts that under constructionism, "reality is fluid and changing" (p. 8) and that realities are indeed plural. In fact, Crotty (1998) argues that many people who describe themselves as Constructionists, are really describing a subjectivist stance. Therefore, it is perhaps not a problematic tension, and instead an overlap in subjectivist and Constructionist epistemologies. I begin to address these tensions/overlaps in my research by exploring some post-structural theories which are generally aligned with subjectivist epistemologies (Crotty, 1998). Post structural theories test the boundaries of Constructionism, in that they break down the subject and object binaries inherent in realist, humanist research (Crotty, 1998). Although I recognise some tensions here, I am drawn to some post-structural theories in the ways they inform my conception of relationships and friendships, with the goal of navigating the ambiguity of friendship generally, and more specifically in the dementia context. I will outline these theories and how they inform my study in both my theory section as well as in my literature review.

1.4.3 Theory: Critical Theory, Cultural Relational Theory

In my research, I am informed by both critical and relational theories. Acknowledging and understanding my guiding theory is paramount in a research project as it informs methodological choices, influences overall research design, frames analysis, informs language choices, and guides final representations. It is one of numerous, consistent threads that ties the research process together. It also guides the researcher's focus onto certain research questions and what types of issues/concepts are important to look at (Creswell, 2014). As per Berbary and Boles' (2014) description of scaffolding, theory must be tied quite intimately to ontology and epistemology. The way one understands reality and knowledge is reflected in the theory one applies to further understand and or uncover both. In my research, as outlined earlier, I position myself within the social constructionist epistemology. This has led me to explore critical theories as they align well with social constructionism because both emphasize the social and cultural nature of knowledge construction. Critical theories complement this epistemological belief by challenging, questioning, adding to, and deconstructing the social and cultural knowledge that currently exists (Crotty, 1998). Additionally, both critical theory and social constructionist tenets assert that there is some level of shared cultural reality or truth (Gannon & Davies, 2012). Both aim to understand and unpack the social construction of meaning that is built onto this reality, and view culture as playing "a central role in the production of hegemony and common-sense interpretations of everyday life" (Rexhepi & Torres, 2010, p. 687).

As mentioned, my research is guided by many tenets of critical theory. However, critical theory is a very broad umbrella under which a variety of unique theories fall such as critical disability theory, feminist theories, and critical race theory, to name a few. It is also described and interpreted by different theorists and academics in diverse ways. Therefore, it seemed necessary to me to make the distinction between the overarching influence of critical theory on this research, and the particular branch of critical theory that has informed me the most; that is, Relational Cultural Theory (RCT). For the purpose of this thesis (and because it resonates with me at a deep level), I have chosen to employ RCT as the specific critical theory with which to guide my research. That said, the more general tenets of critical theory are still relevant for my thesis. I will thus outline the tenets of critical theory that inform my work and give a thorough overview of RCT and how it fits into critical theories.

1.4.3.1 Tenets of Critical Theory

The overarching tenets of critical theory that are most important for my study are: interrogating, critiquing, and re-imagining structures and dominant discourses that oppress and marginalize; the emphasis and exploration of power and power relations; and the notion of praxis. Whether it be critical disability theory, critical race theory, feminisms, or other critical theories, all share a common theme: they seek to expose, challenge and reimagine structures and dominant discourses that oppress and marginalize persons or groups of persons. This differs from other, more traditional theories which guide research to discover, understand, categorize, or define (Crotty, 1998, Watkins & Shulman, 2008). The goal of critical research is to uncover emancipatory knowledge and to instigate transformation for all participants at an individual level as well as contributing towards larger-scale cultural and societal change (Crotty, 1998; Rexhepy & Torres, 2010). Participants in critical research projects take the reins and emphasize their voices and lived experiences, as the researcher acknowledges their own subjectivities and positions themselves alongside their participants (Rexhepi & Torres, 2010). The voices of participants are highlighted as a way to challenge and interrogate dominant discourses and begin to imagine new possibilities for being and relating. This is particularly important given that the perspectives and voices of individuals who are marginalised are so often silenced or neglected, and are entirely analysed through a researcher's own subjective lens (Rexhepi & Torres, 2010).

Often, in a further attempt towards liberation, participants themselves are encouraged to think critically about the topic at hand. Critical theories are "rooted in the needs and sufferings of the most oppressed populations, while arguing how many were unaware of their true material circumstance and the structural and social barriers underlying their condition" (Rexhepi & Torres, 2010, p. 685) and therefore aim to foster such critical thinking in participants. Through thinking differently about the way things are in the present, participants can then collaboratively develop ideas about what the future could be. In the process of reflecting on how society is currently constructed, uncovering the roots of those constructions, and imagining alternatives, participants of such critical projects also engage in proposing solutions for themselves. The goals of this process are to offer alternative, emancipatory discourses; to make space for participants to feel empowered; and to change perceptions so as to abolish stigma, challenge assumptions, and advocate for inclusion (Gannon & Davies, 2012).

Power is of importance to critical research, as it is interested in how society marginalizes some, and keeps others in positions of privilege and power-over. Power is a difficult concept to describe concisely as it has a plethora of meanings and interpretations (Lord & Hutchison, 20017; Owens, 2015; Wrong, 1968). To name a few, there is social power (Wrong, 1968), individual/internal power (Lord & Hutchison, 2007), physical power, bio power, and power relations (Foucault, 1975). I understand the concept of power as relations or dynamics which have the potential to fluctuate and change. By conceptualizing power as relational, as an un-stable, inter-personal process, we establish it as something changeable that does not belong to one person and not another (Foucault, 1975). Given that this research is focused on relational theories, this conception of power as a relational process opens the door for relational theories to affect change in the hierarchies and societal privileges that exist today. Jordan et al. (2004) also describe power in the context of relationships in a way that is particularly relevant to the discussion of marginalization and stigma. It is described as "the power to name, to shame, and to define another's value or lack thereof, the power to distribute resources" (Jordan et al., 2004, p.5). This power to stigmatize and ascribe social status can exist at an interpersonal level as well as a larger, societal level (Jordan et al., 2004). As mentioned above, encouraging critical thinking in research participants can also help individuals reclaim their power in power relations and engage more deeply in instigating social change (Crotty, 1998; Freire, 1970). This can leave participants with feelings of hope that extend beyond the scope of the research project. A focus on power relations also encouraged me to reflect on my role as researcher during the research process. Several ways I chose to do this included critically reflecting on the language I use, assumptions that might be shaping my relational processes with participants, and the specific ways that I am relating with others and providing a safe space for my participants to share ownership of the research process with me. I will expand on some of these ideas in my section on rigour later in this thesis.

Praxis is a notion that arises in many iterations of critical theory and is cited by many critical theorists. Praxis is the intersection of practice and theory in what is usually social justice-oriented action (Crotty, 1998). Freire describes praxis as "reflection and action upon the world in order to transform it." (1970, p.7) and elaborates that in critical projects, praxis is a continual process wherein human thought and behaviour come together to achieve liberation (Freire, 1970). When applied to research projects, praxis suggests that the research and its results will not exist purely in theory nor in academia, and that the research itself is a process that contributes to a journey towards emancipation. It is for this reason that critical research is often participatory, highlighting the voices of individuals who are normally silenced, and approaching research as a collaboration between researcher and participants (Freire, 1970). This resonates with the notion of praxis as it creates change even during the research process itself, given that critical thinking can itself be seen as praxis as it is "a search for knowledge, to be sure, but always emancipatory knowledge, knowledge in the context of action and the search for freedom" (Crotty, 1998, p. 159). This is especially true for research participants who experience oppression, as they reflect critically on the societal and historical factors contributing to their oppression. In so doing they begin the process of their own emancipation and empowerment to challenge such factors (Freire, 1970). Further, truly critical research becomes applicable beyond academia, and must focus on actual engagement in the social sphere (Rexhepi & Torres, 2010).

My understanding of the spirit of critical theory is that it is more than just a theory that one applies to a research project. It becomes a lifestyle; a constant state of critical thinking, teaching, learning, and acting. It is a continual process of reflexivity and checking in with one's own subjectivities as well as society's. It is a way of being. As Rexhepi and Torres (2010) say, from an education studies perspective: “Dialogue and reason cannot take vacations if one hopes to seriously pursue the dream of social justice education and peace” (p. 692). In other words, advocating and thinking critically for/with those who are oppressed or marginalized is more than a research-based endeavor, it is a full-time, on-going vocation. I believe this is achieved through the aforementioned tenets of critical theory: challenging oppressive structures in society, focusing on power relations, and emphasizing praxis. That said, the nature of my research is such that I was drawn to Relational Cultural Theory to guide me more specifically in exploring my research topic of friendship in dementia caring.

1.4.3.2 Relational Cultural Theory

Relational Cultural Theory (RCT) looks at the way our culture in Western societies shapes and is shaped by the way we view and engage in relationships. Relational Cultural Theory (RCT) falls under the critical theory umbrella for a variety of reasons. Perhaps most importantly, RCT is predicated on the need to challenge the dominant discourses and structures in society that encourage us *not* to engage in meaningful relationships. It seeks to emancipate and liberate people from societal expectations that shame us and keep us from engaging in relationships that help us grow, feel safe, and feel connected (Jordan, 2017). Though RCT has evolved from its feminist roots to encompass a broader range of marginalization, it continues to look at the individual lived experience of disconnection and pain as being part of a larger societal issue, as opposed to a personal failure or problem (Jordan, 2008). Therefore, like other critical theories, RCT advocates for the bringing together of otherwise silenced voices to offer alternative discourses and instigate social change. Furthermore, RCT asserts that our competitive, self-sufficient culture encourages all of us to hold power-over others in an attempt to secure our own individual success at the detriment of others (Jordan, 2017). As such, power in relationships is addressed in RCT, just as it is in the overarching critical theory umbrella.

As I mentioned, RCT is rooted in critical, feminist theories. Its history in feminisms stems from work by Jean Baker Miller, Judith Jordan, Janet Surrey, and Irene Stiver at the Stone Center of Wellesley College, work which initially looked at the experiences of women experiencing marginalization (Jordan, 2008). What emerged from this work was the realization that women were being shamed for their innate desire to connect with others. Women were seen as lesser-than due to their expressed need and desire for dependence and for growth-promoting relationships (Jordan, 2017). This is because society typically privileges 'the self-made man' and what Jordan and colleagues call the myth of separation (Jordan, 2017). The myth of separation is the belief that being independent and having no need for others is the ideal human state for achieving success. Jordan and her colleagues who worked on RCT believe that this separation is not even true or possible, and that those who strive towards it are fighting their own relational nature, thus experiencing unnecessary stress (Jordan et al., 2004). They believe that all human beings - regardless of gender - are first and foremost relational beings, yet we are socialized to believe that this makes us weak and inhibits us from succeeding or competing for success (Jordan, 2017). RCT challenges this belief, bringing relationships back to the center of culture and human existence, and challenging the competitive power-over culture that exists when humans are encouraged to be independent and separate. RCT looks at how connection helps us grow and "achieve a sense of well-being and safety" (Jordan, 2008, p. 2). RCT looks at the benefits of connecting through authentic, growth-promoting relationships. As previously mentioned, RCT defines a relationship that is growth-promoting as generating five good feelings: "zest, creativity, worth, clarity, and a desire for more connection… for both people!" (Jordan, 2017, p. 235). Further, RCT looks at how a lack of engagement in such relationships creates relational trauma, disconnection, and pain in society as a whole (Jordan et al., 2004).

RCT also looks beyond interpersonal, individual level relationships between two human beings; it looks at our relationship and connection with everything, including our earth/ecosystem, which humans historically believe they have power-over and thus use to their own advantage (Jordan, 2017). Bringing this idea full circle, Jordan explains "The earth is treated as ours to master and despoil. Where is the compassion, the mutual empathy in such a prevailing stance? What of the future of our children and grandchildren? What of those suffering around the world from starvation, terrorism, and untreated illnesses?" (Jordan, 2017, p. 242). Overall, RCT points out the consequences of an independence-centric culture and looks to steer society towards a more relational way of being. Jordan (2017) describes this as a hopeful future that would ease our paranoia and selfishness, and instead bring society a healthy dose of optimism for the potential of human selflessness and connectedness.

I think it is easy to believe that a relationship-focused approach to the world is 'fluffy', that relationships are "add-ons, or worse, signs of weakness and inadequacy" (Jordan, 2017, p. 237). That is the exact mentality that RCT is hoping to challenge; there is nothing fluffy about relationships, instead our need for connection is vital to our survival, our happiness, and our well-being (Jordan, 2017). I believe that RCT addresses this concern well, as it takes a practical approach to what constitutes a 'good' or growth-promoting relationship. It does not require that relationships always be at their best. In fact, Jordan (2017) talks about the difference between acute disconnection, where people experience resolvable conflict in good relationships, and chronic disconnection which create pain and can lead to pathology (Jordan, 2017). The argument is that if both parties work through acute disconnection and grow through such conflicts, then the relationship is still contributing to mutual growth and well-being.

Interestingly, RCT has recently embraced neuroscience. Work being done in neuroscience supports the theory that disconnection causes us pain, showing that the brain processes emotional pain from disconnection the same way as it does physical pain (Jordan, 2017). On the flip side, connection changes our brain activity for the better, and humans are wired to seek connection in times of stress and danger (Jordan, 2017). RCT theorists embrace these discoveries cautiously so as to not diminish the value and importance of interpersonal meaning making and peoples' lived experiences. However, they acknowledge these discoveries as they challenge hegemonic ideas of a 'scientific', biological competitiveness which has historically been viewed as necessary for human survival (Jordan, 2017). Further, the implications of valuing emotional pain equally to physical pain challenges many cultural beliefs about the separation of mind and body. The mind-body dualism is particularly relevant when discussing the stigma of dementia and other illnesses, which I will describe in detail in my literature review.

Finally, the implications of RCT in my research project are as follows. As previously explained, my research project is guided by critical theory in that it is social justice oriented. By specifically taking an RCT approach and looking at the LTC setting, I seek to interrogate the ways cultural and institutional circumstances and discourses influence individual, inter-personal constructions and experiences of relationships between persons with dementia and paid care partners. RCT contributes to my conception of relationships as being central to human well-being and supports my overall interest in relationships in the dementia caring process. As for the research process itself, RCT has guided a variety of my choices. Participants' active participation in all phases of the research, and the highlighting of their voices as a form of alternative discourse is an important aspect of RCT and other critical theories. These aspects of critical research are evident in both my collaborative arts-based approach and the use of the Voice Centered Relational approach for analysis, both of which I will outline in detail in my Methodology section of this thesis. RCT stresses the importance of the relationship between the researcher (or 'professional' of any kind) and the participants. Thus, my research design and approach honours the relationships that are cultivated throughout the research process. Given that in critical projects, research is seen as an active collaboration, my position in the research process is not that of an expert or an objective, un-attached party. I was engaged throughout the process in relationship with the participants. In order to express and account for my subjectivities as a collaborator in the research, I have taken numerous steps to account for my reactions and feelings throughout the project. I will outline the steps I took later in my thesis in sections about analysis and rigour, but I will begin this process by now sharing my initial subjectivity statement here.

1.4.4 Subjectivity Statement

I have worked with persons with dementia for more than five years now. It all started as a small, part time job working with someone once a week while I was finishing art school. I would visit her and paint with her for an hour every Monday, and we developed a very enjoyable relationship discussing paint colours, flowers, and more. She made me think of my grandmother, Betts, who also had dementia, and I felt both happy and sad because I had never had the chance to paint with my grandmother as an adult. I knew what joy painting brought my grandmother as her dementia developed, and it was nice to see it in action while working with this person, as an adult myself. I looked forward to painting with her every week.

After a year or so, I moved away temporarily and she started attending the DBWA while I was away. The DBWA happened to be very close to my home, so when I moved back I began volunteering there because I loved the work and wanted to continue painting with her. Of course, I would paint and draw and dance and sing with so many more people than just her, and I began falling even more in love with the work. I especially loved our philosophy of relational caring and found it a very natural way of being; my understanding of what it meant to have dementia changed dramatically, particularly in that I no longer believed persons with dementia experience an innate loss of self. I also loved the concept of relational caring, though I didn't know much about it other than experiencing it in practice. I expressed my interest in having a job there and transitioned from volunteering to facilitating and teaching my own art sessions at the DBWA. When art school ended, I realized I didn't want to stop doing this work. Being a freelance artist, sitting behind a desk drawing and painting, using a computer screen to email clients, felt incredibly lonely. I realized that the reason relational caring at the DBWA felt natural to me, is because I am equally social as I am creative, and I value and need to balance both in my work and life. Upon realizing all of this, I went back to school for my Master's in Recreation and Leisure at the University of Waterloo and had the opportunity to study relational caring theory and relate it back to my years of lived experience. It was wonderful learning about why we've been doing what we do at the DBWA, and why it feels so good for all of us. I hope to continue doing this work for many years to come, as there is truly no time where I feel more at home than when I am spending time with the Academy members, learning and exploring together through the visual arts. It is an honour and a privilege to facilitate the sessions I teach at the DBWA, and I wouldn't trade the experience for the world. I am increasingly proud of the relational community we have built over the years and the relational work we do there.

Furthermore, the learning didn't end with relational caring theory and how it might apply to my work! As I read about and began documenting my understandings of relational caring, I often found myself reflecting on my childhood. Much of the pain I experienced when I was younger was rooted in relational trauma, so to speak. The work of Jordan et al. (2004) on relational cultural theory, which describes relationality beyond the dementia caring setting, really helped me come to terms with this. I had no 'real friends' as a child, yet I always craved close relationships with peers, cousins, siblings, adults and really, anyone. I couldn't understand why close relationships weren't happening for me. There is a poignant memory of mine that resurfaced while I was preparing the proposal for this research. I was six years old. I had just entered grade one, and was standing by the garbage can by the door of the school, waiting for recess to be over so I could go inside and not feel so alone. I can picture exactly how I was standing: arms behind my back, leaning against the rough brick wall, watching all the other kids run and play and scream and shout. I remember looking at the pebbles in the concrete of the garbage can to occupy myself, picking favourite pebbles. The competitive spirit never really existed in me, and I could not keep up in competitive social dynamics. I was always the last one chosen or left behind altogether. This was much like being the last chosen for sports teams in gym class when you're bad at sports (which I also, always experienced). I would not insert myself into situations as I was too shy and polite to force people to hang out with me if they didn't want to. I don't think people disliked me, I just think they were playing a social game I couldn't figure out. This vignette is indicative of my attitude throughout my childhood – though I tried to make friends, I never wanted a relationship that wasn't reciprocated, I never wanted to play social games, and I never quite found friends who accepted me until I switched schools halfway through high school to take part in an art program. I suddenly became friends with what felt like everyone, though all were real connections, and many of the friendships still exist today. The effect of different social contexts on my well-being is obvious now when I look back with the critical lens I have developed, viewing the two schools as having different cultures, different power dynamics, and different social norms.

Undoubtedly my memory of the loneliness and the unreciprocated feelings of friendship has influenced my interest and focus on friendship in research and the dementia caring process. I know how good I feel when I am connected in friendship as well as how horrible it feels to be lonely and disconnected, and I imagine I can't be the only one who knows these feelings. When I realized that friendship can be taboo and that relationships are so often restricted in the traditional dementia caring process, I became concerned with how something that to me seemed so good could be constructed as something so negative just because it is being looked at in a different context. As such, I felt the need to interrogate and challenge the way friendship is perceived in the dementia caring process through this project. There is so much power in friendship and I want to maximize the potential of friendship for others who are, or could be, feeling lonely.

Ultimately, my subjectivity exists in my passion for friendship as well as my passion for working with persons with dementia. I deeply believe in fighting ageism and the stigma around dementia, and I deeply believe in the culture change movement which I hope to contribute to. I also have enough experience working with persons with dementia and their care partners to have felt confident in conducting this research in a way that is fair, ethical, critical, fun, respectful, and most of all, transformative for both myself and my research participants.

Chapter 2: Painting the picture: Cultures of care, relational caring, and friendship in the LTC context.

In this section I will first paint a picture of the culture of care that existed when I started to work on this project, a culture of care rooted in a historically dominant biomedical model, which I argue makes LTC an unappealing place to live and work. As previously mentioned, the COVID-19 pandemic has called attention to many of the problematic aspects of the LTC home culture, which I outline and explore in this section. However, the pandemic has also initiated a process of change that will shape what the LTC home field looks like in the future (for better or for worse). This literature review was completed prior to the pandemic and reflects that moment in time. With that in mind, I will discuss how the biomedical model of care and the associated stigma on disabilities such as dementia contribute to chronic disconnection and a lack of growth-promoting relationships for individuals living and working in LTC. I will subsequently provide a thorough discussion of relational caring, a proposed philosophy of care which is aligned with the tenets of Relational Cultural Theory as previously discussed. Relational caring addresses many of the problematic aspects of the biomedical model of care and aligns well with the calls for culture change in LTC towards more humane and relational approaches (Arai et al., 2015; Dupuis et al., 2016b). Finally, once relational caring has opened the door for focusing on relationships in the caring process, I will explain why friendship - as a particular manifestation of relationships - should be considered and celebrated in the dementia caring context.

2.1 An Overview and Critique of the Biomedical Model

It must be evident at this point in my thesis that the biomedical model is not one that I position myself within, not in my work nor my research. That is not to say that the biomedical model has not been beneficial; certainly, it is a space where many advancements have been developed, bettering lives every day. However, biomedical ways of caring have been problematized and critiqued for perpetuating stigma around disease and illness, negating peoples' personhood and humanness, and silencing individuals' voices, (Engel, 1977; Frank, 2002; Kontos, 2005). The larger culture change project then, is to "broaden the approach to disease to include the psycho-social without sacrificing the enormous advantages of the biomedical approach" (Engel, 1977, p.131). That is to say that while the biomedical model helps many, it also tends to reduce individuals to their bodies, their sickness, or their disabilities, and does not acknowledge the relationality of human beings nor the relational nature of the caring process. We see this effect amplified during the pandemic, as the focus of caring settings becomes survival amid outbreaks, and relationships fall to the sidelines.

2.1.1 Evolution of the Biomedical Model and Associated Stigma

In order to understand the biomedical model as it exists today, I believe it is important to pinpoint certain moments in history that have helped it evolve in the way that it has. This understanding of the biomedical model is important to this discussion because it has played an important role in shaping the culture of LTC and how relationships are understood within that context. Engel (1977) summarizes the origins of the biomedical model of medicine, stating that it comes from a basic human need to establish explanatory systems for understanding phenomena, particularly ones such as diseases which concern and disturb us. Additionally, our Western biomedical model has many of its roots in religion which was at a time largely influential and not separate from science (Engel, 1977). When the Christian church allowed for the study of the human body through autopsy, it reinforced a mind-body dualism wherein the body is viewed as merely a vessel for the soul, and the mind is something else entirely (Engel, 1977). Furthermore, as Western cultures departed from religious domination, rationalism became the dominant movement wherein people sought logical and rational ways of understanding the world in all aspects, including medicine (Hewa & Hetherington, 1995). With the societal focus on efficiency and the economic benefits of rationalism, the human spirit became all but neglected, resulting in the "total alienation of the human spirit from the scientific and rational world" (Hewa & Hetherington, 1995, p.131).

Through such cultural and scientific advancements, the human body became a machine over which physicians claim expertise, thus exerting control over those who come to them for assistance (Engel, 1977). Hayes and Hannold (2007) describe this shift in power as relating to the aforementioned advances in science and religion, given that: "The inside of the body, which had previously remained invisible and mysterious became visible. It became the focus of clinical expertise, regimentation and control" (Hayes & Hannold, 2007, p.354). In attending to a 'machine' with a problem to be fixed, as opposed to a whole, relational person, professionals within the biomedical culture are effectively objectifying the human beings who come to them. Therefore, those working in caring contexts are no longer relating to individuals as equals, and instead engage with them as 'failing' bodies whom they hold power over, with the sole purpose of fixing the broken 'machines'. This unquestionably creates tension in how professionals relate to individuals in their care, individuals who are experiencing care not as a mere body, but as a full human. To illustrate, Frank (2002) writes about his experience as a patient, saying: “When a person becomes a patient, physicians take over her body, and their understanding of the body separates it from the rest of her life.” (p. 53). Frank (2002) also shares his specific experiences of the dehumanization of care, including: a nurse referring to him (to his partner), as “the seminoma in 53” (Frank, 2002, p.52) thus neglecting his personhood and name entirely; physicians actively avoiding eye contact the more Frank’s disease progressed; and his disease and body being referred to as “this”, again removing the human element, as well as any potential for human connection from the situation.

I particularly like the way that Engel (1977) highlights medical professionals’ assumption of power, succinctly highlighting “the historic function of the physician to establish whether the person soliciting help is “sick or “well”; if sick, why sick and in which ways sick; and then to develop a rational program to treat the illness and restore and maintain health.” (p.132). Right from the beginning of the care process which Engel (1977) outlines here, the medical professional holds the power of establishing whether a person is even sick at all. The implications of this power are enormous; an individual’s experience within their own body is less important than the opinion of the medical professional, backed up by “science” (Engel, 1977; Frank, 2002).

Unfortunately, the biomedical discourse plays out in society much like how it does in the medical field: it stigmatizes and controls peoples’ bodies, focuses on the way(s) a body does or doesn’t ‘work well’, and thus neglects the social and relational side of human beings experiencing illness or disability (Engel, 1977; Hayes & Hannold, 2007; Kontos, 2003). To elaborate on how the medical culture extends into society, Engel (1977) makes the important distinction between scientific models of phenomena and culturally derived belief systems which are referred to as popular or folk models. In Western culture, the scientific model has very much become our folk model (Engel, 1977). I understand this to mean that the scientific biomedical model of disease has significantly, if not entirely, shaped our dominant discourse of disease and care. The overlap between the biomedical model and cultural discourse is also emphasized by Hayes and Hannold (2007) who discuss the way that: “Medical discourse quickly extended outside the confines of medical institutions, with medical knowledge being applied by lay people throughout society – by applying that knowledge, a very specific form of self- regulation was enacted” (p.354). The prescriptive culture and focus on ‘fixing’ bodies that exists in the medical world thus became part of everyday life, outside of medical or care contexts. An example of this is evidenced in the way that even leisure activities become prescriptive treatment (Genoe & Dupuis, 2014), and in so doing, the biomedical perspective and expectations of ‘wellness’ and ‘health’ seep into our daily activities. One of my favourite encounters I’ve had with this in my own life is how something as purely recreational as drinking wine becomes prescriptive when headlines blare and word of mouth spreads the notion that one glass of red wine a day contributes towards heart health, of all things. Further, Estes and Binney (1989) describe the process of the biomedical model spreading into everyday life specifically in the context of aging. They outline how the medicalization of aging has had a profound impact on public opinion; aging is viewed as a process of irreversible decay and disease, thus it is viewed as something that must be fixed and can only be fixed through medicine. Within such a view, the societal cost of such medical support leads to the blaming of older adults for healthcare and economic crises (Estes & Binney, 1989). The consequences of the medicalization of aging is a good example of how the biomedical focus also impacts public perception of persons with illness and disabilities.

As Estes and Binney state, “The undesirability of conditions labeled as a sickness or illness transfer to those who have those conditions, shaping the attitudes of the persons themselves, and those of others toward them.” (1989, p. 588). Persons living with illnesses and disabilities are thus viewed by others and themselves in a thoroughly negative light.

The biomedical model also has enormous implications for persons who are unable to participate in their treatment plans or cannot be “fixed” (Hayes & Hannold, 2007). As experts with scientific knowledge, the treatment plans that medical professionals dole out become a moral imperative one must participate in so as to return society’s normative expectations (Hayes & Hannold, 2007). Individuals seeking help from medicine are expected to be passive, obliging participants who follow such prescribed treatment plans to return to their most self-sufficient, independent, “normalized” selves (Fritsch, 2010; Mitchell et al., 2020; Nolan et al., 2003; Welie, 1999). If a person cannot achieve this state even with ‘expert’ help, they are viewed as lesser-than, powerless, abnormal, weak, or ‘bad’, due to their dependence on others and their inability to contribute to society in the way we typically value (economically) (Fritsch, 2010; Jordan et al., 2004; Mitchell et al., 2020).

The reduction of human beings to their bodies and illnesses, their perceived ability/inability to return themselves to normative standards, and the ‘burden’ they place on society, creates an enormous stigma for persons living with disabilities, including persons with dementia. This stigma marginalizes persons living with disabilities, in turn leading to discrimination, stereotyping, exclusion, status loss, etc. (Grue, 2016).

2.1.2 Implications of the biomedical focus for persons living with dementia in LTC

While the stigma associated with the biomedical focus exists at a larger cultural level, the consequences of the stigma are particularly evident in the dementia care and LTC contexts. For one, the separation of body and mind that emerged alongside the mechanisation of the human body has serious implications for persons living with memory loss. Society presumes a complete loss of self in the individual with dementia (Kitwood, 1995; Kontos, 2003; Mitchell et al., 2013). Within such a view, all that is left is a body which, due to pervasive ageism and the association we make between age and disease, is presumably a frail body prone to illness (Estes & Binney, 1989). Further, the biomedical perspective reduces individuals with dementia to “a catalogue of cognitive deficits and behavior disorders” (Kontos, 2003, p.157) and, as previously outlined, ignores important social, emotional, and human aspects of what constitutes the individual as a whole (Arai et al., 2015). Such dehumanizing and objectifying discourses inevitably become internalized, causing persons who are diagnosed with dementia to feel negatively about themselves (Kontos, 2003). Persons with dementia see themselves and are viewed by others as useless, incapable, lost or no longer ‘themselves’, and ‘empty shells’ (Kontos, 2003). All of this is attributed to a person’s dementia, as opposed to a consequence of the stigma and dominant discourse surrounding dementia. For example, Dupuis et al. (2012c) quote an individual with dementia involved in their study who says that “Many think it is the disease that causes us to withdraw, and to some extent I believe this is true. But, for many of us, we withdraw because we are not provided with meaningful opportunities that allow us to continue to experience joy, purpose and engagement in life.” (p. 240). To me, this quote illustrates how the exclusion and the dominant discourse on dementia define and reinforce the role that persons with dementia are expected to perform. That is to say that the behaviours of persons with dementia which are typically pathologized are often not the result of a disease, but the result of how others treat them (Dupuis et al., 2012b). One such behaviour as mentioned in the above quote is withdrawal from social interactions and the outside world. However, as the quote also mentions, it is a lack of opportunity that often causes this withdrawal, a lack of opportunity that is wholly a social phenomenon. In my experience, I have seen this lack of opportunity manifest in the form of people talking over and speaking for persons with dementia; people constantly correcting persons with dementia; and people not giving persons with dementia enough time to answer or contribute to conversations. All of this is behaviour that could inspire anyone to withdraw from any given social encounter. Unfortunately, this withdrawal is often perceived as a sign of a loss of self in individuals with dementia, as opposed to a sign of what would simply be rude behaviour in any other context.

The presumed loss of self in persons with dementia creates a huge barrier to genuinely connecting and relating. People report immense loneliness and loss of social connections in dementia. This experience is common for both persons living with dementia and their family care partners (Dam et al., 2017; Milne, 2010). The pathologized behaviour of persons with dementia (Dupuis et al., 2012b) and perceived loss of self are a large part of why individuals diagnosed with dementia, as well as their families, so often experience isolation, loneliness, and loss of friendships (Mitchell et al., 2013). In LTC settings especially, the view of persons with dementia as empty bodies inevitably leads to care that is focused entirely on the body and not the social and relational aspects of the human being, thus perpetuating the isolation, and dehumanization of persons living in LTC homes. Caring in such settings thus becomes, as previously described, impersonal and task-focused, leading to chronic disconnection in a space where so many people live and work every day. This chronic disconnection has been dramatically exacerbated due to the COVID-19 pandemic, as one of the earliest protective measures taken was to ban visits from families and non-essential workers from the LTC homes. Currently, the increasingly survival-focused interactions with stressed, over-worked, undervalued paid care partners who are scared for their lives, are the primary relationships residents get to experience in these settings.

The biomedical culture dominant in dementia care and LTC settings also has enormous implications for paid carers working in these settings. With the primary focus being on efficiently performing tasks and bed and body work (Gubrium, 1975), personal support workers (PSWs), nurses, and other frontline paid carers frequently express their struggles trying to juggle time sensitive tasks while also caring for the social side of individuals living in LTC (Rockwell, 2012). Paid carers working in LTC have noted that they fear discipline from superiors or coworkers as a reaction to not completing required tasks, and have identified economic limitations due to increasingly tight health care budgets (Morin & Leblanc, 2005; Rockwell, 2012). For example, a study in Quebec showed that with funding only covering up to 70% of the hours needed to meet all care needs, the participating nurses prioritized physical care needs such as feeding and medical treatment over interpersonal activities and communication with residents and families (Morin & Leblanc, 2005). All of these factors can lead to what is called moral distress and moral residue. Moral distress occurs when someone is faced with a situation wherein they are not able to act on what they believe to be ethical or right (Hardingham, 2004). In health care, and LTC settings in particular, this conflict arises when paid carers such as nurses and

PSWs experience institutional barriers to acting in a way that aligns with their own values (Edwards et al., 2013). Moral residue describes the subsequent, lingering feelings associated with moral distress when the initial issues are not addressed or resolved (Edwards et al., 2013). Hardingham (2004) shares an example of a moment in her own practice that has left her with moral residue, when she experienced a physician stuff a cloth into a restrained woman's mouth when she would not stop verbally resisting care and being restrained, everyone laughed and Hardingham left the room. Hardingham writes "I now wish that I had found the courage to walk over to the patient, remove the washcloth and say why I believed the doctor's act was wrong, but this action did not seem to be open to me at the time." (Hardingham, 2004, p.129). In this particular scenario, the strong, engrained institutional culture that Hardingham did not know how to challenge or break from at the time was a barrier to her acting on her own moral beliefs, and her moral residue from such distress remains 16 years later (Hardingham, 2004). Moral distress and residue are pertinent issues faced by paid carers in LTC settings, largely due to barriers caused by the biomedical culture of caring.

2.1.3 Implications of the Biomedical Model for Relationships

While I have touched briefly throughout this section on the way that the biomedical model impacts relationships, it is important to elaborate further on the many ways in which the culture and stigma it perpetuates affect relationships in caring contexts, and the relational pain it causes the individuals involved.

2.1.3.1 Power-Over Relationships

Of particular significance in the way we relate in caring processes is our conception of power in such contexts. Earlier in this thesis, I mentioned how practitioners are perceived as experts and thus hold an amount of power-over individuals seeking care who may not have the same knowledge. The usual language for such individuals, ‘patients’ or ‘clients’, is problematic in itself. Such labels harken back to the neoliberal perspective of human interactions being transactional, which is why I do not use this language in this research.

The power dynamics of traditional biomedical hierarchies are especially relevant in the context of dementia or cognitive impairment, as the privilege we ascribe to cognitive function, which we assume houses our ‘personhood’, prompts us to believe that with cognitive impairment comes a loss of self and thus a loss of agency (Jenkins, 2013; Kontos, 2005). There is a presumption that persons with dementia are unable to properly articulate their needs or desires (Dupuis et al., 2012a). Persons with dementia are subsequently not viewed as equals in decision making, and are left out of their own caring decisions, often entirely (Dupuis et al., 2012a). Care thus becomes a unilateral, contractual arrangement with an authoritative professional who is perceived as morally superior, as they provide care to a person who is not believed to be able to care for themselves in certain ways (Fritsch, 2010; Welie, 1999). Caring professionals assume power-over individuals with dementia, setting the tone for relationships that are far from mutually growth-promoting. Adams and Gardiner (2005) discuss the multiple dimensions of a dementia care triad, including the person with dementia, an informal care*giver* (such as family), and a healthcare professional. In such a triangular relationship, coalitions are likely to form wherein two parties hold power over another (Adams & Gardiner, 2005); often the informal caregiver and professional take this position.

Within such relationships, professional boundaries are adopted and never crossed. Professional boundaries define the nature of the relationship and interactions between professionals in the medical world and individuals who seek medical attention/help (The Canadian Medical Protective Association, 2014). Such boundaries are based on socially acceptable behaviours as well as regulatory authorities (The Canadian Medical Protective Association, 2014). These boundaries are in place for a variety of reasons: notions of professionalism, normative definitions of friendship as a symmetrical mutual phenomenon (and the power-over dynamics which inhibit reciprocity), and fear of burn out for the paid carers (Eustis & Fischer, 1991). Paid carers in LTC also maintain professional boundaries to avoid breaching policy, to avoid being reprimanded for crossing a boundary or wasting time, and on the extreme end of things, to avoid being accused of elder abuse (Abrams et al., 2018).

These professional or ‘role’ boundaries often leave relationships between paid carers and persons with dementia impersonal while inherently intimate, creating an awkward balance of physical closeness and emotional distance (Eustis & Fischer, 1991; Fritsch, 2010). Delineating between a personal/social or professional relationship in itself suggests a lack of acknowledgement of the social nature and personhood of the individuals involved in the so-called ‘professional’ relationships. Professional boundaries also reinforce power dynamics and professional hierarchies, wherein a paid carers hold power-over individuals they ‘care for’. Power relations that render individuals unequal in any way have enormous consequences on how we relate to one another (Jordan, 2017). In the caring context, if we view caring as unilateral and imbalanced, there is no room for the mutuality or reciprocity necessary for growth-promoting relationships. This is not because the individual with disease such as dementia cannot give anything in return, it is because the paid carer's assumption of power-over and treatment of the individual does not create any space for reciprocity to occur. These power relations thus limit and shape the types of relationships that can occur in the caring setting, causing chronic disconnection for everyone involved (Fritsch, 2010; Jordan et al., 2004).

Additionally, the biomedical model promotes a hierarchy of power not only between professionals and "patients", but also between professionals themselves (Nolan et al., 2003; Powell & Davies, 2012). The physician, as previously described as an 'expert' on the 'machine' that is the body, as it has traditionally been constructed (Engel, 1977), is usually positioned at the top of the medical hierarchy of staff (Powell & Davies, 2012). PSWs and nurses are thus often treated as though the work they do is much less significant than their 'expert' counterparts (Nolen et al., 2004). Traditionally, 'caregiving' as a career is reflective of many racial, gender, and class tensions that exist in society. Caregiving is often perceived as female work, highlighting many patriarchal assumptions about gender, empathy, and caring (Jordan et al. 2004). It is also seen as relatively unskilled work, and therefore is generally under paid work (Women & Health Care 'Reform, 2009). "[A]s a result of this work being low-paid and often taken up by people who are non-status, visa holders, or are newly immigrated and unable to find other work" (Fritsch, 2010, p. 9), this perspective on the 'caregiving' work reinforces many power relations in the caring context, both between those who work there and those who live there.

Unfortunately, the power hierarchy that exists in the LTC sector has significant impacts on the attitude workers bring to their work at the LTC home and the nature of their interactions with their residents (Nolan et al., 2003). The power hierarchy sets the stage for inherently disconnected, uncaring care work and shapes interactions between frontline workers and the persons with whom they work in LTC as well as interactions with other team members. In my opinion, it is not only of vital importance to challenge the ways in which we undervalue and marginalize persons with dementia, but also to challenge the role that paid carers such as PSWs have historically been put in. As we are witnessing during the COVID-19 pandemic, there has never been a more important time to advocate for just treatment, support, and appreciation for PSWs. There is no friendship for persons with dementia if there is no friendship for paid carers partners as well. It is thus paramount that their work, personhood, and relational being also be highlighted, acknowledged, and celebrated, just as much as the personhood and relational being of persons with dementia. I understand 'relational being' here to signify the individual's experience as a relational human being in a social world, existing in relation with others. For this reason, my research looks to the valuable input of both persons with dementia and paid care partners to understand and interrogate my research questions on friendship in long term care.

2.2 Alternative, Relational philosophies of care

In Relational Cultural Theory (RCT) we are told that human beings thrive off of relationships and that connection helps us survive and survive well! Therefore, through an RCT lens we can conclude that the biomedical culture, while supporting some on their path to wellness, misses the mark on many levels by perpetuating a culture of separation and stigma, while neglecting the centrality of relationships for human well-being. As a response to the critiques of the biomedical model, several alternative cultures/philosophies of dementia caring have begun to emerge. In this section I critique some such philosophies and address how Relational Caring fills the gaps left by earlier culture change initiatives.

2.2.1 A Brief Overview and Critique of Person Centred Care

One of the first and most prominent alternative models of care that emerged in the 1970's is Person Centered Care (PCC). PCC is a theory that was spearheaded in dementia care by Thomas Kitwood (1995) and gained particular popularity in nursing. PCC emphasizes the autonomy, dignity, and personhood of every individual receiving care. As such, individuals theoretically experience care that is tailored to them, their needs are considered above organizational or staff needs, and they are treated with respect and dignity (Rockwell, 2012). While this might initially come across as the ultimate vision of quality care, and despite gaining wide-spread popularity in the healthcare world, PCC has been critiqued for a variety of reasons (Dupuis et al., 2012a; Morhardt & Spira, 2013; Nolan et al., 2003; Rockwell, 2012). For one, little is known about how PCC is implemented or how it is defined, leading to a variety of interpretations that do not necessarily fulfill PCC's initial focus on individualized, empathetic, quality care (Nolan et al., 2003; Rockwell, 2012). Second, PCC fails to acknowledge the interconnected, interdependent, social context of individuals and the complex network of relationships that they exist within, including with their healthcare professionals and with the broader social cultural and political context (Adams & Gardiner, 2005; Dupuis et al,, 2012a; Nolan et al. 2003). All of this shapes what a person is willing to reveal or conceal about the self at any given time and within particular contexts (Wiersma, 2007). PCC thus has the potential to ignore, exclude, and alienate others involved in the care context including informal and formal carers involved in someone's care (Rockwell, 2012), as it so clearly puts the needs of the individual receiving care above all else. Nolan and his colleagues (Nolan et al., 2003) argued that it was impossible to provide quality care experiences to the people being cared for if all in the care context, including family and paid carers did not also have quality care experiences. For these reasons, PCC does little to address the chronic disconnection that exists in the biomedical model of caring.

2.2.2 A Move to Relational Caring

In order to fill the gaps left by the biomedical model and PCC, researchers have been advocating for the implementation of relational caring in long term care, dementia care, and mental health work (Backlien & Bongaardt, 2014), among others. I should note that, while much of the literature refers to relational "care", the word *caring* has been used so as to move away from the concept of unilateral care that was briefly critiqued earlier in this paper (Mitchell et al., 2019). I will therefore use 'caring' in my research so as to accurately reflect my conception of relational caring and to distinguish it from care as a unidirectional, often task-focused activity. I also use language of 'care partners' rather than 'caregiver' and 'care receiver' to reflect the reciprocal nature of care in relational caring.

Relational caring is a philosophy of care that, like RCT, puts relationships back at the center of care processes. Building on relational theories (for example, Jordan et al., 2004; Nedelsky, 2011), relational caring advocates for care that prioritizes authentic, mutual, and on-going connection between everyone involved in the caring process (Dupuis et al., 2016b). This approach to caring explicitly challenges the clinical, power-over care of the biomedical model (Dupuis et al., 2018; Fritsch, 2010; Kontos et al., 2017), as well as the myth of separation that permeates all aspects of our culture (Jordan et al., 2004). Relational caring instead focuses on reciprocity and the perspective that interdependence, compassion, and growth-promoting relationships are "at the core of human wellness" (Dupuis et al., 2016, p.1). As Nolan et al. (2003) put it, in relational caring "relationships are created and sustained in situations where all parties appreciate the need to achieve an appropriate balance between independence, dependence, and interdependence" (p. 47). The value of interdependence is put ahead of the societal fixation on independence, just as in RCT. Relational caring also looks beyond the interpersonal relationships between individuals and acknowledges that all relationships exist within a broad and complex web of connections including relationships with the environment, with social, political and other institutions, as well as other cultural and social influences that shape our relations (Dupuis et al., 2016b, 2018). With this in mind, relational caring encourages us to view the caring process as a set of interconnected relationships that impact our experiences in caring.

Relational caring has also been described as a model that expands its focus from the individual to include their entire social circle; their "family, [paid care partners], and community" (Rockwell, 2012, p.244). This is an important difference between PCC and relational caring: though the individual is still valued as a full person and a central decision maker in their care, relational caring does not neglect the family nor other care partners who make up the individual's network (Rockwell, 2012). In relational caring, nobody is of more or less importance, everyone's input is important, and all are valued individuals who shape and are shaped by the caring experience. In such a view we begin to see something akin to Dupuis et al.'s (2012a) concept of authentic partnership, which advocates for the inclusion of persons with dementia in all care decisions, as well as the rest of the individuals in their caring team. A partnership suggests a significant shift in power dynamics from what is traditionally a power-over relationship, as previously described. In partnerships, persons with dementia are able to reclaim the agency that has historically not been afforded to them. Nedelsky (2011) specifically writes about agency as being relational. To be an autonomous individual in society, there must be an opportunity to be autonomous, whether that opportunity lies in interpersonal relations or at a larger societal scale (Nedelsky, 2011). The notion that agency is not only an individual responsibility but is instead a collective responsibility, is a direct challenge to the way the biomedical model views disability as existing within the individual. As we enter authentic relationships and partnerships with persons with dementia, we begin to dismantle the dominant discourses that marginalize and oppress persons with dementia by neglecting their ability to engage as equals in society.

Relational caring helps us reframe our societal perception of persons with dementia in other ways as well; namely that they have lost their personhood, that they are unable to contribute to society, and so forth (Kontos et al., 2018). In viewing persons with dementia as being able to care for others in reciprocal relationships, the dominant discourse on persons with dementia begins to shift. Personhood and loss of self are no longer in question if the person with dementia is engaging as an equal partner in an authentic relationship. Additionally, a sense of purpose, the opportunity to care for others, and the ability to contribute are cited as some of the ways that persons with dementia maintain quality of life (Dupuis et al., 2012a; Rockwell, 2012). If the aim is to support persons with dementia in achieving optimal quality of life regardless of their diagnosis, it does not take much – other than a massive culture change - to accept the caring they can give back to paid care partners. Furthermore, by embracing interdependence and viewing growth-promoting relationships as a strength in caring, we begin to break down the stigma on being dependent on others, as in the case of persons with disabilities who seek assistance. In so doing, persons with dementia have an opportunity to reclaim their agency empower themselves, to fight against oppressive and dehumanizing practices using their own voices, and rise above the stigma that so often weighs upon persons living with dementia (Kontos et al., 2018). Relational caring thus has enormous potential to be emancipatory and empowering, to break down stigma, and truly change the culture of LTC for the better.

2.2.2.1 Relational Caring from the Perspective of Paid Care Partners

Again, as I focus on the experiences of persons with dementia as a historically silenced group who I believe need to be heard, I must also turn back to the experiences of persons working in LTC if I am looking at mutual relationships such as friendships. Paid carers often describe the weight and 'burden' of caring *for* others (Dupuis et al., 2012a), as opposed to caring *with* others. As previously mentioned, plenty of research has been done on the moral distress and mental health issues that can arise for caring professionals, as well as possible ways we can alleviate these stresses. For example, Woodhead, Northrop, and Edelstein (2016) write about nursing staff burn out in LTC, and the positive impact that social support can have in preventing burn out (interestingly, the support they examine is solely peer, supervisor, or familial support –

not from persons living in LTC). In relational caring, social support is viewed differently, as caring becomes mutual and reciprocal between paid care partners and persons living in LTC (Rockwell, 2012) and even their loved ones. The professional boundaries are blurred in relational caring, meaning that we can hug, we can laugh with one another, and we can support one another in a reciprocal relationship (Rockwell, 2012; Wilson & Davies, 2008). From personal experience, I know how quickly a hug from one of my participants at work can turn my day around.

An additional benefit of relational caring is that it impacts the workplace culture as much as it does the approach to caring, which are unsurprisingly connected and dependent on one another. In fact, I do not believe there should even be a distinction between the two. In Rockwell's (2012) study with social workers working in an LTC home, paid care partners expressed immense satisfaction and personal fulfillment in their jobs when building relationships with residents and taking the time to individualize care (Rockwell, 2012). Relational caring has also shown to positively affect interdisciplinary team dynamics (Dupuis et al., 2019; Nolan et al., 2003) and has the potential to promote organizational benefits, as relational caring encourages mutual emotional support, kindness, recognition and appreciation between colleagues in all different roles in LTC (Dupuis et al., 2019; Nolan et al., 2003). The change that relational caring could bring to an organization would be an enormous improvement for LTC, reducing staff turnover and absenteeism (Dupuis et al., 2018; Arcare, 2014), and generally making LTC a friendlier place to work.

As promising as relational caring is to changing the culture within LTC homes, there are many barriers within the current culture that make it challenging to adopt. One of the most significant barriers to culture change in dementia care is the limitations of policy and regulations in the LTC sector. Staff in LTC homes describe the burden of care not only in how they experience the caring process emotionally, but also describe tight time constraints, budget limitations, and subsequent poor staffing, all of which leads to less personalized care (Dupuis et al., 2019). This results in the privileging of the biomedical aspects of care that only attend to the physical well-being of elders in LTC settings. This care leaves little time or energy for staff to individualize care or build meaningful relationships with individuals (Dupuis et al., 2018). However, Rockwell (2012) suggests that relationship centered-care "offers creative ways to improve the socio-emotional milieu of residential facilities even though they are restricted by higher-level policies or funding priorities" (p.245). That is to say, as previously mentioned, that relational caring does not have to be "extra" work (Wilson & Davies, 2009). Instead, it can be a different way of approaching the caring that is already happening. For example, in a study by Wilson et al. (2013), a paid care partner shared one of the changes she made to her process during a culture change initiative in the LTC home she worked at: "I make the bed from the other side so she [the resident] can see me and we talk about things that way. I still do my work in the same time but this way I can speak with her." (p. 84). In a study by Dupuis et al. (2019) wherein a relational caring learning series was piloted in four LTC homes in Canada, participants noted post-pilot that just taking the time to say hello, or stopping to acknowledge a resident, perhaps with a touch on the shoulder, was enough to feel more connection with residents. Rockwell (2012) also describes some good examples of doing the same work but doing it differently, suggesting something as simple as knowing which residents in an LTC home to introduce to one another based on common interests, or inviting individuals to be the teachers or leaders of activities in the home with other residents. Both of Rockwell's (2012) suggestions emphasize that: “Increasing the pool of relational ties available to residents could improve the types of meaningful activity available with minimal requirements for increased funding or staff” (Rockwell, 2012, p.246).

In summary, I believe that relational caring is exactly what dementia care culture needs to turn to in order to address the hurt and chronic disconnect that is experienced by everyone involved in the caring process. With relational caring we can change the landscape of dementia care settings, we can fight the oppression and stigma that emerged from the biomedical model. Most importantly, we can create environments that foster growth-promoting relationships between persons with dementia and paid care partners (Dupuis et al., 2018), bringing RCT’s ‘five good things’ to everyone living and working in LTC: feelings of zest, creativity, worth, clarity, and a desire for more connection (Jordan, 2017).

2.3 Friendship

2.3.1 Why friendship?

It is my interest in relational caring that has led to my particular interest in friendship. Friendship in the caring context is a particularly compelling concept to me, given that the way we traditionally understand friendship is vastly incongruent/incompatible with the way we traditionally perceive relationships in the caring context. That being said, when we begin a culture change shift towards honouring the relationships that exist between paid care partners and persons with dementia, feelings and experiences begin to emerge that can be likened to those we associate with friendship.

2.3.2 Traditional Perspectives on Friendship

What makes a relationship a friendship to begin with? Friendship is an ill-defined concept, yet we as human beings are constantly negotiating and navigating friendships in our lives. There is little question that friendship is an important aspect of the human experience at all stages of life, and that friendship enriches peoples' lives. On a day to day basis, I don't believe that most of us linger on the question of 'what is friendship', we simply live it. However, those who are more deeply interested in friendship – enough to do research about it – have conducted many research projects, posited many hypotheses, and developed many "check lists" with the goal of better understanding what friendship actually is, and more specifically what differentiates it from other types of relationships. In order to establish a better understanding of friendship, in this section I will briefly go over the studies and findings that stood out to me, as well as some similarities and disparities between them that I found significant or of interest and relevant to my study. That said, for a more thorough overview of the friendship studies I refer to in this section, please see my Friendship Typologies chart (Appendix A).

To begin, Parks and Floyd (1996) write that friendship is most often measured or judged in comparison to other relationships. They continue on to examine peoples' meanings for closeness and intimacy and how individuals identify, define, and relate these concepts to friendship (Parks & Floyd, 1996). In their study, Parks and Floyd (1996) conducted surveys with open ended questions with 270 university students (n=270), with an age range of 17-55 years of age, but with the largest portion of that group being 18-21 years of age. Their results were analyzed with a grounded theory approach and the following list in descending order of importance was determined as indications of closeness between friends: self-disclosure, help and support, giving advice, shared interests/activities, relational expression, global affect, comfort and ease of interaction, trust/acceptance/understanding/respect, frequency of interaction, and length of duration of friendship (Parks & Floyd, 1996). Similar characteristics have been found in other studies. For example, Adams et al., (2000) developed a typology of friendship in 'the third age' – meaning active older adults – and explore age, gender, and geographical location as factors to how friendship is experienced. While the researchers critique the notion that "people share common criteria for friendship" (Adams et al., 2000, p. 130), they present a typology of five broad categories that were defined based on a thorough review and synthesis of existing research. Their broad categories are: behavioural processes (e.g., self- disclosure, assistance), affective processes (e.g., compatability, care), cognitive processes (e.g., loyalty, shared values), structural characteristics (e.g., solidarity), and proxy measures of processes (e.g., frequency and duration of contact) (Adams et al., 2000). Guided by this friendship typology, Adams et al. (2000) then asked 117 participants (n=117) open-ended questions about friendship and found that, on average, each individual respondent identified or described at least three various characteristics from their list. Behavioural processes were named most often, and within that category, self-disclosure was the most frequent characteristic identified (Adams et al., 2000). This is consistent with Parks and Floyd's (1996) findings. Other studies also show that self-disclosure is one of the more important aspects that distinguishes friendship from other types of relationships (Argyle & Henderson, 1984; Felmlee & Muraco, 2009).

A similarity among many studies on friendships has been the discussion, discovery, and inclusion of both positive and negative aspects of friendships. Conflict is a fairly consistent finding amongst researchers who found negative aspects of friendships in their studies (Furman & Adler, 1982; Furman & Buhrmester, 1985; Parker & Asher, 1993). I find it interesting to note that conflict is so consistently identified, and how this challenges a general conception that friendship is wholly positive.

Many researchers have explored gender differences between perceptions of friendships. Findings vary, with some studies determining that there are significant differences between male and female perspectives on friendships (Adams et al., 2000; Felmlee & Muraco, 2009), and others stating that there are no significant differences. For example, Felmlee and Muraco (2009) conducted a study on friendship norms wherein women showed to be more disapproving than men of a friend who had 'broken a friendship rule' such as disclosing a secret. Women were also shown to have higher expectations of intimacy and of friends confiding in them (Felmlee and Muraco, 2009). Adams et al. (2000) echo some of these differences in gender, noting that when looking at "the differences in the friendship patterns of women and men, the former highlighted emotional qualities and the latter were more likely to endorse indirect, proxy indicators of friendship such as frequency of contact or length of acquaintance." (p.130). Important to note is that this distinction does not account for queer identifying individuals who may not be part of the gender binary of male and female, and few studies acknowledge or address this limitation. It is important to note that social constructions of gender are intimately connected to social constructions of relationships such as friendships, as highlighted in RCT in the way it takes up the implications of womens' relational socialization and men's socialization to be less relational (Jordan et al., 2004). Social constructions of gender may therefore influence participants' perceptions of friendship. Further, the gender perceptions around caring work and the PSW role

(Jordan et al., 2004; Women & Health Care Reform, 2009) may also impact participants' perceptions of friendship in their caring processes.

Another repeated theme in the literature is the differences in friendship perceptions across the lifespan. Researchers make the distinction between childhood friendships, adolescent friendships, adult friendships, and the friendships of older adults. Again, some researchers note a significant difference and others do not. For example, Felmlee and Muraco (2009) note that amongst older adults, friendships tend to be fewer yet the expectations around friendship norms and rules is not dramatically different from those of young adults. On the other hand, Adams and colleagues (2000) note that: "With age, men increased their use of affection or appreciation and women decreased theirs. The opposite pattern emerged for loyalty or commitment." (p.119). Given that my research focuses on how friendship is taken up, or not, in caring contexts from the perspectives of older adults with dementia and paid care partners, this meant that I was also working with individuals across multiple generations. It was important for me to consider differences in participants' ages in the analysis of my data.

In their introduction of the topic of friendship in their research paper, Adams et al., (2000) note that it has become a bit of a cliché to preface research papers with the fact that friendship is complicated and difficult to research. They comment that researchers all too often "either ignore the complexity [of friendship], bemoan it because when they compare people's friendships they are inappropriately comparing different entities, or eliminate it by instructing the people they interview to use a limited definition in discussing specific relationships" (p. 118). However, they then continue to attempt to determine categories and typologies, regardless of their commenting on the subjective nature of friendship (Adams et al., 2000). I find it ironic that so many papers do this; lamenting the difficulties of researching and attempting to reduce/categorize such a subjective phenomenon only to proceed to try to do just that. Why, with their own concerns in mind, do these researchers not see the need or potential for approaching the subject in a completely different way? With this critique in mind – it is my intention to *embrace* the complexity of friendship and to celebrate the subjectivity of each person's experience with friendship in my research. I believe friendship can be wholly subjective, situational, and relational. It is nonetheless important to keep in mind that there are traditional ways that friendship is constructed by researchers and otherwise, and that this plays a significant role in how we collectively perceive friendship, or the lack thereof, in the dementia caring process.

2.3.3 Traditional Friendships Complicated in the Dementia Caring Process

Friendship in the caring context is constructed as a taboo in the LTC and dementia care contexts. This is due to an interconnected range of things including the dominant discourses that are informed by (and in turn inform) professional boundaries and power relations within care settings, the stigma surrounding dementia and illness, fears of abuse, and the predominant biomedical and transactional cultures of care (Allen & Ciambrone, 2003; Fritsch, 2010).

2.3.3.1 The Taboo of Friendship

Given the combination of power relations, professional boundaries, and stigma of the biomedical model, friendship has arguably become a taboo for persons with dementia and paid carers. I use the term taboo here, not to mean that the notion of such friendships is too repulsive to speak of, but rather that in society it is implicitly understood that friendship between persons with dementia and paid carers are prohibited.

Friendship is generally considered one the most important types of relationships and connections that we make in our lives. Yet, it is not culturally (or even legally) acceptable for a paid carer to *genuinely* befriend someone living with dementia who is considered 'under their care'. In respect to my own work with persons with dementia, I've been told to my face that I'm just 'paid to be nice', or that I am 'lying' about being their friend just to make them feel good. To be told how I do or see my work by others is problematic on many levels, but most apparent is the fact that people in and out of the field seem to believe it is not possible that I am really developing friendships with my participants with dementia. It is also frustratingly difficult to find so little literature addressing such friendships in LTC, especially as someone who is doing her Master's research on the topic. What I find most often instead is work that looks at the friendships between persons with dementia, as though it is some form of miracle or special occasion when two persons living with memory loss can make new friends.

For this reason, there is scant literature about friendship in the dementia caring process, and little is known about our understanding of what friendship actually means in such contexts. The goal of this thesis is to get to know what friendship means to individuals in LTC and interrogate why it remains a taboo. Due to the fact that little is currently known about friendship in dementia caring processes, this section of my paper explores how friendship might be problematized in these contexts based on my knowledge and understanding of biomedical cultures and traditional understandings of friendship.

2.3.3.2 The Problem with Checklist Friendships

In the dementia caring process, a definition of friendship as per the checklists, typologies and categories developed by researchers might be problematic. For one, the mere fact that such checklists are defined by researchers and disseminated as though they are generalizable, is problematic as it does not create space for individuals to define friendship based on their own experiences. From a critical perspective I believe it is particularly problematic to hold individuals such as persons with dementia, whose voices have historically been silenced, to a definition of friendship determined by persons who do not share the same lived experiences. I also believe that a checklist definition defining parameters of friendship leaves little room for fluidity and changing perceptions, which is also problematic when working with relational beings who exist in an ever-changing social climate. For example, the ways in which friendship might have been defined, and certainly the ways in which they are experienced, have shifted during the COVID-19 pandemic, and will likely be understood differently after the pandemic as well. I know that my personal understanding of friendship, what I value most in a friendship, and how I communicate with my friends, are all quite different in the context of this pandemic. We have all had to adapt, and these changes are likely to have long-term effects in perspectives on friendship down the road as we collectively move forward after the pandemic.

The individual points on the checklists for friendship also present some tensions if applied in the dementia caring context. For example, if we let the aforementioned research inform our conception of friendship, then we might look at self-disclosure as a sign of friendship between a person with dementia and their paid care partners. This has me thus begging the question: how do we define self-disclosure? In the literature, a concrete description for self-disclosure is hard to find. Some researchers use terms such as closeness (Bukowski et al., 1994; Furman & Adler, 1982), intimacy or intimate exchange (Argyle & Henderson, 1984; Furman & Buhrmester, 1985; Mendelson & Aboud, 1999; Parker & Asher, 1993), trust and the sharing of one's secrets (Adams et al., 2000; Argyle & Henderson, 1984; Bukowski et al., 1994; Felmlee & Muraco, 2009), or simply someone you can talk to (Roberto & Kimboko, 1989). With such a vague description of self-disclosure in the literature, I wonder if the embodied expressions of persons with dementia (who may have difficulty expressing themselves verbally) would be considered self-disclosure in LTC? In my experience, self-disclosure can occur in a wide variety of ways. One of my favourite ways is through dance. For example, there are individuals at work with whom I had not previously connected with, in part because of a lack of verbal conversation. However, upon dancing with them for the first time, the connection was sparked and I feel now as though we know one another or least have disclosed something about each other – they know I am not the most comfortable dancer but that I like to get silly and let loose anyway. I know perhaps that they are very traditional dancers or hesitant dancers or serious about dancing or goofy in their movements or romantic at heart or groovy disco dancers… the things you can disclose about yourself through dance are endless. Kontos' (2005) work on embodied selfhood supports this notion, arguing "that fundamental aspects of selfhood are manifested in the way the body moves and behaves." (Kontos, 2005, p. 556) and that agency and citizenship exist within the body as much as they do within the cognitive human brain (Kontos, 2017). Dance is an obvious example of the way our selves can be revealed through our bodies. Embodied expressions of self are pre-reflexive and exist beyond conscious decision making (Kontos, 2005); holding hands, smiling at a friend, the way one holds their cutlery, reaching to clean spilled food, and beyond. That said, I don't believe that the researchers trying to typify and define friendship have such a fluid and open conception of self-disclosure. In fact, multiple researchers specifically cite verbal self-disclosure, for example Roberto and Kimboko (1989) discuss friends who are confiders, in that they are seen by friends as “someone whom they could talk to” (p.13).

Additionally, when we are looking at the experience of individuals involved in the caring process, certain types of self-disclosure might not be a choice. Persons with dementia have much of their private information shared between care partners. This makes self-disclosure the choice of an external party as opposed to a choice made in friendship. I would imagine that the self-disclosure identified in the literature on friendship assumes that this self-disclosure is a mutual choice between both individuals. Further, on the part of the paid carer, self-disclosure might be considered a breach of professional boundaries, as previously discussed (The Canadian Medical Protective Association, 2014). As the most mentioned criterion for friendship in the literature I have explored, self-disclosure is a great example of how one might problematize the criteria of such checklists in the dementia caring context.

2.3.4 Examples that Suggest Friendships are Already Occurring

As we shift towards relational caring, we begin to see the biomedical ‘patient’/’caregiver’ relationship shift and evolve. As the relationship evolves, perhaps my concerns with the traditional friendship categories and typologies become less relevant. When the relationality of human beings is recognized and privileged, the door is opened up for friendships to occur more freely than in the biomedical model. As I noted in the section on relational caring, these relationships have the potential to form authentically and naturally, encouraging mutual caring and empowerment for all parties. Within such a relational space, there is no reason why relationships within it cannot be labeled friendships. When I look back to my introductory vignette, my relationship with Rosie occurred naturally in a setting where relational caring was in place, and we transitioned from simply ‘a good relationship’ to ‘friends’ very organically. That said, if we had found ourselves in another context, one more engrained in a biomedical model, I wonder if I would have ever thought it appropriate or possible to label us as friends. In this way, at the DBWA I have been spoiled with an environment that was founded with a relational philosophy in place. Therefore, my relationships with persons with dementia at the DBWA were honoured from day one. It was never a stretch for me to use the term ‘friend’ to describe these relationships. I don’t know what it’s like to hold back for fear of breaching policy, of angering colleagues, of personal burn out, and so on. For this reason I was curious to know whether or not my experience is paralleled in LTC settings, perhaps ones that are more, if not entirely, engrained in biomedical culture. Perhaps they are occurring without the possibility of labeling the relationships as friendships. Before I started this research, I had a feeling that friendship experiences were occurring, though I hesitated to assume or declare it given my particular and unique experience in dementia care. That said, I was able to find several wonderful snippets of literature that supported my suspicions.

In a study conducted by Eustis and Fischer (1991) with home-care paid carers and elderly persons with physical disabilities, participants shared numerous stories of ‘extra work’ or time spent with one another outside of scheduled, paid hours. These stories included accompanying each other to weddings or parties, calling one another at home, simply spending time together, and more (Eustis & Fischer, 1991). In the same study, Eustis and Fischer’s (1991) participants outline experiences that suggest mutuality in the caring relationship, for example: “One client taught her worker how to play certain card games; they also watch soap operas together during the worker's scheduled visit.” (Eustis & Fischer, 1991, p.450). From my perspective, the person with dementia teaching their paid carer a card game is an act that shows reciprocity; the give and take that is possible in such relationships. The shared activity of watching soap operas together suggests a mutual interest, a shared activity that both enjoy together as opposed to one party deciding on the subject matter without the other’s input. Ryan et al. (2008) conducted a similar study with paid care partners providing respite for persons with dementia and their informal/familial care partners. In the study they spoke to paid care partners, persons with dementia, and their families, who shared multiple stories of leisure engagement that went beyond the scope of traditional care or recreational therapy, and are more akin to social leisure (Ryan et al., 2008). A quote that stood out to me was a response from a paid care partner who said: “I take one man ten pin bowling every Friday. It is his focus of the week. He knows I am coming on a Friday and he has a pint of bitter and he loves it.” (Ryan et al., 2008, p.84). Bowling and beers sounds to me like an evening out with friends, enjoying leisure activities together. There is also evidence of friend-like experiences in the language people use when describing their relationships. For example, in the study by Eustis and Fischer (1991), “Clients were asked: "How do you regard the worker — as a friend, as part of your family, as a worker — or what?" Almost two-thirds of home care clients and about half of workers used non-contractual terms in defining their relationships — such as "a friend" or "like family." (p. 450).

Stories such as these left me hopeful and encouraged me to pursue this research project to illuminate these experiences and of course, to label and honour them as possible friendships.

2.3.5 Friendship in Philosophy

In order to move away from the potentially problematic, normative descriptions and definitions of friendship that many researchers have developed, I have found the work of a few philosophers quite helpful, particularly Derrida's *The Politics of Friendship* (2005). What draws me to a conception of friendship informed by Derrida is the ambiguity and tensions in life that he acknowledges, which are traditionally fought against for the purpose of rigour and validity in traditional research paradigms. Embracing this ambiguity and paradox is especially relevant when traditional notions of friendship become problematized in the dementia caring process, as previously discussed with the example of self-disclosure. More ambiguous philosophical understandings help us explore the more liminal spaces of human existence. To me, these are the human experiences that we cannot seem to categorize or explain as being one particular way, the experiences that are more fluid. These liminal spaces are perhaps more evident in the experiences of persons with dementia, who are often in a state of flux between past, present, and future, here and there, etc. Some of the ideas presented in this section veer towards a post-structuralist epistemology, and are included here to help inform my ambiguous and open-ended perception of friendship.

In his book *The Politics of Friendship*, Derrida (2005) explores the notion of friendship by describing how we relate to 'the other', as human beings. His understandings are informed by Cicero and Aristotle (Derrida, 2005). While Derrida's work is extensive and covers many intriguing concepts related to friendship, of particular interest to me is Derrida's assertion that the other is inherently a reflection of the self and it is in this way that we understand ourselves and our position in the world. This is strikingly similar to the tenants of RCT and social constructionism, wherein individuals exist within and generate knowledge through a complex social/relational network (Crotty, 1998; Jordan et al., 2004). Of course, this is not unique to Derrida's philosophy, in fact, it is arguably one of the biggest questions that philosophers over time have tackled. For example, *I and Thou*, an existential text written by Martin Buber (1923), touches on "the realm of subjectivity in which the I apprehends simultaneously its association and its detachment. Genuine subjectivity can be understood only dynamically, as the vibration of the I in its lonely truth." (Buber, 1923, p. 422). Both Derrida and Buber have me considering the relationship between subjects/objects, or rather people, as a dynamic, relational process wherein both subject and object remain separate as entities, but are inextricably linked and exist in relation to one another. This particular interpretation of their texts brings my understanding of friendship back towards my alignment with social constructionism, though it admittedly pushes the boundaries of what social constructionism can mean. That is to say that Derrida and Buber interrogate the individuality as well as the interdependence of human beings, but also push a little further and begin to break down the binaries of I/thou, self/other. The break down occurs because the interdependence of self and other that they address goes beyond just human need and well-being, as in RCT. Rather, it is the notion that it is only in relating with the other that we have an understanding of our own humanity, as our humanity is reflected back to us through interaction with someone else (Buber, 1923; Derrida, 2005).

Derrida's (2005) text is particularly relevant as he goes in depth about the specific relation between self and other that we call friendship. In his eyes, friendship is a way of loving, and is first and foremost an act of love. Derrida asserts that "the act of this activity, the intention of loving […], is more proper to friendship itself […] than the situation which consists in letting oneself be loved or inducing love, in any case in being loved" (Derrida, 2005, p.8). There are several reasons that it being an 'act' of love is important to Derrida. For one, Derrida views being-loved as inherently passive and potentially even un-knowing, whereas the act of loving comes with the knowledge and awareness that you are engaging in loving friendship. Further, knowing what loving means and what it feels like to love is the only way Derrida conceives of understanding what it means to be loved in return. Another intriguing reason Derrida gives for the importance of love as an act, is that loving can occur after the object of the love has passed away. In this way, the act of loving a friend extends beyond life itself. It is for this reason that Derrida suggests that: "One must start with the friend-who-loves, not the friend-who-is-loved, if one is to think of friendship" (Derrida, 2005, pg. 9). This concept of loving as the most important act of friendship contradicts the mutual expectation that we so often fall back on when describing traditional notions of friendship. We can love a friend after they are gone or passed away and cannot expressly return your love. I experience this with Rosie, the friend from my story in the introduction to this thesis. I cannot know that Rosie loves me back after death, but I do know that she is still someone whom I love, still my friend, and I can continue to love her, to see her as a friend. That said, I maintain that mutual caring and reciprocity in friendship is an important consideration, and I disagree with Derrida's assertion that: "Being loved – what does that mean? Nothing, perhaps – nothing in any case of friendship itself in which the loved one, as such, has nothing to know, sometimes nothing to do." (Derrida, 2005, p.9). I instead believe there is enormous value in both the act of love and the being loved, as both are part of a relational process and genuine connection. However, I do share Derrida's thoughts on the difference between loving and being-loved, as it indicates a more ambiguous understanding for what constitutes friendship by acknowledging that the *act* of loving is a particularly critical aspect of a friendship. If someone calls someone a friend, whether or not it is reciprocal, I believe that there is something of value there. This contradicts the mutual/reciprocal ‘checkbox’ of traditional understandings of friendship. Therefore, informed by Derrida’s advice for those who are to think of friendship, I approached my research participants as potential ‘friends-who-love’; individuals who can speak to their own actions and feelings, while simultaneously exploring their experiences of being-loved. Viewing first and foremost the ‘friend-who-loves’ in all of us is congruent with my approach to research which involves honouring, trusting, and learning from my research participants as empowered individuals, rather than questioning whether someone’s identification or experience of friendship is valid as per a traditional check list.

I was also interested in expanding on Derrida’s notion of friendship as an act of love. Paulo Freire in his critical work on the ‘authentic’ liberation of oppressed peoples, suggests that liberation has to come from solidarity as an act of authentic love (Freire, 1970). It is through these acts of love that oppressors and the oppressed transform the distinction between them that dehumanizes them both. It is also through acts of love that society (the oppressed and the oppressors) begins trusting others, dialoguing *with* one another as opposed to explaining *to* others, which Freire argues is the only way that liberation can begin. He asserts that “trusting the people is the indispensable precondition for revolutionary change.” (Freire, 1970, p.60). This trust, dialogue, and love is what restores the humanity of the oppressed/oppressors and allows them to return to Freire’s idea of the ultimate vocation: becoming more fully human (Freire, 1970). Freire’s use of the word ‘love’ arises in a fairly different context than that of the dementia caring process. His is a pedagogy of the oppressed with goals of liberation for all, as opposed to a specific disruption of oppressive culture in the caring process. However, the concepts in his work extend beyond and are applicable anywhere that oppression occurs. Freire's work also notes that oppression dehumanizes everybody – not only the oppressed. Liberation is thus a goal that society as a whole must strive towards (Freire, 1970). This again brings to mind the goals of relational caring, wherein everyone involved is included, not just persons with dementia. Therefore, I believe that Freire's assertion that acts of love are acts of liberation is relevant in the context of dementia care. This is especially so given the power relations that exist at multiple levels in the caring process, which can be oppressive to all individuals involved. It is also for this reason that relational caring is such a transformative concept, as it works to acknowledge and honour everybody involved in the caring process. By leading the way with love, we start towards the deconstruction of the oppressor/oppressed dichotomy, which Freire argues we too-often try to *reverse* in liberatory change, rather than *abolish* for the purpose of true liberation for all (Freire, 1970).

With that in mind, I believe that friendship has the potential to be liberating for individuals in the dementia caring process, as an act of love, trust, and dialogue that deconstructs dehumanizing practices that oppress those in the dementia caring process. If we accept this more ambiguous, fluid and subjective understanding of friendship, then the shift towards relational caring, and thus friendship, has the potential to be empowering, liberatory, and wholly transformative for all those involved in dementia caring processes.

Chapter 3: Methodology & Methods: Drawing on the arts to explore friendship together.

Returning to the eight-point scaffolding for research design (Berbary & Boles, 2014), methodology is an overarching rationale for the methods chosen and how the chosen methods connect to the other points of the scaffolding. In order to align my methodological approach and methods with critical and relational theories, I chose to draw on a critical arts-based methodology to address my purpose and research questions. In this chapter I will outline the reasons why critical arts-based methodologies are an appropriate methodology for critical research projects in general, as well as how they align with my specific research focused on friendship between persons with dementia and their paid care partners in LTC. Critical arts-based methodologies create a space for inclusivity in research design and have many transformative, critical, collaborative possibilities. In this section I will outline my data collection and data analysis processes, informed by arts-based methods and a Voice-Centered Relational Approach framework (Bright, n.d., Byrne et al., 2009). A voice-centered relational approach guided me to look at the polyvocality of my research participants, meaning the different voices and perspectives in the way a person acts and talks about their actions (Bright, n.d.), supporting a more nuanced and complex understanding of participants' experiences within specific contexts, moments, or situations (Parry & Johnson, 2007). A voice-centered relational approach also helped me to look at the relationality of my participants, as well as the relationality of the research process.

Both critical arts-based methodologies and a voice-centered relational approach helped me address my purpose and research questions. To remind the reader, the purpose of my research is twofold: I hoped to interrogate and challenge how friendship is understood in LTC dementia caring contexts, as well as to collaboratively imagine future possibilities for friendship between persons with dementia and paid care partners, specifically PSWs. My research questions explore: 1) Dominant discourses of friendship and how they are experienced in LTC, 2) How the current culture within LTC shapes friendship relationships, 3) How friendship might be reconceptualized in the dementia caring process, and 4) How visual art might help us re-imagine what friendship could be in such contexts.

3.1 Critical Arts-based Research

Critical arts-based research has become increasingly popular amongst social science researchers who aim to conduct research that is critical and transformative, inclusive, collaborative, and accessible. The emergence of arts-based inquiry appears to coincide with social justice movements occurring in the mid to late twentieth century and reflects a number of their transformative goals (Finley, 2014). Much like social justice initiatives, arts-based inquiry is often coupled with critical theories and intentionally makes the research process and representation more accessible for a broader audience. For example, in considering traditional oral/verbal interview methods, there are many individuals in the world for whom this type of interview is not conducive to full, reflexive participation, subsequently excluding them from traditional research. Arts-based inquiry is an alternative as it is accessible to participants who, through the arts, can express themselves, think critically, self-reflect, share their stories, and define their lived experiences in their own ways (Kantrowitz et al., 2017; Welsby & Horsfall, 2011). It makes sense, then, that political, moral, arts-based research would emerge in tandem with other social movements advocating for change and fostering critical thinking.

This emphasis on fostering critical thinking and learning from research participants' own modes of expression ties in well with education studies, which is the field that seems to have one of the largest bodies of literature on arts-based inquiry. In 1999, the American Educational Research Association formed an Arts-Based Educational Research Special Interest Group (Piantanida et al., 2003). In February of 2000, the first annual arts-based research conference was held in Albuquerque, New Mexico (Piantanida et al., 2003). These were some of the first, organized events/groups meant specifically to recognize arts-based research. Both of these venues sought to challenge the traditional 'norms' of research, which is reflective of a turn in education studies wherein scholars began to push for new approaches to research that relied less on scientific expectations and rules, and more on interpretation (Piantanida et al., 2003). Additionally, I have come across numerous works in various fields that draw upon academics in the education studies field, such as Paulo Freire (for example: Mitchell et al., 2011), whose *Pedagogy of the Oppressed* was previously mentioned in this paper. Many researchers, including me, draw upon Freire and other critical pedagogy scholars for guidance on how to change perceptions and educate through their research processes. The arts fit so nicely into research that aims to challenge and transform, as they provide an opportunity to instigate dialogue in and through research, to learn from one another in dialogical spaces created by art (Finley, 2014), and even to use as a tool for thinking and deeper self-reflection (Kantrowitz et al., 2017). Furthermore, art has the potential to "foster critical awareness, to facilitate understanding, and nurture sympathy" (Kontos & Poland, 2009, p.7), allowing for new dynamics in education to occur. Using arts-based inquiry in such a way can have the same effect outside of education studies and in other fields, such as dementia care, where researchers seek to be critical, accessible, and transformative.

Arts-based inquiry collapses “the divides between previously distinct phases of data manipulation” (Finley, 2014, p.532) and uses the arts in various phases of the research process. I understand this to mean that the arts are used consistently throughout the process of data collection and analysis, at times combining the two in the same moment. Creative works that were made during analysis can also then be considered new data. Researchers have used various kinds of art in their research projects, such as: theatre (e.g., Dupuis et al., 2015; Kontos et al., 2018; Mitchell et al., 2011), poetry (e.g., Finley, 2010), visual arts (e.g., Dupuis et al., 2016a; Kantrowitz et al., 2017; Welsby & Horsfall, 2011), and in differing contexts with diverse participants. It is important to note that in arts-based inquiry, the arts are not exclusively the product of the research. Instead, the arts can act as the process through which participants and researchers explore topics in ways that offer new understandings and new possibilities of expression (Dupuis, et al, 2016a; Kantrowitz et al., 2017; Welsby & Horsfall, 2011). Any art created in the process can also be used as textual data, starting points for discussion, and final research representations (Kontos et al, 2018; Maratos et al., 2016; Finley, 2010, Mitchell et al., 2011). Creative outcomes from research do have the potential to reach broader audiences and are more easily accessible to individuals outside of academia or distinct fields within academia (Finley, 2014). However, these outcomes are also the basis for one of the biggest critiques of arts-based inquiry as a methodology.

Where does the researcher draw the line between using art to facilitate and enrich the research process, and using the research process to create great, evocative art? This is a commonly asked question about arts-based inquiry and is regularly coupled with a critique of this methodology (Piantanida et al., 2003). I can understand this concern, for I had previously caught myself day dreaming about the beautiful, representational opportunities of my arts-based research, and have then worked backwards in my mind to consider how my research could be designed to make that happen. However, I agree with the notion that the art making process is more important than the artistic outcome, and entered my data collection unconcerned with the aesthetic value of the art made during the sessions. I am dedicated to the idea that the process is the most important part of the project. But, I also feel it is still valuable to consider the aesthetic quality of the final representation, as this can play an important role in how the arts evoke and have lasting impact. That being said, I can see why the critique emerges, and how easy it is as a researcher to draw the line between artistic process and artistic result in the wrong place.

Furthermore, post-positivist tenets are often still an expectation in the research community, and 'science-based' research is more commonly accepted as 'valid' or 'legitimate' as opposed to arts-based research. Subsequently, using arts-based inquiry puts researchers in a vulnerable position (Piantanida et al., 2003). The academic community struggles to identify criteria for judging arts-based research, and researchers struggle with how much to justify, how much to explain, and how much to let the art do the talking (Piantanida et al., 2003). This critique, however, seems to lie on the assumption that the artistic outcome is also the research product or final representation. As previously mentioned, this is not the only way that the arts are used in the research process. Additionally, arts-based inquiry is not exempt from the need for rigor, and to assume that it is inherently without rigor ignores the other decisions that the researcher has made in their research design. For "just as artists make a host of decisions as they craft a particular piece of art, arts-based educational researchers make numerous decisions as they craft a particular inquiry" (Piantanida et al., 2003, p. 186). In fact, rigor is a way for researchers who use arts-based inquiry to mitigate some of these critiques from the onset of their research projects, the exact same way that rigor and good research design is important for researchers that employ other methodologies.

For these reasons, the visual arts in this project acted first and foremost as the process through which participants explored the topic of friendship in a way that encouraged new understandings and new possibilities of expression. This focus on process is an important aspect of critical arts-based inquiry as participant(s) subsequently guide the project, take something away from it for themselves, and contribute in any way that feels right to them (Harter et al., 2006; Osei-Kofi, 2013). The art work that was made in this project did not necessarily strive to reach particular aesthetic value. Instead, the arts were used as a process of communication, as a way of creating safe space for participants' self-expression, and as a way to collectively imagine friendship differently. This approach also mitigates concerns often brought up about arts-based research revolving around the issue of analyzing or judging artwork. If the process is prioritized, then the analysis does not solely rely on a subjective interpretation of an equally subjective art piece. For this project, the art products are indeed considered to be data, but were analyzed initially by research participants themselves through the collaborative drawing method which will be described in detail later in this chapter.

An example of arts-based inquiry used in a study that touches on leisure, inclusion, and exclusion is the study by Welsby and Horsfall (2011) that explores the experiences of women with intellectual disabilities as described and discussed in the participants' own words. The primary method used in the study was group art workshops, which were followed by one-on-one semi-structured interviews. Participants engaged in five workshops wherein an art teacher provided multiple mediums and techniques to work with. The researchers intentionally chose an arts-based research methodology as they wanted their participants to hold "epistemic privilege" (Welsby & Horsfall, 2011, p. 796). They viewed their participants as experts of their own experiences, and wanted the women in their study to share their thoughts and feelings in their own way(s). Through this process, participants focused on the themes they felt were most important to them, some of which were not anticipated by the researchers, such as inclusion and exclusion in their everyday experiences. In this particular study, the artistic outcomes were not of primary importance. Instead, they used "artistic processes to create discursive spaces that would enable the women to speak if and how they wanted" (Welsby & Horsfall, p. 798). Welsby and Horsfall (2011) found that the women seemed more comfortable in the group setting where "conversation flowed" (p. 798) and women felt it safe to engage in individual storytelling. An interesting ethical concern emerged from this comfort, as participants became so relaxed in the art making process that they were at times put off guard, expressing that they had forgotten that they were participating in a research study. The researchers mitigated this concern by using a continual consent process, regularly reminding their participants that they were taking part in a research project and not just 'hanging out' (Welsby & Horsfall, 2011). I adopted a similar process in this research project.

Dupuis et al., (2016a) are an example of researchers using arts-based inquiry specifically with persons with dementia. For this particular critical arts-based research, persons with dementia, family members, researchers, and artists came together to dialogue and “co-create an artistic reflection of what [the] partners with dementia wanted the world to know about them” (Dupuis et al., 2016a, p.364). These artistic reflections, a series of painted plaques, showed the emergence of new, co-created narratives that challenged the negative perceptions of dementia through positive stories of loving networks, embracing life, remaining active, and seeing possibilities in life (Dupuis et al., 2016a). Throughout the artistic process, participants and researchers all noted that the art-making “provided a transformative space where persons with dementia and others could escape the confines of the tragedy discourse and construct and embrace contradictory narratives and reconstitute a more positive sense of self-in-relationship.” (Dupuis et al., 2016a, p.370). Therefore, not only was the art-making process helpful in challenging stigmas and taken for granted beliefs, it also contributed towards growth-promoting relationships within the research process itself. As previously stated, I am interested in not only forwarding the cause of relational caring, but in conducting my research relationally as well. Thus, Dupuis et al.’s (2016a) research provided inspiration for how to do so through collaborative arts-based inquiry.

3.2 Method: Collaborative Drawing

I was inspired by the aforementioned research that used group, arts-based workshops as a form of data collection, and chose to use a Collaborative Drawing process for my data collection. Compared to other arts-based methods, collaborative drawing is less explored and is primarily found in education studies, psychology, and health related research (Guillemin & Westall, 2008).

As a research method, it has shown to be a beneficial tool for accessing lived experiences that may be difficult to share or express, and adds meaningful dimensions to data that can't be accessed through other more traditional methods such as verbal interviews (Guillemin & Westall, 2008). Like many arts-based methods, collaborative drawing has started to be adapted for use for a wide range of research that aims to be transformative and accessible. In order to outline my conception of collaborative drawing as a transformative research method, I will draw on literature about other collaborative arts-based methods as well as literature that explores the act of drawing.

The process involved in the method of collaborative drawing is precisely that: a process. The act of drawing has been described as being in itself a process of meaning making, of thinking *through* drawing (Knight et al., 2016). This occurs because drawing involves a process of "visual deconstruction, comparison, synthesis, analogical transfer and repetitive cycles of construction, evaluation, and revision" (Kantrowitz et al., 2017, p.52). Through this process there is room for recognizing and interrogating the ambiguity and tensions of certain topics; for example, friendship in the dementia caring process. It is also a process that "makes it possible to gain insights invisible to words alone" (Kantrowitz et al., 2017). This means that drawing can be conducive to uncovering embodied, corporeal, sensory, reflective, responsive, and relational meaning and knowledge (Driessnack, 2006; Kantrowtiz et al., 2017; Knight et al., 2016). These forms of knowledge may be more appropriate for certain research topics than 'intellectual', 'rational' types of knowledge, which traditional research methods seek to get at. Drawing is a valuable tool for thinking and reflecting on one's self at a conscious as well as 'non-thinking' level, because drawing is such a different process than traditional 'intellectual' thinking. Thus, other types of knowledge and deep feelings have the potential to emerge through the drawing process (Kantrowitz et al., 2017). Additionally, these other ways of knowing and meaning making have the potential to play a crucial role in transformation. Through uncovering otherwise unknown knowledges, which are hidden precisely because they have been silenced or ignored, we open the door for these realities to be symbolized, recognized, discussed, and reflected upon with the goal of furthering transformative change. For:

> [w]ithin buried layers of symbolic meaning, there are resources for lives lived otherwise, a compost where energy is building, where seeds of hope and transformation may take root. Because many of these resources will have never been spoken fully, the best access is often through image-making in the arts (Watkins & Shulman, 2008, p.233).

The meanings that emerge from the process are honoured and respected, as are the subjectivities and relative truths of the research participants (Roberts & Riley, 2014).

My conception of collaborative drawing is similar to the draw-and-tell method described by Driessnack (2006) in her work with child-centered approaches to research. While Driessnack's (2006) study works with children and not adults/persons with dementia, her goal is to stop children in research being treated as objects to observe and instead as full human beings with valuable insights to give. This is similar to my intentions for my research participants. The draw-and-tell method is meant to facilitate thought processes and then conversation wherein the child describes their drawing and analyzes it themselves – a challenge to methods wherein typically researchers alone perform the analysis and interpretation of childrens' drawings (Driessnack, 2006). Given that I prioritize centering the voices of my participants and not my own, the draw-and-tell method gave me a lot to consider in how I structured my collaborative drawing process. It is important to note that, while the emphasis of this method is on the process of drawing and how it helps us think through ideas differently, communicate in our own ways, and prompt conversation, the final drawings can also serve as part of the data collected. This was important to me because I expected the possibility that some participants may have had difficulty expressing themselves verbally, and I would have been remiss to exclude anyone from contributing to the research in whatever way(s) worked best for them.

Knight et al. (2016) also explore the potential of collaborative drawing as a critical research method for working with children, with a focus on early childhood education. They posit that drawing collaboratively, in this case intergenerational collaboration, is an altogether different process than the creation and interpretation of individually made art (Knight et al., 2016). The collaborative aspect is important as it allows for a dialogical process wherein participants ask questions and discuss, share knowledge, experiences, ideas, and stories, and can thus prompt deeper reflections amongst one another (Knight et al., 2016). Collaborative drawing is in itself a relational process as the collaboration requires interaction and a back-and-forth flow of ideas. Given that the topic of this research is friendship and is informed by relational theories, it appealed to me that this method is also inherently relational. Additionally, the importance of collaboration in critical projects is echoed by Watkins and Shulman (2008), who repeatedly emphasize the importance of group work and collaborative, community-building efforts in liberation/critical projects. One of the reasons for this is the way the collective can validate and empower the personal. To explain, they write that "[w]hen work is done in groups, awareness quickly develops about oppressive social conditions that need to be transformed while self-recrimination and fears of personal guilt evaporate." (Watkins & Shulman, 2008, p.256). Thus, in sharing personal experiences and recognizing the overlapping shared experiences with others, we shift our perspectives and come to new realizations, create new meanings, and construct new knowledge. Critical reflection through the act of collaborative drawing is consistent with Freire's call for encouraging critical thinking in individuals with whom we work (Freire, 1970). It is through fostering critical reflection and dialogue with others that people become aware of not only their situation, but of their own power to challenge and transform it (Freire, 1970).

Dupuis et al. (2016a) describe similar effects in their aforementioned collaborative study on narrative citizenship for persons with dementia. Dupuis et al. explain how the collaborative aspect of their study created a space where "everyone in the room together had a chance to hear and learn from the stories of persons with dementia or family members about what they experience and how they feel about the dominant messages of loss, decline, and dysfunction" (2016a, p.364). While this research looked at challenging the dominant discourses about persons with dementia and illuminating the voices of their participants with dementia, the researchers also explored the potential of collaborative art-based inquiry for transformative projects (Dupuis et al., 2016a). Throughout the process, four relational processes emerged which all strongly support the employment of collaborative arts-based methods for conducting relational, critical research. Mutual storying, the first process, is the process through which hearing others' stories transforms our own stories and opens us up to new possibilities within our own narratives. The second process, letting go amid vulnerability, showed how collective vulnerability and the opening up of everyone's stories helped all participants be vulnerable and let go of their assumptions and fears, and instead have hope in working together and not being alone. Third is the process of inspiring relational possibilities wherein participants felt inspired by others and felt new hope in the way(s) things could be, and how “in being awakened to the capacities of others, artists, actors, and researchers, all described how they too were opened up to new possibilities in their own lives” (Dupuis et al., 2016a, p.368). Finally, co-transformational emergence outlines how participants felt invigorated, energized, and personally transformed through the relational, collaborative process of the research project. Participants felt called to action and described a tangible change in their thoughts and actions. Through this study, Dupuis et al. (2016a) demonstrate the transformative power of collaborative art making and how it can facilitate a change in all participants, challenging our taken for granted ideas, and counter stigma and damaging dominant discourses (Dupuis et al., 2016a).

Collaborative drawing involves two or more individuals, one of whom is the researcher, working together on a single piece. In my experience facilitating art programs with persons with dementia, I find a balance between flexibility and structure to be the key elements in order to create a safe space for individuals who may or may not have any experience making art. I believe this to be true for any art making setting, whether the participants experience memory loss or not. While the collaborative drawing process I brought forth to my participants was intentionally flexible, as I was conceptualising this project I initially used the following arrangement as a guideline to provide my participants. A large scroll of paper would be laid out on a single table, with multiple dry arts materials (markers, pens, pencils, crayons) spread out around it and accessible for multiple people around the table. Side by side, participants could begin to draw on the paper in front of them. Participants would be prompted to draw various symbols or images related to friendship over the course of the session and would be asked to describe their drawings of friendship throughout, and participants would be encouraged to engage with each others’ sections of the drawing. While the end results might ultimately be contained to each individual participant drawing in the space in front of them, the act of working on the same piece of paper side by side and discussing our work as we progress would be considered in this case a valuable part of the collaboration. The discussions would be audio recorded so as to transcribe and reflect upon the spoken discussions during the analysis of the data. This vision of how the collaborative drawing would unfold did change to some degree as the project unfolded, due to the advising of the administrators at the home, and of course, the way that participants took to the activity in the moment. More about the step by step of my method and how it ultimately played out will be provided in the next section, after I describe my research site and recruitment process.

3.3 Procedures

3.3.1 Research Site

For the purpose of this study, I organized collaborative drawing workshops with my participants living and working at Goldside Long Term Care[2] home run by Northcare Inc.[3]. in Ontario, Canada. I was connected to Goldside through the Director of Long Term Care at Northcare Inc, a person with whom I have worked in the past on mural projects at another LTC home. I knew that this Director had taken part in relational caring culture change initiatives in her previous role, so I asked her over email if she'd be interested in having me do my research

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[2] Name of LTC home has been replaced by a pseudonym to protect the anonimty of research participants

[3] Name of parent organization has been replaced by a pseudonym to protect the anonimity of research participants

related to the same relational caring theories at the home she now directed. She provided me with some details that made this LTC home appear to be an appropriate site for my research.

Goldside was selected because it is an LTC home that was relatively accessible for me and had a primary contact for me to work with. It does not have a dementia specific floor, but there are indeed individuals who live there who are living with memory loss. Research would suggest that the majority of people who live in LTC settings have some form of dementia (Canada Institute for Health Information, 2018). This home was also not undergoing any major culture change initiatives at the time of the research which was important in my selection process as I was curious to know what attitudes are like about friendship in the dementia caring process before being introduced to relational caring approaches. If participants had already begun exploring relational caring, this would impact their perspective on the topic of friendship in this context. Of course, this would not be a negative thing, but it would definitely have shaped the findings of this research. Therefore, I sought out a home that might, in theory, have a more traditional, biomedical culture and might not yet be challenging dominant discourses and attitudes within LTC at the time of data collection.

3.3.2 Ethics and Consent

The process for consent is always of importance in research. As previously noted, working with persons with dementia in the current culture of dementia care comes with particular considerations. For example, many persons with dementia are not legally in the position to give consent without a third party. While this issue is a reflection of the biomedical paradigm I hope to challenge, "due to the prescriptive nature of third party consent," (Rogers &

Tuckwell, 2016, p.628), I must acknowledge third party consent due to the legal process that is currently in place. That being said, while consent was obtained from whomever it is legally necessary to obtain it from, the participants in my study were addressed and asked for their personal consent and/or assent, in a continual process of ensuring consent/assent. Dewing's (2007) approach to a process of consent for research with persons with dementia is in line with relational theories and approaches to care and rejects traditional competency-based approaches to consent (Dewing, 2007). Instead, process consent "acknowledges that capacity is situational, that capacity can be present even after the usual legal threshold has been crossed, and that it is often strengthened or even reinvigorated within an enabling and caring relationship" (Dewing, 2007, p.13). Therefore, consent is also a relational process that is continual, flexible, and re-established throughout the research process. Such a process helps develop participatory partnerships between research participants and the researcher, and was used both with persons with dementia and paid care partners in this research.

It is this assent that was first and foremost respected and continually revisited throughout the research process. Issues around consent were also previously mentioned in the context of Welsby and Horsfall's (2011) research with women with intellectual disabilities, and how a continual process of consent was adopted to ensure that their participants continued to consent throughout the research process. Ethically, this is of importance for all participants no matter their diagnosis or lack thereof. However, given the element of memory challenges inherent in the dementia context, it was especially important for me to address assent and constantly be aware of it in this particular research project. It would be unfair and ethically wrong to assume what my participants did or did not understand/remember in terms of consent, and therefore regular checkins occurred, as well as the acknowledgement and respect for non-verbal cues that indicate a refusal or hesitation to participate. Using a Protocol for Obtaining Assent (Appendix F) to guide and document my process for assent, I made sure to remind participants of the purpose of my study and what was going to unfold during each session before we started. This was followed by obtaining participants' assent which was then checked throughout the session and documented with the Protocol for Obtaining Assent for each participant after each session. Process consent ended up being particularly important as I elaborate on in my discussion of recruitment and sampling procedures as well as my reflections on my arts-based collaborative workshops.

Additionally, this study was reviewed and received ethics clearance through the University of Waterloo Research Ethics Committee (ORE#40923), as well as through the LTC home's own Ethics Committee. Both of these approvals further ensured that all language and ethical considerations ensured the ethical treatment of all research participants. Approved ethics documents including the interview guide, information letter, demographics profiles, have been included in the appendices for reference (Appendix B-H). There were multiple versions of some documents, including the interview guides, consent letters, and demographics profiles, to account for changes in language for residents, paid care partners, and third party decision makers (i.e., "your participation" vs. "your loved one's participation). I have included multiple versions of each document under the same appendix.

3.3.3 Recruitment and Sampling Strategies

Recruitment and sampling for this project was convenience based and purposive and defined by a handful of criteria. Convenience sampling is a method that researchers choose "because the elements are readily available to the researcher" (Bryman et al., 2012, p. 219). That is to say that researchers work with individuals who they can easily gain access to (Bryman et al., 2012). In the case of my research, I had a prior relationship with the gatekeeper at this home – the aforementioned director - which made it easier for me to gain access to potential participants at Goldside than it might have been at another home where I am not known (Creswell, 2014). The Director had indicated to me that she was willing to assist me in the recruitment of potential residents and PSWs to participate in my study, and ultimately connected me with a staff member who became my primary contact for recruitment and scheduling.

My sampling strategy was also purposive in that I selected participants based on specific criteria. The criteria for participation in this research project began with this: individuals had to either be: a) an individual with memory loss who lives in the LTC home, or b) a paid PSW who works at the same LTC home. I was not interested in relationships between specific pairings of persons with dementia and paid care partners in this case, and therefore participation was open to anyone who fit the following criteria:

- ***Participants had to have lived/worked in the LTC for a minimum of six months***. This criterion was selected because I wanted participants to have had a chance to get to know the particular LTC environment and to have begun to build relationships at the home. If someone had just recently begun working/living at the LTC home, they may not yet fully know the culture within the home, and may not have had time to begin to develop relationships within the home.
- ***Participants had to have some level of ability to participate in the arts-based workshop***. Persons living with dementia needed to be able to participate with little support beyond

what I could provide as the facilitator. Since I have experience working with persons with dementia, I was comfortable providing some support in terms of assisting in art making, prompting, etc. That said, working in a group meant that I would not be able to help everyone in activities, such as holding the drawing utensils, throughout. Additionally, due to the nature of the subject of the workshops and with the emphasis on creating a safe space for people to express themselves honestly, I did not want participants with dementia to require a paid care partner to be in the room with them during the workshop. This is because I did not want anyone feeling they couldn't share their real feelings for fear of hurting others or facing repercussions, nor did I want others interpreting for persons with dementia.

- ***Participants had to be able to communicate verbally in English to some degree*** and be able to contribute to the conversational and reflective aspect of the art making. I wanted participants who would be able to describe and discuss their drawings to some degree.

Using these criteria, I was looking to recruit three to four persons living with dementia who lived at Goldside and three to four PSWs who worked there. A small and intimate sample size was selected as it was conducive to building rapport and having intimate, honest, and safe conversations with all participants. That said, given the physical space the workshops would be taking place in – the recreation room on the 5th floor of the LTC home - I was cognizant of the fact that residents may believe the session was like any other arts program hosted by the recreation department. I wanted to be open minded and respectful of being in other peoples' homes and workplaces, so should someone really want to participate, who maybe does not fit into each element of my criteria, I decided to be inclusive. This ended up being relevant, as one of my resident participants fit all my criterion except she had only lived in the home for 3 months. The group had all been seated prior to my arrival, had taken part in a creative activity beforehand, and wanted to continue. Since we were able to get all of her consents, we proceeded and this participant was included in the data collection. I have taken into consideration how her shorter time living in the long term care home, relative to my criterion for inclusion, may shape her experience and the stories she has shared with us. I discuss these considerations and observations further in the following "findings" sections.

3.3.3.1 Reflections on Recruitment

In following with this project's theoretical underpinnings, the recruitment process was designed to be as relational as possible with both persons with dementia and paid care partners at the LTC home. A verbal script for recruitment (Appendix G) was designed and approved by the University of Waterloo Ethics Committee to be used as a starting point/guide to help with my recruitment process. I arranged to meet with my primary contact at the LTC home to discuss potential research participants from either grouping who fit the aforementioned criteria. Once potential participants had been identified by Goldside's managers/administrative staff, I requested to meet these individuals. Because I wanted the process of recruitment to be determined collaboratively so as to be convenient and suitable for everyone at Goldside, I was open to being introduced directly to individuals by leadership, or to setting up an information session so that potential participants could identify themselves as interested after hearing about the project. After initial conversations with leadership, I began my recruitment as I had envisioned: Starting with casual meetings and introductions, I met with a handful of participants, residents in the home living with dementia whom the leadership had identified as fitting my criteria. I shared a little bit about myself and my project and asked a few questions about them in return. I shared and went through the information letter for participants living with dementia which had received approval from ethics (Appendix C). If the person seemed interested and fit my criteria, at the suggestion of the leadership, I had participants sign a participant consent form for participants living with dementia (Appendix D) to indicate their interest, and then followed up with their POA should they require their consent and signature as well in order to participate.

I discussed the consent process one-on-one with the residents and addressed any concerns or questions they had about the research process. These meetings were either in the resident's room, if they invited me in, or in the common areas in the home, and were casual sit-downs wherein the participant and I could briefly familiarize ourselves with one another. The act of familiarizing myself with my participants was of great importance to me as well as to my research project, as it can help create a safe, relational, honest space for sharing stories and experiences (Bright, n.d.). Bright (n.d.) writes about entering relationally in the research process with participants, stating "that developing relationships helped create a relational research environment which might facilitate communication and understanding of people's experience" (p.4). Byrne et al. (2009) echo this sentiment and write that in relational research projects that hope to engage participants at many levels of the research process, "the negotiation and development of research relationships will occupy much of the time resources of the project" (p.68). Unfortunately, this was the only time I was able to meet with potential participants prior to the data collection days.

For that first recruitment day on-site, I had brought my police check from a previous job, as well as my immunization records, both of which had been requested of me at our ethics meeting a few months prior with various leaders and staff at Goldside. To my disappointment, they had failed to tell me that they needed the police check to have been completed within the previous six months. So began my encounters with policy, red tape, and waiting, waiting, and more waiting. While I waited for months for my new police check to come through, one of the participants I had initially recruited passed away. I was saddened at this, as I had enjoyed connecting with her a lot. Following that, my main contact went on a month-long vacation during which time I heard back from none of the alternate contacts she had tried to connect me with. Suddenly, someone from their corporate office caught wind of my project and started expressing their concern, asking for more information before proceeding. I provided as much information as possible, and thankfully, that blew over. Given the difficulty of communications and speed bumps in the process, for the sake of completing this thesis which had already gone long over the expected time limits, I accepted when they offered me dates for data collection without additional prior visits for recruitment and relationship-building. Unfortunately, this impacted my ability to relate with and explain the project in my own words to some potential participants ahead of time. However, in the end it is what worked for the home and their comfort level, and they were able to organize and recruit individuals on their end. I decided that my introduction on data collection days would have to do. Ultimately, two of the original participants I had met with took part in the resident's group, and three of the resident participants were new to me. Neither of the original participants indicated that they remembered me, therefore I do not know if I can really say that we had started building a relationship prior to data collection. Regardless of this speedbump, I do think that we were able to engage in open and safe conversation throughout the session nonetheless, relating with one another quite well as a group. As for the PSW group, I was introduced to each individual the day of data collection, and therefore did all my introductions, and discussions of the information sheets (Appendix C) and obtaining consents using the consent form for paid care partners (Appendix D) prior to beginning the data collection. The PSWs were selected and invited to participate by the nursing manager and other leadership in the home and offered an extra paid hour at the end of their shifts to participate. I am so appreciative that the home offered this paid time to the PSW participants.

As previously described, an extra consideration for my research was that I needed to ensure that I received consent from any outside parties who may have power of attorney for my participants with dementia. I determined this with the leadership contact who would have this information. Collecting third party consent for residents who needed it was only one part of my consent process and did not negate ensuring that participants with dementia provided verbal assent to participate in the research throughout the process.

3.3.3.2 Demographics and Participant Profiles

Eight participants consented to participate in my research, including five residents with dementia and three PSWs. Though I had not specified this in my criterion for inclusion, all the participants who took part in my data collection identified as female. This is not surprising as the majority of people who live and work in LTC are female. There was one male resident recruited initially, though on the day-of he decided he did not want to participate and left before I began my questions to the group.

I collected demographics through a demographics profile (Appendix E) asking for participants' age, gender identification, and how long they had worked/lived in the long term care home. The PSWs were asked additional questions about whether they had worked at other homes, to get a clearer picture of their experience working in the field. Demographics profiles were filled out by participants day-of, but prior to the data collection sessions starting. Information that was missing from resident demographic profiles was obtained from my primary contact in the home after the session. The participants with dementia were somewhat more diverse in age and time spent in the home when compared to the PSW group. The participants with dementia ranged in age from 62 to 95 years. The residents had lived in the home for different lengths of time with the newest to the home moving in three months before data collection, and the participant who lived there longest being in the home for four and a half years. On the other hand, all three PSWs who agreed to participate were in their mid-fifties and had worked at the LTC home for 15+ years. Given the length of time these PSWs had worked in the LTC sector, it meant that they had been embedded in the dominant culture of care for a significant amount of time and could provide a 'bigger-picture' perspective of LTC compared to someone younger or who had entered the field more recently. I have taken this into consideration when analyzing and reflecting upon the data.

So as to humanize my participants and represent them, I have chosen to include participant profiles as opposed to a chart or table, using pseudonyms to share a bit about who they are, their individual perspectives on friendship and my personal reactions and impressions of each person. I have chosen pseudonyms for each participant based on what I know about them, using Google to look up names that come from similar origins, similar time periods and so forth. I also picked names that I personally felt matched my impressions of them, based on the time I was able to share with them.

Resident Profiles:

Anne-Marie (Anne)

Anne-Marie, who goes by Anne, is from England. She has bright eyes and a pleasant smile. Anne is 88 years old and has lived at the home for two years. She comes across as very gentle and describes herself as a widow, “that’s just the way it is”. Anne also has sons who she says care about her very much. She frequently returns to the story of one son in particular, who took charge of finding her a spot in a LTC home. She describes this process as a thoughtful one, that he made a good choice encouraging her to accept a room at this particular home. Anne repeats that she is now “out of his hair” and that he doesn’t need to worry about her anymore as she is well taken care of and the staff here are good and friendly. Many of the questions asked in the session brought Anne back to this story. The first thing that came to mind for Anne when asked about friendship was that “friendship is always a helping hand”, and that “sometimes you need it [help]”. Anne was relatively quiet in the session, but piped up with sweet moments of humour; when I asked who she could talk to at the home, she said “to myself!” with a big smile and a laugh. I felt she was a very warm and charming person.

Cora

Cora is pleasant and thoughtful. She is 83 and has lived at the home for 7 months. Cora comes across as self-aware, often asking her fellow participants if they've experienced the same thing in the home. Cora highlighted a particular friendship she has with the "pill lady" in the home, who came by during our session and who Cora pointed out as being her friend. Though she calls her "pill lady", she repeats that what's most important is what goes beyond the pills. Cora was particularly articulate about her drawing choices, sharing why she chose specific colours and drew things at certain sizes. When asked about friendship, the first thing Cora shared was that friendship makes you feel "relaxed". Cora is soft spoken, which she described as "I have a monotone voice" that people have a hard time hearing, but she shared plenty of insights into her experiences in the home nonetheless. I remember feeling Cora was very wise, and I loved listening to her thoughts.

Heidi

Heidi is 70 years old and is relatively new to the home, having just moved in three months ago. Heidi wanted to participate in the session so we gladly had her join us. Her insights were just as thoughtful and insightful as others' were. She seemed to appreciate people who are genuine and down to earth; that "one of the helpers" she identified as a friend in the home "doesn't go "gaga"", which she likes about her. Heidi also seemed ready to talk about things that others didn't initiate; namely a few negative experiences with "miserable people" who "grumble" in the home. She subsequently helped others open up about their similar experiences, creating a safe space to share. Heidi has a sister who works in the hospital attached to the home, but doesn't see her often. When asked about friendship, Heidi's first response was that a friend is "someone you can question", which to me was indicative of Heidi's admiration of people who are genuine. I really appreciated Heidi's honesty and attitude. She reminded me of my aunt, in a very good way.

Miriam

At 62 years of age, Miriam is younger than the majority of the participants in our session, and in the home. She was the primary carer for her mother, after her brother died unexpectedly. When Miriam had a health event that left her seeking support, she and her mother both came to live in the LTC home as residents. She has lived there for 2.5 years. She sighs heavily when she shares this with us. She has a sister in Egypt, and another in Kuwait. She calls me 'Habibi" by the end of the session, and I was glad that we seemed to connect enough for her to use a term of endearment to address me. She shares enthusiastically throughout the entire session. She also shares that she is a Christian, and this is a significant part of her life. Miriam likes to help; she offered to photocopy my papers for me, insisted I pull up a chair to sit with her, and encouraged other participants to respond to the prompts during the session. When asked about friendship, Miriam had a lot to say, but the number one thing for Miriam is trust. She is vibrant and full of energy, often interrupting others but apologizing after. I remember her big smile very clearly.

Betty

Betty is quieter than the other participants – even quieter than Anne. She is 95 years old and has lived at the home for nearly 5 years. She seemed to have a harder time answering questions, but would insert pieces of wisdom and humour throughout the session. Betty said that in friendship, you had to “have a heart”, but also that “you can’t love everybody”. She was curious and often picked items up from the table – including the audio recorder – to look at it more closely and see where it was made. Betty made jokes such as “I don’t K-now!” emphasizing the K and smiling quietly after. Betty drew hearts and flowers on her paper, and shared that she likes marigolds. My favourite moment with Betty is when she asked me, somewhat cheekily, if my teeth were my own.

Paid Care Partner profiles:

Gemma

Gemma comes across as a bit of a leader in this group. She is 56 and has worked in the home for 16 years. While she remained friendly and compassionately engaged with us all, she spoke with authority and from a place of knowing. She spoke passionately about her job, and takes great pride in helping others. She shared a story of helping an elderly couple into their car at a Walmart parking lot, and how her husband and children praised her for her kindness. Gemma acknowledged others' statements with "Yes", and I can still hear her gentle way of saying it clearly in my mind. She also physically demonstrated how she approaches residents, touching my shoulder and holding my hand to show me how she would do so with a resident. To Gemma, friendship, caring, and love are reciprocal, and she repeated that what you give to residents, you will get in return. It is also important for Gemma that she is a friend who people can rely on. In terms of drawing, Gemma captioned many elements in her piece. I was particularly touched when I saw that she wrote, on a reference image of scrubs, "this uniform make you more beautiful."

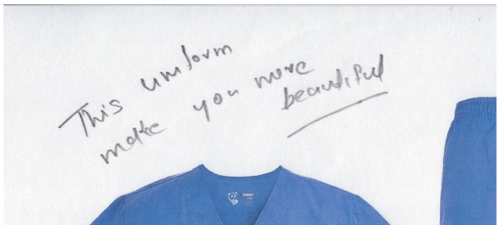


Figure 1 Gemma's notes next to a photo of blue scrubs. "This uniform make you more beautiful"

Joy

Joy is 55 years old and has worked in the home for 17 years. She is quite lively and engaged others with stories of shared experiences. She also prompted others to recall their stories that relate to the topic or question at hand, which spoke to the benefits of a collaborative, group approach to data collection. Joy understands friendship as an integral part of the job, asserting that "*if there is no friendship, you can't get to nowhere*" with the residents. Joy frequently referred to the residents and others in the workplace as second family, and the home as a second home. She even shared that sometimes on her days off, she forgets that she isn't working and comes to the home anyway! Joy works on the same floor as Gemma, and I could sense their camaraderie. However, they never left Risa out, and seemed to be nearly equally as familiar and friendly with her as they were with each other.

Risa

Risa is 54 years old and has worked at the home for 15 years. She seemed quieter at first, compared to Joy and Gemma. However, with the prompting of her colleagues and further questions from me, Risa began to share very openly. Risa identified very specific friendships in the home and was able to speak about them at length, addressing the reciprocity and caring she would receive from residents, as well as the challenges/barriers she faces in engaging with these friendships. She also shared a touching and vulnerable story about losing her husband, and the way residents reacted when they found out. Risa loves to sing, though she says she does not share that much in the home. To Risa, friends are people we sometimes feel more comfortable with than family members, and she emphasised that it is important to be able to talk with a friend.

3.3.4 Data Collection Strategies

3.3.4.1 Separate Collaborative Drawing Focus Groups

Initially, I had envisioned my data collection occurring in two phases: separate collaborative drawing groups, followed by a second workshop that would bring all participants together to create a collaborative piece to reflect and represent a collective understanding (and possibly a reimagining) of friendship in LTC. I wanted to leave it up to participants to decide whether or not they wanted to participate in a second collaborative workshop. This is in keeping with most critical arts-based projects, which, in order to be truly participatory, require the researcher to step back and let participants guide the project (Byrne et al., 2009; Watkins & Shulman, 2008). The second workshop could have been an opportunity to co-create the final representation for this research project, what Berbary and Boles (2014) call the "explicit sense making" (p.404) for an audience. While participants seemed open to the idea of seeing me again for a mural or other arts based project, after speaking with the leaders at the home, we decided not to plan that as part of my research, simply due to challenges around timing and scheduling. Therefore, my data collection focused on the two separate, collaborative drawing workshops which I describe next.

Data was collected in collaborative drawing focus groups; one with the five residents living with dementia and one with the three PSWs. I intentionally chose to conduct two separate groups because I wanted participants to be able to speak freely, openly and honestly about their perceptions of LTC and understandings of friendship in the home. In order to create a safe space for these conversations to happen, I felt that it was important to conduct the workshops separately. Informed by my experience teaching and creating with persons with dementia, I believed that an hour-long workshop was the ideal length for this kind of creative workshop, both for persons with dementia and paid care partners. If the workshops were too long, I knew that some may tire or lose focus. I also know about the time constraints felt by PSWs and did not want to take up too much of their precious time. Thus, both workshops were designed to be approximately an hour in length.

The sessions took place in a separate room from main shared areas with a table and chairs where we could do the workshop in privacy without too many interruptions. Despite best intentions, there ended up being several interruptions, including a resident who was not participating coming by and listening in quietly for a few moments before leaving, several overhead announcements, phones ringing, among other things. These experiences reflected, in some small part, the realities of living and working in LTC (at least, before COVID 19) and the challenges of conducting research in these spaces. For the most part none of the interruptions threw us too off topic throughout the session, or interrupted the focus too drastically.

The workshops provided groups with the opportunity to explore the concepts of friendship in the dementia caring process from their unique and shared perspectives, as well as what they would like to see happen or change in the future. We explored these topics using the interview guide (Appendix B) which acted as a starting point for interview questions and drawing prompts. Several elements of the interview guide were inspired by Derrida's (2005) assertion that to understand friendship, it is best to start with the perspective of the *friend-who-loves*, that is to say that I was inspired to approach participants as knowing, acting friends, rather than being in a passive role, just receiving friendship. I was also inspired by the idea that friendship can be understood as an act of love (Derrida, 2005), which I explored more deeply in my literature review. Derrida's ideas manifested in my interview guide as a prioritization of participants' language and perceptions of friendship, and an exploration of the word "love" in participants' understandings of friendship. As such the first question asks: "I would like you to think about friendship: what does friendship look like for you? How does it feel?" with a follow up prompt asking: "Does love fit into your conception of friendship?". Subsequent prompts were left open-ended so as to use language uncovered through this first section of the interview guide, prompting participants to draw-and-tell (Driessnack, 2006), for example: "Please pick a pencil and create a drawing of a time YOU showed _______ towards someone who works/lives here." This same interview guide was used with both participant groups.

As the researcher, I remained present and participated in the drawing activities instead of writing notes on what people said. A volunteer note taker attended the sessions to help capture what I was not able to as I facilitated and participated, and they did not participate in the art making. This individual took notes on body language and other things that may not be captured through audio recording or post-workshop memos that I wrote after participating in the workshops. That said, there were moments where the volunteer note taker supported participants, especially in the resident group with higher numbers of participants than anticipated; their support was mainly in the form of reiterating questions for the participant sitting next to her, and helping that individual focus on something other than my audio recorder, which she frequently picked up to analyze. I was grateful for the extra help that the volunteer note taker provided as I would have had a harder time supporting that individual while simultaneously facilitating the discussion.

The first workshop was conducted on Friday, September 13th, 2019 and the second was conducted on Tuesday, November 12th, 2019. I intentionally conducted the two workshops on different days so that my reflections on each session could be more detailed and thorough, and so that I was not overwhelmed with new information and ideas. I wanted to have time in between workshops to reflect and recharge. It was also far more challenging to schedule the paid care partner workshop.

3.3.4.2 Reflections on the collaborative drawing sessions

The session with the residents was conducted first. I remember it was a Friday the 13th and I felt nervous, even though I typically am not superstitious. When I first arrived with my volunteer note taker, there were more participants than I had hoped for at the table they had arranged for me. As a reminder, I had originally hoped to have three or four participants in each group. When I arrived for my first session, there were six residents waiting for the workshop to begin, some who I had met during my recruitment visit and others who were new to me. That said, I was adamant in my approach not to exclude anyone who may want to take part, and to find a way to work around it should they join us day-of – keeping in mind the need for consent and to ensure POA consent if necessary. Thankfully, we were able to get consent from all of the 6 individuals prior to the session, for which I am very grateful to my main contact at the home. As I began to explain my project to the group, one individual opted out, so consistent with process consent we said farewell and one of the carers at the home escorted him out of the room. The other five participants remained for the workshop.

Guided by my interview guide (see Appendix B), we sat around the table and drew and chatted as expected. I asked a question to prompt drawing and the drawing would prompt further probes. The only other change to my plan was that I did not have everyone draw on a single scroll of paper. At the suggestion of the contact who helped me organize the sessions, we decided to stick to individual sheets of paper so as to make it clearer what was expected of participants. Based on this individual's experience leading recreation programming, they felt that a whole piece of paper might confuse participants, and there was one individual participating who had expressed a strong sense of ownership over her art pieces in the past, and may have an issue with a collaborative sheet of paper. With that advice, I put out single sheets of paper in front of each participant instead. I gave each individual a pencil to start their drawings with, and distributed reference images as well as coloured markers and pencils throughout the workshop.

There were many moments during the session that elated me: a staff member came in quietly to give one resident her medications at 3 p.m., and as she left the resident turned to me to say "now that's a friendship right there"; a participant explicitly brought up barriers to connection they experience in the home; a participant asked for warm colours to draw the PSW in her drawing because this person is warm towards her. Each of these moments and more told me I was onto something, and that I needed to do justice to the incredible contributions my participants were providing. The participants expressed how nice it was to talk, and to do this. At the end of the session, they asked me to come back the following week to do this again.

My experience with the group of PSWs was similar. I had the expected number of participants, three, and I knew that each of them needed to leave immediately after the session, one for another job, another to make food for her whole family after a long shift. Having them tell me this right off the bat made me feel like they didn't want to be there, but I was pleasantly surprised at how enthusiastically they began to share and engage once we got into our drawing and conversations. Again, I was elated and had to contain myself to some degree when participants shared with me; " if there is no friendship, you can't get to nowhere", or "you have to give them the love, and they give back to you.". They even shared explicit references to challenging rules and policies in order to engage relationally. I suspect my group was particularly compassionate and naturally relational, as they had all been working as PSWs at Goldside for more than fifteen years. At the end of the session, these three participants expressed how nice it was to have the opportunity to talk about these concepts and ideas with each other, and wanted to hug me goodbye. I hugged them back and thanked them from the bottom of my heart. I was so thrilled and relieved to have collected what I felt was going to be amazing data.

3.4 Analysis: Voice Centered Relational Approach

As previously described, all conversations and discussions had throughout the collaborative drawing process were audio recorded and transcribed verbatim. Additionally, I wrote reflection memos every day after I was on-site or interacting with research participants. I describe these reflection memos later when I outline how I attended to rigour in my process. I then used the voice-centered relational approach for analysis. The voice-centered relational approach was an ideal analysis framework for this project as it relies on the same relational theories guiding the rest of this project and allows for a non-linear, polyvocal analysis uncovering the tensions and multiple realities within data (Bright, n.d.). The central principles of the voice-centered relational approach are:

- The researcher and participants are in an on-going relationship throughout the research process.
- People exist in inter-dependent relationships, relationships with themselves, with others and with their context.
- Knowledge is constructed through interaction with the self, with others and with the broader context the individual researcher and participant/s are located in.
- People act in response to the meanings objects hold; these meanings are constructed through social interaction and can be ever-changing.
- Multiple constructed realities exist. Accordingly, knowledge is multi-layered and never complete. It is always partial and situated within the context it is constructed in. (Bright, n.d., p. 4).

These principles parallel many of the philosophies which guide my research project. I am particularly drawn to the idea of research as a relational experience in itself, which Bright (n.d.) acknowledges through the voice-centered relational approach by explicitly engaging in trust-building relationships with research participants. Bright writes that she attended to her relationships with participants before completing consent as well as throughout the data collection process by taking the time to talk and share with participants and their families (Bright, n.d.). In so doing, Bright (n.d.) considers that a safe space for open communication was established. As previously outlined in my section on recruitment, I had hoped to engage in a similar process with my participants at Goldside, and while I experienced some barriers to doing so, I was able to meet a few participants prior to data collection. The relationship between researcher and participant does not end at the analysis phase (Bright, n.d.). I believe this is reflected in the data collection method selected for this project, wherein participants collaboratively started to analyse the data, as they described and analyzed their own drawings during the session (Driessnack, 2006). I also understand this continuing relationship as being inherent and impossible to separate from because it is also about my relationship to participants' art, to their stories, and to the time we spend together in the collaborative drawing workshops. My continued relationship to the data and participants' stories is addressed in the framework for the voice-centered relational approach.

The framework for the voice-centered relational approach involves four readings of the data and does not separate different kinds of data (transcriptions, visual data, observations, researcher's reflections, etc.) (Bright, n.d.; Byrne et al., 2009). The first reading focuses on the overall plot of the data; what story is the narrator telling, and how does the researcher relate to this story. Bright (n.d.) succinctly calls this reading "the story and response" (p.8). The second reading focuses on the "I" in the narrator's story; how does the narrator situate and perceive themselves in their story? This reading includes questions around the role(s) participants see themselves playing, what pronouns they use to describe themselves, how participants describe themselves, how participants think others see them (Bright, n.d.), and so forth. The third reading looks at the relationships in the story; whenever the narrator discusses the "you" or an "other" in their story. The questions around this reading are similar to the second but revolve around the other people and relationships that participants describe (Bright, n.d.). Finally, the fourth reading interrogates the context and setting in the story, whether that be the institution or overarching culture that gives context for the story. This final reading looks at the broader social context that participants describe, including the underlying social values in the story, the taken-for-granted notions, what is privileged and what is not (Bright, n.d.; Byrne et al., 2009). During each reading, I asked specific questions of the data and these are presented in Table 1.

These four readings allow for a polyvocal, multilayered analysis that highlights the multifaceted nature and cultural embeddedness of the stories (Bright, n.d.; Byrne et al., 2009). When I started my analysis, I understood this to mean that the four readings and multiple perspectives at different layers allow for the researcher to acknowledge and explore tensions, paradoxes, and ambiguities that might emerge from the different readings of the data. Given that my participants and I were simultaneously exploring the dominant discourses in dementia care, particularly around friendship, and challenging such discourses, I believed that an approach to analysis that creates room for tensions, paradoxes and ambiguities was necessary and better able to capture the complexities of friendship in this context. The voice-centered relational approach also makes the research analysis process much more explicit and encourages researcher reflexivity (Byrne et al., 2009). This is particularly evident in the first reading, where the researcher is prompted to ask, "What is my emotional and intellectual response to the participant" (Bright, n.d., p.8). This is part of why I have included my emotional and intellectual responses and reflections throughout this thesis.

Table 1: Reading and Listening Guide for Voice Centered Relational Analysis

Reading	**Questions**
Reading One: The story and response	- Who is telling what story? - What are the events, sub-plots, characters, and metaphors? - What are the recurring phrases, words, themes, and key images? - What is my emotional response to the participant and their story? - What is my initial intellectual response to the story?

Reading Two: Participant voice, how the participant represents themselves	- Who is speaking and with what voice? - How does the participant experience, present, speak of, and feel about themselves? - How does the participant believe others see them? - What pronouns does the person use when speaking of themselves? - What emotions, reflections, opinions, actions and intentions are expressed and evident? - How are people acting (doing/saying)? How do they expect to act? How do they do things and how did they develop that knowledge? - What roles are participants playing in their stories? - How do they perceive situations, words and actions? How does this impact on action?
Reading Three: Others and relationships	- Who is spoken about? - What are the relationships, emotions, statement and stories associated with those spoken about? - Who is related to who in what way? - How are people positioned within the relationships and interactions? - What are people saying and doing? - How do they do things and how did they develop that knowledge? - What roles are participants playing in relationships described? - How do they perceive situations, words and actions? How does this impact on action? - What are the consequences of such relationships
Reading Four: Context and social structure	- What are the broader social, political, cultural, professional, structural, and./or institutional contexts surrounding the participants' stories, experiences, actions and interpretations? - What is spoken and what is unspoken? Overt and taken-for-granted? - Whose voices are heard or described as informing the situation? - What social values surround the interaction? - Why do people act in some ways and not in others? - What is institutionalized? - What is the 'right' way to do things? Where did this value come from? - How have different roles in the stories come about? - What is privileged in talk and/or action?

(Adapted from Bright, n.d., and Byrne et al., 2009.)

The representational practice of Creative Analytic Practice (CAP) informed the artistic, representational choices I made in this project. CAP is a creative process where research is analyzed and represented through artistic forms, allowing for more complex, evocative, and critical representations of research findings (Parry & Johnson, 2007). CAP is appropriately matched to an arts-based methodology as it provides the opportunity to explore and represent the data creatively as well. This is applicable in my study as I wanted to create opportunities for my participants to engage in the analysis of their own stories and artwork. In the end, participants engaged in analysis throughout the workshop sessions, as the draw-and-tell concept encouraged participants to interpret their drawings as the workshop unfolded (Driessnack, 2006).

CAP ultimately acted as an opportunity for me to engage with the data creatively, using visual representation to formulate my own understandings of the data. That is, during my analysis process I used my own creative process as a way to engage more deeply with and understand my data, while simultaneously creating visual representations to represent these understandings in a more accessible way (Parry & Johnson, 2007). I believe that the visuals I created throughout my analysis are accessible and aesthetically pleasing representations of the patterns in the data. It is important to me that the outcomes of my research are accessible and meaningful for my participants, for other people who are like my participants, and for the general public. The evocative nature of arts-based representation also gives CAP projects the potential to transform perceptions, to stir emotions in others, and to move the viewer into new understandings (Watkins & Shulman, 2008). It is my hope that the visual representations I created help facilitate understandings of the data and promote thoughtful, critical reflection of each pattern.

3.5 Rigour

Arts-based methodologies and representations are slowly becoming more widely accepted throughout academia (Forinash, 2016), however there is still an overarching demand in academia for traditional research requirements: validity, generalizability, ‘scientific methods’, objectivity, and so forth (Crotty, 1998). While I have already outlined why some of these tenants are not applicable nor valuable for my particular research project, I must still conduct my research process with rigour. Rigour to me means that my entire process is conducted with sufficient and thoughtful reflexivity and documentation, has social significance and impact beyond the scope of the project, and that all my research puzzle pieces are aligned with one another and justified/supported by the literature. In this section, I outline some frameworks that have informed my understanding of rigour, as well as the specific expressions, and tools/methods I used to ensure rigour in my research process. I borrow the term “expression” of rigour from de Witt and Ploeg (2006) who use the term expression instead of criterion in order to move away from the rigid and traditional connotations that come with the term criterion.

3.5.1 Reflexivity

I believe reflexivity to be one of the most important aspects of a rigorous research process (Dupuis, 1999). Reflexivity in this case is a constant process of self-reflection about how I felt throughout the research process and how my subjectivity may have impacted my relationship to the research, my data, and my participants. Manning (1997) describes fairness as an expression of rigour which includes reflexivity (Manning, 1997). De Witt and Ploeg (2006) also touch on research reflexivity in their expression of rigour titled *Balanced Integration*, which

I will also discuss. Their version of reflexivity focuses specifically on philosophy in research, and that the researcher's philosophies should align with the methodologies and methods used and should not take over the voices of their research participants (de Witt & Ploeg, 2006). While de Witt and Ploeg (2006) describe philosophies and theories that the researcher is tying into the research project, I believe it to extend to all of the researcher's personal philosophies and thus, subjectivities. In order to address reflexivity throughout my research process, I wrote reflective memos at all stages of the research that explored my feelings and reactions, as well as my interpretations of data and what they may be based in.

I begun the process of reflexivity with my subjectivity statement and outlining how my life experiences have informed certain parts of my research choices. My reflexivity continued throughout the recruitment, data collection, and analysis phases. I engaged with regular, written reflection memos after engaging with the research participants and/or materials. I used a notebook or my laptop, depending what was most readily available, to write out my thoughts, feelings, and reactions after every meeting at the LTC home. I engaged with free writing for these memos, allowing my reflections to flow and reflect what I had experienced and how I felt about them at the time of writing. These memos would also reflect when procedures had to be changed and why. When writing memos throughout the steps of VCR analysis, I would write in accordance to the questions asked in the Reading and Listening Guide (Table 1), beginning by writing these questions out at the top of the page. I also included sticky notes throughout my analysis notes, to make note of thoughts that may have been reactions or tangents to revisit and connect with other concepts throughout. Finally, I also wrote memo notes when faced with barriers and challenges to conducting my research, as well as when I was faced with successes and feelings of gratitude. These notes were perhaps the most emotional reflections, occurring at times that didn't necessarily follow an interaction (often actually following a lack thereof), but at times where I was really *feeling* things during the process of conducting this research project.

The memos written throughout the research process provided a space for me to add my voice to this project, making my voice explicit, and providing a forum where I could reflect on the process, the stories being shared, and the images being used to tell those stories. This helped me with my initial reading in the Voice Centred Relational approach to analysis, which guided me to read for the story that was being told as well as how I as the researcher related and reacted to the story. My memos also informed my process through the rest of the readings of the voice centered relational analysis, treating them as data, and comparing my in-the-moment reflections, reactions, and interpretations with the analysis of other data. This has helped further support the multi-layered, polyvocal analysis and representation of all data. Comparing my initial reactions to later interpretations of the data also allowed for a thorough examination of the tensions in the data – particularly in moments where I noticed that I felt torn between multiple understandings and possible interpretations.

3.5.2 Social Significance

Instead of generalizability of findings or "validity" of the research results, many arts-based researchers look instead to the transformative, evocative, and social significance of such research projects (Forinash, 2016; Watkins & Shulman, 2008). It is in this way that I believe a rigorous research project should have impact in the world beyond me. This is particularly important for projects informed by critical theories. A rigorous and successful arts-based research project looks to prompt “nonlinear and nonverbal expansion of knowledge” (Forinash, 2016, p.44) in those who engage with the results, as well as those who participate in the research process (Manning, 1997). In addition to fairness, Manning (1997) describes several expressions of rigour that focus on the participants’ experiences: ontological authenticity (did participants grow through the process?); educative authenticity (did participants’ understandings expand?); catalytic authenticity (did the process instigate action from participants?); and finally, tactical authenticity (do participants feel empowered to act on the findings?). I hope that this was the case for my participants. Several participants from both groups expressed how nice it was to speak together about shared experiences in the home, and that they normally did not have a chance to do so. There was some indication that their understandings of friendship may have expanded, especially when I asked if love fit into the picture of friendship for them. Participants also expressed enjoying the art making process. It was my sense that participants were able to share and connect in ways they normally do not, however I was limited in my ability to follow up with participants to properly reflect on ontological, educative, catalytic, or tactical authenticity with them. As previously described my hopes of a second workshop did not work out, and with the COVID-19 crisis over the past few months, the possibility of re-connecting with my participants in the home was shut down. It is possible that participants, having enjoyed reflecting and sharing during our time together, felt empowered to continue sharing with one another outside of the workshops.

As a critical arts-based project, this is exactly the goal of my research and it is the precise reason why arts-based methodologies are appropriate for addressing my research purpose and questions. Manning’s (1997) framework for authenticity in the research succinctly emphasizes the transformative expressions of rigour that guide this project. That said, I would also like to pull from Forinash's (2016) idea that the research should have broader social significance. I understand this as relating to Manning's (1997) levels of authenticity, but extending it to the audience that engages with the research project when it is complete. De Witt and Ploeg (2006) use the term resonance to describe this concept. Specifically, they describe it as "the experiential or felt effect of reading the study findings upon the reader" (de Witt & Ploeg, 2006, p. 226) and posit that this effect can be likened to an epiphany that changes the reader's understanding of the text, of themselves and of their world. Again, the transformative and evocative impact of a research project is proposed to be an important expression of rigour (de Witt & Ploeg, 2006) which I will specifically use to help gauge the rigour of my research project. While this is not possible to gauge before the project is complete and released into the world, certain measures can be taken to promote social significance. For example, using creative analytic practice and having an artistic representation of the data can lead to particularly evocative and accessible research products that can reach broad audiences and evoke emotional responses in readers/viewers (Watkins & Shulman, 2008).

3.5.3 Balanced Integration

Another expression of rigour suggested by de Witt and Ploeg (2006) is balanced integration. Balanced integration means that the entire research design process is congruent, from research topic, to theory, to specific methods, to the researcher's position and behaviours (de Witt & Ploeg, 2006). This process begins with the research proposal, outlining the appropriateness of the entire research design for the topic at hand. I believe the explicit cohesiveness of all parts of my research design have been outlined sufficiently to address this expression of rigour, especially in following Berbary and Boles' (2014) scaffolding to support my research design. Balanced integration is especially important for arts-based research, in that the mode of art making must be used for a reason and be specifically chosen for its ability to address the purpose of the research (Forinash, 2016). The arts should not be chosen just for the sake of doing art for research. The reasons for my choices in methods and methodology have already been outlined in detail in this section; namely that visual arts, especially collaborative art making, are in themselves relational, helping us think and conceptualize our ideas differently, and are accessible for individuals who may experience difficulty with verbal expression. As previously mentioned, de Witt and Ploeg (2006) also conceptualize balanced integration to mean that there is a fair balance between the researcher's interpretation and philosophical understandings, and the study participants' voices. I address this aspect of it through reflexivity and worked hard in my presentation of findings in the next Chapter to explicitly emphasize my participants' voices over my own.

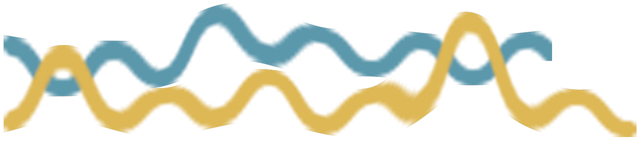
Chapter 4: Growing Understandings: Patterns in participants' insight on friendship in the home.

4.1 Introduction

In this Chapter I present the "patterns" that reflect how my participants constructed understandings of friendship, especially in the context of LTC. I chose to use the term pattern as opposed to "themes" to steer away from traditional, objectivist expectations of research findings. To me, the term pattern does so because it connotes a more fluid conceptualization of the findings that emerged in the data, leaving room for the ambiguity and contradictions present in the data. This is aligned with my social-constructivist positionality wherein there is no singular, fixed truth (Grbich, 2007). In this section I will explore two overarching umbrella patterns and the multiple patterns that integrate together to make up the overarching patterns. I also explore ideas from the patterns in relation to existing literature, including how they challenge certain ideas in existing literature and dominant discourse. Following this chapter, I will also include a discussion of the social-justice, theoretical, practical, and methodological implications of these findings and recommendations for future research in this area.

4.2 Patterns & Findings

For the most part, overlapping concepts, ideas, and words emerged in both groups. That said, these patterns did not always emerge in the same way, with each group telling similar but different stories. Through the various readings of the VCR approach, patterns that seemed to be recurring and parallel at first, became apparently more divergent. I envision them as adjacent waves that fall apart and overlap at different intersections, something more like the sketch below, if each coloured line represented the story of the pattern told by each of the two groups:



In order to represent the complexity of how the themes showed themselves to me, keeping in mind the differences, the overlaps, and the relational embeddedness of the stories and insights from both groups, I have taken a somewhat visual approach to organizing some of the themes. A visual approach to laying my findings out is in keeping with the tenets of CAP, wherein the art is used throughout all phases of the research process (Parry & Johnson, 2007). Although still dominantly text-based, using summaries as well as direct quotes from participants, different themes required different approaches to visualization, which I will explain in each of the following sections. Some themes felt more straightforward, with simpler visualizations, and others felt more complex, eliciting more extensive visualization to capture the nuances and tensions I saw in the data. Incorporating a visual approach allowed me to include the drawings of participants in unique ways, as well as their own interpretations of the drawings shared during the sessions. Additionally, using a visual approach aligns with my epistemological stance which views reality as relatively fluid, socially situated, and multiple, as outlined in Chapter One. By sharing and organizing my findings visually, I am able to integrate multiple voices (my own and different participants) and capture the back and forth, the liminal spaces, and the layers of the experiences that were shared with me by my participants. Given my background in the arts and being a visual learner myself, this has also proven to be an important means by which I could personally engage with and explore the data, and understand the patterns at a much deeper level. I hope that they give you a unique perspective on my findings and how they came together for me.

As mentioned above, two umbrella patterns came together to describe understandings and experiences of friendship for the persons living with dementia and PSWs who participated in this project. Those umbrella patterns are:

- **Multifaceted Understandings and Manifestations of Friendship in LTC homes:** this pattern describes the complexity of friendship, how it is understood by participants, and what they value most in friendship. In this pattern, I try to capture some of the complexity by reflecting a degree of comparison between the responses from the different participants.
- **Institutional/Cultural context: Navigating barriers to friendship:** this pattern highlights blatant examples of aspects of policy and the LTC culture that affect participants' freedom to engage relationally. It also reflects the more subtle and implicit ways the institutional context shapes relationality in the LTC home. Despite these circumstances, participants find ways to challenge constraints in order to relate with one another.

4.2.1 Multifaceted Understandings and Manifestations of Friendship in LTC homes

4.2.1.1 Friendship is preferential "Not everybody can be a friend"

Both PSWs and residents expressed in their arts-based workshops how friendship is preferential. However, how this pattern showed up was different in subtle but important ways. Given that this was one of the more oft-repeated patterns in participants' descriptions and discussions about what was most important to them in friendship, it fits well under the Multifaceted Understandings and Manifestations of Friendship in LTC homes umbrella pattern. This is also why I have chosen to start this section with this pattern. The graphic on the following page was created as part of my CAP process, wherein I used the visualization process to better understand the data and how I was interpreting it (Parry & Johnson, 2007). It helped me to organize my thoughts as I explored the similarities and subtle differences between the understandings from persons with dementia and from PSWs. This image is a reflection of how I processed those subtle differences, as well as a way of laying out the pattern for the reader without being confined to a more linear, purely written format. In the graphic, I chose to separate the data from either group into separate colours. I have also included 'side comments' in handwritten font. Throughout the visual, there are also collaged elements from participants' drawings from the workshop, to help illustrate the ways that the ideas emerged in the art-making part of the data collection as well. The inclusion of participants' drawings in my visual representations of each pattern was also a small way for me to include participants in the representation of the data, given that I was not able to explore representation with them directly due to the previously mentioned barriers to organizing a second workshop. I will go into a deeper explanation of the ideas that stood out to me after the graphic.

FRIENDSHIP IS PREFERENTIAL

PSWs "not everybody can be a friend" **RESIDENTS**

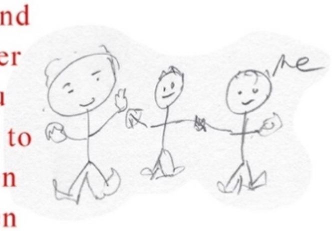
"We have to choose the right one... Not everybody is a good friend"
-Risa

"Sometimes I discover like not anybody can be a friend... You have to have a wisdom, who you choose. Yes.Very important."
-Miriam

power and choice
in who we choose
to be our friends

PARTICIPANTS FROM BOTH GROUPS ONLY IDENTIFY "ONE" "OR TWO" PEOPLE IN THE HOME WHO THEY CONSIDER A FRIEND (IE: PSWS IDENTIFY ONE OR TWO RESIDENTS, AND RESIDENTS IDENTIFY ONE OR TWO PSWS). IT IS NEVER EVERYBODY

"Well, I have a resident, every time after lunch, her daughter leaves, the only person she comes and. It's me. You know, wherever she see my face and everything after the daughter goes. That's why I said, you know, that's how I'm trying to picture it [drawing it]. When she leaves and goes and then she comes to me, you know, she stays with me."
- Joy



"This is a really good friend relationship. Friends. Yeah, we are really good friends. And also I don't know how to explain. I know. She's my resident, right? Yeah, she's my resident. She's my friend. That's it."
- Risa

"I've got one or two [PSWs], I've gotten quite friendly with."
-Anne

"One. I have one [I can talk to].... Oh really, She's very kind. She'll come to another floor. For her to make sure I have my pills.... I look forward to seeing her... and not only for the pills! ... We will stand at the window and say about the trees, we did that this morning, about how they're turning. "
- Cora

"I talked to one of them... This woman? She's one of the helpers in here. Yeah, she seems very nice. She almost gives me stuff before I even say it! "
- Heidi

‘‘You know, sometimes, just your voice, they can recognize. I have a resident who just passed away. NAME. I come in the morning that day he passed away at past eleven, so in the morning I talk to him, Good morning. Bon giorno! It's me, Gemma! He opened his eyes. Yes. .... And then he just open his eyes and then. So I told him, don't worry, it's me. ’’

- Gemma

interesting that the PSWs identify residents who have chosen them as their preferred 'friend' in the home, and these are the 'friends' they mostly identify

‘‘One or two. ...She's a wonderful lady. I love her so much. I can tell her, this lady, I can tell her anything, oh, she's very comfortable like, to me. And she can give me anything you want or whatever a word she give it to you.’’

- Miriam

While both groups identify one or two specific people, the PSWs talk a lot about the residents that like, respond to, and trust them. Residents talk about the PSWs that they particularly like, and what they like about them.

THERE WERE A FEW MOMENTS WHERE PARTICIPANTS IN EACH GROUP AGREED THAT ONE PERSON IN PARTICULAR WAS A GOOD FRIEND TO BOTH/ALL OF THEM (EVEN IF IT WASN'T CLEAR IF THEY WERE TALKING OF THE SAME PERSON OR NOT)

Heidi: This woman? She's one of the helpers in here. Yeah, she seems very nice. She almost gives me stuff before I even say it!

Miriam: [NAME]? is it [NAME]?

Heidi: I'm not sure of her name though.

Katia: She gives you stuff before you need it?

Miriam: Yeah she is [NAME]! She's a wonderful lady. I love her so much. I can tell her this lady I can tell her anything, oh, she's very comfortable like, to me. And she can give me anything you want or whatever a word she give it to you.

Miriam was so confident here that Heidi must have been talking about this particular PSW. Something about the description Heidi gave must have aligned with Miriam's experiences with this lady.

Katia: And so, Heidi, What kind of things would you say? What other things might you say about this lady that helps you?

(Here, I was trying to ensure Heidi, the quieter of these two participants, had a chance to elaborate after Miriam had taken over the conversation a bit)

Heidi: She's very friendly and good. But she doesn't go gaga like she's not over the top. No, she's very nice. She's kind of quiet in a way, and she kind of just does it, yknow?

Gemma: ...he's so, he's a good man. Yes. And but sometimes he had his own ups and down. So just show it to him how you care. By telling like this, I'm your friend. Whatever you need it. I'm here for you.

Joy: He was a hockey coach!

(Another example of PSWs mentioning residents who prefer them over other PSWs)

Gemma: ... Yes, He stay with me just go to there later. So is every time I mean, he stay with me wherever I go especially past 10:00 or what I'm bringing him all the time with me.

Katia: Nice, and how does that feel for you?

Gemma: Oh, it's very satisfying. Yeah. Yes. I love it.

Katia: Oh nice!

Comparing to family -
More on this later!

Joy: I am his "sister in law", [laughter] because we're in the same wing! Right.

Katia: Okay. all three of you?

Risa: No, no, no. I am the east wing.

Katia: Oh OK. OK. Right.

Gemma:So it's very –

Joy: So one day she's the sister, I'm the sister in law! One day she's the daughter, and I'm the – [laughter]

Gemma: And she can say something about her daughter, about his son. He's gonna tell you his stories. So we're just listening.

Katia: And he likes to share with you?

Gemma: Yes.

“I DON'T K-NOW! YOU CAN'T LOVE EVERYBODY.”

- BETTY

I chose to start the graphic off with two remarkably similar quotes from two participants from separate groups, Risa and Miriam:

> "We have to choose the right one… Not everybody is a good friend" (Risa)
>
> "Sometimes I discover like, not everybody can be a friend… You have to have a wisdom, who you choose. Yes. Very Important." (Miriam)

While both of these comments were said about friendship in general, I believe this belief was apparent in the data in a myriad of ways. Notably, the way that residents, when asked in various ways "do you have someone you consider a friend here", responded with "I have one or two" (Anne), "One. I have one." (Cora), etc. Not a single participant living with dementia responded with statements indicating a larger or more numerous amount of friends. In their stories and drawings, resident participants only identified, at most, one PSW each that they consider to be a friend. That said, when asked how many individuals she would put in her drawing if she were to draw friendship in general, Miriam responded with "Me? A lot! ... I have a lot of friends. But not everybody is my friend." The concept of not everyone being a friend was especially important to Miriam, though it was reflected in the words of other participants, especially when Betty – otherwise not contributing verbally as much as other participants were – insisted "I don't K-now. You can't love everybody." (She emphasized the K on the "know", sneaking a smile and seemingly being silly).

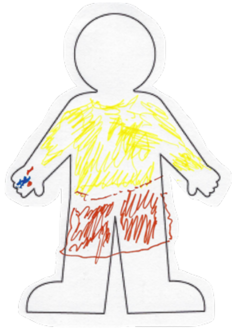


Figure 2 Cora's drawing of the woman she identifies as her friend, "pill lady".

Further, resident participants included only one individual as a “friend” in their drawings. One participant, Cora, didn’t even draw herself in the image; just her friend “pill lady”.

PSWs were more vague in their numbers, saying that they tell “them”, the residents, that they are their friends. For example: “*Sometimes if they're agitated and you say something. Always remember, we are a friend, we are telling to them. I'm one of your friends a lot in this home. It's your friend too.”* (Gemma) This comment is not strictly identifying specific people they feel are friends, rather it describes residents in general as their friends. Invoking friendship was used as a way to comfort. That said, when discussing specific stories of friendship, each PSW participant identified a maximum of three residents they considered as friends. To illustrate why this adds to a preferential picture of friendship, PSWs spoke to having at minimum 8-9 residents to take care of at a time on each unit (“*So for me, when I come I know, I have eight family members I have to look after*.” - Joy). This suggests to me that, while they do share that they use the word friendship to support and comfort residents in general, there are only specific individuals with whom they form what they’d identify as friendships.

While both sets of participants spoke of a few specific friends they have in the home, the way they spoke about these friends was slightly different. The resident group shared what made that particular person a friend to them, identifying specific qualities they associate with friendship such as: being nice, giving them whatever they need/want, having time, or being ‘comfortable’ to them. For example:

> “she **seems very nice**. **She almost gives me stuff** before I even say it!” (Heidi)

> “She's **a wonderful lady**. I love her so much. I can tell her this **lady I can tell her anything**, oh**, she's very comfortable** like, to me. And **she can give me anything you want** or whatever a word she give it to you.” (Miriam)
>
> “Yes, **and she has time. It seemed**, although I know she's working hard, **to go up and make some comments rather than; Here are your pills and take them!**” (Cora)
>
> “Yeah. **Very comfortable.** Sometimes I cry when I talk to her. She say "Miriam! No, you have to pray and give everything to the Lord and he can do for you whatever you want.".” (Miriam)
>
> “They're **very approachable**. And, I'll **ask them, you know, where things are.** What stuff is going on? All this stuff.” (Heidi)

The PSW group, on the other hand, shared stories of friendships with residents that were often about the resident preferring *them*, rather than identifying specific qualities they saw in the person or relationship that made it a friendship. These stories indicated that the PSWs valued feeling needed, being remembered, or when a resident trusts or chooses them over other staff in the home.

> “Well, I have a resident, every time after lunch, her daughter leaves, **the only person she comes and. It's me.** You know, wherever she see my

face and everything after the daughter goes. That's why I said, you know, that's how I'm trying to picture it [drawing it]. When she leaves and goes and then she comes to me, you know, she stays with me.” (Joy)

“This was for me, is for the person don't know, English and has a dementia. I don't know, me for her is somebody, you know, **she's attached to me**. She comes in the morning with me to the dining room. If they come to take her, she won't go with nobody. If hold her hand, I'm bring her. She comes with me. So it shows she knows me. Even maybe don't know my name. You then don't know, you know. You know, these are the feeling I get from her.” (Joy)

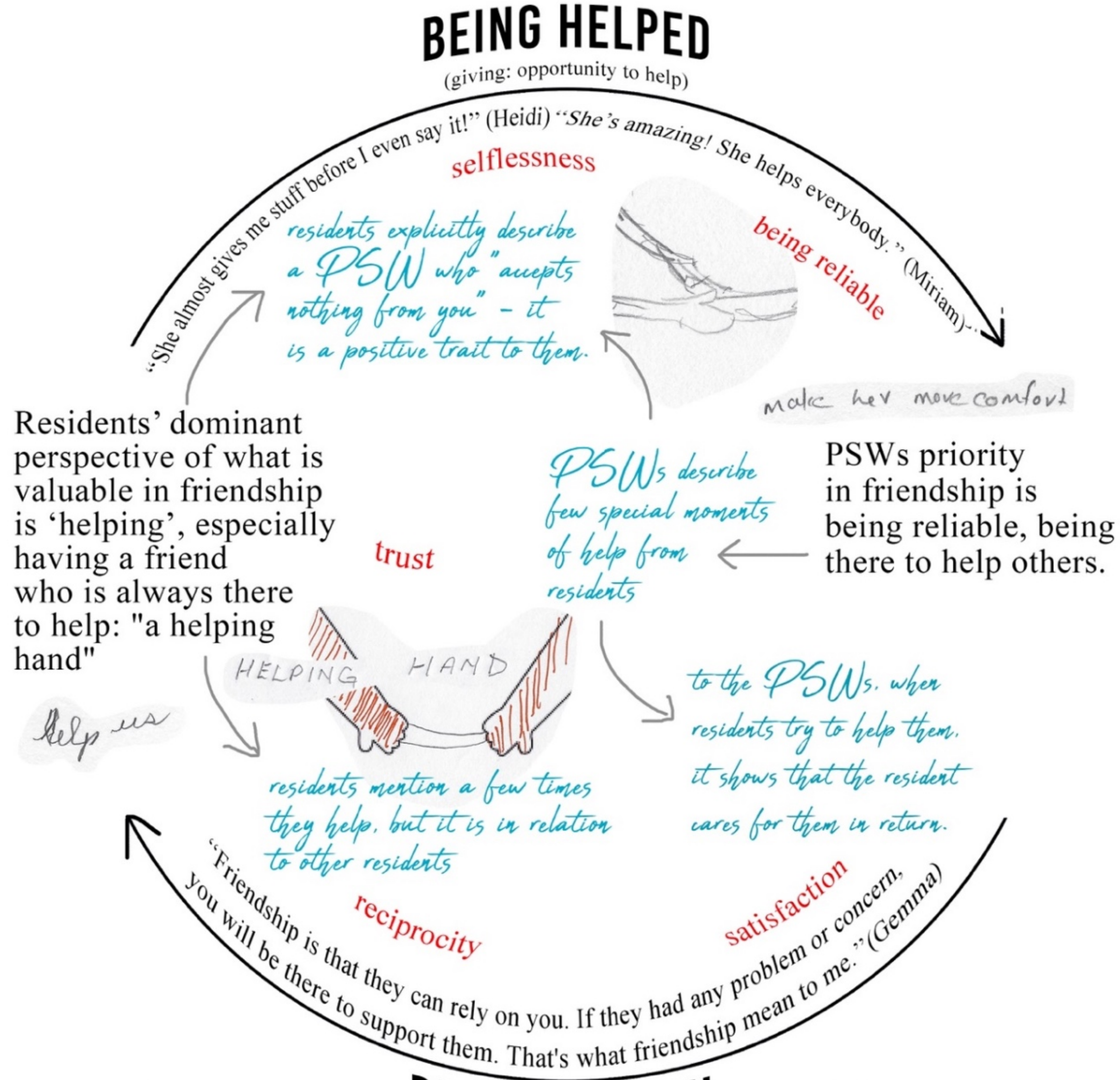
“Once in a while she making problem, But I know now that she like coffee, I make coffee for her. And also she want, **sometimes she asked me to come and sit beside me. I want to hold your hand**… even in [unintelligible: The UC? Unit Charge?] was asking me what [unintelligible: has changed with NAME?] She never complain about you, Risa…” (Risa)

“And I asked him, well could you, could, you could help me. Can you just turn a little bit? “I could do this for you.” Although he was exhausted, he didn't want nothing to... He did turn for me. Yeah. He turned over that side or this side. And I could, you know, fix him fixing, change him or whatever. And he did it. "**Only for you Always. It's only for you**".” (Joy)

The difference in how residents and PSWs shared experiences of friendship in the home are very interesting to me. I believe it speaks to a unidirectional dynamic between PSWs and residents, one that becomes more evident to me the further we go along through the patterns that became apparent in the data, and hopefully will become more apparent to you. This unidirectional dynamic suggests a passivity in the residents and a role of action and choice in the PSWs, which I believe is seen in the way residents describe what PSWs can do *for them* that indicates friendship, compared to the PSWs describing stories of how *they* interact with and approach residents as signs of friendship.

4.2.1.2 Help: Being helped and Being helpful

The various ways 'help' was taken up showed up with both groups. It was mentioned by participants while discussing both understandings of friendship, and relationships specifically in the home. I have categorized it under this first umbrella pattern, precisely because it shows many ways understandings of friendships intersects with participants' experiences in the LTC home. Given the nature of caring contexts, "help" is a particularly relevant and complex concept to explore when looking at relationships in LTC homes. I have included the visual I created to understand and represent this pattern on the following page:



BEING HELPED

(giving: opportunity to help)

"She almost gives me stuff before I even say it!" (Heidi) *"She's amazing! She helps everybody."* (Miriam)

selflessness

being reliable

residents explicitly describe a PSW who "accepts nothing from you" – it is a positive trait to them.

Residents' dominant perspective of what is valuable in friendship is 'helping', especially having a friend who is always there to help: "a helping hand"

PSWs priority in friendship is being reliable, being there to help others.

trust

PSWs describe few special moments of help from residents

to the PSWs, when residents try to help them, it shows that the resident cares for them in return.

residents mention a few times they help, but it is in relation to other residents

reciprocity

satisfaction

"Friendship is that they can rely on you. If they had any problem or concern, you will be there to support them. That's what friendship mean to me." *(Gemma)*

BEING HELPFUL

Residents describe "helpers" in the home positively; they seem to respect and appreciate their ability to help them, and others in the home.

It is important to the PSWs that their residents trust them & know that they are there for them.

Is the experience of being helped/helping any more or less impactful for the individual in the LTC home, than it would be outside of the institution?

The reason I designed the graphic for this theme as a circle, designating a cycle, is because helping requires two roles: someone who helps, and someone who receives the help, thus, giving the opportunity for someone to help. These two roles were made very clear in the data, with both groups positioning the residents firmly as those who receive help, and the PSWs as the “helpers”. These distinct roles emphasised through their stories, as well as the language they chose to use, and was especially relevant when discussing the LTC context in particular. I believe that being helped is a valuable role for both groups to play, as it allows others an opportunity to help in return. While the overarching roles were clear, there were moments of the roles reversing, showing us the value of both being helped, and being helpful.

The stories shared by both groups evidently put residents in positions of being helped.

From participants with dementia:

> “Oh really, She's very kind. She'll come to another floor. For her to make sure I have my pills.” (Cora)
>
> “And she knows if somebody can't come to eat. She took the food for her. And help her to eat. And even whatever. She's. Like who ever handicapped or whatever can stand. She knows them very well so she can go and help them.” (Miriam)

From Paid Care Partners:

> "So the best thing that we're giving it to him is just to read the paper for now. But there's some time that he's coming to me, going there while I'm doing something. That's why I'm holding his hands. And then just come stay with me." (Gemma)

> "We give them a coffee. TV's on. Did you give them a coffee cookie? But I stay with her until volunteer or someone to come and take her to group activities." (Joy)

The data also showed how participants saw the PSW's as being helpers, which was especially apparent in the PSWs stories even from outside of the LTC home context, sometimes referring to how they are also the carers at home, or even just in public. Being helpful, trustworthy, and reliable was something that was important to PSWs. For example:

> "**Friendship is that they can rely on you**. If they had any problem or concern, you will be there to support them. That's what friendship mean to me." (Gemma)

> "For me like I have a big family **I have to organize everything**, you know. …. So for me, when I come [to the LTC home] I know, I have eight family members I have to look after. And **from this time to this**

> **time, I make sure they eat, make sure they bath, make sure that everything**." (Joy)
>
> "I went to Walmart two weeks ago and there's a couple, an older couple. The guy's driving and the lady coming outside the Walmart. And he's wearing that cane like that. So it's too hard for her to get in the car. So I talked to the lady. **I'm going to help you. I know the how to do this**.... "No, the thing is, I have a knee surgery. And how many months? No, but he's still hurting." So I helped the lady go inside the car and they told me, thank you very much." (Gemma)
>
> "… we are telling to them. I'm one of your friends a lot in this home. It's your friend too. **So Always remember that we're here for you**." (Gemma)

The PSWs describe being able to help and be there for others as fulfilling, and extremely satisfying. And as Gemma said: "*When you go home, your conscience is clear.*"

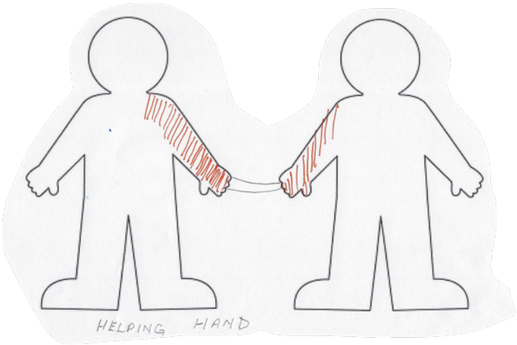


Figure 3. Drawing by Anne, "Helping Hand"

Residents on the other hand placed themselves in the position of being helped. Again, I believe this speaks to a unidirectionality in the way residents and PSWs are relating in the home. This is consistent with the current, traditional culture of care which I had outlined in my literature review. In this culture of care, it is the paid care partner – practitioners of any kind – who are in positions of action and power over the "patient" or “client” who is meant to be compliant, receive care and follow directions given to them by the “experts” (Engel, 1997; Fritsch, 2010; Hayes & Hannold, 2007).

Another layer to the data that placed residents as being helped, is reflected in their drawings. Not a single resident identified moments to draw wherein they helped a staff member or PSW at the home. They identified and drew friends who help them – but not the other way around. The only indication of reciprocal helping might have been in Anne’s drawing, where the bridge of a “Helping hand” does not indicate that the help goes in any particular direction. The idea of the “helping hand” was important to Anne, and came up many times within the group. One of my favourite moments discussing helping hands, partly because of the humour in it, was as below while discussing Anne’s drawing:

> **Katia:** The idea of the helping hand?
>
> **Betty:** Sometimes.
>
> **Katia:** It's a good idea?
>
> **Anne:** You need them sometimes!
>
> **Katia:** You need a helping hand sometimes. Yes, I agree.
>
> **Betty:** Sometimes.
>
> **Katia:** Do you ever get to lend a helping hand around here in the home? Do you get to help?
>
> **Cora:** Linda?

> **Katia:** Do you get to lend a helping land to anybody?
>
> **Cora:** Oh lend, [laughter around the table] Yes, sometimes you help.
>
> **Miriam:** Sometimes they don't know, I can help them with whatever.

I like the way this snippet shows a tentative response to being able to give help, describing it as having the opportunity “Sometimes”. Unfortunately, participants did not expand on these ideas and had trouble identifying moments where they were able to give said help. Cora did however describe one specific instance where she was able to help another resident who was new to the home:

> “When you're the new person, a resident came in and she was [unintelligible: overlapping conversation] taking her and showing her where her room was and so on. And then that she kept getting lost… So, quite a while before... And we became, when she went up to me one night, she was up and wandering, and shouted out my name. And so I went and then took her to the nurse’s station.” (Cora)

Miriam was also apparently a helper, even during the session. She offered numerous times to help me during the data collection process, offering to photocopy papers, offering me a chair, trying to help when one participant picked up an audio recorder in order to investigate it, and encouraging other participants through the process of drawing. She began to identify a moment where she tried to help a PSW in the home, but the point of her story was actually that her help was refused. Though she did not describe feeling hurt by it and instead suggests it shows selflessness from the PSW:

> **Katia:** Awesome. So is there any time that you get to do something for her?
>
> **Miriam:** No. She doesn't accept anything. Honestly she doesn't accept anything from you. Yeah. If she's the one Heidi is talking about. She's very nice lady. Just very good.
>
> **Katia:** Can you think of a time that you tried to do something for her? Even if she said no?
>
> **Miriam:** No. I sometimes I give her food like, sorry [to Heidi for interrupting her story], but if she's the one she is talking about.

Heidi suggested, subtly, that she has experienced barriers to helping in the home: "*Not go round where, and literally you do stuff for them there, they're like: *grumble noises*.*" (Heidi)

While participants with dementia had a difficult time identifying moments they were able to help PSWs, when asked, the PSWs had no difficulty identifying specific moments where residents helped them. A lot of these moments were made possible by the PSW creating an opportunity for them to help, especially with work and care related tasks. Joy in particular seemed to identify the importance of creating these moments for residents. For example:

> “I used to have one resident he passed away. Long ago when we moved him here, he was on dialysis, one leg gone, paralyzed on one side. Mr. [NAME]. Remember. Oh, my God. This guy love me so much, you know? And if he comes from dialysis and, you know, they get really exhausted on four hours on the machine and everything. So I had to change him or, you know, fix him in the bed and everything. He never wanted me to do by myself first of all, and if I can not find anybody. And I asked him, well could you, could, you could help me. Can you just turn a little bit? “I could do this for you.” Although he was exhausted, he didn't want nothing to... He did turn for me. Yeah. He turned over that side or this side. And I could, you know, fix him fixing, change him or whatever. And he did it. "Only for you Always. It's only for you".” (Joy)

> “In the morning you feed this lady. If I am pushing wheelchair, if I want her to come. I let her to push with me the wheelchair. All right. Because this is helping her to come with me and also, you know, she's helping.” (Joy)

I was particularly touched by two stories that Risa shared, about the same resident, who seemed to care a lot about her and often tried to help. The other PSWs in my group supported the stories, one of them even bringing up the story first and then letting Risa tell it:

> **Joy:** … Remember your, what happened [gesturing to Risa].
>
> **Risa:** My husband passed two years back. Yeah. You remember [NAME]? [NAME] was my resident. After few days I came, I was telling my son [unintelligible]. Yeah. I told my resident and she's cried. She cried, [NAME].
>
> **Joy:** Yeah, I remember.
>
> **Risa:** She said, she was ask everybody my phone number. She want to come and visit my house.
>
> **Katia:** Ohhh.
>
> **Joy:** Yes, she said she was so upset. She passed away now.
>
> **Risa:** … Yeah [unintelligible]. [Joy at this point reaches over to comfort Risa, as she was tearing up]

With the resident in Risa's story wanting to come to her home after the passing of her husband, possibly to support Risa in her grieving, I understand that there was an emotional caring from her. Risa also shares a story of this resident helping her in a more functional, work-related way. This story again is supported by Joy:

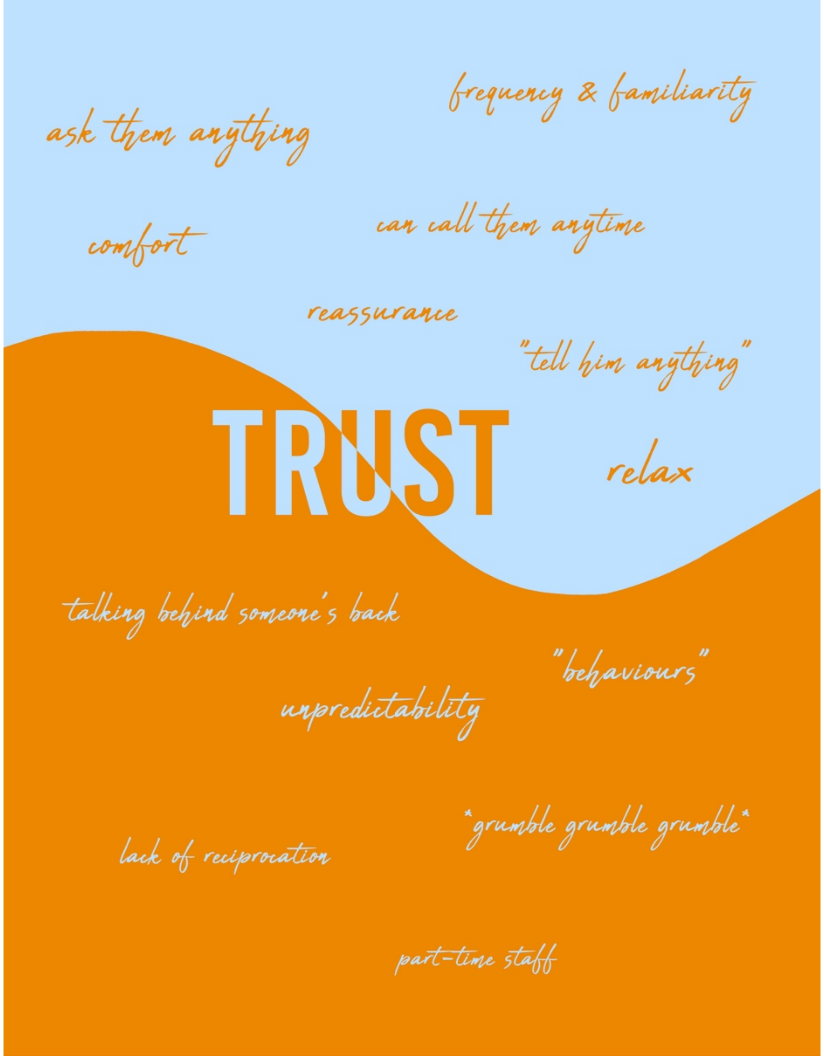
> **Risa:** Yeah, I have the same resident, the lady [NAME], that's the one you know, she's the one always showing the love. The POC we start the [unintelligible: new computer system?]. I was really struggling with the

> first few weeks. Yeah. And also I have, I finished my job, I went and sit there. But I was so thirsty. And I was, I start already and I start doing, She came and sat beside me. She has a wheelchair.
>
> **Joy:** It's scooter, scooter.
>
> **Risa:** A scooter, She came and she watched me. And I'm doing like this, and she go “Are you okay?” I said, I am OK [NAME] I'm very busy. I actually ignore it because I want to concentrate [unintelligible]. Right?
>
> **Katia:** Right.
>
> **Risa:** All of a sudden she was just doing like this. She came and gave me, You know, the juice box. Somebody put, or she asked somebody to put the straw inside. Yeah. She said drink this one and do that. She was like that. I said [NAME], [unintelligible] she went into the kitchen and she opened the fridge and she take it. She went on fast, and she give. Honey. Uh, She called me something always “Risa -something”, Drink this and do the job. You are so thirsty. I can see that, you know.”
>
> **Joy:** She was very caring.

With all this nuance in mind, which I will elaborate on in my discussion section, it is apparent from both groups that helping and being helped is highly valued by participants in friendship and in their lives. As Anne says: “*I just feel that friendship is always a helping hand. Always a helping hand*”.

Further, at the very bottom of my graphic, you'll notice a note made in red. These are some questions around the theme which I would also like to explore further in my discussion section. I ask: "Is the experience of being helped/helping any more or less impactful for the individual in the LTC home, than it would be outside of the institution?". Based on the insight participants from both groups shared with me, I wonder if the positive feelings associated with helping/being helped are experienced in much the same way, regardless of context. It was important to both residents and PSWs, and it was described in decidedly positive ways. I am curious to explore what more the stories shared by both groups tell us about the value of being helped and helping, and how it relates to their roles in the home and the particular dynamics that exist between someone who is paid to work there, and someone who has no choice but to be cared for.

4.2.1.3 Trust: Importance, barriers, and reliability



Trust manifested in similar ways to the theme of help, with residents expecting trustworthiness from others, and the paid care partners hoping to be trustworthy and reliable for others. This graphic, however, is meant to show both the positive ways that trust came up for both groups, as well as the negative ways it emerged. I chose to show this with a visual separation of blue and orange sections, with quotes and words that emerged around the theme of trust which fit into either positive (on the blue background) or negative (on the orange background) sections. I chose to use orange and blue tones to represent the two sides of this, because they represent complimentary colours that are direct opposites of one another yet, as colour theory shows us, they are often experienced in relation and contrast to one another.

Trust was a big part of the way participants saw relationships and friendships in the home and contributes to the complex picture of how friendship does (or doesn't) manifest in the LTC home. While the importance of trust was a more prominent theme for the resident group, it was also evident in the stories shared by paid care partners. For this reason, I will begin with the way it showed up for residents, followed by a brief overview of ways it came up for paid care partners.

The biggest thing of concern for residents when considering PSWs in the home who could be friends, was trust. It was one of the barriers to friendship that the residents identified, largely because trust was, second to "help", one of the most important things identified as part of their understanding of friendship. This also tied in with the idea of friendship being preferential, as participants noted that not everybody is worthy of your trust.

> "You trust him or trust her so you can tell him anything about your life." (Miriam)
>
> "That you trust somebody." (Heidi)
>
> "I love everybody, but I can't trust everybody" (Miriam)
>
> "You can't trust everybody. You can't." (Betty)
>
> "You hope that they're worthy of your trust." (Heidi)

Residents also expressed other things of importance in friendship that imply a degree of trustworthiness. These include: being able to speak freely with someone, being comfortable and relaxed with someone, and trusting that they are there should you need them. I take these to indicate trust, because in order to speak freely and to be comfortable with someone you must trust that you will not be judged and that they will listen to you. To know that someone will be there for you also implies that they have shown themselves to be dependable, and you trust that you can depend on them if you need to. The following quotes are examples of this implied trust:

> "Being Able to question them and ask them things**… Asking them anything.**" (Heidi)
>
> "And **if you are ready to speak to him from your heart** with everything happening." (Miriam)
>
> "**being able to relax** easily…" (Cora)
>
> "And **call them any time**. And **there's no barrier between you and her**." (Miriam)
>
> "It's always, I feel **there's somebody there for me** if I needed any help." (Anne)
>
> "I can tell her this **lady I can tell her anything**, oh, **she's very comfortable** like, to me." (Miriam)

On the flip side, residents identified times where they did not feel the could trust someone in the home. Some of them felt that when a PSW “grumbled” or didn’t smile back when the resident smiled at them, it meant that person wasn’t somebody they could trust:

> “Not go round where, literally you do stuff for them, they're like: *grumble noises*.” (Heidi)
>
> “I think you would find out very quickly, because they don't – They would say … they won't say hello when you say hello, that's it.” (Cora)

Multiple participants agreed that grumbling or not reciprocating was significant. This led to a discussion during which they described when they hear PSWs talk about someone amongst themselves, and how it makes them worried about what they might be saying about *them*. This was also an element of untrustworthiness they described.

> **Katia:** How does that feel when people kind of grumble?
>
> **Cora (?)**: Walk away.
>
> **Katia:** You walk away?
>
> **Miriam:** Well. I mean, you don't want to talk to them because you can't trust them, because you can't trust!
>
> **Heidi:** You wonder what the heck they're saying about you!

> **Miriam:** Exactly!

When asked why it is they thought PSWs would talk about people that way, the response was fairly resigned to the expectation that some people just are the way they are:

> "They're natural – **like they can do that by their nature**. The nature. Like they can do that, because they do that. Yeah. I hear people to talk about people in their back. I hate it." (Miriam)
>
> "Well, sometimes – **sometimes they're just miserable people**… You're going to get some of that, you are gonna get some. I mean**, it sometimes just happens, right**?" (Heidi)

I will revisit this concept of talking behind someone's back more deeply in my discussion on institutional and cultural context, as I believe it might relate to the required sharing of information amongst staff in an LTC home, but it might also suggest a certain understanding of dementia and perspective on the residents in the home. For example, talking about others, whether it be residents or otherwise, is an action that significantly shaped residents' opinion on whether or not someone could be trusted. Especially for Miriam, who repeated the concept, saying "*It's not right*", and "*I hate it*." It is often assumed that persons with dementia won't remember something or properly understand a situation (Mitchell et al., 2020). I know from my experience that I have often had people make light of my work, suggesting that I could do the same lesson plan every week without the participants realizing (it is these moments that test my patience and social graces). This is a significant misconception in the dominant discourse of dementia, and I believe these stories show us that persons with dementia observe, absorb, and interpret actions to know whether or not someone can be trusted, among other things.

The idea of trust came up more subliminally with the paid care partner group, with the word trust never actually being said. However, the PSW's positioned themselves as striving to be trustworthy to their residents in much the same way that they wanted to be helpful to them. Their desire to be trustworthy is evident in the way they describe being reassuring and being there for their residents:

> "Sometimes if they're agitated and you say something. Always remember, we are a friend, we are telling to them. I'm one of your friends a lot in this home. It's your friend too. So **Always remember that we're here for you**." (Gemma)
>
> "**We always say, we are here for you.** This is your home and we are here for you… Give me your hands, give me your whatever, you know." (Joy)
>
> "… **we tell them, you will be okay.** [Gemma reached over and touched my arm as she said this, simulating how she would to a resident]" (Gemma)

> “And he's so, he's a good man. Yes. And, but sometimes he had his own ups and down. So just show it to him how you care. **By telling like this, I'm your friend. Whatever you need it. I'm here for you**.” (Gemma)

It also came up that trustworthiness comes with time and familiarity; because they are there for residents everyday, they gradually learn to trust them, even if they experience memory loss, and that residents take notice when they’re not working:

> “Yes. Because sometimes if part timers or other people coming, and they don't know them. Right. They're not comfortable. Right. So us everyday they're looking at us. We're there for them.” (Gemma)
>
> “And then later on every day, they're going to see that it's you giving a nice friendship and love, they will remember.” (Gemma)
>
> “… like full time, as every day we are working with them, they are more comfortable and know you are here!” (Risa)

> “Because when you're not even here for a couple days or three days... They will ask, you know, they will ask you, where did you go? How are you?” (Gemma)

> “The routine I have with them, they recognize is that same person, you know, because each person has different method of working, you know.” (Joy)

The only occasion that paid care partners described a particular lack of trust in a resident, was when speaking of Miriam. This is something that I will elaborate on in my discussion chapter, as I had an emotional reaction to the way they spoke about her, considering the fact that I was also able to engage with her in my resident group, during which she told me how much she disliked people talking about her behind her back. The PSW’s described Miriam as unpredictable, having “behaviours”, and as sometimes taking advantage of their friendship:

> “We are really good friends. And also I don't know how to explain. I know. She's my resident, right? Yeah, she's my resident. She's my friend. That's it. More than that, I don't want to go more because she take more advantage from me. I know that. I always keep distance with her, not too close. I know, Because the behaviour is like we said, we can't predict, you know, the next.” (Risa)

This quote from Risa demonstrates a variety of tensions in her experience. Risa describes Miriam as her friend, but simultaneously describes not wanting to “*go more*”. She says they are really good friends but that she keeps her distance and does not get *“too close*”. Is it possible to be friends and keep your distance at the same time? If you view it as setting a boundary to protect yourself from being taken advantage of, as Risa describes, then it could fit into a picture of a friendship wherein you have to set some boundaries. I wonder, however, how much of the boundary setting that Risa feels she has to do is shaped by policy, expectations of professional boundaries, the ‘friendship as taboo’ discourse in the LTC sector, and the institutional culture. Risa also emphasises “*she’s my resident*”, a loaded statement that suggests to me that the dynamic of resident-PSW specifically impacts how close Risa is willing to get to Miriam. I will expand on this idea later.

That said, there is also a lack of trust apparent in this quote that is related to the individual themselves – it appears to be important to the PSWs that someone’s behaviour and actions are consistent and predictable, so that they may build trust with them. When residents’ behaviours are labelled unpredictable, it is much harder to build trust. As Risa says, she distances herself from Miriam because “*we can’t predict, you know, the next*.” Unpredictability can also be very frustrating and disruptive for staff working in LTC homes (Dupuis et al., 2012b).

The below example shows us what can happen in the absence of trust. Risa describes that, before forming a relationship with Miriam (and presumably knowing a bit more about what behaviour and actions she can expect from her), she would go so far as to hide from her:

> “She have some issues, behaviour problems. She was, when I start with her started, actually have a lot of problem with her, you know, behaviour. I, I don't know how to handle it. I tried to ignore her. I was really hiding from her, sometimes.” (Risa)

I believe this quote from Risa shows that without trust in the person's actions, it can lead to very explicit avoidance and an unwillingness to connect with the individual. This makes me wonder how the discourse around residents' behaviours and the unpredictability of residents' actions (Dupuis et al., 2012b) factors into overall distancing in the home between PSWs and residents in general, beyond the relationship between Risa and Miriam.

These experiences with Miriam – and presumably with other residents at times – are difficult to navigate, both as the person living it and as the researcher. Ultimately I believe they tell us a lot about the complexities of relationships and trust in the institutional context; how "she's my resident", "she's my friend", and "we are really good friends" and "I always keep a distance with her" can all exist in the same relationship. As previously described, the assertion that someone is both friend, but also a resident, suggests to me that the role of 'resident' imposes unspoken but understood boundaries between the resident and PSW that only allow a certain degree of closeness and trust – I can only go so far with my friendship –. Is there room for complete trust in one another with these boundaries and clear roles in place?

This pattern in the data has me reflecting on my own relationships with participants at work, and which participants I find I am closest to – are they in some ways individuals I trust more than others? It is a different context, as previously described, as we explicitly centre relationships and have the time it takes to build trust and connections. However, I can pinpoint specific moments where I can recall avoiding individuals based on their unpredictable behaviour. I can remember a gentleman once belittling me and calling me names as I tried to facilitate an art session, when we had chuckled and chatted over tea earlier in the day. I had just never framed these interactions in the context of trust before reflecting on the concept of trust as I have here.

The importance of trust and the questions emerging from this pattern, begin to show how trust and thus friendship both get complicated within the LTC home.

4.2.1.4 Love & Caring: Warmth, Reciprocity

everyone agreed love can be
a part of friendship

Cora describes
a PSW as
"warm towards me"

paid care partners describe
giving and receiving love & care
(but residents, don't really mention it)

"Yeah. Yeah. Nobody can cheer like, I mean like if you're close to your friend. You love him so much or love her so much." (Miriam)

In the above graphic, I have included the primary concept, love and caring, as well as two related concepts, warmth and reciprocity, into a water colour design. The blended edges with each colour seeping and mixing into one another is meant to represent how intrinsically linked these concepts seemed to be in the data, sometimes more strongly with one group than with the other. I included short, text-based explanations to go with each section, indicating who or which group it showed up most strongly for. The primary concept of Love & Caring came up with both group, which is why I chose the larger water colour form for it, putting it central in the visual, and using the most saturated and bold colour for it. For the two related concepts, I used less saturated but still warm colours and made the shapes smaller, to make clear that they are not the primary concepts. Warm colours evoke for me a plethora of positive, comforting, and for lack of a better word, *warm* feelings that are associated with love and caring.

Love was an important part of my personal conception of friendship. I included it in this umbrella pattern, as it was a specific word and concept I explored with participants while discussing understandings of friendship, and specifically friendship in the home. However, when I asked participants in both groups "*does love fit into your idea of friendship?*", the responses were mostly lukewarm…

> "In a way it does! Yes, friendship, yeah." (Heidi)
>
> "It's a kind of love." (Cora)

… with a few people – namely from the PSW group - agreeing more strongly.

> "For sure, you have to love the person. I mean eventually you will, yea." (Joy)

> "Because if you have, for example, me, I have a resident that once they pass away, you can feel. Yes. Your love, it's like gone because she's gone, too. That's how we feel." (Gemma)

Nobody objected to the idea that love could be part of an understanding of friendship, with one participant, Heidi, acknowledging that usually when we speak of love, there are "*Those who think more sexual*." However, a couple of enthusiastic comments about love came naturally when participants, in particular Miriam, spoke freely about friendships and relational experiences:

> "Yeah. Nobody can cheer like, I mean like if you're close to your friend. You love him so much or love her so much." (Miriam)
>
> "She's a wonderful lady. I love her so much. I can tell her this lady I can tell her anything, oh, she's very comfortable like, to me." (Miriam)

And of course, there is the page full of hearts that Betty drew. When I asked Betty about her drawing, she said "*Eight hearts and a flower!"*. She updated us frequently throughout the session on the amount of hearts she had drawn so far; "*Two hearts*", "*Six hearts!"*. I then asked the group "*What do we think of Betty's drawing*?", Miriam responded with "*She loves a lot. She loves everybody!"*. I really appreciated the exchange that followed:

Katia: Betty, do you, do you love everybody? Do you love everybody?

Betty: Well, I guess so! [Laughter]

Katia: That's a good position to be in.

Betty: I don't know. I don't K-now! [emphasizing K in "know" as a joke] You can't love everybody.

Katia: You can't? Why is that?

Betty: I don't know.

Figure 4 Betty's drawing, hearts and flowers.

Betty was prone to saying “I don’t know” or “I guess so”, as responses to my questions. She would also repeat or agree with what others around the room had just said. For example:

> **Katia:** You have a heart. Tell me more about, um, Betty, if you don't mind me asking about having a heart in friendship. What does that mean for you to have a heart?
>
> **Betty:** Have a heart!
>
> **Katia:** Have a heart. What does that lead to in a friendship?
>
> **Betty:** I don't know.
>
> **Heidi:** Asking them anything.
>
> **Katia:** Asking them things, yeah.

Cora: Helping them.

Betty: Helping!

When I asked Betty about how her hearts fit into her conception of friendship, she would count how many hearts she had at that time, often interrupted from sharing anything further by other residents. That is one of the reasons her elaboration, "*You can't love everybody*", felt poignant to me as it disagreed with what Miriam had just suggested as an interpretation for her drawing. The idea that you can't love everybody was an important part of the theme of friendship being preferential, but also prompted further discussion around love, trust, and other insights from all the participants which provided rich data around the other patterns as well.

PSWs spoke more than residents about giving love to people in the home in general, as well as receiving love from residents in return. Reciprocity seemed to be intrinsically linked to their conception of love and friendship, which is why I included it as a secondary colour/section in the graphic that blends into the main section of "Love & Caring". The following are quotes where Gemma and Joy speak of love:

> "… when you do your job, you love your resident. Then you put your love in them. It's satisfying." (Gemma)
>
> "Long ago when we moved him here, he was on dialysis, one leg gone, paralyzed on one side. Mr. NAME Remember. Oh, my God. This guy love me so much, you know?" (Joy)

> "That they're so happy too. They're so happy. They will love you, too. They will show they will care." (Gemma)
>
> "Yeah. That's how they can show their love to us too. Yeah. By caring to us." (Gemma)

The word love was used in relation to and sometimes interchangeably with the word "caring", especially when the PSWs spoke about how residents can show they care about them in return, as reflected in the last two quotes above.

Some of the explicit actions that suggested to PSWS that the residents cared for them included caring when they are off work, caring that they do not injure themselves, and actually wanting to take care of them. Descriptions of love and caring shared by participants also overlap with the "help" theme, in that PSWs identified moments that indicate how much they value being able to help, and how residents helping them shows they care in return:

> "If you go on vacation, you're telling them, oh, did you enjoy? So you come back. Now you're okay now? Yes. They're gonna ask a lot of questions. So that means they care about you." (Gemma)
>
> "She came and she watched me. And I'm doing like this, and she go Are you okay? I said, I am OK NAME I'm very busy. I actually ignore it because I want to concentrate [unintelligible]. Right? … All of a sudden

> she was just doing like this. She came and gave me, You know, the juice box. Somebody put, or she asked somebody to put the straw inside. Yeah. She said drink this one and do that. She was like that. I said NAME, [unintelligible] she went into the kitchen and she opened the fridge and she take it. She went on fast, and she give. Honey. uh, She called me something always Risa something, Drink this and do the job. You are so thirsty. I can see that, you know." (Risa)
>
> "I have a resident in semi private room for sure. Oh, I'm doing in the morning the other resident on the other bed and the other guy. Hear me. "Okay. Be careful with your back!" Yes. "Because if you hurt yourself, we cannot see you for how many days?" So every time I'm thinking about that and I'm telling him that it's OK. We are using the machine. So the back is not too much... Always protect your back." (Gemma)
>
> "Yea! Now she start telling me, "I miss you."… Oh it's really wonderful. Yeah." (Risa)
>
> "They will ask, you know, they will ask you, where did you go? How are you?" (Joy)

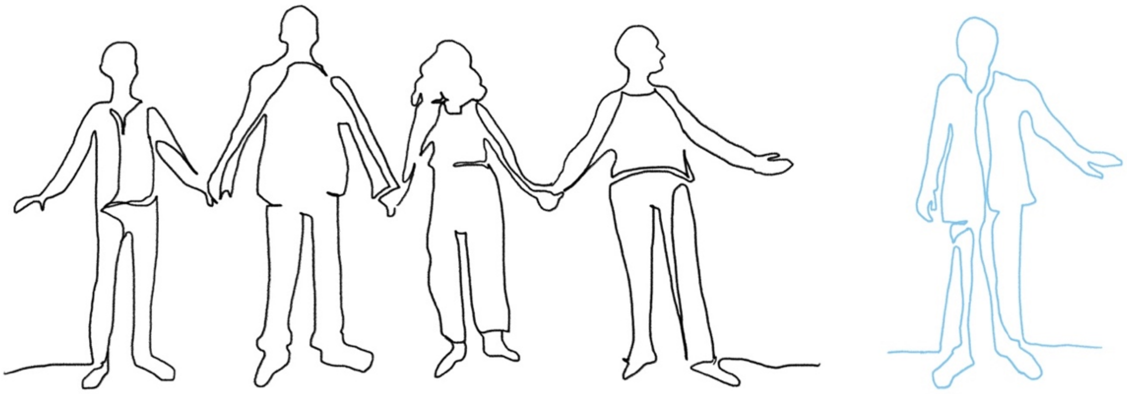
Connected to love and caring was the idea of warmth for one of the residents. It is for this reason it is represented as a different colour that leaks into the main category of love in the graphic. When asked what colour she wanted to colour her drawing of "*pill lady*", Cora responded as follows:

> **Cora:** What are, what are, um, warm colours?
>
> **Katia:** Some warm colours. Why would you choose warm colours?
>
> **Cora:** Because I think, you know, your friendship. What I was talking about, was, it was warm in comparison to... She's not cold towards me, she's always there to say, you know, my name.

Of course, while I felt validated in my methodology choice in that moment and was delighted at the way the arts-based approach helped bring this insight into words, I was also grateful to Cora for sharing this idea of warmth as I believe it is indicative of a certain authenticity in caring, caring with warmth, perhaps even caring with love. There is also nuance in her single sentence, with a few unfinished statements that could tell us many things – this PSW is warm in comparison to whom? What is it about always saying Cora's name that is important for Cora? I suspect that this reflected to Cora that to this particular PSW, Cora was more than just another resident, more than just a number or a task to be completed. Being called by her name was significant to her, perhaps signalling to her that she matters.

4.2.1.5 Being Family: comparing to, and comparing against

Language of 'family' appeared in many of the descriptions of relationships between residents and PSWs. For thie graphic below, I drew a group of people holding hands using the "single-line" drawing technique, demonstrating both through the hands and technique that they are connected and co-existing. I did not want to assume what family does or does not look like for different people, as I know that it can take many shapes and forms. I was also wary not to suggest through my graphic that every individual in the home sees themselves as part of this "family", as the data showed this not to be the case. Therefore, for this visual, I chose to demonstrate a connectedness between a group of individuals through the holding of hands, connected whether each individual understands the group to be family-like or not. I included a separate figure to represent someone who participants consider to be family but who are not present in the LTC home, hence their separation from the group. It is a symbolic figure of family whom participants either compared to, or against, when describing other people in the home. This figure is light blue, as they are not actually present in the data, and in some peoples' stories they are people who have passed away or are far away.



I noticed through the various readings of VCR, namely the third where I read for stories of "the other", that both residents and PSWs were more likely to use language around family than language around friendship when describing relationships. It is for this reason that I have included it under the umbrella theme looking at understandings of friendship in the home; while

I was asking them about friendship, participants kept returning to the concept of family. I found this significant that their understandings of friendship and family were somehow tied together. The residents shared stories of their families and compared staff against family, whereas the PSWs used family as metaphor for describing their relationships to residents. This is one of the patterns in the data where, while it emerged in both groups, it was brought up in such different ways. If we revisit my "adjacent waves" diagram from the beginning of Chapter 4, the theme of family would be two lines with very few overlaps. I chose to include both perspectives as a single theme, however, because I thought the participants' readiness to veer into conversation around family instead of friendship was significant, and it came up quite often.

When residents shared stories of their families, it was often to note that their family members were the people who they felt connected to most – many times in comparison to people in the home. When I would ask questions around identifying someone they felt friendship towards or felt close with, a few participants would bring up someone in their family. The way it came across to me was as a subtle longing for and missing of their family members:

> "No, I haven't got my family here so I've got my friends." (Anne)
>
> "I'm close to my sister. Sister in Greece. We have one here, one in Yemen, and one in Greece."[4] (Miriam)
>
> "I had an uncle …. He was a pretty cool." (Heidi)

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[4] Locations have been changed to protect the participant's anonymity

> "I just live on my own, yep, I'm a widow. Oh. It's just how it is. And I have two sons that are very supportive." (Anne)

At one point, when I prompted further about a staff member she indicated that she had tried to draw, Miriam and I had the following exchange:

> **Katia:** Can you tell me more about her?
>
> **Miriam:** She is. She helps everybody. She. And she knows if somebody can't come to eat. She took the food for her. And help her to eat. And even whatever. She's. Like whoever handicapped or whatever can stand. She knows them very well so she can go and help them.
>
> **Katia:** Right. So she gets to know everybody so that she knows what they need?
>
> **Miriam:** Yeah.
>
> **Katia:** And you were saying earlier that you feel like you can say anything to her. Tell me, how does that feel?
>
> **Miriam:** But not like my sister.
>
> **Katia:** So even, even though you can say almost everything?
>
> **Miriam:** Do you mind if you sit? [instead of me crouching at the table next to her, as my seat was at the opposite end from her].

> **Katia:** Oh ok I'll move a chair over. So even if she is someone you feel like you can say a lot, to. There are some things you can't say?
>
> **Miriam:** No, not yet. Yeah, she's Christian. I'm Christian. So I can tell her something yes, we can pray together.

Even though we were talking about someone Miriam thought highly of as a friend in the home, she stood firm in the idea that there was no one in the home quite as close to her or who she could speak to like her sister.

Heidi on the other hand has a sister nearby – in fact she works in the adjoined hospital to the LTC home. Heidi brings this up when I ask if there's anyone she can talk to when she's having a bad day: "*Well, my sister works in the other hospital, the second floor. Fifth floor, scuse me, I'm on the second floor.*[5]*"* However, when I asked her if she gets to see her frequently, she responds with "*No, not really*." and leaves it at that. I felt for Heidi as she brought up her sister as someone she can talk to but followed up with the suggestion that she doesn't get the opportunity to experience that relationship often.

The paid care partner group spoke of family in a different way. The residents in the home were referred to generally and described as extended family, or being treated as family. As previously mentioned, family seemed to be a context wherein the paid care partners saw themselves as nurturing, caring for, others. PSWs talked about this role in relation to their own

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[5] Floor numbers changed to protect the anonymity of the participant and their sister

families. An explicit example of this is when one participant turned to me before we started the session to ask if we were likely to go over time or not because she had to get home and cook for her whole family. But this caring role was also transferred to the LTC home in relation to caring for residents; caring for others happened in multiple social arenas for these women. If paid care partners view caregiving as part of their identity at home, too, then the comparison of residents to family, all of whom they care for, is an easy parallel. It is also apparent in the way they make the comparison:

> “They're part of our family. Especially they're telling your full time job. It's your second home. So home; the family is there.” (Gemma)
>
> “So they said that you're you know, you have a house, but you're... the next... Your job. It's like a second house. So it's like we treat them as our family members.” (Gemma)
>
> “We treat them as [unintelligible]... as Our next family.” (Gemma)
>
> “For me like I have a big family I have to Organize everything, you know. So when I come I have this one, this one, this one. It is not easy to look after 8 to 9 resident. … we have , you know, they don't feel good. They don't want to get up. Yeah. All these things. So for me, when I come I know, I have eight family members I have to look after. And from this time to this time, I make sure they eat, make sure they bath, make sure that everything. Yeah. So everything in my mind is when I'm driving everything, you know. Yeah. When I walk in, what I'm going to do. You

> know what I'm going to dress them. What I'm going to. Everything you have to remember. Yeah.” (Joy)

With the PSW group, there were also references to specific residents during which comparisons to family came up, specifically in the way(s) they compared themselves and residents to being siblings, in both positive and less-positive ways:

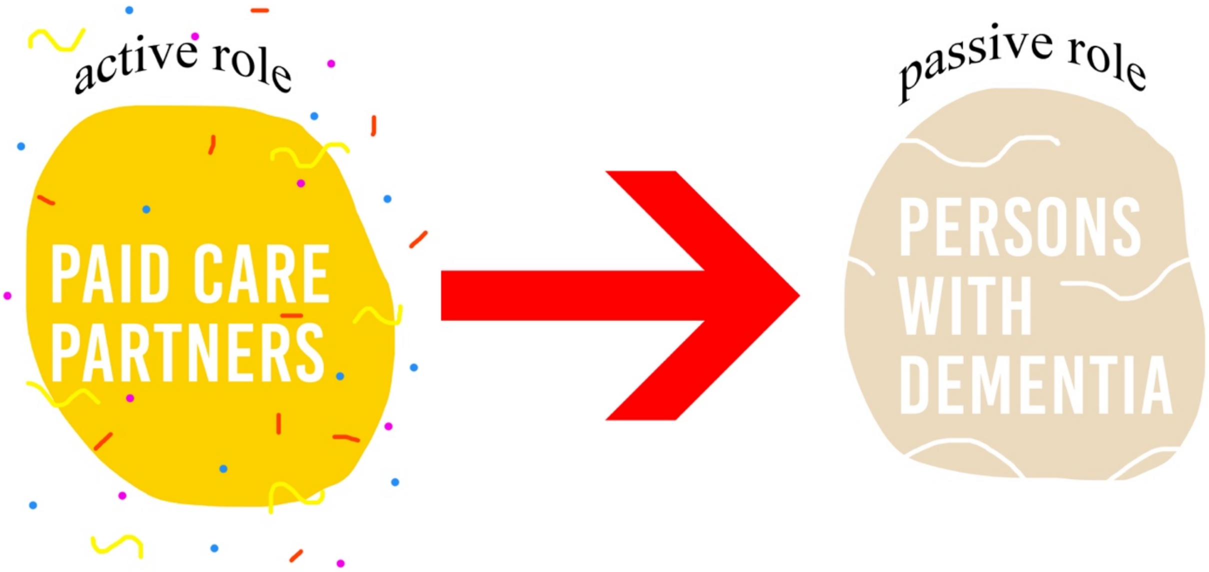
> “So she always [criticizes?] my uniforms, whenever I wear my uniform She said, “oh, this one never wear again, OK. I don't like this.”… She said, “oh this colour suits you. Next time use this colour” …. Even my hair, my lipstick or everything. Now she's like my more sister sometimes behave like that.” (Risa)
>
> “I am his "sister in law”, because we're in the same wing! Right…. So one day she's the sister, I'm the sister in law! One day she's the daughter, and I'm the... [laughter]” (Joy)

I am really intrigued by the way PSWs felt so strongly about family in the home, whereas residents never brought it up in such a way. Could this difference in perspectives relate to having choice? I am reminded of the popular phrase, “friends are the family we choose”. Residents have much less choice in being at the home, residing there, than PSWs do working there. I wonder if this choice and the power of choice is part of the reason PSWs are more likely to use language of family to describe residents. What is also interesting to me is the language the PSWs use to describe the relationship; residents are "treated" as family rather than being referred to "as family" or "like family". There is more distance in this comparison, rather than any assured assertion that residents *are* family. In my discussion chapter I will revisit this contrast and how it relates to the theme: "Second home, or department?" which is similar to the pattern of family but focuses more on perspectives of the institution itself. Ultimately, family seemed to be important to both groups and is a significant factor in how they shape their perspective of others.

4.2.2 Institutional/cultural context: Navigating barriers to friendship

While one of the main aims of this research project was to view the LTC home as fertile ground for friendship to blossom between paid care partners and persons with dementia, the data showed how challenging it is to allow it to be such. This second overarching pattern speaks to the dominant ways of relating informed by policy within the institutional culture that make it difficult for friendship to flourish. Although both residents and PSW groups view friendship as existing in the home, the stories shared have raised questions for me about who is benefiting most from this version of friendship, who and what facilitates friendship development, and how can it be made more reciprocal – if it needs to be? I explore the following themes with these thoughts in mind, and will touch on these questions further in my discussion chapter as well

4.2.2.1 Underlying unidirectional roles: Passive vs. active, gatekeepers to action.



Nearly every pattern under the "*Multifaceted Understandings and Manifestations of Friendship in LTC homes*" umbrella showed unidirectionality in the different ways the pattern played out with both groups. While my intention in interviewing both groups was not to compare and contrast, the different ways friendship and relationships were talked about by individuals within the different groups became clearer and clearer to me as I analysed, and I found myself attending to these differences more and more. The differences were more apparent as well as more nuanced with each reading I did of the VCR approach. In every case, the differences between both groups highlight a strong unidirectionality as the dominant way of relating and how the participants perceive themselves and others in the home. For this reason, I am including it as a separate pattern under this umbrella, while specifically looking at how the institutional culture might influence this unidirectionality.

One of the apparent ways unidirectionality showed up is in the way residents place themselves both in language and in stories in passive positions of receiving, being done unto, and having to “accept” things for how they are. I was not surprised by this finding, given the traditional culture of unidirectional caring in LTC that I describe in my second Chapter, but I was surprised at the ways this finding showed up in the subtleties in language and phrasing that the VCR analysis guide (Table 1) prompted me to look at. In the second and third reading of the VCR analysis, wherein the reader focuses on the ways participants talk about themselves (second reading) and talk about others (third reading) (Bright, n.d.), it became clear on a deeper level that residents are used to a passive, receiving role. When describing themselves in relation to others in the LTC home, residents almost always use language of others giving or doing unto them:

> “… she can **give me** anything you want…” (Miriam)
>
> “She almost **gives me** stuff…” (Heidi)
>
> “…or whatever a word she **give it to you**.” (Miriam)
>
> “…She's not cold **towards me**…” (Cora)
>
> “One of the ladies that **helps me**.” (Heidi)

The passive role seems so engrained in how the residents talk about themselves and their relationships that they indicate it in a variety of contexts. For example, when Anne discusses her family and how her son made the decisions for her about moving to a LTC home, she describes how she had to “come to terms with it”, and how she was glad to no longer be a burden on him:

> “He just wanted me to be somewhere where I would be safe. And he wouldn't have to worry about me.” (Anne)
>
> “Oh. It's just how it is.” (Anne)
>
> “But I've said that I think we've gotten to terms with it. So it's off your hair, I'm Well, looked after. Right. You know, get on with your life, right?” (Anne)

One moment of passivity that stood out to me was when I asked Miriam about her drawing. There was a ghost of a drawing left behind that she had worked on and erased. I asked why she had erased it and she responded that the drawing emerged and evolved in a way that was not her intention: *“No, actually, I am planning to draw a lady, but it came as a boy*!”

Figure 5 the remaining "ghost" of Miriam's erased drawing

While I personally think this is a magical expression of how art making unfolds, with the art itself “coming” as something unexpected, I thought Miriam put herself in a passive role in the way she said “*it came as a boy*”, as though the drawing did something of its own accord, beyond her control. That said, one could argue that the act of erasing it puts Miriam back into an active role in the drawing process. It is not the most poignant example of being in a passive role, but I did find this moment in the data an intriguing suggestion of passivity in the art process, which reminds me of my insistence on prioritizing the process of art making as a vehicle for story telling, rather than the final product, as discussed in my methodology section.

This passive role for residents is strongly in contrast to the group of paid care partners, who use language around the self that indicates an active role, in helping, supporting, and connecting with residents. There is an apparent pride, enthusiasm, and passion in the way the PSWs speak of their work and relationships with residents that is not apparent with the residents who instead come across as somewhat apathetic and resigned. This contrast inspired my use of a colourful, celebratory design around the paid care partner bubble in the graphic for this pattern, compared to the more muted and beige bubble for the residents. The language used by the paid care partners is full of active words around knowing and doing, of power and "allowing" in the home:

> "**Everything I could see**. Even her facials, because she can't tell you. Expression. Or, you know, **I could tell what's going on**. If She's in pain. **I could tell. If she's hungry. I could tell.** You know." (Joy)
>
> "Once in a while she making problem, **But I know now that she like coffee, I make coffee for her.**" (Risa)
>
> "This is what **we're trying to bring for them**, you know?" (Joy)
>
> "It's by **giving them the love, the care they need it from you as a PSW**. Your care and **everything you're doing everyday to them**, it's fulfilling." (Gemma)

> "**I don't want to go more** because she take more advantage from me. I know that. **I always keep distance with her**, not too close. I know, Because the behaviour is like we said, We can't predict, you know, the next." (Risa)
>
> "...**when I come I know**, I have eight family members **I have to look after**. And from this time to this time**, I make sure they eat, make sure they bath, make sure that everything.**" (Joy)

The way PSWs describe their interactions with residents in these quotes shows a level of being active and in control, especially as they describe moments of caring and compassion for residents; knowing what's going on or what a resident likes, bringing and giving to their residents, and making "sure that everything" is happening for their residents. Even in moments of distancing, as in Risa's quote, "*I always keep distance with her*", demonstrates an active role in Risa's choice to not get too close to her resident.

When discussing reciprocity with residents, there were mixed messages. While the PSWs spoke of moments where residents would show them they care and "*give it back*", they would also explicitly suggest a lack of reciprocity from residents. For example:

> "Yeah but we remember we, we're here for them. We are having, we are giving them the friends. We know we're not going to get back." (Joy)

Which was followed shortly after by this exchange:

> **Risa:** Because what you are giving them, they're give it back.
>
> **Joy:** Somehow yes.
>
> **Gemma:** They can feel. Yeah. They cannot Say something to you. But you will feel that they care about you too. Yeah.

These messages were conflicting, suggesting to me that there is indeed tension in the ways that PSWs perceive and speak about residents' capacity to give back, while simultaneously experiencing caring in return from some residents. That is to say that there appears to be tension in being engrained in a dominant discourse that does not align with their lived experiences of caring in the home.

There was also tension in the data between the two groups regarding how much residents are able to give back. As previously mentioned, the residents were not able to identify many moments where they are able to help around the home, with only a few examples mostly centred on helping fellow residents. This is likely because there are rarely opportunities for residents to contribute to the home or the lives of others in the home. However, the paid care partners were readily able to identify moments both explicit and more subtle where residents were able to help them, even identifying moments where they facilitated "helping encounters" with residents. That said, a majority of these moments were intended to make the task at hand easier for the PSW, helping them balance the needs of multiple residents. For example, when Joy shares that she supports a resident to push another's wheelchair with her:

> "If I am pushing wheelchair, if I want her to come. I let her to push with me the wheelchair. All right. Because this is helping her to come with me and also, you know, she's helping." (Joy)

And when Gemma shares about her approach with getting residents to help in their own care:

> "That's what we're telling them sometimes. You're doing, You will be a good partner to see? You're helping us." (Gemma)

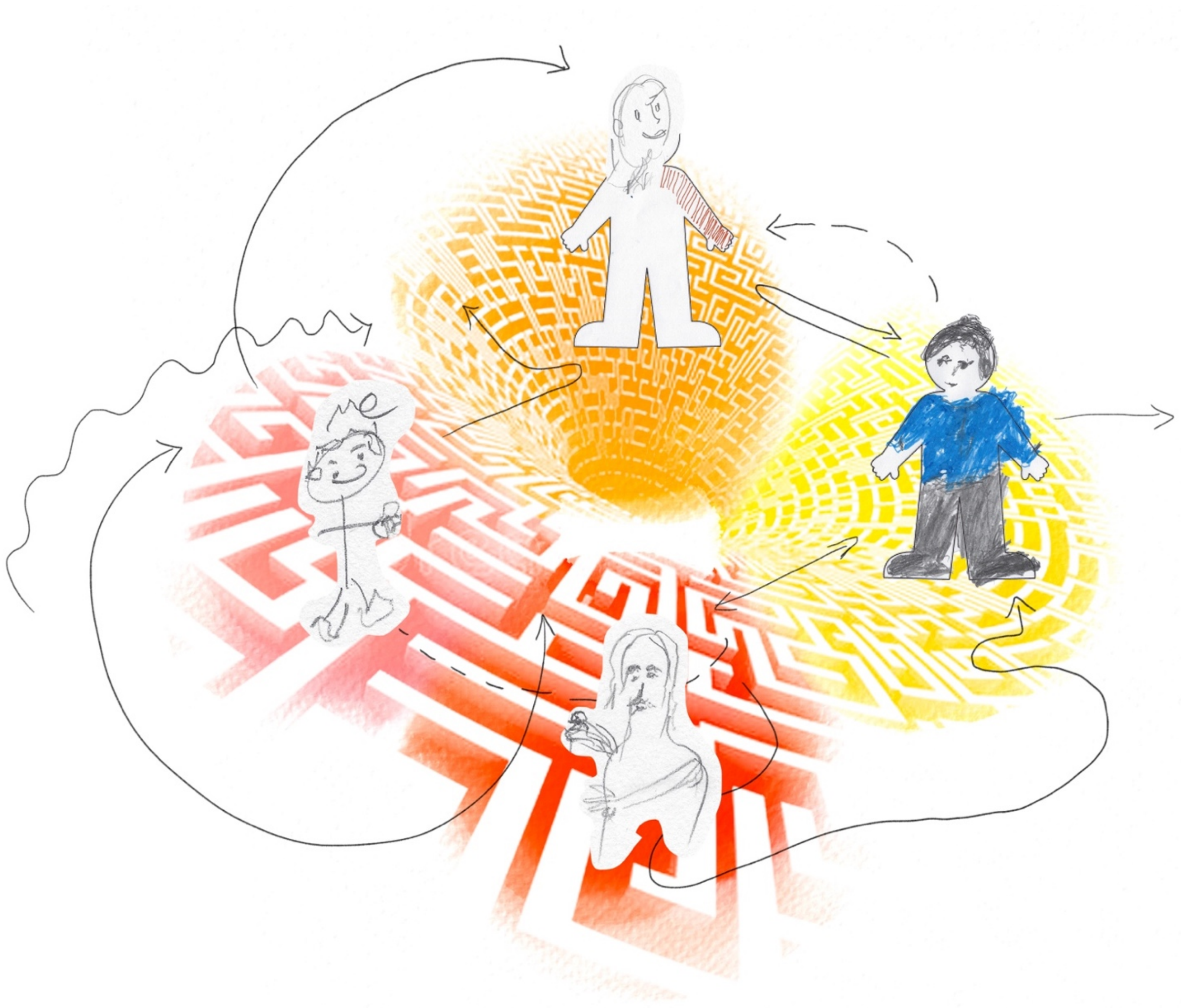
While at the surface, these are instances that help the PSW complete the care tasks required of them, I do believe that Joy and Gemma can see the value in residents helping; that it is a valuable experience for residents even though the primary intention is to complete tasks. This is not surprising given the traditional task oriented culture of LTC homes I described earlier in this thesis. Further, the PSWs are ultimately the ones "letting" the resident help, as though the PSWs are gatekeepers to "helping" and determine when they can put policies and practices aside to allow residents to help, and when they adhere to dominant practices prescribed by the institutional context.

These barriers exist primarily as policies that shape ways of relating– which I will describe in the following section – but also as personal and emotional walls that paid care partners put up. For example, each paid care partner engaged in a conversation around withholding as a way of protecting their residents. The following conversation occurred after Risa shared an experience she had with Miriam and choosing to withhold a code for the showers:

> **Joy:** Yeah but we remember we, we're here for them. We are having, we are giving them the friends. We know we're not going to get back. Yeah. Right. We have to really watch how we are. Yes. Because we can't say, oh last night I had a fight with my son. This, this, this this happened, because it's going to affect her day.
>
> **Gemma:** Yeah don't bring your problem here at work.
>
> **Katia:** No, you don't bring your personal problems in?
>
> **Joy:** We know theirs, but we don't give ours.
>
> **Katia:** Right. What do you think would happen if you did share?
>
> **Gemma:** Oh, no!
>
> **Joy:** Some of them cannot tolerate.

They then brought up the story of the resident who was deeply upset for Risa when her husband passed away but not supported to provide comfort to Risa when she needed it. To me this was a good example of how paid care partners are in positions of power over what they do and don’t share, compared to how much they know about the residents. As Joy said, “We know theirs, but we don’t give ours.”. I also believe this one snippet of data says a lot about perceptions of dementia and how it limits peoples’ engagement with persons with dementia. The idea that “some of them cannot tolerate” is a problematic assumption about the emotional capacity of their residents and persons with dementia, and I will be revisiting this idea in a subsequent section focused on perceptions of dementia. However, it is valuable to note that the intention of the paid care partners is to protect – even if that intention might be based on assumptions and an avoidance of negative feelings, rather than an opening to vulnerability from both sides that allows everyone to feel what they’re feeling at any given moment. It is also a clear indication of the detached culture of LTC wherein staff leave their emotions at the door and do not get emotionally involved with residents. Which raises the question: can one be a friend without an emotional engagement/connection?

4.2.2.2 Co-existing within policies



The above visual represents my understanding of the pattern of "co-existing within policies" and how it came up for the group of residents and the group of paid care partners. I chose to use warm colours, echoing Cora's description of her "pill lady" as warm, because this is how the participants in this study came across to me; all were warm and none came across as being uninterested in doing good for one another in the home. The colours are in watercolour and blend into one another to represent the individuals (individual colours) coexisting and interacting (blending edges). The people in this visual are drawings done during the workshop sessions. I specifically chose to collage drawings people made where they identified they were depicting themselves (hence the one figure with the word "me" over it). I over-laid this vintage map image onto the background colours to suggest a navigation of a set of policies within an institution, some that lead to dead ends and yet others that may be better suited to encourage connection and engagement. Finally, the various arrows represent the paths each individual takes as they navigate policy as they interact with one another. Some lines are direct, some take more curves and turns, some are unidirectional, and some head towards someone only to veer back as though hitting a barrier or changing one's mind. These arrows are visualizations of how I imagined my participants interacting with one another, sometimes going around policies, navigating them, and sometimes stopped entirely by policies, based on the stories they shared with me, which I will share and unpack in the rest of this section.

Among the stories shared with me, there were a few explicit examples of participants engaging with specific policies in the home, and some insight into how these polices shape relational engagement. Because these policies are informed by and in turn inform the institutional culture of a LTC home, it is under the umbrella pattern looking at how participants navigate friendship within this particular institutional culture.

First was Risa's story about calling a man "Dadda" as she found it an effective way to communicate and connect despite a language barrier. By calling the man Dadda, Risa was able to make the man feel comfortable enough to be fed. However, Risa acknowledged: "I *said Dadda, dadda, I'm not supposed to, but you know… he's really, really comfortable and open the mouth,* *and eat, and all the staff they're doing now. Dadda."* This story echoes the concerns brought up by administration and management at the home when I presented my project to them at an ethics meeting. As I described relational caring as a premise for my study, they immediately moved to confusion over how they were to implement such a model when they couldn't even call people by their first names: they are supposed to stick to "Mr" or "Mrs" so and so. When I heard that from the administrators and managers – though I assured them I would not ask them to implement relational caring, that it was just part of my research rationale – I was curious to see whether the same attitude was reflected in the data, and sure enough it came up. There were a few instances where paid care partners referred to residents as "Mr" or "Mrs", but they would default back to using peoples' first names. I cannot imagine feeling 'at home' in a context where I am constantly referred to as "Ms. Engell". Where is the comfort of home in such formality (and don't get me started on the gendered, old fashioned use of such indicators)? Whatever the case, there was clearly an understanding among staff that there was a proper way to refer to residents in the home and the PSWs found ways to navigate through that policy.

Second, was the story Risa shared about Miriam and the showers. As she described her friendship with Miriam, Risa shared that while they are close, she finds herself having to set firm boundaries with her. As previously described, this is partly due to fear about Miriam's unpredictability, but it is also because their friendship pushes Risa to challenge institutional policies, such as whether or not to allow Miriam to shower herself, by providing her with the door code to access the showers. Risa shares her struggle with this as follows:

> “Always put the boundaries. Because last time she went to the shower room, we have lock, she asked someone and she know the code. And she did. She showered herself. But I noticed that, I didn't ask her oh, Miriam, What are you doing? But she was in the middle [unintelligible]. But I had to ask them to change the code. But she didn't know I am the one to report. The next day I came, she said somebody reported me Risa, can you please tell me that code? Because you're my friend, right? And I said, I don't know the number ok, Miriam? Like…” (Risa)

In this quote, Risa does not want to tell Miriam the real reason for her withholding of the code to the showers, which is that it is an institutional policy that residents cannot shower on their own and they must both abide by this policy. Perhaps she wants to protect the friendship she feels with Miriam, perhaps she didn’t want to explain to Miriam that it would be against institutional policy, or perhaps she just doesn’t want to deal with Miriam’s reaction or persistence. There is also a suggestion of feeling guilty that, while Miriam unknowingly came to her with her request (perhaps because she trusted her), she is the one who reported her in the first place and as Risa said, Miriam “*didn’t know I am the one to report*”. Risa ended her story with a sort of shrug and a sense that she was not satisfied with lying and didn’t know what other option she had.

This tension calls to mind the concept of moral residue (Edwards et al., 2013; Hardingham, 2004) and the way individuals feel when they are faced with making choices that do not align with their own morals or values. It can be hard to withhold information from friends, especially when it is for reasons that are out of your control. I wonder if it is also difficult for PSWs to use policy as an excuse for their actions, and why it might be difficult. Could it be because these policies contradict the authentic relationships they seem to want to build with residents?

It also appears to be a challenge for Risa to navigate the expectations of friendship that Miriam seems to have, given the fact that Miriam asked Risa "*you're my friend, right?"*. Miriam seems to know that Risa is not supposed to give her the code and hopes that she will make an exception based on their friendship. This is an interesting shift in their power dynamic, because Risa might worry that Miriam will lapse into her unpredictable "behaviours" if she does not do what she wants, and Miriam puts her in a position where Risa has to take a risk either way.

Experiences of policy arose briefly in the data from the group of residents as well. Though this was not specifically around engagement with a paid care partner, it shows the emotional and relational impact policies have on residents. Cora shared a story about how she was able to help a fellow resident when she was new to the home, and that this person became a friend. Unfortunately, this friend had to go to the hospital, and Cora is now left in the dark about what is happening with her:

> "Now though, Unfortunately, she's in hospital and they don't know why… You don't know, they're not allowed to tell you." (Cora)

It is not clear to me whether Cora meant "*They don't know why*" or if she was correcting herself when she restated "*You don't know, they're not allowed to tell you*." This statement made me feel for Cora, and it reminded me of the way the paid care partners described withholding information in order to protect residents. While I would imagine this is more so to protect the privacy of Cora's friend as she is in hospital, I wonder if there is an aspect of it that is also patronizing, not disclosing upsetting information as a way of protecting them. I know from personal experience that we, at times, choose not to share with participants at work when someone they grew close to has passed away, even if their families are OK with us sharing the information. We have many conversations about it as a team, and the individuals' loved ones, and often navigate the situation as it comes up, often depending on whether or not the participant asks about their friend or not. I am not usually privy to this decision making process in all of its stages, but I have taken part in a few of them. I can imagine now from Cora's short comment that it must be emotional and difficult for persons with dementia – who certainly do remember their friends and notice when they are missing – when they are not given any information to help them understand the circumstances or any possible way to receive it. I wonder if any of the PSWs have thought to ask the family of Cora's friend for permission to share her health status with her? I wonder if anyone ever considered what it might mean for Cora and her friend if Cora was provided with the opportunity to visit her friend in hospital? I suspect these opportunities are never considered.

In a more subtle way, experiences of policy came up with regards to when residents pass away. I was surprised to hear, as Risa shared her story of the woman who got quite upset for her when her husband passed away, that she had to ask permission from this resident's family to bring flowers for her, something this resident had requested when she was still alive:

> "And She asked me too, to bring yellow flower for her when she died…
> Yellow rose. Yeah. I said to her daughter, she said it's okay Risa it's fine.
> I asked her, can I do it?" (Risa)

Even though the resident had asked her to do so, and Risa obviously felt close with this resident, I would imagine it is policy that kept her from following her own emotional instincts and bringing flowers for this woman regardless of permission. This story reminded me of my thoughts on how friendship allows a different level of grieving for residents who pass away, one that might actually help and allow the grieving process to unfold naturally for paid care partners. Similarly for Cora and her friend in the previous example, should her friend pass away, would Cora benefit more from being allowed to grieve for her, or from being kept in the dark, left wondering what happened to her friend?

Another example of what I assume is a navigation of policy is when the care partners shared with me that they sometimes dress residents in clothing they get from the lost and found. I assume this is a navigation of policy because PSWs spent time justifying their decisions or understanding others' decision, as Joy says, "*I get it from my standpoint*". To me this suggests that distributing clothing from the lost and found is not a typical occurrence nor encouraged by leadership. It seems to be a decision that the PSWs have made themselves.

> **Risa:** Yesterday [NAME] came by my side, she was doing the lost and found … I said [NAME]? What are you doing? Most of the time I'm seeing this [unintelligible]. She said "You know what, Risa, I want to find my residents … This is all my resident's clothes. They don't have nothing to wear.""
>
> **Joy:** Some of them they don't have anything! I get it from my standpoint. I give it to them.
>
> **Katia:** Just something nice to wear?
>
> **Gemma:** Because we don't want them to wear pyjama when they're in the chair. They should look presentable at you, too. Yes.
>
> **Katia:** So helping them feel this way?
>
> **Gemma:** Yes, feel good, yes.
>
> **Joy:** You know everything it change your mood.

The paid care partners explained further that they feel residents should be given the opportunity to feel and look presentable for when family members visit, or when doctors or nurses come. I sensed they wanted to preserve their residents' dignity, and I appreciated this sentiment very much. They did however share a story that suggested, in a light hearted way, how they needed to be very careful when doing this and the downside to distributing lost and found items to residents:

> **Joy:** But you know what happened? One time I put it, Mrs. [NAME]. And somebody said, that's MY coat!
>
> **All:** [laughter].
>
> **Risa:** Most of the clothes, You know, no label. Right. Maybe check, no label. You know, we can’t find them. That's the way. We don't know what the label is.
>
> **Joy:** Nobody touching it, she has nothing to wear. So I picked it up and I put it on her nicely and everything!

I am still not sure if paid care partners were breaking any policies or not with the lost and found, as they only allude to it being a negotiation of the rules as they justify their choices in the story. However, I really appreciated this subtle action that paid care partners take in the home to support the people who live there, helping them maintain their dignity and feel special.

This snippet also warmed my heart, and I had a very fun realization when I went home after the final data collection day. After my first session at the LTC home, I forgot my sweater in my contact’s office as we were all rushing to wrap up and allow the staff to go home at the end of their self-described long days. It was a sweater that felt special to me, as I had worn it backpacking to the UK, and relate it closely with that period of time. When I went back to the home, it had been so long that I suppose my contact had lost track of my sweater and it was nowhere to be found. I now imagine, with joy, my sweater being gifted to a resident in the home who might feel comforted, pampered, or otherwise special by wearing it. What better way is there to lose a sweater?

4.2.2.3 Perceptions of the space: Second Home, or "department"?

While the concept of "home" was not evidently related to the topic of this research project, home, as a place of relating, can both support or limit close relationships. The idea and language of home was prominent with the paid care partner group. It was also one of the patterns that only emerged with the paid care partner group and is in sharp contrast to the way the institution and space were described by the persons with dementia. Given that this project looks at the institution as a context for relationships, and 'home' can indicate a very particular set of relational dynamics, I thought it valuable to include as a pattern under the umbrella of "Institutional/cultural context: Navigating barriers to friendship". The potential importance of understandings of the LTC context became especially apparent in the final reading of the VCR approach, which looks at how individuals are relating to and speaking of their institutional/cultural context. This pattern also adds a layer of complexity to the comparison between the way residents and PSWs engage in the space.

I chose to visually represent this theme using a simple house shape as the visual frame for the action within. The LTC *home* is, after all, the physical, systemic, and cultural context that houses relational encounters between the paid care partners and persons with dementia who participated in this study. I also wanted to make clear in the drawing that, while in the following section I outline a significant difference in how PSWs and residents saw the space, it is not meant to portray the LTC home in a negative light, and most participants still spoke of the space in positive terms. It is for this reason too that I used bright colours within, and included a little sunshine graphic at the top.

I did choose to use cooler colours, arguably more "clinical" in tone, to denote quotes/moments depicted that refer to the space in more institutional terms, and then warmer colours for home-y quotes and moments to suggest the comfort and warmth I associate with home. I used drawings made during the two workshop sessions to illustrate the human interaction in the image. I did however make a few edits; I drew the individual in the wheelchair, as I wanted to have fair representation for the participant who shared that quote with me, but only drew the other person in her story. I also added a pointing hand and face to the character that says "*I do have a home already*", to contextualize it and make clear that she was in fact, talking about somewhere other than the LTC home. I showed this by having her point towards an image of her and her husband (who she mentioned in the sessions) in front of a house, in contrast to an image that is meant to show two people in the LTC home, one with their arm around the other. I tried to denote that at least one of the individuals in this image works at the home: a v-neck to suggest scrubs, and a lanyard with a badge on it.

The other two "décor" pieces in the home show a white board with a chart on it, to show the institutional side, and a flower to show the more home-y side. I wanted to include both so as to show the duality I saw in the data regarding whether or not participants view the space as a home. I will now explore this tension further using specific quotes and observations from the sessions.

Similarly to how the paid care partners described their residents as an extended family, they spoke of the LTC home as precisely that – a home. They describe it as a second home for themselves, and as a home for the residents:

> “But, you know, **we become part of this home**, too. Yes. I know. I have **a second home**, as you said. You know. Right. Doesn't matter. Young or old. **When I come, I know I have a home here**.” (Joy)
>
> “They're part of our family. Especially they're telling your full time job. **It's your second home**. So home; the family is there” (Gemma)
>
> “I'm one of your friends a lot **in this home.** It's your friend too. So always remember that we're here for you.” (Gemma)
>
> “We always say, we are here for you. **This is your home** and we are here for you.” (Joy)

The PSWs appear to be attentive to residents feeling at home, given that they remind residents that it is their home. They describe these reminders quite compassionately, with the promise of “*we’re always here for you*”. As previously mentioned, each of the PSWs have worked in the LTC home for over 10 years, which may add to the comfort and familiarity that comes with feeling like a place is “home”.

Comparatively, residents never once referred to the LTC home as ‘home’. When doing a document search of the words “home” and “house” on the transcript for the resident group, the only time, other than repeating my question, that the word “home” was said by someone other than myself or my volunteer note taker, were as follows:

> “**I do have a home already**, but my grand son is living in it!” (Anne)

> “No **not here, back home**. I called her. and I can talk to her.” (Miriam)

These quotes specifically reference a home that is not here, a place elsewhere that they have that they consider home.

Further, the residents use institutional words to describe their current living situation, even when describing it positively:

> “One thing I feel is the people in this **department** are very kind, they talk to you.” (Cora)
>
> “Well, my sister works in the **other hospital**, the third **floor**. Fourth **floor**, scuse me, I'm on the third **floor**.” (Heidi)
>
> “She'll come to **another floor**. For her to make sure I have my pills.” (Cora)
>
> “not like other **people here working here**. She is a **PSW.** Not like other people who are, not like nurses or whatever.” (Miriam)
>
> “I find, you know, **the staff** very good.” (Anne)

I found it interesting that despite the PSWs insistence and persistent use of the word and concept of ‘home’, and even their acknowledgement that it is the residents’ home, not a single participant with dementia described the home as a home. In fact, their language surrounding the institution didn’t even veer into “home-ly territory”, sticking quite strictly to institutional or vague language, such as “department” or simply “here”, where the people are “staff” or “helpers”. It is important to note though, that the way residents described the space was generally positive, as you can see in the quotes above, particularly Cora’s first quote, and Anne’s last in the above list. Just because they use institutional language does not mean that they do not think good things about the space and the people they share it with. This pattern parallels that of ‘family’ as I previously explored, where PSWs enthusiastically described residents as family, yet the residents never got close to it. I believe perspectives on the institutional context is both mirrored in and affected by the perspectives on relationships happening within it. It is thus inextricably linked with perceptions of friendships in the LTC home context.

4.2.2.4 Perceptions of Dementia shaping engagement

Perceptions of dementia are an important factor in how the institutional culture of LTC homes has been constructed. As written about in my literature review, the perception of dementia as ravaging the mind, leaving behind an “empty shell”, contributes largely to the dehumanizing and task-focused culture in LTC contexts (Gubrium, 1975; Kontos, 2003). It is an important perspective and discourse to look at when exploring how the institutional culture of LTC shapes how individuals experience friendship in the home. This pattern came up exclusively with the care partners, as I had decided while designing my research that I would not be engaging persons with dementia on the topic of memory loss. This decision was made primarily because the sessions were in a group format, and I did not know whether participants were aware of their memory loss, or if it might be upsetting for them to discuss. While I addressed this in my methodology section, I want to reflect on the pros and cons to having made this decision that I now see in hindsight. I will start this theme with this reflection, and share the visual I have created for it later on.

On the one hand, I feel as though I have chosen to work from a place of assumption, namely assuming that participants might get upset at the mention of dementia/memory loss and not easily work through the negative feelings. I noticed this protectionist behaviour from the PSWs group, in particular when they shared that they avoid discussing their own issues with residents to protect their feelings, and I have thus noticed it in myself. It has me considering whether or not I should have challenged this instinct in myself and explored this topic with both groups in equal measures.

On the other hand, protecting research participants from an ethical perspective is an important consideration that I do not take lightly. If this had not been a research project, I might have been more willing to engage my participants with dementia on the topic of dementia, risking an emotional reaction from them. I might also have been more willing to do so if the drawing workshops had been one-on-one and I could have approached the situation more individualistically, seeing how comfortable or not each individual might be with the topic of memory loss at the time of the study. Opening up to vulnerability in this way with residents may have provided additional insights I was not able to uncover by not going there.

Although the topic of memory loss also did not come up naturally or explicitly with persons with dementia, it was an important topic that came up in the PSW workshop without my prompting, with participants mentioning memory and memory loss in their stories, as well as in how they describe feeling reciprocity from residents:

> “You know, unfortunately, she won't remember, what the daughter said. But at least when I'm in there.” (Joy)

> “So as soon as we finish eating in the morning, he's going to exercise. But sometimes he doesn't remember. So the best thing that we're giving it to him is just to read the paper for now. But there's some time that he's coming to me, going there while I'm doing something.” (Gemma)

> “This was for me, is for the person don't know, English and has a dementia. I don't know, me for her is somebody, you know, she's attached to me… . If they come to take her, she won't go with nobody. If hold her hand, I'm bring her. She comes with me. So it shows she knows me. Even maybe don't know my name. You then don't know, you know. You know, these are the feeling I get from her.” (Joy)

In particular, the quotes from Joy show complexity in how residents with dementia are seen as both not-remembering and remembering. “*She knows me. Even maybe don’t know my name*.” The presumed not-remembering and simultaneous remembering is apparent in multiple discussions of dementia, often associated with the fact that a resident may show signs of remembering them as individuals, despite seeming not to remember other details or facts.

It struck me that the dynamic of not-remembering/remembering present in the way PSWs spoke of their residents, is perhaps, actually an acknowledgement of **different ways of remembering.** Why do we distinguish remembering someone's name and remembering someone's voice under the umbrella memory *loss*, rather than a *difference* in memory? This ties into theories around embodied selfhood as well, namely that our memories can be more physical than cerebral (Kontos, 2005), as in Joy's suggestion that a resident remembers her because of her distinct touch:

> "So for me I may hold hand for her, She might Hold her. You know. But that's how they know who is with them, right? I mean, I'm holding hand maybe someone hold like this, or maybe I hold like this, so they know they could recognize what you are." (Joy)

I am using the words "suggestion", and "belief" around the quotes shared here by PSWs. I do this intentionally because these are the PSW's interpretations of residents' expressions and responses and it is hard to know if these interpretations represent actual moments of remembering. And, perhaps it doesn't matter – as informed by Derrida (2005), it is valuable to look at experiences of the friend-who-loves, the act of friendship, giving value and honouring the individual's perspective on a friendship. That said, to use the above quote as an example, there are numerous reasons why someone might respond differently to a touch on the hand rather than a touch on the shoulder, or elsewhere. It may not have anything to do with memory or remembering them. However, it is fair that it can be interpreted as such by the PSW and as mentioned in reference to Derrida (2005), it is important that they are interpreting it as such as friends-who-love. This interpretation and meaning making is especially understandable if there is no verbal communication, as illustrated below:

> “You know, sometimes, just your voice, they can recognize. I have a resident who just passed away… I come in the morning that day he passed away at past eleven, so in the morning I talk to him. Good morning. Bon giorno! It's me, Gemma! He opened his eyes. Yes. So I explain it to him what I'm going to do to you like this in the morning. And then he just open his eyes and then. So I told him, don't worry, it's me.” (Gemma)

Of course, there is likely a reason why the PSWs are finding meaning in these moments, and constructing them as moments of being remembered by their residents. I can speak from personal experience that it is meaningful when someone remembers me – whether or not they have a diagnosis of memory loss! It is a sign, to me, that I am valued and that the individual cares enough to absorb who I was into their memory. When working with persons with dementia, it is especially valuable, and sometimes emotional, to feel remembered, and it can make a difficult job feel very worthwhile and fulfilling. It can also be very satisfying to believe that you have provided a sense of comfort at the end of life. This is an interesting consideration that I will explore more deeply in my discussion section. With the importance of this feeling in mind, I have created the following visual to represent the different ways of remembering/being remembered that were identified by participants – including some ideas from the residents as well.

I chose to use the imagery of an identification badge to represent how the PSWs feel they are identified by residents with memory loss, and the different ways that residents identified specific paid care partners when they spoke of them. I created a composite for this badge, combining ideas and insight from various participants. I used the portrait drawn by a resident of a specific paid care partner wearing her scrubs for the “photo” of the ID. (I am reminded of a note written by one of the PSWs, next to an example photo of scrubs, with the words “*this* *uniform make you more beautiful*"). The use of "*It's Me*!" rather than a specific name is intentional, as the paid care partner group noted that residents do not necessarily remember their names. This is also a direct quote from Gemma, from the story wherein she re-introduces herself to a resident she felt close with. Also, a majority of the residents did not identify PSWs in their stories by name. Instead, residents shared that the person in their story often had her hair up, or would say their name to them. One resident shared that they knew the PSW's schedule, looking forward to seeing her on the weekends. This was also relevant because PSWs noted that it is meaningful to them when residents notice they aren't working on their usual days, particularly when residents inquire about where they'd been. I included Joy and Gemma's specific ideas about giving love and friendship, as well as the idea of touch, as they explicitly referenced these as ways that residents remember them even if they seemed to not-remember other details. The rest of the graphics on these badges were made to mirror the badges I know well and see in LTC settings, with the organization logos included (for this I am using the pseudonyms I have selected for the LTC home in this study, and their parent organization), as well as the colourful stickers that I have seen PSWs wear on their badges to denote certifications or trainings, as well as just a cheerful addition to an otherwise very institutional symbol that workers are made to wear at all times in such settings. In fact, I used a photograph of my own badge as the base for this image which I then photoshopped the details onto.

A lot of the findings above came naturally and emerged through conversation on other topics during the drawing session. When asked directly how they think dementia specifically impacts friendship in the home, the paid care partners did not hesitate in explaining why dementia wasn't a barrier for them, providing more examples of different ways that they believe residents remember them, as well as more tension in the presumed not-remembering/remembering dynamic:

> “So for me, the one that don't remember what they did an hour ago, they eat and went to the washroom, all those things. The routine I have with them, they recognize is that same person, you know, because each person has different method of working, you know.” (Joy)

> “Just introduce yourself. If a friendship. If they don't remember you, just introduce yourself in a good way. And then later on every day, they're going to see that it's you giving a nice friendship and love, they will remember. Yeah.” (Gemma)

As described above, Gemma and Joy were quite certain that they can feel when a resident knows them and sees them as a friend, even if they don’t seem to know their names or remember them at any given moment.

When considering the different ways of remembering identified by the PSW group, dementia does not seem to be considered a barrier to friendship with residents in the home. That said, the way paid care partners described not wanting to share their problems with residents for fear of upsetting them, did suggest an unconscious assumption about the emotional capacity of persons with dementia. This assumption both affects and is affected by the culture of care and policies as I previously discussed. They said that they think residents cannot “tolerate” being told about their personal problems; that they become too upset. I will dive into why this is problematic in my discussion, but this does suggest a lack of vulnerability from PSWs in their interactions with residents, based on an assumption they’ve made about them. Assumptions are also somewhat evident in Risa’s avoidance of Miriam prior to developing a relationship with her, due to her unpredictability and “behaviours” which could be associated with her memory loss. I want to be clear that I am not criticizing the PSWs involved in this study – the three of them radiated kindness and caring, even towards me in the hour or so that we interacted. They care deeply about their residents and about treating them well. I am simply pointing out assumptions that showed up in the data, which I believe reflect dominant discourses and the institutional culture that PSWs engage with in their work and lives that may shape ways of relating in the LTC context.

4.2.2.5 Perceptions of Death shaping engagement

While not explicitly about aging, the concept of death came up several times with the PSWs. Death is closely associated with illness and ageism, particularly when looking at perceptions of older adults (Bytheway & Johnson, 1990; Estes & Binney, 1989). It is also an inescapable part of experiences in the LTC home context, and we are seeing experiences of loss increase exponentially as LTC workers navigate the COVID-19 pandemic. Loss and grief are thus parts of the experience in LTC homes, for PSWs as well as for residents (which was alluded to when Cora spoke of her friend who had been taken to hospital, leaving Cora with no answers or information about her wellbeing). The ways in which aging and death are understood within the institutional culture of the LTC home can provide insight into how PSWs and residents in LTC might protect themselves in their relationships, knowing that death and loss may be inevitable experiences in any given friendship. The three paid care partners in this study all expressed sadness about specific residents who had passed away, as well as the general fact that you lose people often in this line of work:

> "That's why when he passed away I cannot even go inside. It's like, my, It's hard. It's too hard for us if they pass away and you get involved or you loved him for how many years? Yeah. That feeling is very hard." (Gemma)
>
> "Yeah, Because they're not there no more, you know. Waiting for you to come. You know, whatever. They were upset at you or whatever. But you still you missed them. You know." (Joy)
>
> "She said.. "Come on". I said, [NAME], don't [unintelligible]. No." Ohh, I really miss her... not only me, not only me. Everybody" (Risa, about a resident who had passed way)
>
> "Because if you have, for example, me, I have a resident that once they pass away, you can feel. Yes. Your love, It's like gone because she's gone, too. That's how we feel." (Gemma)

When I asked if that sadness ever stopped them from trying to befriend residents, they responded fiercely that no – it is worth it to connect with residents despite the sadness experienced when they pass away:

> **Katia:** Do you find that… does it stop you from trying to be their friend?
>
> **Gemma:** No. Just continue. Yes, just continue the friendship and love and care you're giving to them. Yes. It's still worth it.
>
> **Joy:** They're family.
>
> **Gemma:** They're part of our family. Especially they're telling your full time job. It's your second home. So home; the family is there.

I was touched by the way Gemma and Joy were adamant in their objections to my questions around this topic, and the way Risa spoke so vulnerably about missing the resident who had passed away. However, as previously discussed there were several moments in the workshop wherein PSWs discussed setting boundaries and creating distance with residents, and I wonder to what extent experiences of death and loss have informed these boundaries. The grief associated with loss is painful, and speaking from my experience, to experience it regularly in a workplace setting is a heavy and sometimes difficult thing to navigate. I am fortunate that my work gives us space to grieve, to cry, and to accept invitations to go to our participants' funerals. This helps the grieving process. On the other hand, I am reminded of the story Risa shared, wherein she had to ask permission to simply bring flowers to a resident's room after she had passed away. Such barriers to even grieving the losses they feel in the home may also inform the boundaries PSWs put up between them and residents, even in cases where they identify positive, friendship relationships.

4.2.2.6 Friendship helps the job: both emotionally and functionally

While the functional aspect of this pattern is not why I am interested in friendship in LTC homes, it is something that proves valuable when advocating for culture change in a currently task-oriented, underfunded, understaffed context. It shows us the value of relationality, even as it exists in an institutional culture that does not readily support it, which is why I have included it under this umbrella pattern exploring the existing institutional culture. This pattern helps demonstrate the value of relational caring to people in administration and leadership who may still value very different things than those of us advocating for this culture change. For this reason, I was pleased when it came up in the data. Again, this part of the data only comes from the paid care partner group as they described the tasks and the challenges associated with being a PSW.

The paid care partner group shared stories that showed how having built a relationship with residents facilitates tasks in caring, as well as explicitly identifying that friendship helps with the completion of tasks:

> "And if he comes from dialysis and, you know, they get really exhausted on four hours on the machine and everything. So I had to change him or,

you know, fix him in the bed and everything. He never wanted me to do by myself first of all, and if I can not find anybody. And I asked him, well could you, could, you could help me. Can you just turn a little bit? I could do this for you. Although he was exhausted, he didn't want nothing to... He did turn for me. Yeah. He turned over that side or this side. And I could, you know, fix him fixing, change him or whatever. And he did it." (Joy)

"Because. Sometimes if they're agitated and you say something. Always remember, we are a friend, we are telling to them. I'm one of your friends a lot in this home. It's your friend too. So Always remember that we're here for you." (Gemma)

"She safe, yea, and I'm see what she's eating. If she's going to the bathroom, she's not going, what she's going through. Everything I could see. Even her facials, because she can't tell you. Expression. Or, you know, I could tell what's going on. If She's in pain. I could tell. If she's hungry. I could tell. You know." (Joy)

"Everything goes on friendship. If there is no friendship if they don't want, and they don't want … they won't let me to the room, they won't let me to their space. They don't let me to their thoughts. They don't let me to how they're feeling. You don't know, if there is no friendship, you can't get to nowhere." (Joy)

> "I just go sit beside her. She was holding my hand. And even [unintelligible: The UC? Unit Charge?] was asking me what [unintelligible: with [NAME] I see a lot of changes]? She never complain about you, Risa. I say, well now I know how to deal with her. Well before it was really a problem. Now she's [unintelligible] with somebody I say, [NAME], please stop it, right away she stops!" (Risa)

> "That's what I want her to be attached to me. So she won't get lost, won't go out of her room. She won't go to peoples', other people, or walk out of the building. I want her to follow me so I know where she is. I could monitor her." (Joy)

Similarly, they describe familiarity as an aspect that aids in friendship, which helps them in their job too:

> "Sometimes part timers or other people coming, and they don't know them, right. They're not comfortable. So us everyday they're looking at us. We're there for them. So they adjusted already to us. That's why" (Gemma)

> "Because I am the first one she sees in the morning. And even though when the daughter leaves, she tells her in her language because she has an English problem. She's going to stay with you. She's refused. Go with her. So she does what she stays." (Joy)

More in line with my personal values in regards to relational caring and culture change, was the emotional benefits of engaging in friendship that the paid care partners identified. Rather than expressing their frustrations and focusing on challenges, the paid care partners described deep satisfaction and fulfillment and joy in their work associated specifically with relating closely with their residents:

> “And for me, friendship for me, for our resident. It's by giving them the love, the care they need it from you as a PSW. **Your care and everything you're doing everyday to them, it's fulfilling. That's friendship and love**.” (Gemma)
>
> “That's satisfaction, that satisfaction. **Not only the work, we have the emotionally satisfied.** Everything, everything.” (Risa)
>
> “They said that PSW job is stressful. But **when you do your job, you love your resident. Then you put your love in them. It's satisfying. Yes. When you go home, your conscience is clear.** Yeah. Because you gave the love that they deserve.” (Gemma)
>
> “Now she start telling me, "I miss you.” … **Oh it [feels] really wonderful.** Yeah.” (Risa)

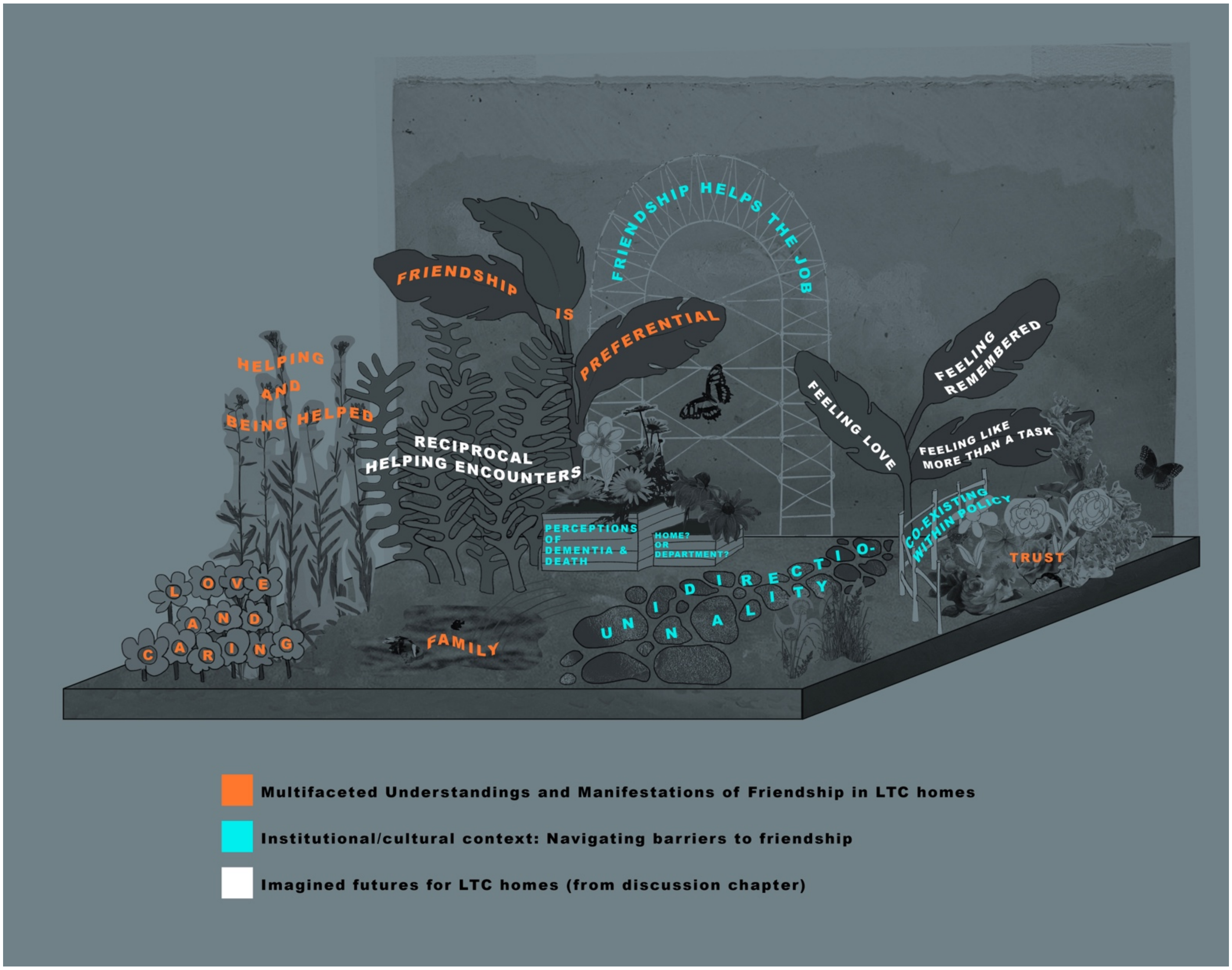
> “They can feel. Yeah. They cannot say something to you. But you will feel that they care about you too. Yeah…. And it's like that. **It's like you're fulfilled**.” (Gemma)

Again, it is important to remember that these three paid care partners have each worked in the field for over ten years. However, this fact might be a factor to their satisfaction, or the effect of their satisfaction in the job, or maybe a bit of both. Either way, I think this is important to keep in mind when looking at this finding, as well as the other themes. I do think that this satisfaction, fulfillment, and joy are evident in the way Gemma, Joy, and Risa express their dedication to the LTC home and their residents, sharing that they sometimes come in when it’s their day off, not realizing they weren’t working that day. Gemma even goes so far as to share that when she retires, she will return as a volunteer. As Gemma says in the quote above, people assume the job of a PSW is stressful. It is not a job that is often held in high esteem, and yet, when engaging in meaningful relationships with their residents, a deep satisfaction, dedication, and love for the job contradicts this assumption about the PSW job.

4.2.3 The Garden: Picturing relational growth amid supports and barriers.

In order to conclude my findings section, I created a two-part visual that is meant to represent the two umbrella patterns, as well as the individual patterns within each. The first of these visuals you have already seen, as I chose to include it at the start of this thesis to introduce the creative work in this project, as well as to set the stage for the tone and ideas within this thesis. I chose the visual metaphor of a garden because it is a living, breathing thing – everything is coexisting, shifting, interacting, and evolving. I would be missing the mark if I tried to represent my findings as anything stable. Gardens sometimes have weeds, certain plants fail to thrive, or are not well kept. At other times, gardens have tremendous growth and are lush, vibrant, welcoming places. Gardens go through seasons and cycles, and sometimes need maintenance and change. In this garden, the diverse natural elements represent the umbrella pattern: "*Multifaceted Understandings and Manifestations of Friendships in the LTC home*", and the man-made elements of the garden represent the pattern of "*Institutional/Cultural context: Navigating Barriers to Friendship*". I chose not to separate the two themes visually nor value them differently in the image, as both umbrella themes are so inherently linked and help explain the complexities of friendship in the LTC and dementia contexts. For example, a man-made pathway leads us through the garden so we can see and access the natural elements. To me this relates to the idea that, without the context of an LTC home, there would be no connection to be had between PSWs and residents in the first place. That is to say that some manmade elements support, and others limit access and growth in the garden (or rather, access to and the building of friendship between persons with dementia and PSWs). In the second visual, I included labels in various pieces of the garden to represent the individual patterns in each umbrella and tried not to place too much hierarchy or moral value in how I depicted them. Finally, the garden visual pays homage to the title of this thesis: Reconceptualizing relationships in the dementia context: Imagining the caring process as fertile ground for friendship between persons with dementia and paid care partners.

The following visual is the secondary version with the labels and a colour key to explain the different choices. I chose to have both separately to elevate the aesthetic value of the first. Ideally, I would have the second visual as an overlay printed onto plastic that can be flipped off and onto the original garden image. In future presentations of the graphic, for example at conferences, I would animate it to flip between both versions, or have physical versions with the transparency effect.



Chapter 5: Discussion: Exploring fertile yet challenging ground for friendship.

5.1 Reflection on Patterns

As I noted at numerous points in my findings chapter, there are a lot of ideas and moments in the data that I would like to discuss further, connecting it to the existing literature and to pose follow up questions that emerge for me. There were so many tensions that became clearer with each read of the data. I am fascinated by these tensions and I believe these tensions illuminate, at some level, the complexity of peoples' experiences working and living in LTC homes, including their experiences of friendships in those settings. A thorough discussion of these findings and patterns will allow me to try and do justice to the rich, layered stories and insights shared by participants in this study.

The two umbrella patterns, **Multifaceted Understandings and Manifestations of Friendship in LTC homes** and **Institutional/cultural context: Navigating barriers to friendship**, address my two first research questions. I will further explore how the data addressed these questions now in my discussion. The insights shared by the participants also provide direction related to my third research question, which looks at how we can collectively challenge and re-imagine friendship in the dementia caring process. I will discuss the ways the data suggests that we can support friendship in LTC homes and what the value of friendship in the home could be. To begin, I will reflect on some of the dominant patterns and concepts that emerged in the findings, and how they stand out in relation to the literature and the purpose of this study. I pose questions that I do not presume to have answers for which I have framed in boxes to highlight. These are questions that could be further explored in future research projects or are simply food for thought that would stray a little far from the confines of this project.

5.1.1 Unidirectionality of Friendship, and engrained power roles in the LTC context

Though I identified unidirectional roles as a pattern in itself, it is truly the thread that ties the findings together and is evident in the multiple elements of friendship identified by participants. From help, to trust, to perceptions of the space, and even to love, there are strong indications within each related pattern that show us how residents and PSWs exist and relate within a predominantly unidirectional dynamic, albeit with a few moments of flexibility and reciprocity.

The prominent unidirectional way of relating aligns with what the literature already tells us when revisiting how power dynamics play out in institutions with a biomedical culture of caring, particularly when dementia and the presumed loss of agency is involved (Fritsch, 2010; Jenkins, 2013; Kontos, 2005). I focused a lot of discussion in my literature review on power and "power-over" relationships and explored how these inform a unidirectional (or unilateral) caring dynamic (Fritsch, 2010; Welie, 1999) as well as chronic disconnection due to a lack of growth-promoting relationships (Jordan, 2017). To refresh our memories, the premise of growth-promoting relationships is that they promote 'five good things' for those experiencing them: feelings of zest, creativity, worth, clarity, and a desire for more connection (Jordan, 2017). Without them, we are not meeting our need for connection which is central to well-being.

Having collected and analyzed the data for this study, it seems to me that the literature is largely aligned with how participants experience relationships in the home. The reasons outlined in the literature for why these power dynamics exist are largely the same as what I have identified in the data as reasons for unidirectionality in the LTC home: professional boundaries and hierarchies informed by culture and policy, and emotional/personal boundaries informed by professionalism and assumptions around dementia as well as loss and death. These boundaries were evident in the way paid care partners shared that they don't disclose much about themselves at work, especially not about negative emotions or problems. It was also evident in the way residents shared that the "*helpers*" who they see as friends, are the ones who take the time to do more than just hand them their pills; those who actually speak with them in the process, those who know and call them by their names. This suggests to me that some paid care partners do not take the time to do so, and that residents also experience the detached, task oriented approach that is synonymous with the biomedical model of caring (Engel, 1977; Frank, 2002).

There were, however, a few factors of professional boundaries found in the literature that did not explicitly show up in my data, for example: fears of care-partner burn out (Eustis & Fischer, 1991), and normative definitions of friendship limiting how relationships in the LTC home are perceived. The care partners argued that relationships do the opposite of causing burn-out, instead lifting them and making their jobs satisfying, easier, and fulfilling – even if it meant feeling the loss of residents when they pass away. None of the care partners or residents in my study seemed to view friendship as a taboo, nor as something that could not exist or even exists differently in the home (though will address how this is just what was shared by participants explicitly). Participants instead suggested that friendship is an integral part of their experience in the home. I revisit Joy's quote to emphasize this:

> “Everything goes on friendship. If there is no friendship, if they don't want, and they don't want … they won't let me to the room, they won't let me to their space. They don't let me to their thoughts. They don't let me to how they're feeling. You don't know, if there is no friendship, you can't get to nowhere.”

That said, the PSWs did seem to contradict themselves at times when describing these relationships as friendships, especially when Risa flip flops in the same sentence between “*she is my friend… she is my resident*”. The duality of these friendships – being both a friend and a resident or PSW - does indeed seem to be related to power, professional boundaries, and hierarchies. As I assert in my literature review, a power-over dynamic leaves little room for reciprocity, as is typically necessary for mutually growth-promoting relationships (Jordan, 2017). However, these findings do have me reconsidering the taboo of friendship – a taboo according to whom? I might have assumed friendship was a taboo, and it might very well be, just not for those who agreed to speak to me for this particular study. During my ethics meeting with administrators and management in the home, there was a lot of vocal concern around friendship and relationship building in the home as I described the tenets of relational caring. “How do we protect our residents and ourselves?” “What if we are part of a regulated health profession with rules and policies to follow?” However, there were no PSWs or frontline workers in that meeting.

Does the taboo of friendship exist with management and administration, as well as literature and research, and not at the frontlines of the LTC home.?

In a similar way, I was surprised that PSWs were more readily and enthusiastically able to identify friendships in the home than residents were. I had assumed that being in a role with more power and more awareness of professional boundaries and policies would make PSWs *less* likely to identify their residents as friends, as they might be more consciously constrained by these barriers. Instead, they came across as passionate about the relationships they cultivate in the home, finding ways to navigate policies that could act as barriers to relationships. The residents on the other hand, were comparatively more trepid in their descriptions and in identifying friends in the home. There could be a variety of reasons for this difference, one of which is meaning making in what can be a difficult occupation. The three PSWs see their jobs as meaningful, but also make a lot of meaning in it through their interpretations. We see this as they describe meanings they assign to residents' actions. For example, the resident who opened his eyes meant that he recognized their voice, or the resident who followed her did so because she was comfortable and familiar with them. It's possible that these were valid interpretations, but it's also possible that they were not but provided ways for PSWs to make meaning out of challenging circumstances. Regardless, it is meaningful to the PSWs to construct these understandings of residents' actions so as to feel satisfied and impactful in their job. Residents on the other hand, shared far fewer interpretations of others' actions in the home.

Is it an assumption that friendship is a taboo in the home, when in reality, it plays out in the home on a daily basis?

Choice might also be a contributing factor to why PSWs identified friendship in the home more than residents did. While contemplating this, I was reminded of the pattern of 'being family' from my findings. In this pattern I outlined how PSWs treated the home and their residents as “a second family”, or “like a family”, whereas the residents often spoke of family that they were no longer able to see often, or how those in the home were not quite as close to them as family. The more I dug into that pattern the more I thought of the popular idiom: “*Friends are the family we choose*”. There is power and freedom in choice, and I wonder if this is a factor in how differently residents and PSWs spoke of others in the home. If friends are the family we choose, and the PSWs are choosing to be there, choosing to connect with certain residents, and also are choosing who they relate with outside of the home, then in theory they would therefore be empowered to view residents as family. These paid care partners were so empowered by choice and so passionate about their work, that they even shared they’d come in on their days off by accident, or plan to volunteer when they retire:

> “I'm telling you, when I, when I'm [unintelligble: old?]. I'm still coming to work part time or volunteer.” (Gemma)
>
> “Sometimes I don't remember it's my day off, I just show up.” (Joy)

Residents on the other hand don’t have much choice once they enter the institution and live within its policy and culture (Wiersma & Dupuis, 2010). This includes choice in who is caring with them that day, or that week, and so forth. They also don’t have choice in whether or not they spend their time in the home at all, whether they live there or not, evident in the way Anne repeatedly spoke of her son making decisions for her and finding her the spot there. This is more limiting, less conducive to a mutuality in friendship and who they choose to spend their time with. Residents do not have the same freedom to leave the home and cultivate friendships outside of the home as PSWs have. Outside friends must come to them, to visit – and even this is limited by time of day and by outbreaks (Wiersma & Dupuis, 2010), as we are currently seeing in the extreme due to COVID-19. This limitation in choice is interesting when we revisit the pattern of friendship being preferential – another important factor to friendship for both residents and PSWs in this study. The importance of friendship being preferential further supports the idea that there is power in choice, and therefore power in choosing your friends. It would make sense then, given the limitation of choice for residents and the power of choice for PSWs, that PSWs were more likely to identify specific friendships in the home.

It is also important to consider that these three particular paid care partners have worked at the home for over a decade, suggesting familiarity could be higher and make them feel more at home, whereas the longest that one of the resident participants had been at the home was 5 years. Again, there are many factors at play that could suggest why there is a difference here, each of which could be explored so much further. That said, given the overall themes of unidirectionality and power-over relationships in the literature and the data for this research, I have focused my discussion on those factors.

5.1.2 Facilitating "Reciprocal Helping Encounters" (and gatekeepers to helping)

Another way that the power-over and unidirectionality of caring emerged in the data is in the pattern of "being helpful and being helped". The PSWs expressed getting so much from being able to help in the home – it is what makes the job worth it to them and something they do with pride. Further, it means so much to the PSWs when residents want to help them in return, yet there are limited opportunities for this to happen. Residents struggled to identify moments where they were able to help and contribute to the lives of others in the home, especially PSWs. In my literature review, I wrote that the paid care partner's assumption of power-over and treatment of the individual does not create any space for reciprocity to occur. I would adjust that statement now to say instead that paid care partners' power-over position puts them in the role of "gatekeepers" to reciprocal helping encounters. The gatekeeper role is evident in the moments where PSWs described allowing or asking a resident to help, though most often relationality ws used to assist them in completing caring tasks. They seem to acknowledge that helping feels good for residents, which is why it makes it easier to work together to complete tasks. It is meaningful nonetheless when residents want to help, as it helps PSWs feel they are cared for and that they are doing their job in a way that residents respond positively to. This relates to one of the characteristics of friendship found in the literature. Help, support, and assistance were three terms used across friendship studies (See Appendix A) that were of significant importance in how participants in those studies understood friendship (Adams et al., 2000, Parks & Floyd, 1996). I find it interesting that this came up so strongly in this study as well, even if it is complicated by the unidirectionality of caring in the LTC context. This brings me back to the question in red from my graphic for the pattern on help: "Is the experience of being helped/helping any more or less impactful for the individual in the LTC home, than it would be outside of the institution?". I would argue that helping/being helped has the same impact, even if one person is paid to help, and one person experiences stronger barriers to helping. Both groups of people in this study expressed how meaningful it was to have someone help you. Residents shared stories of help that had to do with the PSW job, for example when Cora describes her friend the "pill lady" who goes out of her way to find her and bring her the pills she needs on time, but also of less task-related help, such as when the residents describe having people they can talk to if they need anything, even emotionally. The PSWs shared stories of residents helping them with their care tasks, but also of unrelated help, such as Risa’s story of the resident who brought her a juice box while she was busy working. To both groups of participants, helping indicated a level of friendship. The opportunity to help just looks a little different for participants, both for residents who experience barriers to it, and for PSWs as “gatekeepers” to helping. I would like to re-imagine the dynamic of helping/being-helped as an exchange wherein both parties actively help, hence the notion of “reciprocal helping encounters”.

If PSWS are indeed gatekeepers to help, is there such a thing as genuine reciprocity and room for mutuality in their relationships with residents? It must cause a lot of discomfort, and perhaps some moral distress and residue for both groups to be restricted from engaging in such helping-helping encounters. To reiterate, moral distress is the experience of not being able to act in a way that the individual perceives to be ethical or right, and moral residue is described as the lingering feelings of moral distress (Edwards et al., 2013; Hardingham, 2004). These concepts show up in the literature focused on experiences of healthcare professionals, but I have not found anything that extends it to look at the experiences of patients or residents in

How might residents be supported as relational beings? Could we leverage the “gatekeeper” position PSWs seem to be in to create more opportunities for reciprocal helping encounters, especially if gatekeepers find meaning and joy in being helped in return.

How might the blocking of relationality and reciprocity be harmful to residents? Are residents experiencing moral distress and residue from not being allowed to help in the ways they instinctively want to?

healthcare settings. I think of Heidi's comment, how sometimes she tries to do something for a PSW and they just "grumble" in response. It has me wondering in what ways residents are also experiencing barriers to acting in a way that matches their morals and values, and the moral distress and residue this may prompt for them. Paid care partners experience moral distress and residue in many other ways, but I wonder if and how it plays into their experience when they are refusing to accept help from residents.

These questions remind me of a moment many years ago, when one of my participants with dementia said to me that kindness is letting others help you. This quote comes to mind every time I write about the way helping came up in this study. How could we be kind and create opportunities for people to help more in the LTC context? I would start by suggesting a relational approach, namely one that creates space for true reciprocity and challenges traditional unidirectional cultures in LTC homes. Relational caring, which enhances and acknowledges the relational being of everyone in the caring context (Mitchell et al., 2019) would support reciprocity and thus facilitate helping-helping encounters. This furthers my understanding of the benefits that relational culture change could bring to the field of LTC, contributing to the overall wellbeing of residents and care partners, but also suggests to me an entry point into adopting a relational caring culture. Creating opportunities for residents to help and eliminating the barriers and policies that put PSWs into a gatekeeping role, is an actionable

How might the normalization of helping-helping encounters be facilitated for both residents and PSWs, eliminating the "gatekeeper" position that PSWs are in altogether?

start to making room for reciprocity and mutuality in the LTC setting. This would in turn be a step towards adopting relational caring in the LTC home.

5.1.3 Trust & its implications for friendship in LTC

Trust was one of the patterns that stood out in participants' understandings of friendship in this study. This pattern is also consistent with what my literature review revealed as an important characteristic in friendship, showing up in multiple studies and typologies of friendship (see Appendix A). As shown in the data, trust had a variety of implications specific to friendship in the long term care context.

It really struck me that Miriam was so focused on trust and was clearly so bothered by people talking about her and others behind their backs. It stood out to me so strongly because I had several staff members tell me about her, even prior to her being recruited as a participant. On my first visit, she approached us during my tour as I met and visited with potential participants. I was then told her back story in the elevator, including comments about "behaviours". Then again, when I arrived for my first day of data collection and she had been recruited as a participant, I was warned about her. And finally, during my subsequent session with the PSWs, Miriam and her "behaviours" came up in the conversation.

Miriam's trust was being broken in each of these instances, and I felt complicit. Given my background working in a critical space with persons with dementia, I could actively put aside what I'd been told and engage with her in the moment without expectation. But every time she brought up people talking about others behind their backs, my heart sunk a little. I had experienced the other side of it. I would like to believe it wasn't for nothing – I could see how headstrong she was, interrupting other participants and dominating the conversation at times, and I could easily imagine that I was getting the best side of her during my session. I am aware, however, that my assumption that this was Miriam's "best side" is entirely related to how she was presented to me by staff in the home. Nonetheless, I can't help but wonder to what extent her "behaviours" might be a reaction to the power-over social dynamics that exist already in the home, and a lack of trust both ways, between her and the staff. I will expand on how the research relationship might have facilitated trust with participants in my "methodological implications" section, as I believe it gives insight into my side of this experience. Putting my experience aside for now, Miriam's experience gives us some insight into how it felt for her to have her trust broken by the paid care partners in the home.

I suspect that some of the "talking behind your back" that Miriam experienced was in fact information sharing between coworkers, which is necessary in a regulated setting where staff have to report details of peoples' lives throughout the day to a ministry (Rockwell, 2012). Information sharing such as this troubles the notion of self-disclosure in friendships in the LTC context. I had mentioned the possible issue of self-disclosure in relation to traditional understandings of friendship in my literature review, given that self-disclosure is one of the most recurring characteristic of friendship that appears across numerous studies about friendship (Adams et al., 2000; Parks & Floyd, 1996, see Appendix A for more). If individuals are sharing information amongst themselves as staff, or even just with visiting researchers like myself, this is involuntary disclosure of self on behalf of the participant, rather than self-disclosure that arises as we build trust with one another. Trust was identified in the literature as a characteristic of friendships as well, but always separate from self-disclosure, sometimes even in a different category. For example Adams et al. (2000) categorize self-disclosure as a behavioural process, and trust as a cognitive process in their findings. There was one instance where trust was correlated to self-disclosure in a study by Argyle and Henderson (1984) wherein they list both concepts as characteristics of "intimacy". To me, the two are inextricably linked.

Additionally, PSWs specifically cited ways that they withhold information and do not disclose their personal problems to residents. This is not necessarily a personal choice, but a choice reinforced by a culture of distance and professional boundaries. This again ties into the idea of power-over relationships, and who has the choice to disclose or not to any given person in the home. This makes me believe that the literature on friendship has overlooked an important factor to self-disclosure: that it be an option for everyone involved, voluntary, and based in trust. Centering trust in caring, so that voluntary and meaningful self-disclosure can arise is a step towards reconceptualizing friendship in the LTC context in a way that would contribute to growth-promoting relationships that benefit both residents and paid care partners, and challenge the power-over dynamics in their relationships.

How might self-disclosure be re-conceptualised in the context of friendship? Should self-disclosure as a criterion of friendship in traditional understandings, be reconsidered to include that this self-disclosure be voluntary and based in trust?

How could we build trust in the LTC home so as to make space for reciprocal self-disclosure, for both residents and PSWs?

Finally, trust is an imperative part of Freire's conception of liberation. The above story, I believe, is a good example of how a lack of trust can reinforce power-over dynamics that oppress and dehumanize all people in the LTC context. As Freire asserts, oppression dehumanizes everyone involved (1970), therefore not only those who do not hold the power-over position in such a dynamic. With this in mind, it is important to note that this lack of trust is not any individual's fault – I instead view and discuss it as a structural issue, where trust is not fostered, where there is no room for trust to blossom and grow. Not only is this an issue in the day-to-day experiences of individuals in LTC, it is an issue at the culture-change level as well. To repeat a favourite Freire quote, "trusting the people is the indispensable precondition for revolutionary change" (1970, p.60). Considering this discussion of trust and how it played out in Miriam's story, as well as the stories of many others in similar situations, I would suggest that trust, and the reciprocal self-disclosure that can occur with it, be viewed as liberatory acts.

5.1.4 The Value of Friendship in LTC homes – What more can we do to support friendship?

There were several pieces of the data that indicated the value of friendship in the home, beyond the task-oriented benefits described by the PSWs. Here, I would like to focus on the emotional benefits of friendship and why it is so important to find more ways to support friendships in LTC homes. I have identified three specific positive feelings that emerged when discussing the existing friendships in the home that participants spoke about. I chose these as they went beyond simply "feeling good", or "wonderful", which felt a bit vague and less specific to the LTC context – though feeling ‘good’ is also never a bad thing! For the sake of discussing findings that have implications for practice and theory, I have identified “*feeling like more than just a task*”, “*feeling remembered*”, and “*feeling loved*” as three positive feelings that friendship does and could promote in the LTC setting.

5.1.4.1 Feeling like more than just a “task”

One of the positive feelings that came out of the data was the idea of residents feeling they are more than just a “task” to be completed. I recently wrote to a friend: “It feels like a “duh” but the culture encourages task-based attitudes and it’s no good for anyone”. To put it more eloquently, while this seems to me like an obvious feeling to strive for and to strive to impart on others, this was one of the specific indicators of friendship outlined by the resident group. This finding is no surprise when we consider the historically biomedical, objectifying culture of caring (Frank, 2002). It is important to remember that this culture is not beneficial for residents nor paid care partners, even while this is a positive feeling predominantly related to the residents’ experiences. I will outline how this positive feeling might play out for PSWs too, looking at moral distress and residue as possible outcomes of treating others like “tasks” (Edwards et al., 2013; Hardingham, 2004).

Though the work-related help from PSWs was still valuable to residents, as in Cora’s story about the paid care partner who brings her medications to her, what makes the gesture meaningful is that the paid care partner stops and shares a few words with her in the process, connecting with her. “We will stand at the window and say about the trees, we did that this morning, about how they're turning.” (Cora). Other moments of engagement that residents described as meaningful in their friendships in the home were also not related to task-based work, for example: praying together; listening when they need someone to talk to; bringing them to get coffee at Tim Hortons downstairs; to name a few.

As I mentioned, this topic harkens back to the way traditional, biomedical models of caring objectify people seeking care within it, viewing the body as separate from the mind/soul/social aspect of individuals (Frank, 2002), and how this is exaggerated in the context of dementia due to a presumed loss of self (Kontos, 2003). Encouraging more friendship in the home might create space for every interaction to be empowering, helping residents feel that they are more than just a task, that they are not objectified, and that they are fully human. This would have the potential to challenge the chronic disconnection described in RCT (Jordan et al., 2004), contributing to the overall wellness of both paid care partners and persons with dementia in the LTC home.

Encouraging friendship, ideally through embracing relational culture change, has the potential to challenge the objectification and subsequent chronic disconnection for residents and paid care partners in LTC homes.

Encouraging friendship without the above mentioned relational culture change, and asking PSWs to engage with residents relationally, is not a simple request if the LTC setting is left unchanged. As noted in my literature review, PSWs in numerous studies expressed the challenge of completing their required, time-sensitive tasks while also attending to the social and relational needs of their residents (Morin & Leblanc, 2005; Rockwell, 2012). In fact, this was one of the predominant barriers staff identified that would significantly limit their ability to adopt relational caring in their practice (Dupuis et al., 2019). Additionally, there is moral distress and residue which studies show frequently arises from not being able to engage in the way that feels right to them, often due to policy and time restrictions (Edwards et al., 2013; Hardingham, 2004). In this study the PSWs expressed that the relational side of the job, rather than the tasks, were what was most rewarding, and finding the time to engage relationally did not come up explicitly as a challenge for PSWs. When discussing the need to engage with multiple residents at once and in having them help in their own care tasks, there were moments where PSWs implied that time and competing priorities were barriers to relational engagement, even if they still described those moments in relational terms. I feel it is important to acknowledge that there was limited time to ask and explore the idea of balancing tasks and social/relational needs in depth, as it was not the primary focus of my study, and I do wonder what would come up if further studies were to be done with this group. I imagine they'd have rich insight into how they experience task-based work, but that would be a different, though perhaps adjacent study topic. This would be particularly interesting given the tensions and duality apparent in why friendship was important to the paid care partners in this study. On several occasions the PSW group spoke about the utilization of friendship with residents as a way to get tasks done, often when time-pressed and trying to balance the needs of multiple residents at once. Friendship was a way to get things done, as Joy says: "*…they won't let me to the room, they won't let me to their space. They don't let me to their thoughts. They don't let me to how they're feeling. You don't know, if there is no friendship, you can't get to nowhere.*" While this could be interpreted as a meaningful quote on an emotional level, it also shows quite clearly the way friendship in the home becomes instrumental to their jobs. Not being welcome into a resident's room would pose a significant barrier to completing care tasks. Knowing what someone is feeling and experiencing would allow care partners to then attend to those needs. These are all benefits that allow the task-oriented aspects of PSWs' jobs to be completed more smoothly, while simultaneously making the task-oriented aspects of a PSWs' job more fulfilling, leading to tensions in the data around why friendship is meaningful and important to PSWs in the home.

5.1.4.2 Feeling remembered

"Feeling remembered" was an idea that came up predominantly with the PSW group. There are ways in which I think this ties into the residents' experience too, including "feeling like more than just a task", which I will get into after I first discuss what emerged for the PSWs and in what ways feeling remembered was meaningful to them.

PSWs expressed finding a lot of meaning in being remembered by their residents, especially individuals with dementia. They experienced "remembering" predominantly through residents' actions, interpreting certain actions or expressions as signs of remembering when a resident was not able to identify or "remember" them verbally. The nuance around "remembering" was explored more deeply in my findings section, wherein I explained that these were interpretations of action rather than certainties, and that we could look at participants' stories as *different* ways of remembering rather than a *remembering/not-remembering* binary. That said, I would like to acknowledge and respect what these moments mean to the PSWs (namely, feeling remembered) and how they constructed meaning from feeling that. For this reason I am making a distinction between *being* remembered, and *feeling* remembered. Feeling remembered was important to the PSWs and indicated that they were forging special connections with residents. It was an indicator of friendship for them and of being cared for in return, especially when residents explicitly remembered them, for example by inquiring about their absence if they were away from work for a time. Further, feeling remembered was described as a direct result of their contributions to the home, of being valued and valuable to their residents and of doing a good, compassionate job.

Feeling remembered was frequently described in the context of interactions with residents whom they have familiarity with and have worked with on a regular basis. This recalls Adams et al.'s (2000) typology of friendship, wherein the proxy measures for friendship are: frequency of contact, length of acquaintance, and duration of contact. These three proxy measures are taken for granted in the context of a LTC home and it is one of the reasons I believe relationships between residents and PSWs to be so important to explore. While there is staff turn-over and shift changes to take into consideration, in this particular study the PSWs had each worked in the home for over 10 years, so staff changeover would perhaps be more relevant with a different sample group. Generally, PSWs and residents engage in frequent, intimate contact, more so than any other relationship in the home. Though these proxy measures are not definitive routes to friendship, they do create space for friendship to emerge (Adams et al., 2000). Adopting a relational caring approach could make these moments of contact and engagement less task-focused and more relational. The moments of interaction that are already taking place would therefore be more conducive to facilitating meaningful friendship in the home, friendships wherein one feels remembered and thus, valued.

How might friendship between residents and PSWs be further encouraged if the current situation is already conducive to frequent and intimate contact?

Beyond feeling valued, I believe feeling remembered can serve a bigger purpose in the big picture of culture change in LTC settings. I am reminded of Arcare's (2014) dedicated staffing model, which had paid care partners shifting around units less frequently, dedicating them to specific areas of the home and to specific residents. As described in my literature review, their study showed a plethora of positive results, both biomedical and relational, that arose from adopting a dedicated staffing model. One of the results that stood out to me was that there was increased recognition of personhood in older adults (Arcare, 2014). In this study, Cora said something that felt mysterious to me when I first did my analysis, that there is always someone there to say her name to her. It's still unclear, but I wonder how this might have been speaking to feeling remembered and acknowledged on the part of the residents. To me, feeling remembered means someone has acknowledged your personhood, something about you beyond the mere role you play in the structures you exist in. In feeling remembered, we can be liberated from objectifying discourses that dehumanize both persons with dementia and paid care partners in traditional biomedical structures. Imagine how powerful a friendship in the LTC context wherein you feel remembered could be, then!

In feeling remembered, it is as though the human in you acknowledges the human in me, and vice versa, disrupting dehumanizing and objectifying discourses in biomedical, caring contexts. How might we further nurture feeling remembered in the LTC context?

5.1.4.3 Feeling Loved

Going into this project, I was very drawn to the idea of love in friendship, informed by both Freire and his assertion that authentic liberation comes from a place of solidarity and love (1970), and by Derrida who describes friendship as an act of love (2005). Derrida’s conception of friendship and love was unique, as he placed more importance on the friend-who-loves, wherein love is an act, rather than the “passivity” of being-loved. I believe there is equal importance for both loved and being-loved, but looked to this idea when considering my research participants as friends-who-love, who have expert insight on their experiences of friendship. In contrast to Derrida, being – or rather, feeling loved, was one of the positive feelings that emerged from stories and reflections on friendship in the data.

Love was certainly present in the conversations with participants, though perhaps not in the ways I expected it to be. As previously discussed, the paid care partners described love very enthusiastically and used the word frequently to describe their approach to and experiences of caring with their residents. Residents on the other hand, used the word far less, though agreed that it was a part of friendship in general. Miriam was the only resident to verbally embrace the idea of love as she described her friendships in the home, and Betty brought up love through her full page of drawn hearts and assertion, “*you can’t love everybody*”.

When it was described, love in friendship was spoken about with so much feeling – I can hear participants’ voices still when I re-read their quotes about love. I could feel how much they meant it when they said that love makes them feel good, feel satisfied, feel cared for in return. Analysis showed how much love contributed to a positive experience for these participants in the home, particularly for PSWs. Gemma in particular described reciprocal love, and the happiness that comes along with it for herself and residents: “*That they're so happy too. They're so happy. They will love you, too. They will show they will care.*”

Expanding this potential for reciprocity in love and caring, through friendship, would also begin challenging the stigmas associated with dementia. Namely, it would challenge assumptions around persons with dementia’s capacity to show love. As I have explored previously in my thesis, reciprocity and mutual caring have the potential to radically shift societal perceptions of persons with dementia. Research has shown that when persons with dementia are supported as relational beings, space is created for their relational capacity (Kontos, 2017). When our focus begins to shift from disease and diagnosis to capacity to care, capacity to love, capacity to help, capacity to give back, we in turn acknowledge peoples’ capacities in genral. The dominant discourse would no longer be fixated on the ‘fragmented’ individual, nor how ‘ravaged’ they are by disease (Kontos, 2005; Kontos et al., 2018; Mitchell et al., 2013). Through reciprocity in the LTC home it becomes possible to reimagine dementia caring contexts, bringing together persons with dementia and care partners into mutually growth-promoting relationships within caring arrangements.

It is important to reiterate that the benefits of such care arrangements are for everyone. When considering challenges in the current culture of caring, challenges which have been exacerbated by the pandemic such as fear of burn out for paid care partners (Eustis & Fischer, 1991), challenges faced in their work (i.e., task-based demands, under appreciation, moral distress, etc.) (Edwards et al., 2013; Fritsch, 2010; Nolen et al., 2004) as well as the issue of staff turnover in the field, anything that improves the work experience for PSWs and makes it meaningful for them should not be overlooked. Both giving and receiving, generally feeling love in the home, was repeatedly noted as a positive that PSWs felt in their work. Love was felt in moments of reciprocal caring, and in moments of opportunity wherein paid care partners were able to give to and care for residents to their fullest ability, unencumbered by policy and other barriers.

Further, feeling loved through friendship has the potential to help staff when experiencing loss and grief. As previously mentioned, loss and grief are inescapable parts of working in LTC, especially now in the time of COVID-19. I wonder how naming friendships for what they are and naming the feeling of being loved in these friendships, might support PSWs in navigating their grief, rather than assuming a professional emotional distance from residents. Concrete strategies in LTC homes to assist PSWs in acknowledging the loss of loving friendships, and to support them through the grieving process, are needed so as to support the emotional wellbeing of staff, and would also support residents who are also witnessing and experiencing death and loss in the home.

5.1.4.4 More of each of these positive feelings for PSWs and residents

With all that said, I would like to offer some tangible, actionable considerations that could help instill these positive feelings for PSWs and residents through supporting friendship, as informed by the findings of this research project. I have also drawn on work already being done in relational caring to offer insight into what needs to be in place organizationally and structurally to support relational caring (Dupuis et al., 2019; Mitchell et al., 2019). In the spirit of social-justice oriented praxis which is integral to critical theories (Crotty, 1998; Freire, 1970; Rexhepi & Torres, 2010), I believe it is important to take the theory and ideas I have presented in this project and find ways to put them into action. I propose these ideas for action, knowing that culture change is difficult, complex, and often met with many road blocks. That said, we must start somewhere, and I share these more as prompts, possibilities, and starting points rather than prescriptive, final answers.

Create the space for reciprocal helping encounters to occur daily

(Ask residents to help with doing dishes. Ask residents to distribute bingo sheets or other recreation materials. Encourage PSWs and residents to share, if they want, when they are sad or other negative emotions, and help one another emotionally.)

Honour each others' feelings. Residents and PSWs in the home described a plethora of emotions that they experience in the home; joy, love, grief, uncertainty, discomfort, disconnection, etc. Dismissing any emotions as simply part of the job, or part of the disease does not leave room for reciprocal caring, vulnerability, or friendship.

Supporting PSWs in treating all interactions as relational opportunities.

(Use nicknames, make room for more personal interactions; ask each other personal questions that go beyond the task at hand; provide opportunities to take the extra time for relational engagement)

Limit necessary information sharing in-front of residents. Avoid breaking their trust, even if certain policies require information sharing. Ensure sharing information is done out of ear shot of any residents.

Celebrate each others' feelings. Celebrate feeling remembered, feeling loved, and feeling like more than just a task. These are meaningful feelings.

Name friendships as such. Acknowledge that friendship exists in LTC homes and are special and meaningful, and that they are more than just a "good" relationship between paid care partner and residents.

Relational modelling from leadership. Participants in a pilot study implementing a Relational Caring Learning Series (Dupuis et al., 2019) expressed that leadership in the home must model and actively create space for relational engagement in the home, in order for relational culture change to occur. Suggested ways this could be taken up included leadership reciprocity and vulnerability with other staff, working alongside staff to implement change rather than imposing it, and acknowledging and celebrating efforts made by staff to engage relationally in the home (Dupuis et al., 2019).

Acknowledge moral distress and residue for both PSWs and residents. Identify the policies that limit everyone in the LTC home from acting in ways that align with their values and desires.

Acknowledge the feelings that arise around these policies. Do not leave them unspoken.

Look into how relational caring practices could be applied to your specific workplace and practice. Really consider it. Learn about it. Talk to your team about it. Ask your managers. See what other places are trying. **Explore what can be done.**

I feel it is important to make an extra note about recreation and leisure in my recommendations for how LTC homes might support residents and paid care partners in feeling like more than a task, feeling remembered, and feeling love. Shared leisure experiences in the LTC context have the potential to be conducive to nurturing such relationships (Fortune & Dupuis, 2018) wherein paid care partners and residents both feel these three good feelings. Throughout this research, residents cited moments of friendship that fell outside of the context of care tasks: praying together, watching trees and talking about their colours changing, making a trip to the café downstairs when someone has time, etc. They identified these moments more so than they identified moments of friendship related to task-based care. These examples of leisure moments shared with PSWs were noted as special moments because opportunities for such are limited. PSWs on the other hand primarily identified moments of caring and task-based work wherein they felt they connected with residents. This indicates what we already know, which is that leisure activities are often provided solely for the residents, meant to be therapeutic interventions for them (Dupuis et al., 2012; Fortune & Dupuis, 2018; Genoe & Dupuis, 2014), and are run by recreation staff who play a separate role from PSWs. PSWs do not generally take part in recreation alongside residents in the home. Relational caring advocates for the bringing together of paid care partners and residents (as well as others in an individual's circle of care), and this is true for moments of leisure and recreation as well. The Dotsa Bitove Wellness Academy (DBWA) is an excellent example of how bringing people together to participate in arts-based learning and activities (rather than "therapies") create a safe space for relationships to grow and unfold (Mitchell et al., 2019). Activities are intentionally designed to be non-prescriptive, instead being flexible opportunities for individuals to engage, learn, express themselves, and connect. These activities include everyone in the space, allowing for paid care partners and family members alike to take part in all activities (Mitchell et al., 2019) breaking down the professional and social hierarchies which are traditionally present in caring arrangements (Nolan et al., 2003; Powell & Davies, 2012). Speaking from personal experience at the DBWA, it is always exciting to witness the PSWs or other paid care partners transition into the space, often first arriving to the space in scrubs and sitting apart from others during leisure/recreational activities, and eventually easing into wearing their personal clothing and engaging in art making and singing and dancing. The choice in clothing here is a very visual representation of what the space represents for paid care partners, shifting from biomedical, institutional expectations, to a comfortable setting wherein they too can be themselves. Based on these examples, building upon leisure and recreational activities as potential spaces wherein PSWs and residents in LTC homes can connect, might be a valuable and tangible opportunity for LTC to begin implementing relational caring.

5.2 Methodological implications

Alongside the practical and theoretical implications of my research, there are numerous methodological implications considering the arts-based, collaborative methodology I used to conduct this study. As previously described, conducting an arts-based inquiry challenges several normative expectations of traditional objectivist research (Piantanida et al., 2003) and often has social justice goals, making the research process transformative, empowering, and accessible to audiences beyond academia (Finley, 2014; Kantrowitz, Fava, & Brew, 2017; Welsby & Horsfall, 2011). In this section I will reflect on the arts-based process that unfolded in this study and how I feel it benefitted participants and myself through trust and enjoyment, as well as the ways in which it supported my analysis process.

5.2.1 Establishing trust in a relational research process

To look at trust in the research process, I would like to revisit once more my experience with Miriam, and how it compared to the experiences and "behaviours" described by everyone else in the home. Trust was of the utmost importance to Miriam, and she specifically cited it being broken in her experiences in the home. Further, it seemed that the PSWs didn't trust Miriam very much either, citing her actions as unpredictable. The lack of trust was apparent from all sides. My approach going into this study, as informed by critical theories, was to engage with participants as collaborators and equal partners in the research. Participants are the "experts" in a critical study, and therefore a level of trust in participants is inherent for the researcher (Rexhepi & Torres, 2010). Therefore, I wonder if Miriam was responding to my trust in her as a research participant with valuable insights to share with me, and if this is why I did not witness the expressions/actions others had spoken about. As Bright (n.d.) asserts when outlining voice-centred relational approaches, the relationship between researcher and participant shapes the research process, with the potential to create a mutually beneficial research experience wherein everyone, especially participants, are empowered. This is also emphasized by the participatory and emancipatory goals of critical theories (Freire, 1970). I wonder how the shift in power dynamics and trust in the critical research relationship (as opposed to the staff-resident relationship) shaped my interactions with Miriam, as well as with other participants. I felt good about the connections made with my participants, and participants expressed the same to me in return. I also felt quite validated when a staff member who was within earshot for some parts of the resident workshop, said to me after: "*We should have you come in every week – they never say that much with us!*". I can't help but wonder, is that because residents are not normally asked, or treated as though they have valuable insight? This is what is meant to happen in an empowering research process: participants open up and feel the value in their stories, especially participants whose voices are normally silenced, not heard or elevated (Rexhepi & Torres, 2010). I believe this study shows the value in approaching research critically and relationally, by building and establishing trust with participants so that they feel empowered to share and to engage authentically and enthusiastically.

The importance of relational theories begin to appear in every process I take part in, and I am struck by just how wide-spread the benefits of relational approaches can be. Relationality with research participants challenges the ideas of traditional, objectivist research, which is already challenged within a social-constructionist epistemology. To reiterate, a social-constructionist study looks at knowledge as constructed within social, cultural, as well as individual contexts, and does not hope to find generalizable, objective findings. Hence, such approaches challenge objectivist research, which hopes to uncover singular findings that can be labelled as 'truth' or 'fact'. A social-constructionist project instead honours the individual's truth, or truths, the fluidity of those truths, and how those might be shaped by and shifted within socio-cultural contexts (Fischer, 1997) and power dynamics (Crotty, 1998). Similarly, approaching research relationally helped me honour the participant's stories through: relating authentically, with reciprocity; building a rapport that empowers participants; creating space wherein each person is an expert of their experiences; and trusting their subjective stories/experiences as valuable insight. For these reasons, I feel that a relational research approach aligns well with a social-constructionist epistemology.

With that said, my research process could have been ten times more relational than it was, given the time constraints and struggles with organizing with the home. I could have returned a couple of times prior to data collection to recruit and build relationships with each participant, as Bright (n.d.) recommends doing for relationally-oriented research. I had hoped to do so, but there were too many barriers in the process, namely communication with my contacts at the home which would often look like weeks without responses. Considering how in single sessions, the two groups and I were able to build a bit of trust in one another, how much trust and insight we could have shared with more time to connect? If more time prior to or during data collection can be built into research processes, prioritized and valued in the process, organized with the research site somehow, the benefits of relationality and trust during the process could be even more pronounced than what I experienced. However, in the current culture of long-term care, finding the time to schedule and organize these multiple workshops becomes an enormous challenge, as does expecting/asking the home to support PSWs financially more so than they already did for the single workshop.

5.2.2 The enjoyment and nuance of an art-based methodology

The biggest benefits of using an arts-based methodology for this study were twofold: that participants enjoyed the experience of drawing and sharing, and that it opened the door for more layered, nuanced insight into participants' experiences.

Participants from both groups verbally expressed how they enjoyed the art making portion of the data collection sessions, as well as the opportunity to share their stories and engage in dialogue with one another. They thanked me for the opportunity when I thanked them for helping me with my project. When we were done, several participants wanted to chat with me after the session, give me a hug, or ask me when I might be coming back again. While this may be due to many reasons, I strongly believe that the arts-based approach created a safe, comfortable space for us to be vulnerable with one another and enjoy each others' company.

"We appreciate it!" (Heidi)

"I'm really enjoying this! … A long time I didn't paint… this is really good. Thank you so much." (Risa)

"It's very nice to talk to you guys!"

The PSW group also noted that they normally do not have the time to sit and speak with one another, to discuss their job and be creative in the way we were during the session. Similar findings emerged from the Relational Caring Learning Series (RCLS) pilot study, which brought together a variety of staff members in workshops that engaged participants in meaningful discussion, arts, and other interactive activities which supported reflection and sharing in the group (Dupuis et al., 2019). Participants expressed that one of the most beneficial aspects of their participation in the RCLS workshops was the opportunity to connect and share with their team, something they do not have the opportunity to do in their

"I'm happy, I, this is a really good group. I can't. You know that sharing their experience. You know, I. Yeah. You don't have no time to otherwise sit together and talk about this!" (Risa) daily work (Dupuis et al., 2019). This also speaks to the experiences of paid care partners in an otherwise task-oriented context, wherein their relational needs are also not often met. This further enforces the reasons I wanted to work with both PSWs and residents in the same ways, with the same arts-based approaches (It also reinforces that relational caring is for the benefit of everyone in the home, not only for the residents). Arts-based methodologies go beyond making research more accessible to individuals who may not be able to engage with traditional, verbal approaches to data collection. It creates opportunities to share and engage in new ways that are enjoyable and relational for all participants.

Further, the art-making provided layered and nuanced insight into the experiences, thoughts, and stories that participants were sharing with me. With the resident group, I found that discussing their drawings was helpful, but asking about their drawing process – whether it was actualized or in theory, was even more valuable. I was surprised at this, though I really shouldn’t have been considering I advocated so strongly for the valuing of process over product in art-making in my research design. When asked to describe their drawings, residents stayed fairly surface-level, telling me who they drew, what they drew, or what their hairstyle was. However, when I prompted and asked questions about how they might try to draw something, why they erased something, what they might draw next, why they chose a certain colour, etc., I was met with some insightful responses. The following exchange between Miriam and I is a good example:

> **Katia:** Why did you erase him [the boy in Miriam’s drawing]?
>
> **Miriam:** It doesn't make any sense by himself.

> **Katia:** Oh, so if you were to draw a friendship, how many people would you draw.
>
> **Miriam:** Me? A lot!
>
> **Katia:** A lot. Why would you draw a lot?
>
> **Miriam:** I have a lot of friends. But not everybody is my friend.
>
> **Katia:** Not everybody. What makes somebody a friend for you?
>
> **Miriam:** I told you, trust.

I just love that first response, "*it doesn't make any sense by himself*", when discussing her drawing of friendship. I do not believe Miriam meant it too deeply, but for me this resonates, I keep being drawn to it, and it makes me want to yell out loud, YES! We *don't* make sense by ourselves. That is to say, we do not construct meaning in silos independent of others, and simultaneously, we do not make sense by ourselves, it is not how we're supposed to exist; we are relational beings, meant to be in connection with others.

Returning now to the discussion of the insights from the process of art making: at times the self-analysis of process would happen without my prompting, as participants verbally narrated their decision making. For example, when Cora adds some final details to her portrait of her friend:

> "I'm putting in these blue pills … That's the one I can't take down! … I'm gonna make it, It's the worst one to date. So it's going to be a little bigger than the other one."

While these are questions I could have asked myself while analyzing the drawings later, I would be remiss to assume any of these decisions were intentional or thoughtful without the participant's own assertion of it (Driessnack, 2006). The discussion of their drawing process and drawing decisions speaks to the draw-and-tell method, where in research participants describe and analyze their drawings themselves. I chose to draw on this method as it is intended to democratize the analysis process a bit, allowing for the interpretation of drawings to be done by the participants themselves (Driessnack, 2006). I thought it would be an appropriate approach, creating space for participants to participate in drawing and verbal discussion depending on what works for them. I am glad I took this approach, as the interpretations and insight into their drawings was much more thorough than I could have done myself, with the added bonus of nuanced insight into their decision making and drawing process that could not have been captured in just one final, static drawing.

5.2.3 CAP: Using art in the analysis and representation process

The final benefit of arts-based methodologies that I want to discuss is the use of Creative Analytic Practices (CAP). CAP uses artistic practices throughout the analysis and representation process, leading to accessible and evocative final representations of research findings. (Parry & Johnson, 2007). For me, this process inspired me to create visuals as I analyzed each pattern, sometimes starting with a visual to help me formulate my thoughts and organize my ideas. Initially, my plan was to create a single, final visual for my findings. However, without giving myself the time to explore the patterns visually, I was completely lost in the data and unsure how to do justice to the complexity/nuance of the patterns. Approaching these ideas visually provided a way for me to *play* with my data, engage with it in a more active way, allowing my thoughts to flow creatively. Along with Voice Centred Relational Approach, this process helped me engage more deeply with the words participants had shared with me, which then made it easier for me to see the patterns in the data and put them into words. This was a very iterative process for me. I would play and draw and come up with a visual that I felt represented a key pattern. I would then write a description of the visual and my own creative decision making process, followed by writing the actual analysis text. I would then go back to the visual to tweak it, adding or changing it based on ideas that emerged from my writing process. A key consideration for me at this phase was to ensure the visuals were accessible and informative for others. Without the use of CAP, I imagine myself being stuck in the overwhelming amount of data and ideas I had in my mind, with much more difficulty expressing it or exploring it in a useful, insightful way. I hope that the visuals associated with each pattern not only help readers engage with the ideas and concepts, but also create an enjoyable, visually pleasing break from the lengthy text of this thesis. I would also hope that down the road, they can be published alongside other text from this project, allowing a broader audience to access and take something away from the article for themselves and their lives, practices, and work.

5.3 Theoretical Implications

While I have touched on some theoretical implications throughout my discussion, I would like to elaborate on how my research might inform both theories of friendship, specifically in relation to Derrida, and relational theories, as these were central to the foundation of my research.

5.3.1 Reflecting on Derrida's friend-who-loves and being loved.

As previously mentioned, the way that Derrida spoke about understanding friendship from the perspective of the friend-who-loves informed the way I approached my research participants as valuable meaning makers in friendship, whether that friendship was reciprocated in traditional ways or not (Derrida, 2005). While I initially struggled with Derrida's separation of the loving and being loved and his assertion that being loved is a passive role, my research has brought me to consider a complete rethinking of this idea. I again share this quote which demonstrates Derrida's perspective on being loved in comparison to loving: "Being loved – what does that mean? Nothing, perhaps – nothing in any case of friendship itself in which the loved one, as such, has nothing to know, sometimes nothing to do." (Derrida, 2005, p.9). In this quote it is clear that Derrida does not particularly see the value in passively being loved. On the other hand, this research shows the immense value in feeling loved in friendship, and the meaning that individuals derive from it. Though I make the argument that feeling loved is perhaps different than being loved (as it can be an interpretation of others' actions), here I compare being and feeling as they are closely related and participants may not experience them as distinct things. I propose that receiving love be reconceptualized as an action – not a passive happening, especially because it is interpreted and understood by the individual, informed by culture and context. Interpretation is active construction of meaning, and to presume that being loved in friendship is inherently a passive and unknowing experience does not ring true to the insights and lived experiences shared by participants in this research project.

In terms of friendship specifically as it is understood in the LTC context, the data showed how deeply engrained unidirectionality was in all aspects of engagement in the home, which is aligned with existing literature (Fritsch, 2010; Welie, 1999). It also showed how internalized this unidirectional power dynamic becomes, which I found evident in the different ways participants spoke about what is important in friendship: PSWs said that a friend is someone whom they help, and residents said a friend is someone who helps them. This recalls Freire's (1970) assertion that no one is free if such binaries and power roles stay in place. That is to say that residents and PSWs are both conforming to the expected roles that the institutional culture assigns to them, rather than being free to just *be*. Liberation for residents and PSWs then, in Freire's eyes, would be beneficial and freeing for both (Freire, 1970), even if the unidirectional dynamic puts PSWs typically in a position of power over residents. That said, it is important to keep in mind that this is just one dynamic in the home, and a plethora of other dynamics and individuals in other roles shape engagement and hierarchies in the home. As I explore the unidirectionality of this particular type of relationship, I do not mean to put the onus on either residents or PSWs to take on the role of liberating themselves and challenging such unidirectional dynamics in the home.

That the unidirectionality becomes so entrenched that it emerges in participants' conceptualizations of friendship more broadly was an interesting pattern to me as it provided insight into how context can inform conceptions of friendship, and how fluid conceptions of friendship can be. That is to say that this research was conducted in a LTC home and about experiences in a LTC home, so it is likely that participants shared information and insights with me that were specifically informed by this context. This further supports my critique of the existing literature on friendship that aims to create typologies, categories, and check-lists of what friendship is. To reference the specific typologies and studies I have looked to, see Appendix A. While these typologies and check-lists are perhaps a helpful reference point to begin exploring friendship, this research shows the nuance and tensions that exist in different aspects of friendship within the LTC context, nuance which cannot be summarized into a neat check-list point.

5.3.2 Building upon Relational Theories

My goal in conducting this research was not to confirm the benefits of relational theories in caring contexts, as I had already been a firm believer in the good that can come of relational caring. That said, I believe that my research further supports the existing literature advocating for relational caring, providing deep and nuanced insight into the experiences related to relationality in the culture of caring prior to COVID-19. It is also my hope that this research shows the value of bringing friendship into our understandings and conceptualizations of relational caring. While the findings of this research show several tensions in how friendship is conceptualized in the home, for example how PSWs use the language of friendship while simultaneously “using” friendship to facilitate task-based work, friendship is a concept that participants responded to emotionally and identified as a meaningful experience they have in the home. Friendship seems to contribute to the well-being of residents and paid care partners, even if it is complicated by policy and other barriers in the home. Both groups of participants identified *feeling like more than just a task*, *feeling loved*, and *feeling remembered*, as valuable experiences felt through friendship.

These three feelings recall relational cultural theory (RCT)'s five good things which are felt in growth-promoting relationships: zest, creativity, worth, clarity, and a desire for more connection (Jordan, 2017). The three feelings which emerged from this research align particularly well with the idea of feeling one's 'worth' in a growth-promoting relationship, and bring the concept of worth into the LTC context. For example, *feeling like more than just a task* is quite specific to the LTC context and speaks to the way being treated as a full human being with relational, social, and emotional needs can make us feel that we have worth and are valued. This is also true of feeling remembered, which is especially relevant in a context wherein many residents are living with memory loss, and PSWs are working with numerous residents, making *feeling remembered* all the more meaningful. And of course, *feeling loved* and thus valued and appreciated, also aligns with RCT's feeling 'worth' in a growth-promoting relationship. While further work would be required to explore how friendship in the LTC home might contribute to each of the other five good things felt in growth-promoting relationships, I would propose that friendship is one way to conceptualize relationships within LTC homes that could be considered growth-promoting for both residents and PSWs.

5.4 Further growth: Suggestions for future research

In the future, I believe this topic should be explored further in a variety of ways. I would be interested to know what emerges with groups made up of different participants. For example, my study included PSWs with similar lengths of experience working in LTC and it would be interesting to explore paid care partners with less experience in the home. I would also be very interested to see this project play out with groups that are not frontline workers. On group of particular interest to me is leadership and administrators. As previously mentioned, my initial understanding that friendship is a taboo in LTC settings did not seem to be the case with this particular group of participants. I wonder if the taboo might be more present with the leadership group, based on their hesitance when I discussed relational theories with them prior to starting the data collection at the home. Exploring meanings and experiences of friendship with other paid care partners in LTC such as recreation staff and housekeeping staff would also provide additional insights into how different roles may shape friendships in the LTC context. As previously described, Fortune and Dupuis (in review) found that recreation professionals saw a unique role for themselves in the culture change process because of the flexibility of their roles and their focus on personhood and holistic wellness. Considering that recreation and leisure can act as a space for important relationships to form in the LTC context (Fortune & Dupuis, 2018), it is important to consider whether these different roles better support the development of friendship in LTC and what role recreation staff could play in modelling friendship in LTC.

My study also focused on the experiences and understandings of friendship within one home and I would be interested to know if these experiences resonate in other LTC homes or even in other types of residential settings such as group homes for people living with disabilities. Different homes have diverse workplace cultures and ways of doing things. While a lot of the overarching policies and cultural discourses permeate the field as a whole, each LTC home is its own social context with different leaders, different workers, different residents, and different physical spaces. Future research should explore how these different contexts shape understandings and experiences of friendship.

All the participants who agreed to participate in this study identified as women and future research should explore gender differences in experiences and understandings of friendship in the LTC context. The one participant who identified as male and initially consented to participate revoked his assent/consent the day of the workshop and opted out of the study as the conversation began. While my interest was not in the differences in perspectives of friendships amongst different genders, there are studies that have noted gender differences in the perspectives of friendship (Adams et al., 2000). As I wrote in my literature review, though I have critiques of studies working firmly with gender binaries and neglecting to include queer gender identities in their considerations, it is nonetheless important to acknowledge the socialization of different genders and how that shapes what people of different genders value in relationships and friendships (Jordan et al., 2004). Therefore, a study with a wider variety of genders in the sample would yield valuable insight into a wider range of experiences and perspectives.

I would love to see moral distress and moral residue explored amongst residents in LTC homes. The barriers they experience to helping fellow residents as well as paid care partners in the home, while still being privy to and feeling their moments of stress, sadness, frustration, fear, and other negative emotions, must be incredibly difficult to experience. I believe this aligns with the definitions of moral distress and residue enough for these concepts to be applicable to their experiences as well. Further, PSWs seemed to acknowledge the desire residents have to help and be useful, whether they are allowed to or not, and I wonder how their role as gatekeepers to helping might contribute to some moral distress/residue on their end. This topic goes well beyond the themes of friendship that I hoped to explore in this study, and I believe would be an excellent topic to explore in a separate research project.As for methodology, I feel I had a wonderful experience using the arts throughout the entirety of this process. I believe it supported my participants in feeling safe and made the process positive for everyone involved. I am fortunate that my supervisor and committee are very supportive of this approach to researching, and would suggest that others pursue creative research methodologies and encourage it in those they teach/supervise. It adds a layer of complexity, but this layer of complexity is needed in research and addresses the complexity of human experiences, allowing for richer more nuanced research findings. That said, I would recommend smaller groups for arts-based projects that require more in-depth facilitation. The group of residents ended up being larger than I had anticipated. While I am comfortable facilitating large groups for art-making projects, I found it overwhelming at moments. I felt that there were many stories left unfinished and ideas left unexplored because of the interactions and interjections of the group. There was only so much I could prompt while also facilitating enough time for everyone to share their insights with the group. Being able to facilitate more collaborative arts-based workshop over time might have also provided additional depth of understanding to this project.

Further, there was unfortunately no opportunity for me to co-create a final representation with my participants. This was originally proposed as a way to work alongside participants throughout the phases of the research, as is typical/ideal for critical arts-based research, should the participants desire to participate in the creation of a final representation. While my participants seemed open to it when I asked at the end of each session, administration and managers were eager to wrap up their end of the project. I included collaged pieces of participants’ artwork into the majority of visuals for each pattern, and tried to “collaborate” in that way, I recognise that the final representation is my creation and likely would have looked very different if all participants had worked on it together. I do wish there had been a final session to discuss the findings with participants and co-create a final piece. I would recommend that researchers working with arts-based methodologies in the future push (gently) to have this final stage with participants, so as to create powerful and inclusive final representations. I was respectful of the home’s wishes, and grateful for the time they already provided me with, but for me it is disappointing there wasn’t a chance for more!

Afterword – Giving back post-pandemic

As I complete this thesis and prepare for my defense, I am left with the lingering feeling that this project is not over. Given that this is a critical, social-justice oriented study, my hope is to reconnect with Goldside LTC home after the COVID-19 pandemic and organize with them a time to paint a mural in their space. As I imagine it, the mural would be inspired by the garden visual I created as a final representation for this thesis. Not only does the metaphor of the garden represent friendship for me, as inspired by the data in this research, but it is also a calming, colourful, and cheerful visual for a living and work space which would hopefully appeal to most of the people living and working there. Ideally I would work with the home and possibly with participants to elaborate on the garden as a starting point for imagery. I would open up a conversation about adding other key elements of friendship into the image to make it a mural that the individuals in the home would like to see in their space every day. One option would be to explore imagery around the concept of the three good feelings: feeling like more than a task, feeling remembered, and feeling loved. It is my hope that I may continue this project and give back to Goldside and research participants in this way, especially after a global event that has proven to be particularly difficult for people in LTC to go through. For me, and I hope for the home, a mural would act as a great moment of closure for this project as well as a way to let residents and PSWs in the home know how much they are valued. I also hope that the mural could start conversations between residents, family members, and paid care partners, encouraging them to reconsider traditional understandings of friendship in the home and open up to nurturing and celebrating friendship in the LTC context.

Further, I would like to explore the concept of a choose-your-own-adventure style book as a way to represent the nuance and fluidity I noticed within the data. It would be a book where visuals, quotes, prose, and perhaps poetry derived from the data from this project would come together into a single book that sends the reader back and forth from page to page, sometimes through cycles. I would do so by including prompts asking the reader to choose which page they'd like to go to next, rather than simply flipping to the next page. This non-linear form of representation would be an opportunity to push the boundaries of traditional research expectations even further than this project already has. I would love to take the time after finishing this thesis to explore creating a book like this, and eventually having it printed in an accessible format and made available for broader audiences. The goal of this book would be to share the findings from this work more widely, in a physical format, and encourage readers to think differently about it and truly engage with the adventure it would take them on.

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Appendix A: Friendship Typology Chart

Paper and Researcher(s)	**Name of Typology or Scale**	**Categories**	**Description/Comments**
R. G. Adams, R. Blieszner, & B. de Vries, (2000). Definitions of Friendship in the third age: Age, Gender, and Study Location Effects. *Journal of Aging Studies….*	Adams-Blieszner Typology	*Behavioural Processes* - Self disclosure - Sociability - Assistance - Shared activities *Cognitive Processes* - Loyalty/Commitment - Trust - Shared interests/values - Acceptance - Empathy - Appreciation/respect *Affective Processes* - Compatibility - Care *Structural Characteristics* - Solidarity - Homogeneity *Proxy Measures of Processes* - Frequency of contact - Length of acquaintance - Duration of contact	This study looks at age, gender, and location/cultural contexts as factors affecting perceptions of friendship. They had 53 community dwelling older adults answer open-ended interview questions. The researchers combined and eliminated a series of existing typologies to determine their 5 broad categories and typologies. Most participants identified 3 or more of the specific characteristics in their typology. Despite focusing on a typology, the researchers conclude that it is inappropriate to assume that people share common criteria for friendship.
W. M., Bukowski, B. Hoza, M. Boivin, (1994). Measuring friendship quality during pre- and early adolescence: The development and	Friendship Qualities Scale	- Companionship - Help - Security (Trust) - Closeness - Conflict	This scale was determined through literary analysis with a focus on theorists and children's and early adolescents' perceptions of relationships with their best friends. It uses a likert scale

psychometric properties of the Friendship Qualitties Scale. *Journal of Social and Personal Relationships*, 11, 471-484.			with 1=not true and 5=really true. This scale is often cited in the literature on friendship. It is important to note that many of these scales, this one included, cover both positive and negative factors in friendship (ie. conflict).
J. G. Parker, & S. R. Asher, (1993). Friendship and Friendship Quality in Middle Childhood: Links with Peer Group Acceptance and Feelings of Loneliness and Social Dissatisfaction. *Developmental Psychology*, 29(4), 611-621.	Friendship Quality Questionnaire (FQQ)	- Companionship and Recreation - Help and Guidance - Validation and Caring - Intimate Exchange - Conflict and Betrayal - Conflict Resolution	Built upon the Scale by Bukowski et al. (1994)*, this study used a likert scale and conducted their study with child friendship "partners" as opposed to many other studies that explore only the perceptions of one party in a friendship "pair". ** this study cites Bukowski et al.'s scale as being from 1987, but from an unpublished manuscript. The published version seems to be from 1994.*
W. Furman, & T. Adler, (1982). The Friendship Questionnaire. Denver: University of Denver.	The Friendship Questionnaire (FQ)	- Warmth and Closeness - Conflict - Exclusivity - Relative Status/Power - Affective Mismatch	Furman is an oft-cited friendship researcher. This particular Questionnaire uses a likert scale and can be used across relationships to compare friendship to other types.

W. Furman, & D. Buhrmester, (1985). Children's Perceptions of the Personal Relationships in Their Social Networks. *Developmental Psychology,* 21(6), 1016-1024.	Network of Relationships Inventory	*Positive:* - Companionship - Instrumental aid - Intimacy - Nurturance - Affection - Admiration - Reliable alliance - Satisfaction - Emotional support *Negative:* - Conflict - Antagonism - Punishment - Reliable power	This list is derived from a hypothesis by Weiss (1974) and uses a likert scale. It is considered one of the most comprehensive typologies. The focus of this study is on children's perceptions. They note that friendship is a flexible concept and that perceptions of friendship evolve over a lifespan.
M. J. Mendelson, & F. E. Aboud, (1999). Measuring Friendship Quality in Late Adolescents and Young Adults: McGill Friendship Questionnaires.	McGill Friendship Questionnaire	- Stimulating companionship - Help - Intimacy - Reliable alliance (loyalty) - Self-validation - Emotional security	This study looks at 'intangible resources' in friendships in university students using equity theory and equality theory. The researchers conducted the study using questionnaires with scales and explore whether benefit-to-contribution ratios are more important to individuals in friendships (equity theory), or the equality of benefits (equality theory).
D. Felmlee, & A. Muraco, (2009). Gender and Friendship Norms among Older Adults. *Research on Aging*, 31(3), 318-344.	Friendship Norms	- Trust - Loyalty - Commitment - Tolerance - Respect - Consideration - Affection - Self-Disclosure - Assistance	This study involved seniors in a questionnaire based on vignettes. The findings are derived from participants' open-ended answers. This study noted significant differences in gender, contextual considerations, but none regarding age and consistently compare their findings to similar outcomes in research focused on

			friendship perceptions of children.
M. Argyle, & M. Henderson, (1984). The Rules of Friendship. *Journal of Social and Personal Relationships*, 1, 211-37.	The Rules of Friendship	*Exchange:* - Share news of success with the other - Show emotional support - Volunteer help in time of need - Strive to make him/her happy while in each others' company - Repay debts and favours *Intimacy:* - Trust and confide in the other *Third party:* - Stand up for the other person in their absence - Be tolerant of other friends - Don't criticize in public - Keep ondifences - Don't be jealous or critical of other relationships *Coordination:* - Don't nag - Respect Privacy	These rules present the findings of four studies in various cultural/geographic settings examining the rules of friendship. Based on the premise that social behaviour is rule-bound, these researchers seek to find out what people perceive the rules to be. They do some work on the differences in perceptions impacted by age, culture, and gender. They found no significant differences.

K. A. Roberto, & P. J. Kimboko, (1989). Friendships in Later Life: Definitions and Maintenance Patterns. *International Journal of Aging and Human Development*, 28(1), 9-19.	n/a	*Likeables:* - Likeability - Sharing same beliefs - Getting along *Confiders:* - Someone they can talk to - Someone who is always there for them - Acceptance *Trustables:* - Trustworthy - Honest - Dependable	

Appendix B: Interview Guide/Script

Introductory Script:

Researcher (R): Hi everybody, thank you very much for being here today. My name is Katia and I am a Master's student in the department of Recreation and Leisure Studies at the University of Waterloo. I am excited that you agreed to participate in my research on relationships in long term care homes. What we are going to do here today is not like a typical interview. It is an arts-based workshop where we will be drawing a series of prompts together, and then talking about our drawings. If you are nervous about drawing, remember that we are not here to make pretty or 'good' drawings. Instead it is a way to help us think and talk about things differently. So no pressure! The conversations will be audio recorded and the recordings and transcriptions of recordings will only be used for the purpose of this research project. Your identity will be kept confidential, with a pseudonym used in place of your name. Additionally, you'll notice I have a volunteer note taker in the room. They will be taking notes throughout the workshop. These notes will be treated the same way as the audio recordings.

A few reminders before we begin:

- Your participation in the the arts-based workshop is completely voluntary.
- During the workshop, you may decline to answer any questions that you prefer not to answer.
- You may choose to stop participating at any time.
- Your name will not appear in any publication or presentation resulting from this research, however with your permission quotations and the artwork we create today may be used with a pseudonym in place of your real name.
- This study has been reviewed by and received ethics clearance through the Office of Research Ethics at the University of Waterloo (ORE#40923).

R: Do you have any questions?

Participants (P): No

OR:

P: Yes

R: Ok, what is your question?

P: Question(s).

R: Answer(s). Any other questions?

P: No

R: Thank you. Ok, let's start. I will now turn on the audio recording and give you your first prompt.

1. **I would like you to think about friendship: what does friendship look like for you? How does it feel?**
    - *(This first prompt serves as an opportunity to understand and then use the words that participants identify here to describe friendship in the subsequent questions. 5-10 minutes)*
    - Probes:
        - Tell me more about that experience/perspective/word.
        - Can you describe what that means to you?
        - Does love fit into your conception of friendship? If so, how?

2. **Please pick a pencil and create a drawing of a time YOU showed _______ (love, affection, caring….) towards someone who works/lives here. Think about moments, actions, feelings, and please let me know if you need help drawing something.**
    - *I anticipate approximately 15 minutes of uninterrupted drawing time, offering only a helping hand and words of encouragement to anyone who expresses they aren't comfortable with drawing.*
    - Probes:
        - Let's talk about our drawings. Does anyone volunteer to share first?
        - What story are you telling in your drawing?

        - What/who is included in your drawing?
        - What feelings are in your drawing? How did you represent those feelings?
        - Describe the relationship in your drawing.
        - What words would you use to describe your picture?
        - What gets in the way of being able to show _______ (affection, love, caring) here?
        - What makes it possible for you to show __________ (affection, love, aring) here?

3. ***If time allows: Please pick a pencil and create a drawing of a time someone who lives/works here showed YOU _______ (love, affection, caring….).**
    - *(I anticipate approximately 15 minutes of uninterrupted drawing time, offering only a helping hand and words of encouragement to anyone who expresses they aren't comfortable with drawing.)*
    - Probes:
        - Let's talk about our drawings. Does anyone volunteer to share first?
        - What story are you telling in your drawing?
        - What/who is included in your drawing?
        - What feelings are in your drawing? How did you represent those feelings?
        - Describe the relationship in your drawing.
        - What words would you use to describe your picture?

** If time allows, and conversation around the first drawing prompt comes to a standstill, I will explore this second drawing prompt. I want to allow for flexibility in this interview guide, so that if the first drawing prompt generates a conversation that does not end in time to allow for the second drawing prompt, I am not interrupting participants or stopping the valuable conversation.*

Closing Script:

Thank you very much for taking the time to share your insights and thoughts about friendship in your home. Your participation is greatly appreciated. As previously mentioned, this study has been reviewed by and received ethics clearance through the Office of Research Ethics at the University of Waterloo (ORE#40923). I will send you a thank you note with the contact information for the Office of Research Ethics at the University of Waterloo, as well as mine and my supervisor's. If you have any comments or concerns resulting from your participation, you may contact the Office of Research Ethics with your concerns. If you have any questions regarding the project itself, please contact my supervisor, Dr. Sherry L. Dupuis, or myself.

Thank you again for your participation.

Appendix C: Study Information Sheets

Resident information sheet:

DATE

Dear Potential Research Participant,

My name is Katia Engell and I am conducting a research project as part of my Master's degree in the Department of Recreation and Leisure Studies at the University of Waterloo. I am conducting my research under the supervision of Dr. Sherry L. Dupuis. This fact sheet provides detailed information about this research project and will help you make an informed decision regarding your participation.

What is this study about?

- I am interested in understanding the relationships between residents and their paid care partners living and working in LTC, specifically residents and Personal Support Workers (PSWs) at Mackenzie Health.
- I have worked with older adults for about 7 years and consider many people I've worked with my friends. I am curious to know whether or not friendship is something others associate with their relationships in the field.
- The purpose of this project is to explore how friendship/relationships are currently understood in the Long Term Care (LTC) context, as well as to challenge how we typically understand relationships in LTC with the goal of re-imagining the potential for friendship in caring relationships.

What does participation in this study involve?

- You will be asked to take part in a drawing workshop with a small group of residents that will take approximately one hour to complete and will take place on-site at Mackenzie Health.
- You will be asked to complete a short demographics questionnaire before beginning the workshop, which will take approximately one minute to complete
- In the workshop, you will be asked to reflect on your personal experiences with friendship and your relationships with the PSWs at Mackenzie Health.

    - You will be asked to make a drawing that reflects your experiences with friendship/relationships in your LTC home.
    - You will then be asked to discuss your drawings and experiences with the group.
- It is important to note that you do not need experience or talent with drawing to participate in the workshops. The focus is not on making pretty or “good” drawings but to use the drawing as a way to think about friendship differently.
- You will be invited to take part in an optional second workshop wherein you will assist in creating a final piece of art to reflect on the project. No additional data will be collected at this workshop and participation will be completely voluntary.

Who may participate in the study?

In order to participate in this study, participants must either identify as: (1) living at Mackenzie Health LTC, ***OR*** (2) working at Mackenzie Health LTC as a PSW. Further, all participants must:

- have lived or worked at Mackenzie Health LTC for a minimum of 6 months.
- have some level of ability to participate in the arts aspect of the workshop.
- be able to communicate verbally in English to some degree.
- provide written consent, then verbal assent regularly throughout the process for participation in the arts-based workshop, and audio-recording of the discussions during the workshop. If you are not able to provide your own written consent and wish to participate, I will require the written consent from a substitute decision maker who is also your Power of Attorney.

Is participation in the study voluntary?

- Participation in this research project is completely voluntary.
- Should you choose to participate, you or your substitute decision maker will be asked to sign a formal letter of consent stating your consent to participate.
- You may decline to answer any of the questions asked during the workshops and throughout this research project.
- You may decide to stop drawing or leave the session at any time without any consequence. However, due to the collective nature of the discussions, any data you have provided up until that point will be included in the study unless it is possible to discern it and separate it from the collective data.
- Your decision to participate in this research project, as well as your decision to withdraw should you choose to do so, will not affect your current or future living at MacKenzie Health.
- With your permission, the discussion component of the workshops will be audio recorded to facilitate collection of information, and later transcribed for analysis.

What are the potential benefits of the study?

- Participation in this study may not offer personal benefits to you. However, it is my hope that this study will be an enjoyable and empowering experience for participants as they offer their expertise and valuable insights about friendships and relationships in LTC.
- The results of this research will hopefully contribute towards an improved culture of caring in LTC homes and other care settings, highlighting the importance of relationships in care processes while simultaneously challenging stigma that exists both for persons living in long term care and paid care partners.
- This research has implications for the academic community, as we work together to highlight the voices of research participants, demonstrate the value of arts-based research, and challenge preconceived notions of friendship and relationships in caring processes.

What are the possible risks or discomforts associated with this study?

- In discussing our personal experiences with relationships and friendships, it is possible that the conversations will bring up negative feelings and emotions. Please remember that should you begin to feel upset, your participation is entirely voluntary, and you may decline to answer any questions you do not want to answer. If participants begin to express emotional stress, I will pause the workshops and offer the opportunity to withdraw, take a break, or reach out to supports as is appropriate. The well-being of participants will *always* be prioritized over data collection for this project.

How will your information be kept confidential?

- Any identifying information will be removed from all data that is collected and will be stored separately.
- Because the workshops will occur on-site, some limitations in confidentiality exist with staff and other residents in the home. Administrators in the home will also be aware of the research project and assist in scheduling the workshops. In addition, given the group format of the sessions, all participants will be asked to keep in confidence information that identifies our could potentially identify a participant and/or their comments. However, we cannot guarantee that all participants will honour this request.
- Your name will not appear in any paper or presentation resulting from this research, however with your permission quotations and artwork from this study may be used with a pseudonym in place of your real name.
- Any data collected will be securely stored for a minimum of 1 year in an encrypted folder on a password protected computer in a locked office. Any physical data (drawings,

artwork) will be stored in a locked cabinet. Only myself and my supervisor will have access to your information.
- You can withdraw your consent and have your drawings removed from the study by contacting the researchers up until the completion of the final thesis submission (est. Fall 2019). Please note that it will not be possible to withdraw your consent once study results have been submitted for publication.

Has the study received ethics clearance?

- This study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Committee (ORE#40923), as well as through the Mackenzie Health Ethics Committee. If you have any questions for the Committee contact the Office of Research Ethics at 1-519-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For the Mackenzie Health Ethics Committee, please contact _______.

Who should be contacted should you have any questions?

- If you have any questions regarding this study or would like any additional information to assist you in your decision about participation, please contact me, Katia Engell, at 416-708-2393 or by email at kengell@uwaterloo.ca.
- You may also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca

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

Sincerely,

Katia Engell

MA Candidate, University of Waterloo

Department of Recreation and Leisure Studies

Faculty of Applie Health Sciences

416-708-2393

kengell@uwaterloo.ca

Paid Care Partner Information Sheet:

DATE

Dear Potential Research Participant,

My name is Katia Engell and I am conducting a research project as part of my Master's degree in the Department of Recreation and Leisure Studies at the University of Waterloo. I am conducting my research under the supervision of Dr. Sherry L. Dupuis. This fact sheet provides detailed information about this research project and will help you make an informed decision regarding your participation.

What is this study about?

- I am interested in understanding the relationships between persons with dementia and their paid care partners, specifically residents and Personal Support Workers (PSWs) at Mackenzie Health.
- I have worked with persons with dementia for about 7 years and consider many people I've worked with my friends. I am curious to know whether or not friendship is something others associate with their relationships in the field.
- The purpose of this project is to explore how friendship/relationships are currently understood in the Long Term Care (LTC) context, as well as to challenge how we typically understand relationships in LTC with the goal of re-imagining the potential for friendship in caring relationships.

What does participation in this study involve?

- You will be asked to take part in a drawing workshop with a small group of staff that will take approximately one hour to complete and will take place on-site at Mackenzie Health.
- You will be asked to complete a short demographics questionnaire before beginning the workshop, which will take approximately one minute to complete
- In the workshop, you will be asked to reflect on your personal experiences with friendship and your relationships to residents at Mackenzie Health.
  - You will be asked to make a drawing that reflects your experiences with friendship/relationships in your LTC home.
  - You will then be asked to discuss your drawings and experiences with the group.

- It is important to note that you do not need experience or talent with drawing to participate in the workshops. The focus is not on making pretty or “good” drawings but to use the drawing as a way to think about friendship differently.
- You will be invited to take part in an optional second workshop wherein you will assist in creating a final piece of art to reflect on the project. No additional data will be collected at this workshop and participation will be completely voluntary.

Who may participate in the study?

In order to participate in this study, participants must identify as working at Mackenzie Health LTC as a PSW. Further, all participants must:

- have worked at Mackenzie Health LTC for a minimum of 6 months.
- have some level of ability to participate in the arts aspect of the workshop.
- be able to communicate verbally in English to some degree.
- provide written consent, then verbal assent regularly throughout the process for participation in the arts-based workshop, and audio-recording of the discussions during the workshop.

Is participation in the study voluntary?

- Participation in this research project is completely voluntary.
- Should you choose to participate, you will be asked to sign a formal letter of consent stating your consent to participate.
- You may decline to answer any of the questions asked during the workshops and throughout this research project.
- You may decide to stop drawing or leave the session at any time without any consequence. However, due to the collective nature of the discussions, any data you have provided up until that point will be included in the study unless it is possible to discern it and separate it from the collective data.
- Your decision to participate in this research project, as well as your decision to withdraw should you choose to do so, will not affect your employment at MacKenzie Health.
- With your permission, the discussion component of the workshops will be audio recorded to facilitate collection of information, and later transcribed for analysis.

What are the potential benefits of the study?

- Participation in this study may not offer personal benefits to you. However, it is my hope that this study will be an enjoyable and empowering experience for participants as they offer their expertise and valuable insights about friendships and relationships in LTC.
- The results of this research will hopefully contribute towards an improved culture of caring in LTC homes and other care settings, highlighting the importance of relationships in care processes while simultaneously challenging stigma that exists both for persons living in long term care and paid care partners.
- This research has implications for the academic community, as we work together to highlight the voices of research participants, demonstrate the value of arts-based research, and challenge preconceived notions of friendship and relationships in caring processes.

What are the possible risks or discomforts associated with this study?

- In discussing our personal experiences with relationships and friendships,
  it is possible that the conversations will bring up negative feelings and emotions. Please remember that should you begin to feel upset, your participation is entirely voluntary, and you may decline to answer any questions you do not want to answer. If participants begin to express emotional stress, I will pause the workshops and offer the opportunity to withdraw, take a break, or reach out to supports as is appropriate. The well-being of participants will *always* be prioritized over data collection for this project.

How will your information be kept confidential?

- Any identifying information will be removed from all data that is collected and will be stored separately.
- Because the workshops will occur on-site, some limitations in confidentiality exist with staff and other residents in the home. Administrators in the home will also be aware of the research project and assist in scheduling the workshops. In addition, given the group format of the sessions, all participants will be asked to keep in confidence information that identifies our could potentially identify a participant and/or their comments. However, we cannot guarantee that all participants will honour this request.
- Your name will not appear in any paper or presentation resulting from this research, however with your permission quotations and artwork from this study may be used with a pseudonym in place of your real name.
- Any data collected will be securely stored for a minimum of 1 year in an encrypted folder on a password protected computer in a locked office. Any physical data (drawings, artwork) will be stored in a locked cabinet. Only myself and my supervisor will have access to your information.
- You can withdraw your consent and have your drawings removed from the study by contacting the researchers up until the completion of the final thesis submission (est. Fall

2019). Please note that it will not be possible to withdraw your consent once study results have been submitted for publication.

Has the study received ethics clearance?

- This study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Committee (ORE#40923), as well as through the Mackenzie Health Ethics Committee. If you have any questions for the Committee contact the Office of Research Ethics at 1-519-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For the Mackenzie Health Ethics Committee, please contact _______.

Who should be contacted should you have any questions?

- If you have any questions regarding this study or would like any additional information to assist you in your decision about participation, please contact me, Katia Engell, at 416-708-2393 or by email at kengell@uwaterloo.ca.
- You may also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca

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

Sincerely,

Katia Engell

MA Candidate, University of Waterloo

Department of Recreation and Leisure Studies

Faculty of Applie Health Sciences

416-708-2393

kengell@uwaterloo.ca

Third Party Consent Information Sheet:

DATE

Dear Substitute Decision Maker for Potential Research Participant,

My name is Katia Engell and I am conducting a research project as part of my Master's degree in the Department of Recreation and Leisure Studies at the University of Waterloo. I am conducting my research under the supervision of Dr. Sherry L. Dupuis. This fact sheet provides detailed information about this research project and will help you make an informed decision regarding your relative's participation.

What is this study about?

- I am interested in understanding the relationships between persons with dementia and their paid care partners, specifically residents and Personal Support Workers (PSWs) at Mackenzie Health.
- I have worked with persons with dementia for about 7 years and consider many people I've worked with my friends. I am curious to know whether or not friendship is something others associate with their relationships in the field.
- The purpose of this project is to explore how friendship/relationships are currently understood in the Long Term Care (LTC) context, as well as to challenge how we typically understand relationships in LTC with the goal of re-imagining the potential for friendship in caring relationships.

What does participation in this study involve?

- Your relative will be asked to take part in a drawing workshop with a small group of residents that will take approximately one hour to complete and will take place on-site at Mackenzie Health.
- Your relative will be asked to complete a short demographics questionnaire before beginning the workshop, which will take approximately one minute to complete
- In the workshop, your relative will be asked to reflect on their personal experiences with friendship and their relationships with the PSWs at Mackenzie Health.
    - They will be asked to make a drawing that reflects their experiences with friendship/relationships in their LTC home.
    - They will then be asked to discuss their drawings and experiences with the group.

- It is important to note that your relative does not need experience or talent with drawing to participate in the workshops. The focus is not on making pretty or "good" drawings but to use the drawing as a way to think about friendship differently.
- Your relative will be invited to take part in an optional second workshop wherein they will assist in creating a final piece of art to reflect on the project. No additional data will be collected at this workshop and participation will be completely voluntary.

Who may participate in the study?

In order to participate in this study, participants must either identify as: (1) having some dementia and be living at Mackenzie Health LTC, ***OR*** (2) work at Mackenzie Health LTC as a PSW. Further, all participants must:

- have lived or worked at Mackenzie Health LTC for a minimum of 6 months.
- have some level of ability to participate in the arts aspect of the workshop.
- be able to communicate verbally in English to some degree.
- provide written consent, then verbal assent regularly throughout the process for participation in the arts-based workshop, and audio-recording of the discussions during the workshop. If participants are not able to provide their own written consent and wish to participate, I will require the written consent from a substitute decision maker who is also their Power of Attorney.

Is participation in the study voluntary?

- Participation in this research project is completely voluntary.
- Should you choose to have your relative participate, you will be asked to sign a formal letter of consent stating your consent for your relative to participate.
- Your relative will be asked for their assent consistently throughout this project, even if you have given formal consent.
- Your relative may decline to answer any of the questions asked during the workshops and throughout this research project.
- Your relative may decide to stop drawing or leave the session at any time without any consequence. Additionally, you may withdraw consent for your relative at any point during the project without any consequence. However, due to the collective nature of the discussions, any data they have provided up until that point will be included in the study unless it is possible to discern it and separate it from the collective data.

- Your decision to have your relative participate in this research project, as well as your decision to withdraw should you choose to do so, will not affect your current or future living or employment at MacKenzie Health.
- With your permission, the discussion component of the workshops will be audio recorded to facilitate collection of information, and later transcribed for analysis.

What are the potential benefits of the study?

- Participation in this study may not offer personal benefits to you or your relative. However, it is my hope that this study will be an enjoyable and empowering experience for participants as they offer their expertise and valuable insights about friendships and relationships in LTC.
- The results of this research will hopefully contribute towards an improved culture of caring in LTC homes and other care settings, highlighting the importance of relationships in care processes while simultaneously challenging stigma that exists both for persons with dementia and paid care partners.

- This research has implications for the academic community, as we work together to highlight the voices of research participants, demonstrate the value of arts-based research, and challenge preconceived notions of friendship and relationships in caring processes.

What are the possible risks or discomforts associated with this study?

- In discussing our personal experiences with relationships and friendships, it is possible that the conversations will bring up negative feelings and emotions. Please remember that should your relative begin to feel upset, their participation is entirely voluntary, and they may decline to answer any questions they do not want to answer. If participants begin to express emotional stress, I will pause the workshops and offer the opportunity to withdraw, take a break, or reach out to supports as is appropriate. **The well-being of participants will *always* be prioritized over data collection for this project.**

How will your information be kept confidential?

- Any identifying information will be removed from all data that is collected and will be stored separately.
- Because the workshops will occur on-site, some limitations in confidentiality exist with staff and other residents in the home. Administrators in the home will also be aware of

the research project and assist in scheduling the workshops. In addition, given the group format of the sessions, all participants will be asked to keep in confidence information that identifies our could potentially identify a participant and/or their comments. However, we cannot guarantee that all participants will honour this request.

- Your relative's name will not appear in any paper or presentation resulting from this research, however with your permission quotations and artwork from this study may be used with a pseudonym in place of your relative's real name.
- Any data collected will be securely stored for a minimum of 1 year in an encrypted folder on a password protected computer in a locked office. Any physical data (drawings, artwork) will be stored in a locked cabinet. Only myself and my supervisor will have access to your information.
- You can withdraw your consent and have your relative's drawings removed from the study by contacting the researchers up until the completion of the final thesis submission (est. Fall 2019). Please note that it will not be possible to withdraw your consent once study results have been submitted for publication.

Has the study received ethics clearance?

- This study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Committee (ORE#40923), as well as through the Mackenzie Health Ethics Committee. If you have any questions for the Committee contact the Office of Research Ethics at 1-519-4567 ext. 36005 or ore-ceo@uwaterloo.ca.
For the Mackenzie Health Ethics Committee, please contact _______.

Who should be contacted should you have any questions?

- If you have any questions regarding this study or would like any additional information to assist you in your decision about participation, please contact me, Katia Engell, at 416-708-2393 or by email at kengell@uwaterloo.ca.
- You may also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca

Thank you very much for your interest and for considering having your relative participate in this project!

Sincerely,

Katia Engell
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
416-708-2393
kengell@uwaterloo.ca

Appendix D: Consent Forms

Declaration of Informed Consent Form for Participants

- ✓ **I have read the project fact sheet.**
- ✓ **I have asked questions that I have about the project.**
- ✓ **I am okay with being tape recorded.**
- ✓ **I know that my contributions during the arts-based workshops may be used in the project.**
- ✓ **I know that I can stop participating at any time.**
- ✓ **I know that I can call someone if I have any questions about my participation.**

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

I have read the information presented in the study fact sheet about the study being conducted by Katia Engell of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional information I requested.

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

I understand that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40923). If I have questions for the Committee, I can contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For any other questions, I have been told I may contact Katia Engell by calling 416-708-2393 or by email at kengell@uwaterloo.ca . I may also contact Dr. Sherry L. Dupuis at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca

I consent to the following:

I agree to participate in arts-based workshops, wherein I will draw according to given prompts and discuss my drawings with the small group, including the researcher.

☐ YES ☐ NO

I agree to the audio recording of the group discussions to ensure accurate transcription and analysis of the data.

☐ YES ☐ NO

I agree to the use of anonymous quotations and art-work in any thesis, publication, or presentation that comes out of this research and the use of a pseudonym in place of my real name.

☐ YES ☐ NO

I have read and understand the study fact sheet and, with full knowledge of all foregoing, agree to participate in this project:

☐ YES ☐ NO

____
Participant’s name

____ _________________
Signature of participant Date

____
Researcher’s/ Witness’ name

____ _________________
Witness signature Date

Declaration of Informed Consent Form for Participants

- ✓ **I have read the project fact sheet.**
- ✓ **I have asked questions that I have about the project.**
- ✓ **I know that my relative has and will continue to be asked for their assent to participate.**
- ✓ **I am okay with my relative being tape recorded.**
- ✓ **I know that my relative's contributions during the arts-based workshops may be used in the project.**
- ✓ **I know that my relative can stop participating at any time.**
- ✓ **I know that I can call someone if I have any questions about my relative's participation.**

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

I have read the information presented in the study fact sheet about the study being conducted by Katia Engell of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional information I requested. I also know that my relative has received the same information and opportunity to ask questions.

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

I understand that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40923). If I have questions for the Committee, I can contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For any other questions, I have been told I may contact Katia Engell by calling 416-708-2393 or by email at kengell@uwaterloo.ca . I may also contact Dr. Sherry L. Dupuis at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca

I consent to the following:

I agree that my relative may participate in arts-based workshops, wherein they will draw according to given prompts and discuss my drawings with the small group, including the researcher.

☐ YES ☐ NO

I agree that my relative may be audio recorded during the group discussions to ensure accurate transcription and analysis of the data.

☐ YES ☐ NO

I agree to the use of my relative's anonymous quotations and art-work in any thesis, publication, or presentation that comes out of this research and the use of a pseudonym in place of my relative's real name.

☐ YES ☐ NO

I have read and understand the study fact sheet and, with full knowledge of all foregoing, agree that my relative may participate in this project:

☐ YES ☐ NO

____

Participant's name

____

Participant's substitute decision maker's name

____ ________________
Signature of participant's substitute decision maker Date

____
Researcher's/ Witness' name

____ ________________
Researcher/Witness' signature Date

Appendix E: Demographics Profiles

Participant Demographics/Background Information for Paid Care Partners

What is your age: _______________

What is your gender?

☐ Male ☐ Female ☐ Other: ___________

How long have you worked at Mackenzie Health: __________________

Have you worked in other Long Term Care organizations:

☐ YES ☐ NO

If yes, how long have you worked in Long Term Care organizations: __________________

Participant Demographics/Background Information for Participants living with dementia

What is your age: _______________

What is your gender?

☐ Male ☐ Female ☐ Other: ___________

How long have you lived at this home: __________________

Appendix F: Protocol for obtaining Assent

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

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

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

- ✓ **I have gone through the project fact sheet.**
- ✓ **I have asked questions that I have about the project.**
- ✓ **I am okay with being tape recorded.**
- ✓ **I know that my contributions during the arts-based workshops may be used in the project.**
- ✓ **I know that I can stop participating at any time.**
- ✓ **I know that I can call someone if I have any questions about my participation.**

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

Resident Assent to Participate Process – Documentation Form

Resident participant assent was gained from ______________________ (Name of Participant) on ______________________(date) by _____________________________(Researcher).

Assent was expressed in the following ways:

____

____

____

Printed Name of Researcher	Signature	Date

Appendix G: Verbal Recruitment Scripts

Verbal Script for Recruiting Participants Living with Dementia

Researcher: Hi, my name is Katia Engell and I am a University of Waterloo student, doing my Master's degree in Recreation and Leisure Studies. I'm conducting research about relationships and friendships in Long Term Care homes. I was wondering if I could tell you more about my study in case you might be interested in taking part?

Respondent: No

Researcher: Ok, thank you! Have a nice day.

OR

Respondent: Yes.

Researcher: Great! Thank you. I'll tell you a little more about my study: it will be an in depth look at how relationships are understood and experienced here at this home, specifically the relationships between residents who live here and PSWs/care partners who work here. I think it's an important relationship and it hasn't been looked at or researched enough yet. My hope is that this research will help us understand this relationship and then support people in building good relationships with one another. I'm using an arts-based approach for my research. That means we'll be making art together in a small group workshop, and having a conversation about the art for about an hour. This small group workshop will consist of a few other residents, and not PSWs. You don't have to be an artist to participate, just willing to give it a try. We will draw and talk about our relationships here. An example of a question I might ask is: "what does friendship look like for you? How does it feel?" Are you interested in hearing more about the research project?

Respondent: I am not interested.

Researcher: Ok, thank you! Have a nice day.

OR

Respondent: Yes.

Researcher: Thank you so much. Here is an information sheet with details about the study. We can go through it together now if that is okay?

Respondent: No

Researcher: Ok, thank you! Have a nice day.

OR

Respondent: Yes.

Researcher: Ok! (Go through the information letter together)

Researcher: Do you have any questions?

Respondent: Yes.

Researcher: Ok, what are your questions?

(allow time for Q & A)

OR

Respondent: No.

Research: Do you wish to participate in this project?

Respondent: No.

Researcher: Ok, thank you. Have a nice day.

OR

Respondent: Yes.

Researcher: Thank you so much! Once I have everyone set up to participate, I will arrange a date in the next few weeks to do the workshop and let you know. We will then do our workshop and make some art together! I am looking forward to it.

OR

(if participant is able to provide informed consent without a third party, as identified by LTC leadership)

Respondent: Yes.

Researcher: Thank you so much. Here is a consent form. We can go through it together before you sign. (Go through consent form together). Once I have everyone set up to participate, I will arrange a date in the next few weeks to do the workshop and let you know. We will then do our workshop and make some art together! I am looking forward to it.

This research project has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40923). 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.

For all other questions, please contact myself, Katia Engell, at 416-708-2393 or by email at kengell@uwaterloo.ca. You may also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

Verbal Script for Recruiting Paid Care Partner Participants

Researcher: Hi, my name is Katia Engell and I am a University of Waterloo student, doing my Master's degree in Recreation and Leisure Studies. I'm conducting research about relationships and friendships in Long Term Care homes. I was wondering if I could tell you more about my study in case you might be interested in taking part?

Respondent: No

Researcher: Ok, thank you! Have a nice day.

OR

Respondent: Yes.

Researcher: Great! Thank you. I'll tell you a little more about my study: My research will be an in depth look at how relationships are understood and experienced at MacKenzie Health long-term care home, specifically the relationships between residents living with dementia, and PSWs/care partners who work there. I think it's an important relationship and it hasn't been looked at or researched enough yet. My hope is that this research will help us understand this relationship and then support people in building good relationships with one another. This research is part of a larger culture change movement towards Relational Caring. Relational Caring hopes to make care settings more relationship-focused, as research shows that social and relational needs of residents are often neglected, contributing to feelings of loneliness, withdrawal, and social isolation in persons living with dementia. Relationships are also important for care staff but are rarely explored in the context of long-term care. I hope to contribute to this culture change movement by looking at the relationships that already exist in long-term care settings and identify ways to better support them.

I'm using an arts-based approach for my research. That means we'll be making art together in a small group workshop, and having a conversation about the art for about an hour. I have years of experience making art with persons with dementia and facilitating conversation and discussions. I have piloted my process with people with dementia where I currently work, and I expect that it will be a relaxed and enjoyable experience. This small group workshop will consist only of a few other PSWs, and not residents. Participants do not have to be an artist to participate, just willing to give it a try. We will draw and talk about peoples' relationships at MacKenzie Health. An example of a question I might ask is: "what does friendship look like for you? How does it feel?" What are your thoughts or questions?

Respondent: I am not interested.

Researcher: Ok, thank you! Have a nice day.

OR

Respondent: Yes.

Researcher: Thank you so much. Here is an information sheet, a consent form, and an envelope. Please read it over, and if you are interested in participating, please sign the form and leave it in the envelope provided at the main office for me to pick up. You can discuss the information with friends and family if you'd like. If you have any questions, all of my contact information is provided on the information sheet and you may contact me at your convenience. Do you have any questions right now?

Respondent: Yes

Researcher: Ok, what are your questions?

(allow time for Q & A)

OR

Respondent: No.

Researcher: Ok, Thank you again. Once I have everyone set up to participate, I will arrange a date in the next few weeks to do the workshop and let you know. We will then do our workshop and make some art together! I am looking forward to it.

This research project has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40923). 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.

For all other questions, please contact myself, Katia Engell, at 416-708-2393 or by email at kengell@uwaterloo.ca. You may also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

Verbal Script for Obtaining Third Party Consent on the phone or in-person

Preamble:

Researcher: Hi, my name is Katia Engell and I am a University of Waterloo student, completing my Master's degree in Recreation and Leisure Studies. As part of my degree, I am conducting research about relationships and friendships at Mackenzie Health long term care home. Staff have identified your relative as a potential participant for the project. This would involve participating in an arts-based workshop wherein we will draw and discuss the topic of friendship. Is now an OK time to talk?

Respondent: No.

Researcher: Ok, is there a better time when I might call you back to talk about your relative's potential participation in this project?

OR

Respondent: Yes.

Researcher: Great! Let me tell you a bit more about my research project: My research will be an in depth look at how relationships are understood and experienced at MacKenzie Health long-term care home, specifically the relationships between residents living with dementia, and PSWs/care partners who work there. I think it's an important relationship and it hasn't been looked at or researched enough yet. My hope is that this research will help us understand this relationship and then support people in building good relationships with one another. This research is part of a larger culture change movement towards Relational Caring. Relational Caring hopes to make care settings more relationship-focused, as research shows that social and relational needs of residents are often neglected, contributing to feelings of loneliness, withdrawal, and social isolation in persons living with dementia. Relationships are also important for care staff but are rarely explored in the context of long-term care. I hope to contribute to this culture change movement by looking at the relationships that already exist in long-term care settings and identify ways to better support them.

I'm using an arts-based approach for my research. That means we'll be making art together in a small group workshop, and having a conversation about the art for about an hour. I have years of experience making art with persons with dementia and facilitating conversation and discussions. I have piloted my process with people with dementia where I currently work, and I expect that it will be a relaxed and enjoyable experience. This small group workshop will consist only of a few other residents, and not PSWs. Participants do not have to be an artist to participate, just willing to give it a try. We will draw and talk about peoples' relationships at MacKenzie Health. An example of a question I might ask is: "what does friendship look like for you? How does it feel?" What are your thoughts or questions?

I will provide you with a detailed information letter that I plan to distribute to potential participants. This letter includes facts and practical information about the study, in addition to contact names and numbers.

Respondent: I am not interested.

Researcher: Ok, thank you! Have a nice day.

OR

Respondent: I have some questions.

Researcher: Ok, what are your questions?

(allow time for Q & A)

OR

Respondent: Yes, I am fine with my relative participating in this project.

Researcher: Thank you so much. Are you willing to provide me with your email address so that I can send the information sheet for you to read over on your own time, as well as a consent form? Please feel free to call or email me with any questions about either. Please feel free to discuss this with family or friends, too. Do you have any questions right now?

Respondent: Yes

Researcher: Ok, what are your questions?

(allow time for Q & A)

OR

Respondent: No.

Researcher: Ok, Thank you again. Once I have ensured I have consent for everyone, I will arrange a date in the next few weeks to do the workshop. I will then conduct the workshop and make some art with your relative! I am looking forward to it.

This research project has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40923). 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.

For all other questions, please contact myself, Katia Engell, at 416-708-2393 or by email at kengell@uwaterloo.ca. You may also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

Appendix H: Participant Appreciation Letter

University of Waterloo

Date

Dear (Insert Name of Participant),

I would like to sincerely thank you for your participation in my research project about the potential for friendship in the caring process. As a reminder, the purpose of this research project is to understand and challenge how friendship is perceived between residents and paid care partners working and living in Long Term Care (LTC) homes.

Friendship is rarely acknowledged in LTC settings, yet many are calling for new models of care which emphasize the importance of relationships in care settings. The insights you shared throughout this project will help re-imagine friendship and contribute towards a better understanding of what friendship means within the LTC context, as well as what benefits friendship could bring to persons living and working in LTC homes.

Please remember that your participation in this research project will be confidential. Once all the information is gathered and analyzed, I plan to share the information from this project with the research community and the long term care community through presentations, conferences, articles, discussions, and artwork. Once the research is completed, hopefully by Fall 2019, I will send you a summary of my findings. In the meantime, if you have any questions about the project, please do not hesitate to contact me by email or telephone as noted below.

This research project has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40923). 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.

For all other questions, please contact myself, Katia Engell, at 416-708-2393 or by email at kengell@uwaterloo.ca. You may also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

Thank you again for your participation and valuable contributions within this project. I hope that this has been an enjoyable and interesting experience for you.

Sincerely,

Katia Engell
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
416-708-2393
kengell@uwaterloo.ca