

“I could never live without a dog”: Re-storied narratives of persons living with dementia and
their companion animals

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

More than half of Canadians choose to share their homes with companion animals, and for some people an animal may be one of the most important companions in their life. Most research on human-animal companionship highly regards the utility and influence of animals on the health and wellbeing of humans, and countless studies explore the impact of animal-assisted therapies and interventions among marginalized populations, including persons with dementia. However, these approaches fail to conceptualize the interactions and relationships people have with animals as reciprocal, personal, and dynamic. Guided by relational theory and a social citizenship framework, this project aimed to explore how persons with dementia story their relational experiences with companion animals, and sought to understand how companion animals contribute to life and leisure experiences. The methodological approach was structured by narrative inquiry, wherein relational narratives were co-constructed. Photovoice was employed with seven persons living with dementia in the community who share their homes with cats and dogs. Participants were asked to take photos that illustrated their relationships with companion animals, which were used during one-on-one interviews to guide conversations. Data was analyzed using McCormack's (2004) storying stories approach and represented as a re-storied narrative collection (including short stories, poetry, a monologue, photo storybook, and comic-inspired photo essay). I chose to represent my re-storied narratives in different formats based on variations in storytelling. These narratives illustrate the significance and complexities involved in the relationships between persons living with dementia and their companion animals. These stories connect to a number of concepts from Bartlett and O'Connor's (2010) social citizenship conceptual framework and illustrate how persons living with dementia practice citizenship in their daily lives. Caring for animals involves important roles and responsibilities, further, there is a sense of purpose that comes with fulfilling these responsibilities. Continuing to care for animals emphasises persons with dementia as developing and retaining skills and abilities, making intentional contributions to the lives of themselves and others. These relationships are characterized by togetherness and reciprocity, where persons with dementia and their animals share experiences and companionship. By sharing the stories of persons living with dementia from a social citizenship perspective, alternate narratives of dementia are introduced that challenge the dominant biomedical and tragedy discourses of dementia, and provide new perspectives that include persons with dementia within public and private spheres of life as active, contributing citizens.

Key words: dementia, companion animals, animal-human relationships, social citizenship, relationality, narrative

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TABLE OF CONTENTS

CHAPTER ONE: PREFACE	1
Arriving at My Research Topic	1
Dementia	2
Dementia and Animals	6
Animals and Health and Wellbeing	7
An Introduction to My Theoretical Framework	8
Purpose and Research Questions	11
Summary	12
CHAPTER TWO: CONTEXTUALIZING EXISTING RESEARCH	14
My Theoretical Framework	14
Relational theory.	15
Connection.	15
Disconnection.	17
Reconnection.	19
Understanding disability and relationality.	19
A social citizenship approach.	21
Dementia and disability.	21
Social citizenship.	22
Relational citizenship.	24
Animals in the Dementia Context	25
Assistance dogs.	25
Therapeutic recreation.	26
Animals as “therapies”.	28
Defining animal-assisted interventions.	29
Why animals?	30
AAI and physical wellbeing.	32
AAI and social wellbeing.	32
AAI and emotional/psychological wellbeing.	34
AAI and “behaviours”.	36
Limitations of AAI for persons with dementia.	38
Animals as Companions	40
Companion animals and human health and wellbeing.	43
Companion animals and physical health and wellbeing.	43
Companion animals, social support, and emotional wellbeing.	47
Ownership versus attachment to companion animals.	51
Considering power.	54
Attachment, companion animals, and leisure.	56
Companion Animals and Persons Living with Dementia	59
Companionship, purpose, and continued engagement.	61
Persons living with dementia in the community with companion animals.	63
Some challenges of companion animals.	67
My critique of the dementia and companion animal literature.	68
Summary	69
CHAPTER THREE: MY NARRATIVE INQUIRY METHODOLOGICAL FRAMEWORK	71

Why Narrative Inquiry?	72
Narrative Inquiry	74
Narrative Methods	77
Visual and arts-based narrative methods.	78
Narrative inquiry and dementia.	80
Storying Through Photovoice	83
Participant recruitment.	84
Participants.	85
Photovoice.	87
Photovoice research process.	90
Transitioning from Telling Stories to Re-Telling	94
Narrative Analysis	95
Storying stories.	96
Active listening.	96
Narrative processes.	97
Language.	98
Context.	99
Moments as photos.	102
(Not) returning stories to participants.	103
My Re-Storying Process	104
Considering Reflexivity	107
Ethical Considerations	109
Ethical research process.	112
CHAPTER FOUR: RE-STORIED NARRATIVES	115
My Role as Storyteller	115
Role of the Reader	116
My Reflections on Storytelling Methods/ Representation Styles	117
SHORT STORY COLLECTION	121
1. <i>I Can't Take It Anymore, It's Too Lonely.</i>	121
2. <i>There's A Rescue Kitty Out There With My Name on it.</i>	123
3. <i>A Match Made in Heaven.</i>	125
<i>She's My Cat</i>	131
<i>I Could Never Live Without a Dog</i>	132
<i>He's My Everything</i>	136
<i>Back to the pound</i>	139
<i>Play</i>	139
<i>Shit</i>	140
<i>Brush</i>	140
<i>Love</i>	140
<i>I Got the Best Dog</i>	141
<i>Wherever I am, She Wants to Be</i>	143
CHAPTER FIVE: A CONVERSATION ABOUT THE RE-STORIED NARRATIVES	145

Let's Return to Theory	147
Social Roles, Responsibility, and Purpose	148
Roles and responsibilities.	148
Purpose.	149
Continuity.	151
Participation and Contributions	152
Unconditional compassion.	153
Intentionality.	155
Agency and creative strategies.	156
Growth	159
Togetherness and Reciprocity	160
Friends and family.	162
Companionship.	164
Disconnection and Reconnection	166
CHAPTER SIX: EPILOGUE	170
Significance and Implications	170
Broadening the dementia context.	170
Challenging stigma.	172
Discrimination	173
Moving Forward	178
Conclusion	181
AFTERWORD	182
REFERENCES	185
APPENDIX A: EMAIL SCRIPT FOR CONTACTING AGENCIES	201
APPENDIX B: VERBAL SCRIPT FOR MEETING WITH AGENCIES	202
APPENDIX C: PARTICIPANT INFORMATION LETTER AND STUDY FACT SHEET	204
APPENDIX D: RECRUITMENT POSTER	207
APPENDIX E: DECLARATION OF VERBAL CONSENT FORM FOR PARTICIPANTS	208
APPENDIX F: DECLARATION OF INFORMED CONSENT FORM FOR PARTICIPANTS	210
APPENDIX G: STUDY REMINDER POSTER	212
APPENDIX H: INFORMATION LETTER FOR PHOTOS	213
APPENDIX I: INFORMED CONSENT FOR PHOTOS	214
APPENDIX J: INTERVIEW CONVERSATION GUIDE	215
APPENDIX K: PARTICIPANT APPRECIATION LETTER	217

CHAPTER ONE: PREFACE

“Animals are such agreeable friends – they ask no questions, they pass no criticisms”

– George Eliot (1894, p. 202)

Arriving at My Research Topic

I have been drawn towards animals for as long as I can remember. I have always had dogs in my family, and my mom likes to remind me that “dog” was one of my first words. When I see an animal, I feel an instinctual pull to meet them, to interact. There is something about soft fur, big round eyes, and a joyful disposition that I simply cannot resist. I can have trouble adequately expressing my feelings through words, but animals have a genuine honesty, and many possess the ability to pick up on emotions without having to say anything at all.

Despite my affection for all companion animals, there is something to be said for the close relationship I have developed with my own dog, Ruby. She makes me smile and laugh every day, not because she is necessarily trying to be funny, but she’s just herself – a playful, affectionate, alert, happy little dog. I miss her company when I go away on vacation. My home feels empty when she is at the groomers for a few hours. She sleeps beside me, and we cuddle in the evenings. She inspires me to get out of bed on dark mornings, to bundle up when it’s cold outside, and to go for walks because we take care of each other. She is my constant companion, but I am also hers. I always agree to play when she brings me her ball for fetch. We go for long walks and off-leash hikes so she can run and explore new smells, and meet new people. We go to dog-friendly beaches in the summer because she loves to swim and play in the water. I take her to dog daycare so she can play with other dog friends and be a part of a pack. We have been together almost every day for the past six years, and I cannot imagine what my life would be like if we did not have each other.

I am not alone in my love and affinity for my canine companion. People host birthday parties for their dogs (McAteer, 2012), dress them up for Halloween costume parades (Abe, 2019), attend “yappy-hour,” where dogs play and humans socialize (Greenebaum, 2004). Social media accounts document the lives of companion animals; one cat even holds a Guinness World Record title for being the most popular cat on Instagram, with over 4 million followers (Campbell, 2019). Some older adults will outright refuse certain medical procedures if it means being away from their animals (Peacock, Chur-Hansen, & Winefield, 2012). In thinking through how important animals are to people’s lives, I started to wonder what these relationships are like for persons living with dementia.

Relationships are central to our lives, to our identities, and to our wellbeing (Jordan, 2004a; Nedelsky, 2011). Humans are relational beings and seek connectedness with others (Jordan, 2004a). For some, including myself, connectedness includes relationships with companion animals. In fact, companionship is credited as the most common reason for having an animal in North America (McNicholas, 2014; Robinson, 1995), and many people consider their animals to be friends or family members (Cohen, 2002; Greenebaum, 2004; Power, 2008; Rudy, 2011; Walsh, 2009a, 2009b). It is the lasting and caring attachment to animals that makes these relationships so meaningful and important (Thomas, 1996). As people age, their animals may become the most important companion in their lives (Anderson, 2008), particularly for isolated older adults, or for individuals facing changes in health and wellbeing (Beck & Katcher, 2003; Peretti, 1990), such as people living with dementia.

Dementia

The World Health Organization (WHO) has declared dementia a worldwide public health priority (WHO, 2017). It is reported that dementia is one of the most, if not *the most* significant

cause of disability in Canadians over sixty-five years of age (Dudgeon, 2010), “ahead of cancer, cardiovascular disease and stroke” (Chambers, Bancej, & McDowell, 2016, p. 12). In June 2019, Canada launched the first national dementia strategy. *A Dementia Strategy for Canada: Together We Aspire* aims to develop an action plan: (1) prevent dementia, (2) advance therapies and find a cure, and (3) improve the quality of life of persons living with dementia and care partners (Public Health Agency of Canada, 2019a). This strategy was developed in consultation with persons living with dementia, care partners, health care professionals, public health ministers, researchers, and dementia advocacy representatives. A national dementia strategy first and foremost acknowledges the impact of dementia on Canadian society and individuals, and aims to ensure all Canadians impacted by dementia receive the supports and services they require (Alzheimer Society of Canada [ASC], 2019).

An important implication of this research addresses the calls from Alzheimer’s Disease International (ADI) and the Canadian National Dementia Strategy to develop effective strategies to address the stigma of dementia (Batsch, Mittelman, & ADI, 2012; Public Health Agency of Canada, 2019b). According to Goffman (1963), stigma refers to a social attribute which distinguishes someone as undesirable, abnormal, and/or inferior to others. Persons are often stigmatized and stereotyped due to “an undesired differentness” (Goffman 1963, p. 5). In the dementia context stigma is complex and can have various consequences. In the *What We Heard Report: Informing a dementia strategy for Canada*, impacts of stigma are explained:

People living with dementia often face stigma related to others’ assumptions of their capabilities. This stigma can lead to discrimination in the workplace, in the community and in interactions with the health system. Stigma and discrimination can also contribute to fear in seeking diagnosis, resulting in late or missed diagnoses, social isolation and diminished quality of life. (Public Health Agency of Canada, 2019b, p. 15).

Both ADI and the Canadian Dementia Strategy suggest stigma can be addressed by changing public perceptions of dementia through education; “more understanding and awareness of the personal perspective would reduce negative connotation, lead to societal empathy, reduce fear and therefore reduce stigma” (Batsch et al., 2012, p. 10). The stigma associated with dementia is therefore both a societal concern and a personal concern for many individuals and families. In hearing from more persons living with dementia, I am optimistic that personal and societal perceptions of dementia might change.

There are at least 564,000 Canadians currently living with dementia, a number that is projected to reach 937,000 in the next fifteen years (ASC, 2016a). The greatest risk factor of dementia is age, and unquestionably Canada’s population is aging (ASC, 2014). The number of Canadians 65 years of age and over is an increasingly fast-growing segment of the population (Statistics Canada, 2017). In fact, 2016 was the first year that there were more older adults (65 years of age and over) than children (14 years of age and under) living in Canada, as a result of our aging baby boomer generation (Statistics Canada, 2017). Statistics Canada (2017) suggests that “by 2031, close to one in four Canadians (23%) could be 65 years of age or older” (p. 5). While dementia may occur at any age, sometimes affecting people in their forties or fifties, it is most commonly diagnosed in adults over 65 years of age (ASC, 2014; Rabins et al., 2014). However, the impact of dementia reaches much further than the person who is diagnosed.

Dominant discourse rooted in a biomedical model typically tends to focus on dementia in terms of pathology (Gillard, Means, Beattie, & Daker-White, 2007). As such, dementia is often described in relation to symptoms, such as: memory loss, and changes in cognitive abilities, moods, and/or behaviours (ASC, 2016b). The biomedical model prioritizes curing, treatment, and intervention, with a focus on deficits, loss, and disease (Power, 2017). The biomedical

model's understanding of disabilities tells us that a disability is something that must be treated, remedied, and overcome with the assistance of qualified professionals (Withers, 2012). Goodley (2017) explains: "Society tends to comprehend disability as a personal tragedy inflicting damage upon the mind and body, requiring treatment, rehabilitation or (at its most logical extreme) cure" (p. 6). From a biomedical perspective: "disability is a medical problem that resides in the individual – a defect in or a failure of a bodily system that is inherently abnormal and pathological. Impairment and disability are conflated" (Goodley, 2016, p. 7). A biomedical outlook on disability and illness therefore holds that both the problem and the solution lie with the individual (Mobily et al., 2015); this model suggests that impairment is the disability.

Another discourse prevalent in contemporary media is the tragedy discourse of dementia. The tragedy discourse portrays people with dementia as: 'doomed', 'the living dead', and 'victims', who suffer a tragic 'loss of self' (Dupuis, Kontos, Mitchell, Jonas-Simpson & Gray, 2016; Kontos, 2003; Mitchell, Dupuis, & Kontos, 2013). This negative discourse constructs persons living with dementia as passive, incapable, powerless, and suffering. Such oppressive social discourse influences how people think about and interact with persons living with dementia (Mitchell et al., 2013). Language is powerful and shapes thought and practice.

In this thesis I have made an intentional effort to distance my ideas and language from the biomedical model and tragedy discourses, and challenge the negative assumptions of dementia they perpetuate. I particularly appreciate Power's (2017) definition of dementia for its outward rejection of typical medical terminology and symptomology, especially given his professional designation as a medical doctor. He states: "dementia is a shift in the way a person experiences the world around her/ him" (Power, 2017, p. 19). Everyone experiences and interacts with the world in their own ways; dementia is just another way of experiencing the world. While change

can be complex and involve loss, it can also result in new possibilities. Additionally, conceptualizing dementia as a *shift* in experience does not have a negative judgment associated with it. While change is not inherently bad, there is a tendency in research, medical discourse, policy documents, and the media to focus on what dementia takes away from people (Mitchell et al., 2013).

Dementia and Animals

The medicalization of dementia and people living with it has profound impacts on persons with dementia. For instance, persons with dementia are frequently conceptualized as in need of treatments and interventions (Dupuis, Wiersma, & Loiselle, 2012). More specifically, daily activities and experiences are only valued within the medical model as “therapies” (Dupuis et al., 2012). Music, gardening, and animals become “therapy” for an intended functional improvement in physical, social, and/or cognitive domains of persons with dementia (Sylvester, 2015). In North America, therapeutic recreation/ recreation therapy is most often informed by the medical model and uses recreation interventions to elicit change in individuals with illnesses and disabilities (Sylvester, 2015).

Consistent with this, many researchers have implemented Animal Assisted Interventions (AAI) also often known as Animal Assisted Therapies (AAT) with persons living with dementia. The intention of many research projects has been to modify “responsive behaviours” (Kawamura, Niiyama, & Niiyama, 2007; McCabe, Baun, Speich, & Agrawal, 2002; Nordgren & Engström, 2014), increase socialization (Batson et al., 1998; Bernabei et al., 2013; Nordgren & Engström, 2014), and/or enhance level of engagement (Marx et al., 2010) of persons living with dementia. In such studies, the functional outcomes and performance measures are the focus, and researchers do not consider the personal experiences of persons with dementia participating

in these interventions. Further, rarely are the relationships that may form between humans and animals during the therapeutic process considered.

Animals and Health and Wellbeing

A number of researchers have also studied the impact of animal companionship on the health and wellbeing of humans outside of therapeutics. Individuals with dogs had better survival rates following a heart attack (Friedmann, Katcher, Lynch, & Thomas, 1980; Friedmann & Thomas, 1995), and companion animals were noted to provide motivation for physical activity among persons recovering from a stroke (Johansson, Ahlström, & Jönsson, 2014) and for persons living with type two diabetes (Peel, Douglas, Parry, & Lawton, 2010).

Older adults who have dogs as companions are more physically active (Raina, Waltner-Towes, Bonnett, Woodward, & Abernathy, 1999) and visit the doctor less frequently (Siegel, 1990). Additionally, a companion animal may act as a social support buffer for people dealing with stress associated with the loss of a spouse (Garrity, Stallones, Marx, & Johnson, 1989), and for men living with Acquired Immune Deficiency Syndrome (AIDS) (Siegel, Angulo, Detels, Wesch, & Mullen, 1999). Animals can also provide emotional support, for example by: reducing anxiety, depression, and loneliness; offering companionship; fulfilling a sense of security; and facilitating social interactions with other humans (Cohen, 2002; Connell et al., 2007; Knight & Edwards, 2008; Walsh, 2009a).

There has been a considerable emphasis on animals in terms of their impact on human health and wellbeing. This is evident particularly for persons living with dementia, whose interactions with animals are often tied to therapeutic interventions. But a focus on human health outcomes is also prevalent in research on animals as companions. There is a propensity to focus on what animals can and do contribute to human's wellbeing. In addition, little research has

focused on the relationship between older adults, and particularly persons living with dementia, and their companion animals. I find it problematic that interactions and relationships with animals are frequently presented in such an imbalanced way, with no consideration on the animal's experience. There is an assumed right of the more powerful (human) to receive support from the less powerful (animal), without a consideration of the relationships as mutual and growth fostering for both parties involved (Jordan, 2004a, 2004c).

An Introduction to My Theoretical Framework

My theoretical framework for this study is informed by relational theory and a social citizenship approach to dementia. Combined, these lenses provide a new perspective that challenges tragedy and biomedical discourses of dementia, and brings attention to the significance of relatedness and contributions of individuals living with dementia. I describe these frameworks in depth in the second chapter, but will briefly touch on each of them here. Relational theory brings attention to relatedness and mutuality of connection, that is, we all exist within relationships and these relationships are an essential component of our lives (Jordan & Walker, 2004). A social citizenship framework advances understanding of dementia, highlighting the complex lives of persons with dementia, including their contributions and active involvement in life and relationships (Bartlett & O'Connor, 2010).

When focus is shifted away from medical and tragedy discourses, we can see that dementia also affords opportunities. Dementia provides opportunities to live in the moment and be spontaneous; to freely express emotions and love unconditionally; to be curious and explorative; and to have more opportunities to connect (Fazio, Seman, & Stansell, 1999). Richard Taylor, a dementia advocate, wrote a book of short essays about his experiences living with dementia. His candid writing is an insightful collection of ideas, thoughts, and personal

reflections. He remarks on how his life changed after his diagnosis, and notes that the *shift* facilitated a change in his interactions with significant others in his life, and with his relationship with himself. Taylor (2007) speaks of taking more time to talk to and be with people, and of a greater willingness to initiate these interactions. He also reflects on his increased introspection and feels that he is “more in touch with *me*” (original emphasis) (Taylor, 2007, p. 78). What stands out to me is Taylor’s shift in his commitment to nourish relationships with various people in his life, including relationships with: relatives, his spouse, his dog, his students, and with himself; spending more time with people, caring about people, and increasing connections. Authentic, positive relationships contribute to our wellbeing (Jordan & Walker, 2004; Nedlesky, 2011). Essentially, as interconnected social beings we want to be with people, and find value in meaningful relationships (Nedlesky, 2011); this need persists for persons living with dementia.

Unfortunately, the vast majority of literature on dementia does not include the perspectives of persons actually living with dementia. In reading thorough much of this literature, came to understand how this practice is systemically rooted and problematic. The dominant medical and tragedy discourses denote dementia as a loss of self and abilities (Dupuis et al., 2016; Kontos, 2003; Mitchell et al., 2013), and there is a general perception that persons with dementia “are diseased, inappropriate, challenging, passive objects in need of care – ‘the living dead’” (Basting, 2009, pp. 102-103). This creates a belief that persons with dementia lack the capacity to share their experiences, and as such are unreliable research informants (Nygard, 2006). Indeed, “assuming people with dementia cannot participate in research or are unable to share views and experiences is a reinforcement of negative stereotypes of incapacity” (Wilkinson, 2002, p. 10). These practices and perspectives communicate to me that persons with

dementia are not deemed valuable citizens, nor do they have knowledge to share. This exclusion from research further reinforces their marginalization.

While small in comparison to medically orientated literature, there is a growing body of research being conducted *with* persons living with early to middle stage dementia and their care partners. Research focusing on the personal experiences of individuals with dementia challenges the dominant discourse (Dupuis et al., 2012a; Dupuis & Gilles, 2014; Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016; Dupuis, Whyte, Carson, Genoe, Meschino, & Sadler, 2012c; Genoe & Dupuis, 2014; Johnson, 2016; Ohman & Nygard, 2005; Phinney et al., 2007). Johnson (2016) argues, “people with dementia can possess a level of insight into their own experiences, emotions and difficulties which defies popular understandings of dementia” (p. 706). I believe that individuals are the experts of their own lives, and their experiences and narratives should be given more value than they currently receive. By including people with dementia and privileging their stories and voices in my study, I hope to contribute important insights on an area of research that (so far) has received little attention in the dementia context.

There are many individuals with dementia who live well, enjoy life, and continue to participate and contribute to their communities. A social citizenship perspective is important because there has been a tendency to focus on *caring for* persons with dementia (Bartlett & O’Connor, 2010). The assumption that persons living with dementia can only be understood and supported in relation to a care context prioritizes a biomedical understanding of dementia. There is no doubt that persons living with dementia do require increased support throughout their dementia journey. However, I agree with Bartlett and O’Connor (2010), who argue, we “need to go beyond care issues and to see men and women with dementia in a much more contextualized

and dynamic way – as a highly diverse group of people with the ability to affect as well as be affected” (p. 128).

Persons living with dementia are people first and as people, we have an innate need to connect with others, and contribute to relationships in meaningful ways (Jordan, 2004a). Citizenship is supported when persons with dementia have opportunities to engage in and contribute to relationships, for example, “....in comforting someone having a bad day, in their expressions of joy and sadness, in asking someone to dance, or in advocacy work such as organizing a food drive during the holidays” (Mitchell, Dupuis, Kontos, Jonas-Simpson, & Gray, pending, lines 390-392). When we look beyond care, we are able to see that persons with dementia hold many important social positions in life, which may include: friend, parent, spouse, artist, activist, volunteer, employee etc. (Bartlett & O’Connor, 2010). Thus, acknowledging the multidimensionality of persons with dementia as active social citizens is necessary for shifting the societal discourse of dementia (Basting, 2009).

Purpose and Research Questions

I believe it is vital that persons with dementia are included in research as active participants, whose stories are valued and respected for the contributions they can make to understanding what it is like to live well with dementia. Therefore, the purpose of this narrative inquiry was to understand how persons living with dementia story their relational experiences with companion animals.

The research questions guiding this study include:

1. How do persons with dementia story their relationships with companion animals?
2. How do these stories help us understand relationality and social citizenship in the dementia context?

3. How do companion animals contribute to the storying of life and leisure experiences of persons with dementia?

Summary

In this chapter I have introduced a number of important concepts that have guided my choice of a theoretical lens – relational theory and social citizenship – and informed my research topic. To sum up these topics: dementia as a contemporary societal concern; the biomedical and tragedy discourses of dementia; my understanding of dementia; persons with dementia and animals; and the importance of focusing on living well with dementia.

In the chapter that follows I expand on my understandings of relational theory and a social citizenship approach to dementia, which make up my main theoretical framework for this study. In order to provide a more thorough discussion and overview of relevant literature I further describe: dementia and therapy culture, animals as “therapies”, animals as companions, and the limited literature on companion animals and persons living with dementia. In the third chapter I provide an overview of narrative inquiry, explain how it aligns with my study, and describe photovoice, my method of data collection. I walk through my participant recruitment and photovoice research process. I also discuss *storying stories*, the narrative analysis process used, and my own re-storying process. This chapter also includes a discussion on reflexivity and ethical considerations for working with persons living with dementia.

The re-storied narratives are presented in the fourth chapter. These narratives form a short-story collection and are comprised of: dialogue-based short stories, poetry, a photo storybook, a monologue, a comic-inspired photo essay, and a short story. The re-storied stories illustrate the relationships participants have with their companion animals, show the significance of these bonds, and challenge the tragedy and biomedical discourses of dementia.

The fifth chapter involves a conversation about the re-storied narratives that incorporates both my interpretations of the stories and ties back to existing literature. In this section I also connect key stories from the re-storied narratives to notions of relational theory and social citizenship. I discuss how the re-storied narratives illustrate persons with dementia as intentional, contributing citizens, who are active and engaged in life, and consider how companion animals play a role in this for some people living with dementia.

In the sixth and final chapter, I close by identifying implications of this study and describe why I think engaging in this project was important. From a citizenship perspective, I consider some ways that persons with dementia might face discrimination in regards to maintaining relationships with companion animals. I also share some limitations and ideas for future research, and consider how I plan to move forward with sharing the learnings gained from this study.

CHAPTER TWO: CONTEXTUALIZING EXISTING RESEARCH

This chapter provides an overview of four important bodies of literature that pertain to my study. First, I begin with an in-depth discussion of my chosen theoretical frameworks, relational theory and the concept of social citizenship. Following this, I explore understandings of dementia as a disability and the pervasiveness of “therapy” culture. This leads into an overview of animals as “therapies” and therapeutic interventions. In the last section I discuss animals as companions and provide a comprehensive summary and critique of this body of literature. Each of these sections is important to help build a comprehensive understanding of what has previously been done, and highlight the prevailing perspectives, which I have come to understand generally lack a consideration for relatedness and relationships. I invite you to join me on this journey as I attempt to bring these ideas together, and identify where I fit into the story with my research.

My Theoretical Framework

My theoretical framework for this study integrates relational theory and the concept of social citizenship. The foundational aspect of relational theory is mutuality, which generally holds that we exist within series of interconnected, complex relationships (Jordan & Walker, 2004). A social citizenship framework brings attention to citizenship, that is, the human rights and participation of persons with dementia in private and public spheres of life (Bartlett & O’Connor, 2010). Kontos, Miller, and Kontos (2017) further advance social citizenship in what they term *relational citizenship*, considering the body’s agentic role in performing citizenship among persons with dementia. Using these frameworks as a lens for my research, I am interested in how the relationships of persons with dementia with their own animals may help us

understand relationality and social citizenship in the dementia context. I will discuss each of these theoretical frameworks guiding this study in detail below.

Relational theory.

Connection.

Relational theory is premised on a fluid notion of connection, disconnection, and reconnection (Jordan & Walker, 2004). Relationships are an essential component of our lives and identities; people “are both constituted by, and contribute to, changing or reinforcing the intersecting relationships of which they are apart” (Nedelsky, 2011, p. 22). Continuous engagement with relationships is an interactive undetermined process of being and becoming. Nedelsky (2011) explains: “As we act (usually partially) autonomously, we are always in interaction with the relationships (intimate and social-structural) that enable, [or limit] our autonomy. Relations are then constitutive of autonomy rather than conditions for it” (p. 46). Human beings are interdependent and influenced to varying degrees by the relationships (connections) in our lives. However, these relationships are not determinative. There is bi-directionality to these interactions; while relationships are influential and informing, individuals are also active, dynamic players in relationships. An understanding that we exist within social networks, and that identities are constituted within social relationships is termed *relational autonomy* (Mackenzie & Stoljar, 2000; Nedelsky, 2011). Social networks are simultaneously intimate, local, and global; relationships exist on many levels within culture (Jordan & Walker, 2004; Nedelsky, 2011). Who we are, and who we become throughout our lives, is influenced to varying degrees by our relationships, both personal and institutional (Nedelsky, 2011). As a result, relational autonomy differs from an understanding of “autonomy” in the sense of

independence, because relational theorists argue, “we are always dependent on others for the possibility” of connection (Nedelsky, 2011, p. 46).

A relational understanding is significant because it also acknowledges the importance of lived experiences. Our lived experiences are shaped by the various relationships we engage with, not just human relationships. Relationships with our bodies, with our thoughts, with our memories, and with time and space are all meaningful points of connection (Arai, Berbary, & Dupuis, 2015). The lived experience of illness or disability is significant – the embodied experience – and should not be overlooked. We cannot ignore the embodied experience in dementia, because doing so overlooks the significance of the body as a source of agency and relatedness (Kontos, 2011, 2012). According to Kontos (2012), embodied selfhood includes: “the idea that bodily habits, gestures, and actions support and convey humanness and individuality” (pp. 2-3). Embodiment is an innate expression of the way “the body moves and behaves” (Kontos, 2005, p.556). Embodied selfhood, who we are at a pre-reflexive level, is expressed in the way we conduct ourselves, and is a reflection of interactions and relationships we have engaged in throughout our lives (Kontos, 2004). Our bodies, and the bodies of persons living with dementia, therefore tell a significant narrative about who we are and our experiences in the world.

Humans are fundamentally interconnected, and as interconnected social beings, “connection is at the core of human growth and development” (Jordan & Walker, 2004, p. 2). People want to relate to one another, to be included, and to contribute to something beyond themselves. Thus, dependency is central to the relational self, humans have a need to connect and contribute meaningfully, and they rely on others for these opportunities (Jordan & Walker, 2004; Nedelsky, 2011). When individuals experience mutual empathy, good connections, and create

strength in togetherness they experience *relational competence* (Jordan, 2004a). In other words, relational competence involves “the capacity to move another person, to effect change in a relationship, or effect the well-being of all participants in the relationship” (Jordan, 2004a, p. 15). We grow, develop, and create strength with other individuals in relationships; relational competence occurs within the process of community building (Jordan, 2004a). Connection requires a vulnerability and openness to enable mutuality, “where empathy expands for both self and other” (Jordan, 2004a, p. 15).

Disconnection.

Conversely, in relational theory, isolation and disconnection are considered the key causes of human suffering (Jordan & Walker, 2004). Disconnection may be caused by varying factors, some of which include: non-mutual relationships, fear, self-blame, feelings of shame, anger, and/or dependency (Jordan, 2004b). Isolation can have a significant impact on health and wellbeing. Relational incompetence “inhibit[s] our engagement with life and our capacity to love and to move with a sense of awareness to meet others, to contribute to their growth, and to grow ourselves” (Jordan, 2004a, p. 11). Isolation, therefore, may prevent or hinder the development and maintenance of social connection, and impact relational autonomy.

In the dementia context, people often lose significant relationships, social connections, and social roles (Harris, 2004; Ostwald, Duggleby, & Hepburn, 2002; Sterin, 2002). These lost relationships can contribute to feelings of extreme loneliness and social isolation (Harris, 2004; Swaffer, 2016), both among persons living with dementia and their care partners (Batsch et al., 2012). Kate Swaffer is a human rights activist, co-founder of Dementia Alliance International (DAI), and a person living with dementia. In her book *What the Hell Happened to my Brain? Living Beyond Dementia* (2016) she discusses her experience of dementia and loneliness:

I'm not sure the loneliness of dementia is any worse than when you are facing any other terminal disease or major crisis, except that the stigma and discrimination of dementia exacerbates the loneliness as so many cannot seem to get over their own fear of the disease and subsequently stop visiting us (p. 152).

Despite the importance of relationships, persons with disabilities and illnesses, including persons with dementia, are often excluded from social life and opportunities for meaningful engagement. It is “the social stigma of disability [that] continues to be a major barrier to the social integration of individuals with disabilities” (Lyons, Sullivan, Pitvo, & Coyne, 1995, p. 11). In being stigmatized, people with disabilities and illnesses, including persons with dementia, are excluded from participation in social networks.

However, the disconnections persons with dementia experience are not merely with other people, but also with themselves, and their own abilities. Swaffer (2016) remarks:

No drivers licence, challenges catching public transport, the high cost of relying on taxis, changes to cognition and memory, deteriorating maths, writing and language skills, changes to interpersonal relationship, lost relationships, reduced problem solving skills and many other changes due to dementia all go towards increasing the sense of loneliness (p. 156).

Disconnection is complex and multi-faceted, all at once encompassing experiences with others, with the community, and with oneself. Changes in memory can intensify feelings of loneliness, such that people may forget their loved ones visit – feeling like they are always alone – despite having supportive family relationships (Van Dijkhuizen, Clare, & Pearce, 2006). While, intentionally distancing oneself from others can be a coping strategy; some persons with dementia choose to isolate themselves from others to avoid potential embarrassment (Ostwald et al., 2002).

Persons living with dementia may lose important friendships as a result of misunderstandings and stigma of dementia (Harris, 2004; Sterin, 2002). While connection is desirable and satisfying, it does not occur without minor and major disconnections. As Jordan

(2004b) states: “Disconnections are inevitable. Empathetic failures are inevitable. Hurt feelings and disappointments are inevitable” (p. 55). *Relational awareness* involves an acknowledgment of the fluidity of relationships, from connection to disconnection, and reconnection (Jordan, 2004b). Relationships are in constant flux and undetermined.

Reconnection.

While we all experience disconnections at one point or another, “self-empathy and empathy for others can help transform these disconnections and lead to a compassionate attitude in the struggle to stay connected” (Jordan, 2004b, p. 55). Relational theory holds that while complex, it is important to develop self-awareness, and awareness of others in order to learn from our experiences and relational patterns (Jordan, 2004b). Relational awareness therefore supports a transformation from disconnection to relatedness (Jordan, 2004b). I have chosen to use relational theory because it really highlights that while relationships are so important and prominent in our lives, they are equally as complex and imperfect. The constant fluidity from connection to disconnection to reconnection, and varying spaces in between, speaks to the honesty of how relationships are lived and embodied. It is these shared imperfections which connotes the “we” of relatedness.

Understanding disability and relationality.

In this thesis, I adopt a social-relational understanding of disability. In contrast to the medical model, the social-relational model asserts that disability is socially created (Thomas, 2004). More specifically, “disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society” (Union of the Physically Impaired Against Segregation Fundamental Principles of Disability, 1975, cited in Finkelstein, 2001, p. 1). Within the disability literature, social relational theory acknowledges

that people do have impairments, but it is “forms of oppressive social reaction visited upon people with impairments” that creates *disability* (Thomas, 2004, p. 579). For example, people with dementia have *impairments* (e.g., changing cognitive abilities) that pose challenges, however, it is broader societal and structural conditions that create disability (Mitchell et al., 2013; Thomas, 2004). This includes oppressive social discourses that construct dementia as a ‘tragedy’, and people living with it only as ‘patients’, and their experiences only as ‘suffering’ (Mitchell et al., 2013). Subsequently, these discourses create and perpetuate stereotypes of persons with dementia that serve to marginalize, stigmatize, and oppress people.

A social-relational lens also considers how individuals’ bodies are actively involved in the lived experience of disability/ illness (Thomas, 2004). A social-relational understanding of disability identifies the body as an entity onto itself, and recognizes the significance of the embodied nature of illness and/or disability (Williams, 1999). Williams (1999) further explains: “The body in short, diseased or otherwise, is a real entity, no matter what we call it or how we observe it. It also, like all other social and natural domains, has its own mind-independent generative structures and causal mechanisms” (p. 806). The body therefore is an essential component of relationality and the experiences of persons with illnesses/disabilities. It is the interaction between impairments and broader societal conditions which result in disability. It is neither one or the other, but rather “an emergent property one involving the interplay of physiological impairment, structural enablements/constraints and socio-cultural elaboration over time” (Williams, 1999, p. 813). The interactional nature of this speaks both to the relatedness of individuals with their own selves and bodies, and with their broader social-cultural environments.

Social-relational theorists acknowledge that “impairments and chronic illness directly cause *some* restrictions of activity – but such non-socially imposed restrictions of activity do not constitute ‘disability’” (Thomas, 2004, p. 581). As such, it is not merely the experience of the lived body, nor the experiences in the social world which connote disability – social-relational theory argues it is the implicit interaction and interdependence of both. Therefore, given the attention to connection and relatedness, I believe this conceptualization of disability is well aligned with relational theory and emphasizes the dynamic and fluid nature of how experiences are lived and embodied.

A social citizenship approach.

Dementia and disability.

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty that establishes human rights for persons with disabilities. The CRPD sets global legal standards for governments to promote and protect the human rights of people with disabilities (UN, 2008). As an international agreement, it views persons with disabilities as active citizens with rights to participate in and contribute to society (UN, 2008). This conceptualization of persons with disabilities is an important and significant transformation from the dominant biomedical discourse that focuses on persons with disabilities in need of treatment, protection, and/or care (UN, 2008).

According to Article 1 of the United Nations CRPD (2018): “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (para. 2). Under this broad definition of disability, persons with dementia are included, and are thus also protected under the law from discrimination. I am

informed by a social-relational framework of disability (as described above), and the UN CRPD, and as such conceptualize dementia as a disability in this thesis.

Social citizenship.

Social citizenship is a conceptual framework that focuses on human rights, and acknowledges that persons with dementia are contributing social citizens in public and private spheres of life (Bartlett & O'Connor, 2010). Bartlett and O'Connor (2010) define social citizenship for dementia studies as:

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

Social citizenship emphasizes the need for a new, broader framework that sees persons with dementia beyond health and care; if people with dementia are only seen and understood in relation to care, then their social roles are mainly perceived as 'recipients' and 'in need' (Bartlett & O'Connor, 2010). I believe this citizenship perspective is important because it considers other experiences and narratives of dementia, and the complex social roles of persons living with dementia (Bartlett & O'Connor, 2010).

The lack of social status of person with dementia is one of the main concerns for Bartlett and O'Connor (2010), and what they hope to address through a model that views persons with dementia as *citizens*. Social citizenship is guided by human rights and highlights the contributions of persons with dementia "in a range of settings and contexts, including, for example, political campaigns, self-advocacy groups, public meetings, conferences and research studies" (Bartlett & O'Connor, 2010, p. 4). Increasingly, persons with dementia are actively involved in roles and opportunities in their communities that not only challenges the tragedy

discourse of dementia, but also demonstrates their citizenship. For example, Mary-Beth Wighton is a passionate dementia advocate, the chair and co-founder of the Ontario Dementia Advisory Group, a member of the Canadian Ministerial Advisory Board on Dementia, and a person living with dementia. The contributions of persons with dementia to political, social, community, and personal contexts are significant and bring attention to the varied experiences of living with dementia, and reveal active engagement in life.

Bartlett and O'Connor's (2010) conceptual framework of social citizenship acknowledges the contributions and limitations of Kitwood's (1997a, 1997b) personhood movement and Nolan's (2004) senses framework, and proposes a new perspective to consider the wider sociopolitical perspective of dementia. This conceptual framework involves six dimensions: growth, social positions, purpose, participation, solidarity, and freedom from discrimination, which build on and expand ideas from Kitwood (1997a, 1997b) and Nolan (2004) (Bartlett & O'Connor, 2010, p. 39). *Growth* recognizes a person's ability to learn, desire to try new things, and develop (Bartlett & O'Connor, 2010). *Social positions* refer to the intersectionality of people's social positionality, recognizing the complexities of persons with dementia as holding multiple identities and statuses (Bartlett & O'Connor, 2010). *Purpose* involves recognizing that what is purposeful and meaningful varies for each individual, and may or may not be tied to past occupations (Bartlett & O'Connor, 2010). *Participation* considers the active and diverse involvement of persons with dementia in decision making, that is, "...participation will look different depending on retained abilities, personal histories and opportunities" (Bartlett & O'Connor, 2010, p. 45). The fifth dimension is *solidarity*, and expands attachment to identify connections and contributions to an individual's broader community, which may or may not include political actions (Bartlett & O'Connor, 2010). *Freedom from*

discrimination is the final aspect of this framework, they argue: “The right to be free from negative discrimination is central to citizenship” (Bartlett & O’Connor, 2010, p. 47). This framework is decidedly more critical than previous models and frameworks of dementia studies, expanding to social and political perspectives including discussions of power, agency, and sociality.

Relational citizenship.

Citizenship is therefore relational and shaped by interactions with others, and with broader social, cultural, and political structures that may support or threaten citizenship (Bartlett & O’Connor, 2010; Kontos et al., 2017). Kontos and colleagues (2017) expand the concept of social citizenship (described above) to also include embodied selfhood theory. They suggest: “Relational citizenship foregrounds the reciprocal nature of engagement and the centrality of capacities, senses, and experiences of bodies to the exercise of human agency and interconnectedness” (Kontos et al., 2017, p. 182). This inclusion of the body as relational and agentic highlights more personal and micro performances of citizenship among persons living with dementia, and accounts for expressions of citizenship throughout the dementia journey (Kontos et al., 2017).

Thus, a relational citizenship approach provides a more comprehensive social understanding of persons living with dementia. In doing so, the diversity of the dementia context and journey challenges the singular perception of the dementia experience as a tragedy and as recipients of care. Within this framework, persons with dementia are understood as active, complex people who engage in community, society, politics (Bartlett & O’Connor, 2010) and private spheres of life (Kontos et al., 2017). Bartlett and O’Connor (2010) emphasize: “...the

debate about dementia is not just about seeing a person; it is about seeing a person as an active social agent” (Bartlett & O’Connor, 2010, p. 5).

Using this framework, to inform my research approach, my intention is to share the stories of persons living with dementia as relational citizens involved and engaged in relationships and community. Before engaging in this study, I was unaware of any previous research that had taken a social citizenship approach to understanding persons with dementia in relation to companion animals. In my research, Bartlett and O’Connor’s (2010) social citizenship framework was used to consider “...the actual and potential contributions of individuals [with dementia] to everyday life” (p. 4), most notably in relation to companion animals. I chose to integrate this conceptual framework with relational theory because a relational citizenship lens can highlight the complex narratives of persons with dementia and considers their contributions and active involvement in life and relationships.

Animals in the Dementia Context

Assistance dogs.

The interest in dementia, dogs, and support is increasing. In the past few years two pilot programs have been developed that match persons living with dementia with specially trained service dogs that live in their homes. The *Dementia Dog Project* is based in Scotland, with an affiliated program in Australia called *Dogs 4 Dementia*. The goals of these programs are to help people live well in the community with dementia. However, both programs are relatively small, and only a handful of dogs have been matched with humans thus far. In addition, to partake in the *Dementia Dog Project* persons with dementia must meet fairly specific criteria. That is, be in the early stages of dementia, live at home with a full-time care partner (who does not have dementia), live in Scotland, and have a fully fenced yard (Dementia Dog Project, 2019). Because

these programs are so new, there is no research available yet on the impacts of the program on persons living with dementia, their care partners (or on the assistance dogs).

Therapeutic recreation.

Many recreation therapy/therapeutic recreation (RT/TR) approaches in both Canada and the United States have adopted the medical model to inform practice (Sylvester, 2015).

According to the American Therapeutic Recreation Association (ATRA, 2017), RT is defined as:

a treatment service designed to restore, remediate and rehabilitate a person's level of functioning and independence in life activities, to promote health and wellness as well as reduce or eliminate the activity limitations and restrictions to participation in life situations caused by an illness or disabling condition.

With this definition, there is a focus on *fixing* (restoring, remediating, rehabilitating) people and their abilities (Mobily et al., 2015). Mobily and colleagues are critical of TR's association with the medical model, which focuses on improving the functional outcomes of persons with disabilities. However, functional outcomes are considered "one of the cardinal principles of therapeutic recreation, validating treatment interventions designed to improve the health of individuals with disabilities and illnesses in order to enhance their independence" (Sylvester, 2015, p. 179). Interventions are introduced to effect measurable change (outcomes), and in doing so, leisure and recreation are TR professional's "tools" to elicit said change (Sylvester, 2015). For persons with disabilities and illnesses, this means that leisure often becomes a prescribed medical function to achieve some end, as determined by professionals (Aitchison, 2009; Dieser, 2013). Leisure is seen only as having an instrumental function, rather than being an end in itself (Sylvester, 1985). As such, associating leisure or recreation with "therapy" for persons with disabilities and illnesses is problematic because it perpetuates a medicalized view of disabilities

and illnesses as something that can be overcome, or remediated through leisure (Mobily et al., 2015).

Over thirty years ago, Sylvester challenged the association of leisure with “therapy” – this discussion is not new. Sylvester (1985) remarked, “the human urge for expression – the desire to be genuinely human, does not vanish due to the presence of dysfunction. Accordingly, therapeutic recreation may venture beyond dysfunction and mundane treatment roles by directly supporting the neglected area of free human expression” (p.11). All persons deserve the opportunity to be and express themselves. Freely choosing a leisure pursuit for its own sake, and being prescribed an activity to achieve functional outcomes are vastly different experiences (Sylvester, 1985).

The biomedical approach in RT/TR has significant implications for persons with dementia. Past leisure interests are often adopted by recreation therapists to create therapy programs for persons living with dementia, with intended functional outcomes and goals; leisure preferences become “therapy” (Dupuis, Whyte, & Carson, 2012b; Dupuis et al., 2012c). For example, animal-assisted therapy, horticulture therapy, and music therapy are common interventions that link leisure preferences to therapeutics. In doing so, leisure becomes medicalized through assessments, prescriptions, monitoring, documentation, and evaluations (Dieser, 2013; Dupuis et al., 2012b). Recreation guides outline how to develop and implement activities (Dupuis et al., 2012b) in order to improve functional outcomes in the social, physical, cognitive, and affective domains of persons with dementia (Sylvester, 2015). Persons who have always had an animal, or enjoy the company of animals may be “prescribed” animal-assisted therapy (AAT), if such an opportunity or program exists within the LTC home where a person may live or adult day program they may attend. In this view of leisure as activity, leisure

becomes a prescriptive tool used by recreation professionals to elicit functional change (Dieser, 2013; Dupuis et al., 2012b; Sylvester, 2015). As such, the enjoyment that comes from leisure is often considered an insignificant side-effect (Dieser, 2013; Genoe & Whyte, 2015), and opportunities for meaningful engagement and the experiences of leisure are absent (Dupuis et al., 2012b; Genoe & Whyte, 2015; Mobily et al., 2015).

In the next section of this review of literature, and as a way to provide context for my study, I first present a discussion on animals as health “therapies”. Given my above critique of leisure as therapy for persons with illnesses and disabilities, it is necessary to highlight how prevalent this topic is in research and literature. I felt it was important to share with readers the extent of research that has been conducted on the topic of animal “therapies” with varying populations, in different settings, across the lifespan, and cross-culturally. While the literature is extensive, I find the focus on animals as therapeutic tools quite problematic. The literature perpetuates the medicalized idea that persons with illnesses and disabilities need fixing, restoring, and rehabilitating, and that animals can assist with this “treatment” process. Animals are frequently positioned as “tools” to help facilitate outcome-focused health interventions. With such an approach, there is often no regard for relationships between humans and animals. A medical focus perpetuates negative ideologies about persons with illnesses and disabilities, and (problematically) continues to dominate societal discourse.

Animals as “therapies”.

One of the first documented cases of the use of animals for therapeutic purposes occurred in the eighteenth century in a psychiatric hospital in Britain, in which “patients” were encouraged to take care of animals to foster independence (Anderson, 2008). Florence Nightingale, known for her compassionate care approach also advocated for animal companions

for persons with chronic illnesses and disabilities (Anderson, 2008; Beck & Katcher, 2003; Nightingale, 1969). In her book *Notes on Nursing*, first published in 1859, Nightingale wrote: “A small pet animal is often an excellent companion for the sick, for long chronic cases especially” (1969, p. 103). An acknowledgment of the therapeutic influence of animals on persons with illnesses and disabilities is not a recent insight. Contemporarily, animals continue to be used in therapeutic settings with a variety of populations, some of which include: children with disabilities, persons living with mental health challenges, individuals recovering from illnesses and procedures, and persons living with dementia.

Defining animal-assisted interventions.

In research and literature, the therapeutic use of animals is often referred to as: Animal-Assisted Interventions (AAI), Animal-Assisted Therapy (AAT), and/or Animal-Assisted Activities (AAA). While similar, these terms do have different implications. According to Pet Partners (formerly the Delta Society), one of the largest international and well-known organizations in animal therapy, the distinctions are as follows: “Animal-assisted interventions are goal oriented and structured interventions that intentionally incorporate animals in health, education and human service for the purpose of therapeutic gains and improved health and wellness” (n.d., para. 1). As an umbrella term, AAT and AAA are types of animal-assisted interventions. “In these interventions, the animal may be part of a volunteer therapy team working under the direction of a professional or an animal that belongs to the professional” (Pet Partners, n.d., para.1). AAT involves “a goal oriented, planned, structured and documented therapeutic intervention directed by health and human service providers as part of their profession” (Pet Partners, n.d., para. 2). AAT is intended to cause improvements in an individual’s physical, mental, social, and/or emotional health (Anderson, 2008; Kruger &

Serpell, 2006). As a therapeutic tool, animals are considered “living instruments that can be used to affect positive changes in patient’s self-concept and behavior” (Kruger & Serpell, 2006, p. 26). AAT involves a formal approach, where animals are used to effect change at an individual level of functioning. AAA are more informal, less focused on functional outcomes, and as a result “provide opportunities for motivational, educational and/or recreational benefits to enhance quality of life” (Pet Partners, n.d., para. 4). AAA “are delivered by a specially trained professional, paraprofessional and/or volunteer, in partnership with an animal that meets specific criteria for suitability” (Pet Partners, n.d., para. 4). Including animals as therapeutic interventions, whether classified as AAI, AAT, or AAA, focuses on the use of animals to affect change in humans’ functioning, and are well-aligned with the branch of therapeutic recreation informed by the medical model.

Why animals?

It is thought that some of the inherent qualities of animals make them well-suited to providing therapeutic opportunities (Kruger & Serpell, 2006). Visiting with an animal has been shown to lower blood pressure and anxiety, both during and after the visitation, suggesting animals can provide a relaxation effect for persons who enjoy their company (Cole, Gawlinkskin, Steers, & Kotlerman, 2007). Dogs are also conduits for facilitating new relationships. The number of social interactions that occur when accompanied by a dog in public spaces is greater than for persons unaccompanied by a dog (McNicholas & Collis, 2000). As such, animals seem to have a way of bringing people together and increasing opportunities for socializing. Even when not in the presence of an animal, they provide a common topic of conversation and source of connection. Additionally, animals have a way of capturing our attention, and providing a focus (Kruger & Serpell, 2006). While the most common therapy

animals are dogs, researchers and practitioners also employ other animals, including: horses (Borioni et al., 2012; Freund, Brown, & Buff, 2011; Snider, Korner-Bitensky, Kammann, Warner, & Saleh, 2007), donkeys (Borioni et al., 2012), cats (Souter & Miller, 2007), and interestingly, dolphins (Antonioli & Reveley, 2005). There is an increasing development of realistic plush and robotic animals, however, people prefer to interact with real dogs over robotic ones (Marx et al., 2010). It is thought the innate qualities of animals make them well-suited for therapeutic opportunities, particularly among persons with disabilities and illnesses.

Animal-assisted interventions have been employed cross-culturally (Antonioli & Reveley, 2005; Colombo, Buono, Smania, Raviola & De Leo, 2006; Kawamura, Niiyama, & Niiyama, 2007; Kovács, Rózsa, & Rózsa, 2003; Nordgren & Engstrom, 2014), and across the lifespan (Bernabei et al., 2003; Borioni et al., 2012; Colombo et al., 2006; O’Haire, 2013), often focusing on persons with illness and disabilities. Targeting in particular, children with autism spectrum disorder (Martin & Farnum, 2002; O’Haire, 2013), mental health diagnoses (Ballureka, Muela, Amiano, & Caldentey, 2014), and cerebral palsy (Snider et al., 2007). Among adult populations, researchers have focused on persons with intellectual disabilities (Borioni et al., 2012), depression (Antonioli & Reveley, 2005; Souter & Miller, 2007), schizophrenia (Kovács, et al., 2003), fibromyalgia (Marcus et al., 2013), chemotherapy patients (Orlandi et al., 2007), incarcerated women (Jasperson, 2010), and persons recovering from joint replacements (Harvey, Vlassess, F.R., Vlassess, P. H., Ludwig-Beymer, Hackbarth, 2015). Additionally, among older adults, researchers have implemented AAI with persons living with schizophrenia (Barak, Savorai, Mavashev, & Beni, 2001), residents in LTC homes (Colombo et al., 2006), persons with dementia attending a day program (Mossello et al., 2011), and persons living with dementia in LTC homes (Batson, McCabe, Baun, & Wilson, 1998; Bernabei et al., 2003; Kawamura et al.,

2007; Majić, Gutzmann, Heinz, Lang, & Rapp, 2013; Marx et al., 2010; McCabe, Baun, Speich, & Agrawal, 2002; Nordgren & Engström, 2012; Nordgren & Engström, 2014).

The AAI-focused research and literature has explored a range of outcomes. In the next few sections I have broken down AAI research by health/wellbeing focus, including: physical, social, emotional/psychological, and “responsive” behaviors for convenience. Despite the organization, these categories are not rigid, distinct silos because health and wellbeing is holistic and dynamic.

AAI and physical wellbeing.

In terms of physical and physiological changes in health, researchers have identified the impact of AAI on self-reported pain, muscle tone, and walking ability. For example, “therapy” dogs were introduced to outpatients with fibromyalgia in a waiting room. Participants reported a range of improvements, including: pain, mood, and measures of distress after interacting with dogs (Marcus et al., 2013). Similarly, persons recovering from a full joint replacement in hospital receiving AAT required less pain medication than patients not receiving AAT (Harvey et al., 2015). AAI has also been used among children with cerebral palsy, with the intent to improve physical functioning in muscle tone of the trunk and hips; there are results of short-term positive effects for children with cerebral palsy engaged in therapeutic horseback riding (Snider et al., 2007). Lastly, in a case study of an 84-year old woman living with dementia in Sweden, researchers noted that her walking ability improved as a result of going for weekly walks with a dog and it’s human companion (Nordgren & Engström, 2012).

AAI and social wellbeing.

While humans are fundamentally interconnected (Nedelsky, 2011), many individuals lack meaningful relationships and friendships, particularly people excluded from participation in

community life (Lord & Hutchison, 2017). Improvements in social integration and interaction are commonly intended outcomes for AAI, and have been noted among older adults living with schizophrenia (Barak et al., 2001), adults with intellectual disabilities (Borioni et al., 2012), incarcerated women living with mental health challenges (Jasperson, 2010), children with Autism Spectrum Disorder (O’Haire, 2013), and persons living with dementia (Batson et al., 1998). Interacting with “therapy” dogs and their human companions provides opportunities for persons with dementia to engage in conversations, and reminisce about their own companion animals (Marx et al., 2010; Nordgren & Engström, 2014). Batson and colleagues (1998) report that non-verbal communication improved in persons with dementia when a “therapy” dog was present in the room, which included: increased looking, smiles, contact, and physical warmth. Additionally, in a review of literature on AAI and dementia, Bernabei et al. (2003) noted one of the most consistent findings across studies is that AAI increased the frequency and time persons living with dementia spent socializing when in the presence of a dog.

There is frequently a particular focus on change occurring at an individual level within AAI. For example, Nordgren and Engström (2014) state: “When AAI is used in dementia care the human-animal bond is *used to reduce* symptoms and *increase* social engagement and communication” (emphasis added) (p. 8). Researchers intending to improve the quality of life (Nordgren & Engström, 2014), improve social interaction (Batson et al., 1998), and/or level of engagement (Marx et al., 2010) of persons living with dementia, often place the blame for social isolation on dementia (the perceived impairment), with little acknowledgment of the social and cultural climate which contributes to the isolation of persons with disabilities and illnesses. Additionally, although Nordgren and Engström (2014) use the term *human-animal bond*, they do not acknowledge this interaction as a bi-directional, dynamic relationship. While researchers

seem to acknowledge the impact of animals on humans, many do not look at the impact of humans on the “therapy” animals, or the relationships that develop during their time together. On the contrary, in using a dog to help teach healthy coping skills, women in Jasperson’s (2010) study were asked to consider how experiences may have felt for the dog. Despite this one study, participants are not commonly asked to consider an animal’s perspective when engaged in the therapeutic “intervention”.

AAI and emotional/psychological wellbeing.

Researchers have also been interested in the potential impact of animals on the emotional wellbeing of persons with varying illnesses and disabilities. Souter and Miller (2007) report that both cats and dogs are effective at improving symptoms of depression in adults. When visited by a “therapy” dog, people receiving chemotherapy reported a significant decrease in depression and anxiety (Orlandi et al., 2007). In a randomized controlled study, dolphin-assisted therapy alleviated symptoms of depression after two weeks of treatment (Antonioli & Reveley, 2005). Participants reported an improvement in emotions as a result of closely interacting and swimming with dolphins (Antonioli & Reveley, 2005). While definitely innovative and interesting, dolphin assisted therapy is evidently not an accessible treatment option for the majority of people living with depression.

AAIs have also been implemented with persons with mental health challenges, a distinctly marginalized and stigmatized population. Incarcerated women who were part of an inpatient mental health program exhibited a substantial decrease in anxiety and depressive symptoms as a result of interacting with a “therapy” dog during an 8-week psycho-educational group program (Jasperson, 2010). Many of the women looked forward to seeing the dog each week, and “the anticipation made them feel excited and happy” (Jasperson, 2010, p. 426). The

presence of a dog also motivated adults living with schizophrenia to participate in a rehabilitation therapy group (Kovács et al., 2003). While not an intended outcome, dogs gave participants something to look forward to, and contributed to the experience of group therapy sessions.

Experiencing joy in daily life is important for wellbeing. Children with Autism Spectrum Disorder had a “happier, more playful mood and an increase in energy” when in the presence of a dog during therapy sessions intended to address prosocial behaviours (Martin & Farnum, 2002, p. 667). Joy was also experienced among persons living with dementia in Sweden, as a result of interacting with dogs (Nordgren & Engström, 2014). In an Italian day program, interacting with “therapy” dogs increased positive emotions, including pleasure and general alertness of persons living with dementia, as such, measures of anxiety and sadness decreased (Mossello et al., 2011). This changed emotional state in persons with dementia persisted throughout the day, hours after the “intervention” had taken place with the participants (Mossello et al., 2011). Much as joy isn’t something that can be specifically scheduled, Power (2017) suggests:

There must be enough flexibility to go with the flow and build on a spontaneous moment. The introduction of small children or pets into a living environment is another way to create unexpected pleasures, as they are likely to be spontaneous even within a routinized activity (p. 239).

Enabling opportunities for meaningful engagement in life that enhance wellbeing, such as happiness, support people with dementia to experience joy and live enjoyable lives. Recognizing the importance of relationships and connection in how they contribute to happiness and wellbeing is also necessary.

Researchers in Italy conducted a controlled study with residents living in seven different LTC homes, in which residents were given an animal to care for (Colombo et al., 2006). Participants were divided into three groups, one group of residents received canaries in cages to live in their rooms, and were provided instructions on how to properly care for the bird,

including feeding and cleaning advice. The second group of residents were given a plant to keep in their rooms, and were provided instructions on plant care. As the control, participants in the third group were not given anything to care for. After three months, participants who cared for the canaries had improvements in their depressive symptoms, related to psychological wellbeing, in addition to quality of life outcome measures. While the participants who received the plant did benefit from the experience, the findings were not as significant as those who assumed responsibility for the canaries (Colombo et al., 2006).

The Colombo et al. (2006) study is particularly interesting because participants were given their own animal to care for and live with, rather than being visited by a trained animal and human companion. While I admire that the participants were given their own animals, I have to disagree with classifying all human-animal relationships as “therapy”. Simply because people live in a LTC home, does not mean their experiences have to be classified as “therapy”. Doing so continues to medicalize aging as an issue to be treated or managed by interventions (Dupuis et al., 2012b). In this instance in particular, the canaries lived with older adults in their rooms, and the residents were personally responsible for the daily care of their own bird. Just because an experience is *therapeutic*, does not mean it is, nor should be classified as *therapy*.

AAI and “behaviours”.

Research on dementia and “responsive” or often called “challenging” behaviours is both a problematic and growing field of study and concern (Dupuis, Wiersma, & Loiselle, 2012d). The personal expressions of persons living in LTC often become pathologized and problematized as part of the disease (Dupuis et al., 2012d). Rather than taking time to understand the root meaning of the action or expression from a personal, historical, or cultural context, actions and expressions are deemed “problematic” and thus, as a result of a medical focus, are in need of

“interventions” or strategies (Dupuis et al., 2012d). AAI is one such strategy, praised for its non-pharmacological approach, and used in an attempt to address “responsive behaviours”.

In an attempt to determine the effect of AAI on “responsive behaviours” of persons living with dementia, a dog moved into a neighbourhood in one LTC home (McCabe et al., 2002). During the four-week period the dog was a resident, “responsive behaviours” of residents decreased during daytime hours (McCabe et al., 2002). In becoming a resident, the dog lived with the human residents 24 hours a day. This situation is akin to having an animal companion, rather than visits from a “therapy” dog. The structure of such an “intervention” is different from traditional AAIs, in which dogs may visit for 30 minutes twice a month (Kawamura et al., 2007). Even though McCabe and colleagues (2002) do not specifically term this AAI/AAT, their intention was to modify behaviours, so I would argue that it does fall under the AAI umbrella classification.

Most animal interventions are introduced for a set duration of time. Kawamura et al. (2007) found long-term improvement in “responsive behaviours” for persons with dementia who visited with “therapy” animals over a 12-month period. Additionally, persons with dementia were less agitated while engaged in animal therapy sessions, as the animal interventions had a calming effect on participants (Bernabei et al., 2003). In contrast, a randomized controlled trial found “agitated” and “aggressive” behaviours of persons with dementia living in LTC homes remained the same after 10 weeks of AAI, while the same behaviours increased over the duration in the control group (Majić et al., 2013). Restlessness – often considered problematic in LTC – has also been addressed by providing residents opportunities to engage in meaningful activity. For example, for one person living with dementia, grooming and walking a dog made her feel appreciated and needed (Nordgren & Engström, 2012). Power (2017) suggests that truly

knowing people, and understanding what is important to them is necessary for supporting meaningful moments. For some individuals, meaningfulness is connected to caring for and being with animals.

Limitations of AAI for persons with dementia.

Animal interventions are frequently implemented with the intention of modifying the health and wellbeing of human participants (Anderson, 2008; Kruger & Serpell, 2006). As a therapeutic tool, animals are used to effect measurable change, guided by interventions to achieve goals (Kruger & Serpell, 2006; Pet Partners, n.d.). With functional outcomes and performance measures as the focus, most researchers to date have failed to consider or report on the personal experiences of their participants who have participated in AAIs. Additionally, there is little, if no attention paid to the relationships that form during the therapeutic process, and the impact on participants when the intervention ends. While research supports the significance of the human-animal bond, that is, the “dynamic relationships between people and animals” (Esposito, McCardle, Maholmes, McCune, & Griffin, 2011, p. 3), how people feel when relationships they have formed with animals suddenly cease at the end of the research period has not been addressed.

Mobily et al. (2015) aptly suggest, “what if disabled people really did not need therapy as much as a usual (leisure) experience?” (p. 52). Leisure and recreation should entail enjoyable everyday experiences for persons with disabilities and illnesses, just like it does for persons without disabilities. The structured, prescribed nature of therapy informed TR limits personal freedom (Sylvester, 1985). According to persons living with dementia, leisure is not about participating in particular activities, but having meaningful opportunities to remain involved, where they feel included and valued (Dupuis et al., 2012b). For persons living with dementia,

“leisure [is] a space to experience and celebrate life despite dementia” (Dupuis et al., 2012c, p. 245). Leisure is a way of affirming and enjoying life, particularly for persons living with dementia.

Unfortunately, most research studies do not include the perspectives of persons living with dementia. As so often is the case, persons with dementia are not given the opportunity to report on their own experiences and actions. Rather, assessments, observations, and evaluations are conducted by trained nursing staff, specialized professionals, researchers, and/or care partners. In many instances, the perceived emotional states and behavioural observations of persons with dementia are reported before and/or after receiving an animal intervention (Nordgren & Engström, 2014). These paternalistic practices continue to marginalize and oppress persons with dementia (Dupuis et al., 2012a). Assessing at a distance, through third parties, does not include the perspectives and experiences of participants. This practice is both informed by, and perpetuates, the ideology that persons with dementia are unreliable research informants (Nygard, 2006), not capable of contributing to research as active participants. When the voices of persons with dementia are excluded, it serves to reinforce that “persons with dementia are seen to have little if anything to contribute to the decision-making process. The focus becomes one of managing behaviours and addressing the ‘burden’ of care” (Dupuis et al., 2012a, p.429). Presently, managing “responsive behaviours” and improving socialization is the intent of much research on persons with dementia and animal-assisted interventions.

While visiting therapy animals are beneficial for some (Barak et al., 2001; Cole et al., 2007; Harvey et al., 2015; Marcus et al., 2013), and can provide positive experiences for persons living in LTC homes (Bernabei et al., 2003), the nature of a scheduled program with specific goals is unlike the usual experience of interacting with and developing a close bond with an

animal (Thomas, 1996). In LTC, specific residents are chosen to interact with “therapy” animals at particular times, and in certain locations; there is little spontaneity in these encounters, which are arranged by staff (Thomas, 1996).

This artificial construction of experiences fails to recognize persons with dementia as active, contributing citizens who are part of a broader network of relationships, and are capable of contributing to relationships. Thomas (1996) believes: “The real value of the human-animal bond comes from an enduring, caring relationship with a pet” (p. 38). It is the natural development and maintenance of relationships that makes them meaningful. Relationships are central to who we are (Nedelsky, 2011). Relationships with companion animals are mutual and dynamic (Esposito et al., 2011), and should not be overlooked as important points of connection, interrelatedness, and identity.

Animals as Companions

In this next section I provide an overview of literature that has focused on animals as companions. First, I briefly discuss the history of animal companionship and highlight the contemporary relevance of this topic. Following this, I have attempted to contextualize a large body of research that has sought to understand if, and how, animals as companions contribute to the health and wellbeing of humans. Next, I consider the significance of attachment and challenge notions of animal “ownership”. The discussion then transitions to companion animals and leisure, a limited area of research – yet one I hope to contribute to with my work. I then circle back to companion animals and persons living with dementia, and highlight the very limited literature with which this topic intersects. I shine a spotlight on where I hope to bring all these ideas together, by identifying a gap I have come to see and hope to share with others. In an effort to temper my overt enthusiasm for animals, I then discuss some challenges of companion

animals. Lastly, in an effort to draw the circle to a close I consider a number of limitations in past research, and highlight how my research aims to address a number of these concerns.

In Canada, 56% of households have at least one dog or one cat, the most popular choices for companion animals (Perrin, 2009). While more people tend to have cats (35.5%), the number of households with dogs is quite similar (32.3%) (Perrin, 2009). Other species include: fish (12%), birds (5%), rabbits and hamsters (2%), combined lizards, horses, guinea pigs, snakes, frogs, turtles, ferrets, and gerbils make up only 1%, and all other types of animals are less than 1% (Perrin, 2009). Overall, more than half of Canadian households choose to live with companion animals. Choosing an animal is personal and depends on preferences, lifestyle, past experiences, allergies, residential or environmental considerations, finances, and cultural norms (Walsh, 2009b).

In Western societies companionship is identified as the most common reason for having a pet (Robinson, 1995). Our pets are animals we genuinely care for, share our homes with, develop close relationships with, and often consider integral members of the family (Anderson, 2008; Shell, 1986; Walsh, 2009b; Wrye, 2009). In fact, people in North America often consider companion animals to be friends, family members (Walsh, 2009a, 2009b), or even children (Cohen, 2002; Greenebaum, 2004; Power, 2008). This intimate identification places animals within the inner circle of the family, and speaks to their place within household structures (Cohen, 2002).

Pet is the colloquial, affectionate term often used to refer to domesticated animals. However, *companion animal* is preferred by professionals and scholars, “to connote a psychological bond and a mutual relationship” (Walsh, 2009a, p. 465). *Human companions*, denotes that humans have a responsibility and obligation to provide for their animal’s wellbeing

(Walsh, 2009a). Whereas ‘owner’ or ‘master’ imply a power distinction, positioning humans above animals where the animal is an object (Carr, 2014). I have consciously chosen to use companion animal in my writing because it signifies that relationships between humans and animals are mutual, dynamic experiences, in which both parties experience rewards.

The relationships we have with our companion animals has reached a new level of significance in North America (Rudy, 2011). Focusing on dogs in particular, there are a number of spaces and places (for example, parks and beaches, dog festivals, dog bakeries, pet stores, daycares, agility courses, social clubs, and various other organizations and companies) for people to engage in opportunities with and for their dogs. Dogs are also treated to designer clothes, beds, accessories, organic food, obedience and behavioural training, and grooming/spa services. In 2017 alone, Americans spent over 69 billion dollars on their companion animals (American Pet Products Association, 2018). People love their animals and care for their wellbeing, often providing them with the best goods and services they can afford.

While our contemporary fondness and lavishness for animals may be viewed as somewhat extreme, having animal companions “is neither a modern phenomenon nor predominately a Western one” (Serpell, 2011, p. 11). Throughout history, humans have kept animals, and “many prominent ancient Egyptians, Greeks, and Romans were ardent pet lovers and... pet dogs and cats were frequent and long-standing denizens of the imperial households of both China and Japan” (Serpell, 2011, p. 12). The popularity of animals as companions has varied throughout history and geographically (Serpell, 2011). For example, “[i]n Europe and North America, pet keeping did not become widely respectable until the mid- to late 18th century” (Serpell, 2011, p. 12). While companion animals were initially reserved for aristocratic upper

classes, throughout history animals have become common fixtures in families of all socio-economic statuses and neighborhoods (Rudy, 2011).

Companion animals and human health and wellbeing.

The ubiquity of pets in the lives of Western populations is undeniable. As such, there is an extensive body of research and literature on animals as companions. Of this, the vast majority is from a health and wellbeing perspective. The impact of companion animals on the health and wellbeing of their human companions has been extensively explored since the 1980s, and continues to be a popular topic of inquiry. Similar to research on animal-assisted therapies, research on companion animals has sought to understand the potential impact of companion animals on the physical, social, emotional, and mental domains of health and wellbeing. In the same approach as used earlier, here I have attempted to categorize health and wellbeing research into different domains for convenience. Again, I acknowledge that health and wellbeing is holistic, and cannot simply be categorized into neat boxes. However, most health research has a particular focus and somewhat lends itself to such a classification. I want to be upfront with the reader and acknowledge that the overview that follows is a small representation of the vast body of literature on this topic. For example, a simple *Google Scholar* search using the terms “companion animal” and “human health” elicits over 675,000 entries. Therefore, the section that follows provides a general overview on this topic, and highlights a number of the most prominent and oft cited studies in this area.

Companion animals and physical health and wellbeing.

A number of sources have explored the potential impact of companion animals on the physical health and wellbeing of their human companions. It is commonly assumed that people who live with dogs are more physically active (Gillum & Obisesan, 2010; Parslow, Jorm,

Christensen, Rodgers, & Jacomb, 2005). Acquiring a dog leads to an increase in minutes spent walking (Cutt, Knuiman, & Giles-Corti, 2008) and people who have dogs walk more each week than people without companion animals (Brown & Rhodes, 2006; Yabroff, Troiano, & Berrigan, 2008). Dogs motivate their human companions to get outside and engage in physical activity (Cutt et al., 2008; Knight & Edwards, 2008).

I spend at least an hour every day walking with my dog, Ruby, and on the weekend, hiking is a frequent activity for our family. We enjoy finding new places to explore together, spending time outside and being active. We have always enjoyed participating in outdoor physical activities, and before we got Ruby, my husband and I often played tennis and went for bike rides; activities that she cannot participate in. We still do these things occasionally, but are now more likely to participate in activities that are suitable for our four-legged friend, as she is a beloved member of our family.

Researchers have also looked at the impact of companion animals on the physical health of older adults. Having a companion animal helps some older adults maintain, or begin an active lifestyle (Raina, Waltner-Towes, Bonnett, Woodward, & Abernathy, 1999). Among older adults living in Wellington County, Ontario, researchers produced longitudinal evidence that animal companionship may benefit physical and mental health (Raina et al., 1999). While no differences were found between having cats or dogs, people with animals had higher activities of daily living (ADL) scores than older persons without animals (Raina et al., 1999). Likewise, older adults with companion animals reported going to the doctor less frequently than persons without animals during a one-year period (Siegel, 1990). Particularly during stressful life events, dogs – but not other animals – provided a stress buffer against visiting the doctor (Siegel, 1990).

However, there is also research which contradicts the benefits of animals for older adults. Parslow et al. (2005) found Australians aged 60 to 64 did not experience health benefits from living with animals, rather this population had poorer mental and physical health and used more medication for pain relief. However, Parslow and colleagues (2005) suggest a few reasons for their contradictory findings. Firstly, these researchers did not assess the duration of the relationship or level of attachment to the companion animal, rather whether the older adult was the primary carer for the animal. Secondly, the measure used by Parslow et al. (2005) to capture physical health provided a broader self-assessment of physical health, beyond activities of daily living, as used by Raina et al. (1999). Lastly, the study by Parslow and colleagues (2005) was cross-sectional and therefore causal links cannot be made.

Companion animals may also contribute to the health and wellbeing of older adults living in the community with chronic health conditions. Among older adults recovering from a stroke, companion animals were noted to provide motivation for physical activity, including going for walks outdoors and playing indoors with the animal (Johansson, Ahlström, & Jönsson, 2014). Dogs can also support the physical health of older adults living with type two diabetes (Peel, Douglas, Parry, & Lawton, 2010). Physical activity is an important part of symptom management; persons without a dog were more likely to decrease walking over time, whereas going for walks was maintained among persons with dogs, as they provided companionship and motivation for regular walking opportunities (Peel et al., 2010). Both Johansson et al. (2014) and Peel et al. (2010) suggest that the potential health benefits that animals provide should be considered and perhaps communicated to “clients” by frontline healthcare professionals.

It is thought that the strength of human-animal bonds should be supported, and strategies developed to enable the connections to be sustained as people age. Peacock and colleagues (2012) suggest:

Health professionals including clinical psychologists need to understand how to best preserve human-animal bonds to prevent negative mental [and physical] health outcomes. For example, this could be achieved through the development of animal accommodating policies for residents of hospices, aged care facilities, and treatment institutions (pp. 300-301).

In particular, for persons moving into a LTC home, “one of the greatest sources of distress for the [older adults living in LTC] can be the loss of their beloved pets...the elderly person experiences not only the loss of personal independence but also the loss of a real significant other” (Baun, Johnson, & McCabe, 2006, p. 296). Separation from one’s companion animal can be an added stress during the disruptive transition to a new living environment. Therefore, Peacock et al. (2012) suggests in order to best support people to continue living well, it is essential for health care professionals to be aware of what is important to them. This may include relationships with animals for some people, and if so, strategies are necessary to support relationships. I appreciate this perspective, but am torn once again by the fixation on health outcomes.

While most LTC homes do not allow residents to move their companion animals into the home and live with them, many encourage friends and family members to bring animals in to visit regularly. One LTC home and family arranged for a resident to be able to spend her days with her dog; the family would drop off the dog in the morning, and pick it up every evening (Kogan, 2000). Kogan (2000) explains: “Immediately following the introduction of her dog, Nora changed significantly. No longer agitated, she became happier and more content. As a result of the cooperation of the staff and her family, the quality of life for this woman was

significantly enhanced” (p. 37). In recognizing Nora’s disconnection, her family and the team members transformed her disconnection into reconnection. In this instance, agitation and sadness were the result of an acute disconnection from a very specific relationship (Jordan, 2004b). This is a telling example of how important maintaining meaningful relationships are for wellbeing. Additionally, I would be interested to find out if the dog was affected by the disconnection, and subsequent reconnection with Nora, the dog’s human companion. Relationships are mutual; however, researchers and practitioners often overlook the impact of human-animal interactions on the animals, both in AAIs and companion animal relationships.

The impact of animals on the physical health of their human companions is of interest to both social scientists and medical researchers. Varied approaches and a multitude of studies have yielded mixed results, however, Headey (2003) argues, “...the state of debate is that pets probably do confer health benefits, but we don’t know precisely how” (p. 460). As such, Headey (2003) believes this important consideration would benefit from continuing attention, particularly from (yet again) a medical perspective.

Companion animals, social support, and emotional wellbeing.

There is considerable research which demonstrates a positive association between social support and health and wellbeing. Social support is often framed as a coping resource that entails the perception of, and received assistance from, significant people in one’s life (Thoits, 1986; Thoits, 1995). In being conceived in such a way, social support is understood as a tool or buffer for stress management, that has the potential to ameliorate the negative impact of stress on mental and physical health (Lepore, 1997; Thoits, 1986). However, such an approach to social support is limiting, in that the focus is one-directional. These approaches “look either only within the individual for sources of resilience or, in a one-directional way, only from the point of view

of one stressed individual looking for support from some other or others” (Jordan, 2004c, p.32). Relationships are complex, mutual experiences that may buffer against stress, but also contribute to growth and development (Jordan, 2004c).

Animals have been credited with providing emotional support to their human companions. This includes: reducing anxiety, depression, and loneliness; providing companionship; offering a sense of security; and facilitating social interactions with other humans (Cohen, 2002; Connell et al., 2007; Knight & Edwards, 2008; Walsh, 2009a). Companionship is particularly important for persons dealing with stressful life events and changes in health, including a heart attack (Friedmann et al., 1980), losing a spouse (Garrity, Stallones, Marx, & Johnson, 1989), and living with AIDS (Siegel et al., 1999).

Animals can provide a meaningful source of companionship. Personally, I consider Ruby my best friend. She sees me at my best and at my worst; our lives are inextricably tied and we spend the majority of our time together. Being with her makes me happy and feel content. She has been comforting – yet, sometimes distracting – company as I have spent countless hours writing and re-writing this thesis. At times this experience has been isolating and lonely, and I feel fortunate to have her playful energy around to remind me to take break, have a cuddle, get outside, and think about something else.

There are a number of physical and mental health risks associated with social isolation, particularly among older adult populations (Cornwell & Wait, 2009). Researchers identified that older adults living alone and without a companion animal, were most likely to report feelings of loneliness (Stanley, Conwell, Bowen, & Van Order, 2014). While older adults with companion animals were 36% less likely than people without animals to report loneliness (Stanley et al., 2014). Animals can be an important source of social connectedness for some people.

Dogs bring people together and act as social facilitators. When walking with a dog, people are more likely to meet others; dogs are a neutral, common topic of conversation and help break the ice (Wood, Giles-Corti, Bulsara, & Bosch, 2007). Walking with a dog provides an opportunity for socialization, and some people intentionally choose walking routes or places where interactions with other people walking dogs are likely to occur (Knight & Edwards, 2008). However, increased social contact is not merely restricted to other people walking dogs, but also to people without dogs (Wood et al., 2007). Dogs that are friendly with other dogs enjoy stopping on walks to sniff, that is to say ‘hello’. While the dogs are greeting, humans at the other end of the leash also often exchange pleasantries, and over time may come to know one another as a result of the dog-initiated encounters.

Researchers often look at social support within the context of traumatic, stressful, and/or life changing events. In an oft cited landmark study, Friedmann and colleagues (1980) looked at the effects of social isolation, particularly the impact of companion animals, on the health of persons discharged from a coronary care unit. They found a relationship between survival rate and animal companionship. One year after experiencing myocardial infraction or angina pectoris, almost one third of persons who did not have a companion animal died, while three people (or six percent) of the participants who had animals died within the year period (Friedmann et al., 1980). The analyses also demonstrated that the effects of animal companions were not the result of differences in the participant’s age, sex, or the physiological severity of their condition among persons with and without animals (Friedmann et al., 1980). In addition, the energy and care required to take care of a dog was not found to influence the results, as persons with animals other than dogs were still more likely to survive than persons without any animal altogether (Friedmann et al., 1980).

Friedmann and colleagues (1980) study was significant because it was one of the first which demonstrated animal “ownership” (what I prefer to call companionship) and social support as significant predictors of survival. However, like many of the studies that followed, there was no regard for relationality or attachment, the researchers were simply interested in the impact of dog “ownership” on participants’ health and mortality. As another example (34 years later), Stanley and colleagues’ (2014) also disregarded attachment, and other dynamics involved in relationships with companion animals. With a focus on loneliness among older adults, they merely asked whether respondents had an animal or not. The presence of a dog in the home, or “ownership” is different from connection or attachment. I have a number of concerns with this approach and conceptualization of animals as property, primarily that relationality is not considered, and discuss this further in the next section.

Garrity and colleagues (1989) found that companion animals provided significant emotional benefits for some older adults. Among older adult widows who lacked strong social support networks, both animal ownership and animal attachment were associated with less depression (Garrity et al., 1989). Animals motivate some widows to move forward with their lives (Knight & Edwards, 2008). During difficult and stressful times, animals still need to be taken care of, and as much as they provide emotional support, they give people a reason to live (Knight & Edwards, 2008). Thus, a companion animal may act as a social support buffer for people dealing with stress associated with the loss of a spouse. Similarly, among men living with AIDS who had few confidants, persons with companion animals reported less depression, compared to men living with AIDS who did not have an animal (Siegel et al., 1999). Therefore, for men living with AIDS, animal companionship may act as a social support buffer (Siegel et al., 1999).

Ownership versus attachment to companion animals.

It is not merely the presence of an animal in the home that is meaningful. Research has found that attachment to a companion animal is more significant than “ownership” of said animal (Garrity et al., 1989; Peacock et al., 2012; Siegel et al., 1999). Peacock and colleagues (2012) suggest: “to understand human-animal relationships and their impact on well-being, it is pivotal to assess what the relationship symbolizes for an individual rather than simply assessing ownership status” (p. 300). Attachment is different than merely having an animal in the home, as relationships between humans and animal companions are personalized, meaningful, and intimate. The human-animal bond is formed over time, and based on interaction (Horowitz, 2009). Friendships are built and often the result of shared experiences. It is in these relationships that “new ‘families’ are being formed wherein connections with other species may be more powerful than connections with other humans” (Rudy, 2011, pp. 31-32). I think it is particularly interesting to note Rudy considers these connections “families”. Such a designation is typically characteristic of intimate human-human relations. I consider Ruby to be my family; in many ways she is like a friend I get to do fun things with (e.g., hiking, standup paddle boarding, watching movies), and in other ways she is like a child whose wellbeing I am responsible for (e.g., feeding, grooming, taking to the veterinarian). Without doubt we have a strong bond and I would argue that our relationship is not necessarily “more powerful” than with other humans (as Rudy, 2011 suggests), but more so, it is a different kind of relationship altogether.

Morely and Fook (2005) argue that the relationships people have with animals should not be compared to, or conceptualized in the same way as relationships with humans. Doing so, only serves to devalue human-animal relationships as less important, and “we are prevented from appreciating what unique and different attributes such companionship might bring” (Morley &

Fook, 2005, p. 134). Relationships are experienced differently by each individual, as are the type of relationships. Therefore, researchers interested in animal companionship should attempt to understand the nature of the connection and how the relationships are meaningful, if at all.

I have come to understand that most of the research on companion animals and attachment relies on quantitative measurements. In fact, there are a number of scales, surveys, and questionnaires designed to measure a person's attachment to companion animals (Anderson, 2006). For example, Siegel et al. (1999) used the Companion Animal Bonding Scale (CABS) to assess the interaction between men living with AIDS with their animals. The CABS is an 8-item behavioral scale that "was developed to provide a sensitive scale for the assessment of self-reported behavior indicative of the establishment of a bond between a person and an animal" (Poresky, Hendrix, Mosier, & Samuelson, 1987, p. 744). Rather than relying on "ownership" status, CABS was developed to operationalize the quality of the relationship or social interactions between people and their animals (Poresky, 1987).

In considering attachment, Siegel et al. (1999) found that "the most significant impact of pet ownership was among men with high levels of attachment to their pets and low levels of confident support" (p. 167). Similarly, older adults "who are attached to their pets are likely to experience better morale than do those pet owners who are not attached" (Garrity et al., 1989, p. 42). The Siegel et al. (1999) and Garrity et al. (1989) studies acknowledge the significance of strong bonds people have with their animals, rather than mere ownership. By assessing the nature of connection, it was found that attachment to an animal was more significant than "ownership". While attachment considerations are more telling of relationships than "ownership" status, there remains a gap in understanding the nature, dynamics, and complexities of connection. As, the focus for both Siegel et al. (1999) and Garrity et al. (1989) was on what the animal can do for the

human, particularly for someone experiencing a stressful life event and lacking relationship with other humans.

Secure attachment “refers to the ability of an attachment figure to provide a secure basis, or a sense of safety when the other feels threatened or unsafe” (Amiot et al., 2016, p. 557). While humans typically serve as parental figures, taking care of their animal’s wellbeing and needs, Zilcha-Mano et al. (2011) found that animals are also viewed as attachment figures. That is, “a human-pet relationship is, to a considerable extent, a two-way street involving mutual interdependence”; humans and their animals can be attachment figures for one another (Zilcha-Mano et al., 2011, p. 12). More specifically, “the non-judgmental, unconditional love and acceptance that pet owners receive from their pets...promotes a sense of attachment security” (Zilcha-Mano et al., 2011, p. 11).

To further understand animals as attachment figures, Zilcha-Mano and colleagues looked at the impact of losing an animal. The loss of an animal elicits grief, and how people cope with loss is influenced by differences in attachment, consistent with attachment theory (Zilcha-Mano et al., 2011). For example, animal attachment anxiety was “associated with less acceptance of the pet’s death, greater anger toward the dead pet, greater preoccupation and more worries...self-and other-blame for the pet’s death, social isolation...and loss of identity and meaning” (Zilcha-Mano et al., 2011, p. 10). The type of attachments people develop with their animals impacts both how they experience relationships, and the loss of these relationships.

Research suggests that people who are highly attached to their companion animals spend more time per day with their animals than people who are moderately, or less attached (Peacock et al., 2012). In particular, 46% of highly attached individuals spent more than 16 hours per day with their animals (Peacock et al., 2012). Additionally, persons who were highly-attached to

their companion animals were less likely to undergo surgery than individuals who were moderately or least attached to their animals, if it meant spending time away from the animal. Two participants in Peacock and colleagues (2012) study claimed they would outright refuse certain medical treatments if it meant time away from their animals. The intensity of attachment to one's animal may impact personal health care decisions, and long-term health difficulties. Acknowledging the strength of these relationships, and their impact on personal health choices, highlights the significance of the bonds some people have with their animals. However, these findings still continue to privilege health outcomes for humans and a consideration for relationality is limited.

Considering power.

The focus of a number of studies highlighted above (Friedmann et al., 1980; Garrity et al., 1989; Siegel et al., 1999; Stanley et al., 2014) suggests that humans' health can benefit from the companionship provided by animals. However, the way animals are conceptualized suggests to me that they are less important than their human companions. For example, the language "owner" distinguishes the power of one (the human) over another (the animal); this power dynamic is evidently unequal. This is problematic for relationality, as Jordan (2004c) explains: "The more powerful person also has the assumed *right* to receive support from the less powerful, whenever needed and on his/her terms. This system is by definition rigid, not flexible, and decidedly not mutual" (pp. 35-36). Researchers are often interested in what an animal can give or provide to their human, without acknowledging what the animal also experiences from the relationship. Such an explicit focus on a human's condition further demonstrates the imbalance of power in the relationship. Literature emphasizes how animals can provide love, affection, comfort, relaxation, and entertainment to their human companions (Hart, 2006). Hart (2006) also

highlights that these support systems are not only unconditional, but also accessible any time of day or night. While I agree that the flexibility and availability of animal companionship is beneficial for many, I find it troubling how relationships with animals are often presented as innately imbalanced in the literature, in which the assumed right of the more powerful person (human) is able to receive support from the less powerful (animal) whenever needed (Jordan, 2004c).

The way animal companionship is often written about and presented in research suggests that animals offer “some sort of universal panacea” to influence health and wellbeing (Serpell, 2011, p.19). However, doing so fails to acknowledge that human-animal relationships are dynamic, mutual, and complex, as suggested by human-animal bond theory (Esposito et al., 2011). There is a tendency in the literature and research to focus on the impact of companion animals on marginalized populations (Morley & Fook, 2005). This perspective “suggests that the human- animal bond can only benefit those who are socially disadvantaged and marginalized, and whose lives are constructed in terms that imply they are in some way lacking or fulfilled” (Morley & Fook, 2005, p. 135). While I acknowledge that on one hand, I may be reinforcing this tendency by focusing on people living with dementia, I am also challenging it by resisting both a biomedical health perspective and an alignment with recreation therapy. Guided by a relational citizenship approach to dementia studies, my research shares the stories of engaged, active, people *in* relationships.

I also believe it is necessary to open the discussion on animal companionship beyond health and wellbeing in order to better understand relationships as mutual experiences. Relational competence involves “the capacity to move another person, to effect change in a relationship, or effect the well-being of all participants in the relationship” (Jordan, 2004a, p.15). Relational

competence is not about the power to move another, but the quality of influence for individuals and the relationship (Jordan, 2004a). I think it is shortsighted to not consider how relationships impact animals' lives, as well as the relationship between human-animal companions. Therefore, relational competency, the mutually beneficial relationships that we hope to have, are not inclusive of animal-human relationships if scholars continue to focus on the human health benefits of animals in our lives. While Knight and Edwards (2008) identified a number of ways companion animals support the wellbeing of older adults (as discussed above). I think it is perhaps more significant that they also acknowledged how “animals were reported as both recipients and donors of unconditional love” (Knight & Edwards, 2008, p. 444). The vast majority of researchers tend to focus on what the animal can do for the human as a one-way interaction. However, when looking beyond the mere presence of an animal in the home, attachment and relationality are considered. I think this is important because it speaks to the significance of connection. Considering more than half of Canadian households live with at least one companion animal (Perrin, 2009), what else makes these relationships so important and meaningful to persons who choose to share their homes and lives with animals?

Attachment, companion animals, and leisure.

Attachment also contributes to shared leisure activities with companion animals. More specifically, people “who have an emotional bond with their pets (e.g., believe pets are part of the family) will be more likely to have an attitude that favours taking them along when planning to participate in a leisure activity” (Chen, Hung, & Peng, 2011, p. 1659). People who are attached to their animals want to spend time with them and include them in leisure opportunities. I particularly enjoy participating in community events, especially when I am able to bring Ruby along. In the summer, the city of Waterloo in partnership with a few local businesses host movie

nights in Waterloo Park. When attending this event, I pack folding chairs, blankets, and popcorn for my husband and myself, and a small dog bed, water bowl, and treat for Ruby to enjoy. It is a fun opportunity for us to be outside together, spend time with friends, and engage in our community. Watching a movie in the park is a fun leisure opportunity to include Ruby, whereas she would not be allowed in a cinema.

A dog-oriented bakery in Connecticut holds a weekly after-hours social time for dogs and their human companions (Greenebaum, 2004). Yappy Hour celebrates the intimate relationships people have with their dogs, or rather their “children”, with other dog “parents” (how they identify themselves and their animals) (Greenebaum, 2004). The gathering is an opportunity for the dogs and their humans to socialize. Moreover, the group is maintained because of the friendships and community that have been built. Despite their personal differences, it is each person’s relationship with their own dog that brought them all together; “It is through the dogs that a sense of community is formed” (Greenebaum, 2004, p. 129). Identifying companion animals as family members coincides with engaging mutually beneficial leisure opportunities for some (Chen et al., 2011; Greenebaum, 2004).

To date, there has been limited research and literature on companion animals and leisure. Some researchers have looked at dog sports as serious leisure (Gillepsie, Leffler, & Lerner, 2002), including dog agility (Hultsman, 2012) and American Kennel Club (AKC) dog shows (Baldwin & Norris, 1999). Dog sports are characterized by a “culture of commitment” that encompasses substantial time and financial investments (Gillespie et al., 2002, p. 285). As Hultsman (2012) explains: “Most, if asked, will call their participation in agility an addiction that shapes their lives, yard size, vehicle choice, work and vacation schedules, residence choice and interaction with others” (p. 238). Despite the somewhat broad life involvement, a number of

benefits to these events were identified, for example: participants' relationships with their own dogs were strengthened; development of close friends and social networks who shared in the leisure pursuit; opportunity to test skills; and a time to have fun and be with their dogs (Baldwin & Norris, 1999; Hultsman, 2012).

Graham and Glover (2014) explored the roles of dogs and dog parks in facilitating social capital. Investments in social relationships built at the dog park contributed to important community networks and the development of social capital (Graham & Glover, 2014). Humans built relationships with others "based on how participant's dogs behaved toward other dogs and humans", that is, human relationships were contingent on their dogs, and other park users' dogs (Graham & Glover, 2014, p. 223). Although relationships were formed at the dog park, they further developed and extended beyond the fenced boundaries of the park (Graham & Glover, 2014).

Researchers have also explored companion animals and tourism in Australia (Carr & Cohen, 2009) and Taiwan (Chen et al., 2011). A number of people in Australia stated that they would prefer if their dog accompanied them on holidays, because the dog is a member of the family who provides companionship and adds to the enjoyment of the holiday (Carr & Cohen, 2014). Despite this desire, researchers found that in reality most dogs were never taken on holidays because dog-friendly accommodations were limited and challenging to locate (Carr & Cohen, 2014).

The most popular leisure activity people enjoy with their dogs, is simply relaxing together (Carr, 2014). I would have to agree – leisure is not necessarily about doing something specific, it is also a feeling – an experience – and is completely personal. On some days going for walks with Ruby is more of a chore, something I have to do before leaving for work or

school, for her physical and mental wellbeing, and an opportunity for her to relieve herself, despite the rain or cold temperatures. While on other days, going for walks together is a time I truly value, an opportunity to let my mind wander, enjoy the warmth of the sun, appreciate the strength of my legs that carry me, and laugh at Ruby's suspicious curiosity in leaves that blow in the wind. A reminder to be present, and thankful. So, while animals and leisure have been explored by some researchers to date, the literature is relatively new and somewhat niche. In addition, there is a tendency to focus on the experiences of the humans involved, rather than the animals (Carr, 2014). My hope is to add to this literature by considering animal-human leisure experiences more broadly, that is, as defined by participants. How do companion animals contribute to leisure experiences, if at all?

Companion Animals and Persons Living with Dementia

To date, there has been very little research looking at the relationships persons living with dementia have with their companion animals. A couple of studies have explored this from the perspectives of care partners. But, to my knowledge there is no research that has addressed this topic from the perspectives of persons living with dementia themselves – evidently, this is a gap I set out to address with my research.

Relationships with an animal may be *the most important* friendship in a person's life, particularly for older adults living alone, for individuals who are socially isolated, and for individuals facing changes in health or wellbeing (Anderson, 2008; Beck & Katcher, 2003; Peretti, 1990). In a study conducted by Connell et al. (2007), the spouse of a person with dementia explained that her husband referred to their dog as his pal, and he says the dog is "the only pal he has left" (p. 479). The companionship and support provided by an animal may be one of the most significant relationships for a person with dementia. I think this quote is important

because it speaks to two things: first, that companion animals are considered friends and loyal companions; and second, because persons with dementia are a stigmatized group who often experience exclusion, isolation, and loneliness (Harris, 2004; Mitchell et al., 2013; Power, 2017; Sterin, 2002).

For example, persons with dementia are often abandoned by friends and family after sharing their diagnosis (Harris, 2004; Sterin, 2002). Sterin (2002), a person living with dementia, pointedly stated: “this condition does more than rob one of short term memory, inconvenient and aggravating as that is; much worse, it robs one of dignity and the respect of others” (p. 8). She shared that close friends and family members became uncomfortable with her diagnosis of dementia, and stopped treating her the way they used to, stopped talking to her the way they used to, and withdrew from socializing with her altogether (Sterin, 2002). Labels have severe consequences; the friendships of persons with dementia are affected by negative social perceptions of dementia and prejudice. Sterin (2002) spoke of this loss of dignity and respect for persons with dementia from *all others* connected to them, including: spouses, partners, children, friends, and companions. Feelings of extreme isolation are the result of marginalization for persons living with dementia, and are present among persons with both young onset and older onset dementia (Harris, 2004).

Humans are social beings, we form friendships and connections throughout our lives. Jordan and Walker (2004) argue, “connection is at the core of human growth and development” and subsequently, “isolation is seen as the primary source of human suffering” (p. 2). Where connection involves the creation of growth-fostering healthy relationships and social connectedness, social isolation entails a lack of social support, minor social connectedness, and limited or non-existent companionship. As relational theory purports, relationships exist within

the larger culture (Jordan & Walker, 2004). As such, “relationships may both represent and reproduce cultures in which they are embedded” (Jordan & Walker, 2004, p. 3). Persons with dementia are therefore both marginalized by society and by the people in their lives who are the closest to them (Power, 2017). The disappearance of friends and withdrawal from friendships among the social network of persons with dementia speaks to societal (mis)understandings of dementia and what it means to live with dementia. In my study I sought to explore how companion animals might fill this relational gap and contribute to the life narratives of persons with dementia. The perspectives and stories of persons with dementia are shared in chapter four in an effort to disrupt stereotypical perceptions of dementia and re-story dementia narratives.

Companionship, purpose, and continued engagement.

Companionship with dogs provides a daily purpose and responsibility. Even as people age, many preserve the vital human need to be cared for, and to care for others (Thomas, 1996). Companion animals are well suited to satisfy humans’ needs to nurture (Anderson, 2008). Animals have daily care needs that need to be met, such as feeding, grooming, walking, and giving affection. Many of these responsibilities require individuals to be active in their daily routines (Peretti, 1990; Raina et al., 1999). Dogs provide a sense of physical security both when out walking and at home (Knight & Edwards, 2008), and many older adults admit not leaving home without their dog(s) (Peretti, 1990). Caring for a companion animal enables older adults to continue to be purposeful, needed, and relevant.

While abilities change as dementia progresses, it is important that personal and meaningful experiences remain accessible (Phinney, Chaudhury, & O’Connor, 2007). Maintaining a routine and engaging in usual daily activities is important for individuals with dementia to feel a continued sense of normalcy in their day-to-day lives (Ohman & Nygard,

2005). Fazio et al. (1999) explain: “During each individual’s [dementia] journey, opportunities abound to maintain the continuity of lifelong roles and to achieve the satisfaction of giving to others in diverse ways that most have done throughout their lives” (p. 30). I think this quote is significant because it speaks to an understanding of dementia that sees all people as having strengths and abilities. This outlook is so important to changing societal understandings of dementia. Additionally, Fazio and colleagues remind us that people with dementia exist within complex networks of relations, in which they have varying roles and responsibilities.

All too often persons living with dementia are conceptualized and treated as recipients of care, and their opportunities to share and contribute to relationships are not considered. Relationships with animals challenge the perception of persons with dementia merely as care *recipients*. Geisler (2004) shares: “While petting the dog, Paul can experience himself as a nurturer and caregiver rather than a recipient [of care]” (p. 287). Humans innately need to connect with one another, and contribute meaningfully to other lives in some way (Jordan, 2004a). This need does not fade when persons have dementia.

Personal activity interests and preferences do not necessarily change when persons have dementia; continued engagement in meaningful activities provides a harmony in experiences, connecting past and present (Dupuis et al., 2012c; Phinney et al., 2007). It is through *doing* activities that persons with dementia find meaning in their lives; enjoyment is gained through engagement, having a purpose, and maintaining a sense of identity (Phinney et al., 2007). However, leisure exists beyond activities; “leisure is a space for expressing the self, for simply being” (Dupuis et al., 2012c, p.247). Leisure is where we can be ourselves, doing what brings us joy, contentment, or challenge. What is personally meaningful and important for identity looks different for each person. Challenging “leisure as activity” and “leisure as therapy”, Dupuis and

colleagues (2012c) found that persons living with dementia celebrate and live life through leisure. Rather than giving in to their diagnoses, persons with dementia challenge societal expectations of dementia by focusing on “leisure as a means to live life to the fullest” (Dupuis et al., 2012c, p. 245). I was interested to learn where leisure and animals intersect, or overlap (if at all) for persons living with dementia, and how this might challenge perceptions of dementia.

I was also interested in how the social citizenship of persons with dementia is expressed through the relational practices with their companion animals, both within and outside of the leisure context. Leisure supports opportunities for being social and spending time with others. For persons living with dementia, “opportunities that foster a sense of connection and community with others, with the self and with animals and nature, are highly valued” (Dupuis et al., 2012c, p. 247). Being with friends and family members, which may also include companion animals, is important for maintaining connectivity and preventing feelings of isolation (Murray Alzheimer Research and Education Program (MAREP), 2011), because connection is central to our wellbeing as humans (Jordan & Walker, 2004).

Persons living with dementia in the community with companion animals.

Past research that has explored companion animals and persons with dementia living in the community is very minimal. I was only able to identify two empirical studies (Connell et al., 2007; Fritz et al., 1995) and one theoretical paper (Baun & McCabe, 2003) which met this criterion. Unfortunately, neither empirical study sought to understand experiences from the perspectives of persons living with dementia.

The purpose of Fritz and colleague’s (1995) study was: “to determine what effect regular association with companion animals had on the development of *psychological disorders* in AD *patients* living in a private home” (emphasis added) (p. 459). Their findings suggest that persons

living with Alzheimer's disease were less agitated, less anxious, and exhibited less verbal aggression when a companion animal lived in their home (Fritz et al., 1995). Many persons with dementia in their study were noted to spend several hours a day holding or petting their companion animal (Fritz et al., 1995). The intimacy and connectedness between a human and their animal companion is reflected in time spent with one another; people who spend more time with their animals are more attached to them (Peacock et al., 2012).

Connell and colleagues (2003) study is perhaps the least clinical of this literature, and explored the impact of dementia on relationships between companion animals, persons with dementia, and care partners. The researchers identified a number of benefits and challenges associated with companion animals in the lives of families experiencing dementia. Relationships with companion animals changed after the onset of dementia for some, among both persons living with dementia and their spouses or care partners (Connell et al., 2007). A number of persons with dementia and care partners displayed increased affection and emotional closeness with their companion animals, and developed these closer relationships after the onset of dementia (Connell et al., 2007). For example, "one caregiver reported that her spouse 'won't go anywhere without his dog'" (Connell et al., 2007, p.478). The affection expressed by companion animals makes people feel safe (Cohen, 2002) and accepted (Boldt & Dellmann-Jenkins, 1992). Animals therefore make ideal companions, as they generally enjoy the company of humans, listen intently, and do not pass judgments (Anderson, 2008).

Despite a number of apparent benefits of animal companionship, there are challenges associated with caring for and living with animals. Connell et al. (2007) found some human-animal relationships negatively changed after the onset of dementia. Some persons with dementia were described by care partners as less tolerant of, and showed less affection towards

their animals. In addition, some persons spent less time with, and were generally not as close to the animal as before their dementia (Connell et al., 2007). Care partners also reported that some of their loved ones had less patience for their animals, and became less involved in the daily care tasks after their diagnosis of dementia (Connell et al., 2007). As dementia progresses abilities change, and I think it is important to be mindful of this change as not as inherently negative, but as a different way of being in the world.

In their theoretical paper, Baun and McCabe (2003) employ the Reisberg's Global Deterioration Scale/Functional Assessment Scale (GDS/FAST), a clinical seven stage scale to describe and categorize the "the progression of the disease" (p. 45), (I prefer to use the language *dementia journey*). They argue: "[u]sing Reisberg's staging system as a reference, it is possible to propose how pets could affect both persons with [dementia] and their caregivers at each stage of the illness" (Baun & McCabe, 2003, p. 47). For example, Baun and McCabe (2003) suggest, if a family does not already have a companion animal, that they adopt one when persons are in the early stages of dementia. The formation of the human-animal bond is thought to assist persons living with dementia as their disease progresses (Baun & McCabe, 2003). For instance, Connell et al. (2007) found that some human-animal relationships are formed after diagnosis:

Several [care partners] mentioned that they acquired pets specifically for their ill husbands, suggesting that they believed that having a pet would be beneficial and might provide practical help with [caring] by providing a source of comfort and support while they were away (p. 479).

Animals offer company and comfort, provide a distraction, focus attention, and can help calm persons with dementia (Baun & McCabe, 2003; Connell et al., 2007). These special friendships are sources of unconditional love and provide meaning to the lives of persons living with dementia (Connell et al., 2007). Dogs can facilitate active leisure; taking dogs on walks and

playing fetch are purposeful activities for persons with dementia who generally enjoy being active (Baun & McCabe, 2003).

Baun and McCabe (2003) suggest that when the dementia journey nears the middle, or fourth of Reisberg's stages, persons with dementia will require supervision when providing care to the animal. In Reisberg's fifth stage this need for supervision will increase, however, they suggest: "Having to go along on walks and supervise play sessions can provide exercise for the caregiver who otherwise would be confined to the home" (Baun & McCabe, 2003, p. 48). For Connell and colleagues (2007), care partners felt that the companionship provided by animals was more important for their loved ones living with dementia than for themselves. Many animals are comforting, reliable, consistent companions. It is commonly held that companion animals' primary roles include friendship and social support (Anderson, 2008).

Animals' have the ability to relate to persons with dementia despite changes in language abilities (Baun & McCabe, 2003). Connection and unconditional love is considered particularly important in the sixth and seventh stages of Reisberg's scale, when interaction with other humans may be quite limited for both the person with dementia and the partner in care (Baun & McCabe, 2003). Animals continue to provide comfort when persons with dementia move into a LTC home, offering a common interest when care partners visit (Baun & McCabe, 2003).

Animals also bring happiness and joy, easing anxiety to people receiving end of life or palliative care (Geisler, 2004). If lying in bed, "an animal sleeping next to the person provides warmth and comfort" (Baun & McCabe, 2003, p. 49). Oscar the cat is a resident in a LTC home who has the remarkable ability to sense the impending death of residents (Dosa, 2007). His physical presence at someone's side as they near death has afforded companionship for individuals who otherwise would have died alone. Additionally, his presence by someone's side

alerts team members to the resident's condition, who are then able to inform families of their loved one's imminent death (Dosa, 2007).

Some challenges of companion animals.

There are other considerations that must be acknowledged. Caring for animals has associated costs, and the financial responsibility may not be feasible for older adults with low incomes (Boldt & Dellmann-Jenkins, 1992). Past life experiences and personal preferences must also be recognized and respected. If someone has never had a companion animal in their life, they may be less likely to be (or not at all) interested in such companionship as an older adult (Boldt & Dellmann-Jenkins, 1992).

For some care partners the increasing responsibilities of caring for a loved one with dementia results in less time and care available to give to their animal (Connell et al., 2007). While Baun and McCabe (2003) advocate for the benefits provided by animal companionship to persons with dementia and their care partners, they also acknowledge that for some families, adding a companion animal to the home is not feasible. Supporting someone with dementia, and adopting an animal may result in additional responsibilities for the care partner.

The dementia journey is unique for each person and family (Taylor, 2007). I think it is important to consider that human-animal relationships may not be significant for everyone – and that is okay. Our life narratives are messy and complicated. We all have days and relationships that are better than others, things are ever changing. Western society prioritizes independence and doing for oneself. I think a relational perspective in the dementia context is helpful because it reminds me that no one is solely independent, everyone exists within a series of interconnected networks. There is no doubt that persons with dementia require support throughout their dementia journey. However, they also support and contribute to the lives of others. Animal

companionship is also an opportunity for persons with dementia to be understood as partners in care.

My critique of the dementia and companion animal literature.

It is important to note that both Connell et al. (2007) and Fritz et al. (1995) relied on the perspectives of care partners. The responses from persons with dementia were not included. In Connell et al.'s (2007) study, care partners answered a telephone survey on behalf of their spouses with dementia. Similarly, in Fritz and colleagues study (1995) care partners responded to a mailed questionnaire. Far too infrequently do researchers ask persons with dementia about their experiences (Harris, 2004), more often differing to care partners and health professionals' observations.

Additionally, both studies focused on dementia as a pivotal point of change in a person's life. Connell and colleagues (2007) were interested in how individual relationships with companion animals changed, both for persons with dementia and for their care partners, as a result of dementia. Whereas Fritz et al. (1995) focused on the effect of regular contact with companion animals on the development of "psychological disorders" in persons with dementia (p. 459). Connell et al. were interested in relationships between persons with dementia, their care partners, and companion animals, while Fritz et al. sought to determine the specific therapeutic effects of animals on differing "behaviours" and psychological expressions of persons living with dementia.

While Baun and McCabe (2003) give considerations for the significance of human-animal relationships for both persons with dementia and their care partners, the article is clinical and deficit-focused. I find the negative, tragedy language Baun and McCabe (2003) use to describe dementia and persons living with dementia problematic. In addition, they ascribe child-

like qualities to persons with dementia, such as: requiring supervision, having a lack of independence, and engaging in what they presume to be counterproductive activities.

A medical orientation also guides the work of Fritz and colleagues (1995). As such, persons with dementia are constructed as something to be “managed”. The researchers were not interested in the meaning or experiences of human-animal companionship, nor did persons with dementia have the opportunity to give their own feedback. While Fritz et al.’s study focuses on persons living at home, there is an interventionist aspect reminiscent of therapeutics, in which animals are thought to modify the behaviours and psychological expressions of persons living with dementia.

Connell et al. (2007) suggest further research is needed to explore the benefits and limitations of having animal companions in families with dementia. While I agree, I would also argue that we need to hear from the persons living with dementia themselves, and not just from family members or care partners. In reading past literature, I became ever more interested in hearing the stories of companion animal relationships from persons living with dementia, and understanding how these kinds of relationships might contribute to the life narratives of persons living with dementia in the community.

Summary

Relationships contribute to our lives in a multitude of ways. As relational beings, our need for connectedness extends to relationships with animals. For some, relationships with animals may be the most significant connections in a persons’ life. However, most research to date has focused on animals as therapeutic tools in AAI or AAT to improve the health and wellbeing of persons considered vulnerable, ill, or disabled. Many of the previous studies on animals and persons with dementia have been entrenched in a therapeutic recreation approach, in

which animals are a form of intervention to improve physical and/or emotional wellbeing, to manage “problematic” or “responsive behaviours”, or to increase socialization. The attention to “managing” persons with dementia is in itself stigmatizing and serves to further marginalize persons from their own experiences, care, and lives. As Power (2017) argues, dementia is just another way of being a person and experiencing the world.

Human-animal relationships are significant for many people. As with animals as “therapies”, research on animal as companions is often tied to health. There is a tendency to focus on how animals contribute to human’s physical, social, and emotional/psychological wellbeing; an area of research that draws interest from a number of different disciplines. However, a number of researchers have expressed that it is not merely the presence of living with, or “owning” an animal, but rather, the quality of the attachment to the animal that should be considered. Relationships are complex and varied, and this extends to relationships with animals. A few researchers have considered the relationships of persons with dementia with companion animals, yet no one to date had explored these relationships from a first-person relational perspective. The stories of persons with dementia are valuable, and sharing them counters the dominant tragedy narrative of dementia. Therefore, the purpose of this narrative inquiry was to understand how persons living with dementia story their relational experiences with companion animals.

In the chapter that follows I outline my chosen methodological framework, narrative inquiry and method, photovoice. I value the perspectives of persons living with dementia and developed a methodological approach to support them in sharing their stories visually through photography. Stories are a way for us to share our experiences, and animals are a relatively accessible topic of conversation that brings people together.

CHAPTER THREE: MY NARRATIVE INQUIRY METHODOLOGICAL FRAMEWORK

Within qualitative inquiry, methodology is a bridge that links a researcher's philosophical perspectives to the concrete methods facilitating inquiry. While many methodological approaches exist, selecting an appropriate methodology sets boundaries, and focuses the purpose of qualitative inquiry (Schwandt, 2001). It was important that my philosophical, theoretical, and methodological ideas were aligned before I began conducting my research, and collecting data or field texts (Berbary & Boles, 2014). Alignment and consistency among my research framework aim to signify a rigorous and legitimate project; as a researcher, I have a responsibility to be accountable for my work (Berbary & Boles, 2014).

I have been inspired by different writers that contribute to narrative inquiry and wove together insights and methods to form an approach that best addressed my research aims. I draw from Clandinin and Connelly (2000) because they value relationships and the experiences of both participants and researchers in the narrative research process, viewing inquiry as a collaborative endeavour. Further their *three-dimensional narrative inquiry space* highlights the significance and necessity of considering contextual circumstances in narrative understandings (Clandinin & Connelly, 2000). I also integrate creativity in my narrative methodological framework. Defined by Richardson (2000, 2005), creative analytic practice (CAP) is a process that involves moving beyond conventional writing and analysis to understand and express what researchers have learned through evocative and creative writing techniques. CAP influences the methodological framework of a study, as Berbary (2015) suggests: "...different methods will collect different types of data and CAP benefits from more unstructured guides used for more narrative-style interviews" (p. 37). Narrative-based methods evoke detailed, rich, complex

storytelling that allows for creative representation styles (Berbary, 2015). Options for arts-based methods are vast, but I decided to use photovoice, given the opportunity it offers participants to document and communicate what is most important to them through a visual means, and to reflect on experiences in a collaborative narrative process (Wang & Burris, 1997; Wiersma, 2011). I sought guidance from Wiersma (2011) who had previously engaged in photovoice with persons living with dementia. I also draw from Baldwin (2008), who provides guidelines grounded in the model of narrative citizenship for supporting persons with dementia and their citizenship in the research process. I followed McCormack's (2000a, 2000b, 2004) *storying stories* analysis process, because I appreciate how the approach provided different ways of looking at and interpreting the interview transcripts. This enabled me to perceive varied experiences, hear multiple voices, and then ultimately share multiple stories in my creative representations. The use of CAP is further significant given the opportunity it affords readers to engage with the narratives as leisure, and in doing so, form their own interpretations (Berbary, 2015; Diversi, 2008; Parry & Johnson, 2007). Drawing inspiration and insight from different writers I created a methodological framework (that I will describe in detail below) which aligns with my theoretical framework and aims of this study.

Why Narrative Inquiry?

I employed a narrative methodology to understand the experiences of persons living with dementia within the context of having a companion animal. I chose narrative inquiry because it values and celebrates life's complexities and differences (Clandinin, 2013). Further, the experiences of people are considered valuable and meaningful sources of knowing and understanding in narrative (Clandinin, 2013; Daiute, 2014).

Narrative inquiry is also well aligned with relational theory and a social citizenship approach. As humans, we exist within dynamic, multi-layered relationships with people, with ourselves and our bodies, with spaces, with institutions, societies, and cultures (Jordan & Walker, 2004; Nedelsky, 2011). Relationships are, therefore, integral to our life narratives, and “narrative inquiry is situated in relationships and community” (Clandinin, 2013, p. 13). Clandinin (2013) further states: “narrative inquiry is people in relation studying people in relation” (p. 23). People exist in multiple webs of relations; engaging in narrative inquiry brings attention to these relationships and how they shape our experiences and one another.

Relational theory also values relational ways of knowing (Jordan & Walker, 2004; Nedelsky, 2011); knowledge is created in togetherness in narrative and stories are co-constructed as they are lived and told (Clandinin, 2006, 2013). Coming to understand the experience of interest is a process of knowing and relating as co-creating inquirers (Clandinin, 2013).

Clandinin (2013) explains:

As we tell our stories and listen to participants tell their stories in the inquiry, we, as inquirers need to pay close attention to who we are in the inquiry and to understand that we are a part of the storied landscape we are studying (p. 24).

As a researcher employing a narrative approach I recognize that I am firmly embedded in the inquiry and the research narrative. My stories shape and are shaped by what I am researching, simultaneously before, during, and after the research process. It is necessary to acknowledge my position in the story, my impact on the narrative, and its impact on me.

Narrative is also a means for expressing citizenship. It is through the telling of stories that we find ourselves and share ourselves with others in the stories that they tell (Baldwin, 2008). A social citizenship approach was useful in this context because “...there is no right or wrong way of being a citizen, or of being ‘a person with dementia’, as individuals and groups are

determining their own status and citizen identity” (Bartlett & O’Connor, 2010, p. 34). All humans are both storytellers and listeners of other people’s stories. Stories help us understand and assign meaning to our experiences (Smith & Sparkes, 2008). Combining both relational theory and social citizenship with narrative inquiry facilitated opportunities for the diverse narratives of persons living with dementia to be shared and appreciated for the complexity and tensions added to the dementia narrative.

Narrative Inquiry

Narrative inquiry is employed by researchers across disciplines with varying topics of interest. Narrative inquiry is a methodological approach aimed at highlighting stories through different types of narratives (i.e., oral histories, life stories, autobiographical narratives, small stories, counter narratives, antenarratives). The defining feature of narrative research involves stories lived and told (Creswell, 2013; Pinnegar & Daynes, 2007). Storytelling is both a way of sharing information about ourselves, and a means of knowing (Richardson & St. Pierre, 2005). Epistemologically, narratives help us make sense of our lives, as Smith and Sparkes (2008) suggest:

We organize our experiences into narratives and assign meaning to them through storytelling. Narratives thereby help constitute and construct our realities and modes of being. They help guide action and are a psycho-socio-cultural shared resource that gives substance, artfulness and texture to people’s lives (p. 18).

Narratives are thus a means of expressing, organizing, and making meanings (Richardson & St. Pierre, 2005; Smith & Sparkes, 2008).

The central tenet of narrative research involves the storied experiences of individuals (Chase, 2011; Creswell, 2013; Pinnegar & Daynes, 2007). Narrative may be of a particular experience or event, a longer story about an important part of one’s life, or a life-history, that is an account of an individual’s whole life (Creswell, 2013). Given the depth to storytelling,

narrative inquiry typically focuses on the experiences of one person or a small group of people (Creswell, 2013).

While stories are innately personal experiences, they are also impacted by broader cultural, social, historical, and political contexts (Bach, 2007; Creswell, 2013;). As such, there is an appreciation in narrative that our experiences are both shaped by, and shared with others (Bach, 2007). Narrative inquirers acknowledge the interactive relatedness of others', that is with: spaces, places, people, politics, and society that contribute to experiences (Bach, 2007). Riessman (2008) agrees, stating: "stories must always be considered in context, for storytelling occurs at a historical moment with its circulating discourses and power relations" (p. 8). A story is complex and multi-dimensional, and ties into the greater social, historical, and political climate of the storyteller and the reader/listener (Riessman, 2008). Therefore, to understand stories narratively involves both a personal and social context (Clandinin & Connelly, 2000).

Clandinin and Connelly are two prominent Canadian academics who engage in narrative inquiry. They argue: "narrative inquiry is a way, the best way we believe, to think about experience" (Clandinin & Connelly, 2000, p. 80). While there are a number of methodological approaches to narrative, I believe that my theoretical framework aligns with Clandinin and Connelly's three-dimensional space of narrative inquiry approach (Clandinin, 2006, 2013; Clandinin & Connelly, 2000). Most importantly because they identify the importance of relationships in the research process, value experiences of participants and researchers, and view inquiry as a collaborative endeavour. I will further elaborate on each of these concepts in the discussion that follows.

Clandinin and Connelly, education researchers and academics, draw heavily on the work and ideas of John Dewey. Dewey, a philosopher and education reformer of the 20th century was

interested in the nature of experience, which he conceptualized with two main features. For Dewey, experience itself is the basis from which all inquiry sets forth (Clandinin & Rosiek, 2007). The first feature of experience for Dewey involves *interaction*, that is, a fluid engagement with both the personal and social aspects of experience. Experience involves an individuals' inner emotions, desires, feelings, etc., that simultaneously exist within a larger social world, including the environment, community, culture, etc., which individuals engage with and through (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007). For Dewey, “[p]eople are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, always in a social context” (Clandinin & Connelly, 2000, p. 2). The second feature of experience for Dewey involves *continuity*, which refers to an acknowledgment of time as fluid and continuous (Clandinin & Rosiek, 2007); that is, “... experiences grow out of other experiences, and experiences lead to further experiences” (Clandinin & Connelly, 2000, p. 2). Understandings shift and change as a result of engagement in past encounters, and which also shape future experiences; time is an important component of experience, and should be considered.

Inspired by Dewey, Clandinin and Connelly (2000) term their research framework the *three-dimensional narrative inquiry space*. Embracing the two aspects of Dewey's theory of experience, as described above, Clandinin and Connelly add a third dimension – situation. The three dimensions include: *continuity*: past, present, and future; *interaction*: the personal and social; and *situation*: recognition of space and place (Clandinin & Connelly, 2000, p. 50). These concepts provoke the researcher to balance looking inward at the personal and outward at the social, backward and forward in time and anticipate a future, and note the specific places and spaces in the storyteller's environment (Clandinin & Connelly, 2000). This three-dimensionality

highlights the significance and necessity of considering contextual circumstances in narrative understandings of people, events, or things (Clandinin & Connelly, 2000).

Narrative inquirers engage in research and with participants in relational and interactive ways. Researchers and participants each bring their own life histories and experiences to the research, what Clandinin (2013) refers to as *meeting in the midst*. That is, when "...lives meet in the midst of each of our unfolding complex and multiple experiences, we begin to shape time, places, and spaces where we come together and negotiate ways of being together and ways of giving accounts of our work together" (Clandinin, 2013, p. 44). Relationships develop in the sharing of stories and intersecting experiences. Our lives and our stories become woven together at a point in time, and everyone subsequently grows and learns as a result of engaging in the process of research (Pinnegar & Daynes, 2007).

It is this interactivity, and attendance to relatedness that sets narrative inquiry apart from other methodological approaches. Relationships are recognized and appreciated as valuable to the research process. In narrative, the role of the researcher is upfront and forward, because researchers are innately part of the inquiry and situated in the stories they are studying (Clandinin, 2006, 2013). Therefore, a vital part of the research process involves building relationships with participants. It is through relationships with participants that stories are lived and told; in the sharing of stories they become co-compositions (Clandinin, 2006, 2013). It is this collaborative approach to narrative inquiry which really spoke to me and my interest in understanding the relational narratives of persons with dementia and their companion animals.

Narrative Methods

Storytelling is a pervasive form of communication and expression (Daiute, 2014). Storytelling takes many forms; we can use words, text, our bodies, made or found images,

artistic means, or varying other forms of communication. The cornerstone method of data collection in narrative inquiry involves in-depth interviewing to understand participant's stories (Chase, 2011). Johnson and Rowlands (2012) describe in-depth interviewing as an approach where the interviewer is somewhat flexible and follows the lead of the participant in order to understand what is important to them. However, a narrative approach also recognizes the collaborative, relational nature of interviewing, in which participants and researchers come together to actively form narratives; knowledge is created in togetherness (Gubrium & Holstein, 2012). Other methods of data collection in narrative inquiry may include: observations, artifact and document analysis, diaries, letters, autobiographies, field notes, and photovoice (Chase, 2011; Clandinin, 2013; Creswell, 2013; Riessman, 2008).

Visual and arts-based narrative methods.

There are also a number of researchers who use and create visual texts in their narrative inquiry process. This may involve the use and analysis of visual material that already exists, including: photographs, films, or paintings (Riessman, 2008). Other researchers provide participants with tools and support to tell their stories visually through drawings (Guillemin, 2004), body mapping (Lopez, 2018), photographs (Bach, 1998, 2007), videos, paintings, and collages (Bach, 2007; Riessman, 2008). Other approaches involve researchers co-creating visual materials with participants in a collaborative process (Bach, 2007; Banks, 2007; Riessman, 2008), for example, through digital storytelling (Lopez, 2018).

Visual and arts-based narrative methods facilitate new ways of knowing and understanding beyond traditional written and oral texts. By providing opportunities for people to share their stories, the arts can facilitate diverse messages in different formats. Prosser (2011) suggests, "... art should be regarded as a form of knowledge and not merely an ornamental

product of human experience” (p. 488). Art can inform, is a method of sharing knowledge, and challenges perceptions.

The traditional interview format of narrative inquiry privileges one way of knowing and communicating through language (Prosser, 2011; Riessman, 2008). As such, persons with communication and language difficulties – including persons with dementia – are often limited and/or excluded from sharing their stories in research (Prosser, 2011). However, art-based methods facilitate storytelling through other means, and “one of the strengths of visual research is the wide range of response possibilities and their capacity to harness the creative abilities of researchers and participants” (Prosser, 2011, p. 488). Visual and arts-based methods offer diverse ways for stories to be shared by persons often constrained by traditional methods.

With visual and arts-based methods, participants are given time to develop their ideas and story their experiences through and in the process of creating (Gauntlett, 2007). Making something is a reflective process; participants “have the opportunity to consider what is particularly important to them *before* they are asked to generate speech” (Gauntlett, 2007, pp. 182-183) or complete the art piece. Creative methods are somewhat unique in that they give participants time for personal reflection in order to thoughtfully communicate their stories (Gauntlett, 2007).

Art is both expressive and engaging; it can facilitate new ways of seeing and storying lives (Weber, 2008). Weber (2008) further explains: “The reason we need and create art has to do with its ability to discover what we didn’t know we knew, or to see what we never noticed before, even when it was right in front of our noses” (p. 44). Visual and arts-based methods can open participants, researchers, and consumers of research to new understandings in dynamic ways. Weber (2008) argues: “Some things just need to be shown, not merely stated. Artistic

images can help us access those elusive, hard-to-put-into-words aspects of knowledge that might otherwise remain hidden or ignored” (p. 44). Arts-based and visual research touches us on a more emotional and sensory level – that is not as likely to be experienced through text alone (Prosser, 2011). I believe this is partly because:

Art can describe, reflect, and evoke emotion, which dry facts or figures and cool logic rarely do. Art is often about stories, of lives and characters which whom an audience can identify. Above all, art can help us (researchers, participants, and interested communities) imagine what it might be like to live that life (Prosser, 2011, p. 488).

Art is experiential and has the potential to make me feel a multitude of emotional responses. As such, I appreciate visual and arts-based methods for their ability to share important messages and stories, in varied formats, and often from the perspectives of marginalized peoples.

Narrative inquiry and dementia.

As I have mentioned, I am concerned about the exclusion of people with dementia in research. This exclusion is often linked to misunderstandings around the capacity of people with dementia to tell their own stories (Nygard, 2006). Although research with people with dementia demonstrates their abilities to describe their experiences, different approaches may be needed in order to support the telling of their stories (Baldwin, 2008).

Baldwin (2008) stresses the importance of actively including persons with dementia in the research process and provides considerations for doing so grounded in the model of citizenship for persons with dementia. Citizenship “recognizes persons living with dementia as active agents in shaping their own lives and experiences and the important role they can play in challenging the dominant ways they and their lives are storied as tragic” (Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016, p. 360). To actively participate, we must have narrative agency, which involves “being *able* to express oneself in a form that is recognisable as a

narrative, even if one's linguistic abilities are limited" and "[have] the *opportunity* to express oneself narratively" (Baldwin, 2008, p. 225). Individuals with dementia must be provided with opportunities to share their stories, and to do so, they must be afforded necessary supports that enable them to share.

Baldwin (2008) specifically recommends three ways of including persons living with dementia narratively. First, researchers need to provide opportunities for persons living with dementia to share their narratives in a way that is comfortable and familiar for them (Baldwin, 2008). This may involve using visual, artistic, and/or performative means of expression; "stories can be articulated, for example, as much through dance, movement and artistic expression as they can language" (Baldwin, 2008, p. 225). While language is a common form of communication, and interviews are a frequent method of data collection in narrative inquiry (Chase, 2011), there are other ways stories can be shared. Riessman (2008) further supports this: "Words, however, are only one form of communication; other forms (gesture, body movement, sound, images) precede words in human development and continue to communicate meanings through the life course" (p. 141). There are different ways of communicating, and using our bodies and actions is also a meaningful way of conveying information for persons living with dementia.

As such, we cannot overlook the body as a source of agency and relatedness (Kontos, 2011, 2012). According to Kontos (2004, 2005) embodied selfhood is a concept which acknowledges the body as an agentic source of communication. Throughout her research, Kontos (2004, 2005) continually articulates that embodiment is a significant means of communication, particularly among persons living with dementia whose language or verbal communication may be challenged. Expression is a multifaceted experience; our bodies can and do tell our stories.

Another important consideration Baldwin (2008) proposes is the conscious involvement of significant others as co-creators or joint authors in narratives. Working together in storytelling, persons living with dementia and their care partners, and/or loved ones may collaboratively weave a narrative (Baldwin, 2008). We do not exist in isolation, we are all involved in relationships which influence and inform our experiences, and how we can share them. Storytelling is a collaborative adventure of sharing and jointly constructing meaning(s) (Riessman, 2008).

Lastly, Baldwin (2008) suggests that by examining “the contribution made by people with dementia to the narratives of others” (p. 225) narrative agency can be supported. Reading or listening to another’s story subsequently impacts our own stories (Baldwin, 2008). Dupuis and colleagues (2016) comment on the significance of reflexivity:

From this perspective, we need to ask: how do the stories of persons with dementia alter our own life narratives? The verbal and written narratives of persons living with dementia... challenge dominant discourses on dementia and force readers and listeners to reflect on their own understandings and revise their own narratives (p. 362).

In showing how people continue to live well with dementia as active citizens, a new perspective on dementia is introduced, challenging the pervasive negative tragedy discourse that frequently makes headlines. Providing new ways of looking at something impacts our own personal narratives. As such, learning from persons living with dementia has inevitably influenced my own perceptions and personal narrative. I have been working in dementia care settings for over six years, and have met a lot of individuals living with dementia at varying points along their dementia journey. Engaging in research with persons living with dementia further cemented my understanding of dementia as different for each person. The saying: “if you’ve met one person with dementia, you’ve met one person with dementia” could not be more true! Despite my familiarity with dementia, I can honestly say that while completing this study, I have definitely

had my own assumptions about dementia challenged on a number of occasions. And for that, I am ever so grateful. In sharing the stories told to me by persons with dementia with others, I also hope to challenge the perspectives of others and expand understandings of dementia more broadly.

I value the perspectives and experiences of persons living with dementia. Therefore, in my research I followed Baldwin's (2008) suggestions described above. With that framework in mind, I have designed my methodology such that persons with dementia were able to express themselves in a narrative form that was suitable for them and provided interested persons the opportunity to share their stories with support (Baldwin, 2008).

Therefore, in order to understand the relational experiences of persons living with dementia and their companion animals, I chose to use a method that would support participants in sharing their stories visually. Guided by the work of Baldwin (2008) and grounded in a narrative approach, I believe the life narratives of persons with dementia are important, and have a lot to teach about relationality in the dementia context. But, in order to do so, persons with dementia must be supported in the research process (Baldwin, 2008). Therefore, to understand relationships with companion animals, participants engaged in photovoice. Photovoice is often employed by narrative researchers, given the opportunity it offers participants to document and communicate what is important to them, and reflect on their experiences in a collaborative narrative process (Wang & Burris, 1997; Wiersma, 2011).

Storying Through Photovoice

In the section that follows I outline my narrative inquiry research process. First, I describe my participants and recruitment strategies. Following this, I describe photovoice as a research method and identify the process followed using photovoice in my study.

Participant recruitment.

For my study, I intended to recruit three to five persons with dementia living in the Kitchener- Waterloo community, who have companion animals. A small number of participants fits within the guidelines of narrative inquiry and is recommended, given the attention to understanding detailed and complex stories (Creswell, 2013). In order to participate, participants had to identify as having some form of dementia, have at least one companion animal that lives with them in their home, have the capacity to use a camera (i.e., with minimal assistance, with written instructions, or completely independently), and provide consent to participate in both aspects of photovoice data collection, including taking photographs and participating in a conversational interview.

I reached out to the Sunnyside Community Alzheimer Day Program in Waterloo, which also offers services in Cambridge and Kitchener. Sunnyside also facilitates a Young Onset Dementia Association (YODA) for persons living with dementia under the age of 65. Given criteria that participants must be living in the community, and not in a long-term care home, I felt a day program was an appropriate means of informing persons living with dementia in the local community about my study. Initially, I sent an email correspondence to the program supervisor (see Appendix A) to request a meeting to describe my study and ask if they would be willing to help me recruit potential participants. When I met with the program supervisor I described my study in more depth (see Appendix B), answered questions, and went through the Participant Information Letter and Study Fact Sheet (see Appendix C). The program supervisor invited me to share information about my study with members of the YODA group, as he thought there might be a few people interested. I attended one of their weekly meetings in March of 2019 to provide an overview of the study, explain what participation would involve, and answer

questions. Study Fact Sheets (Appendix C) and Recruitment Posters (Appendix D) were provided for program staff to distribute to potential participants. Seven persons from YODA indicated to the program staff that they were interested in participating in this study. The program supervisor provided me with contact information for these individuals and I telephoned and/or emailed all seven potential participants to determine if they wished to participate and if they were eligible. It turned out that one person did not actually have their own companion animal, so they were ineligible to participate. However, the remaining six participants agreed that they would like to take part in the study. I arranged to meet with the interested participants at the YODA program to obtain their informed consent. Participants had the option to provide informed consent verbally (Appendix E) or by signing the consent form (Appendix F).

One additional participant was identified by a member of the YODA group through snowball sampling (Babbie & Benaquisto, 2002). This participant connected me with another individual living with dementia who has a companion animal, a person they thought might also be interested in participating in the study. I reached out to this potential participant and provided them with the Participant Information Letter and Study Fact Sheet (Appendix C) and Recruitment Poster (Appendix D) and they decided to participate.

Participants.

In total, seven individuals with dementia who were living in their own homes agreed to participate in this study. The age of participants ranges from 57 to 72, and there are three men and four women. All participants have either cats or dogs as companion animals. Both participants and their companion animals have been given pseudonyms to protect confidentiality. All participants provided consent for their photographs, including photographs of themselves to be used. See below for a brief biography for each participant.

Rick, 61 is currently single and lives with his rescued cat, Louie on the main floor of a condo in a mid-size city in Alberta. Before retiring he had a high-profile job with Alberta Health Services and now is actively involved the Alzheimer Society of Canada, working on a number of dementia advocacy initiatives, giving presentations and media interviews, writing blog posts, and contributing to research.

Stella, 61 is married and lives with her husband and cat, Luna in a house in Kitchener-Waterloo (K-W). She is close with her two sons, and friends and family often bring their dogs over to visit.

Lisa is 60 years old and lives in a house with her husband and their four-year-old golden-doodle, Max. Lisa and her husband previously lived in a smaller community nearby, but moved to Kitchener following her diagnosis of dementia, so they would be closer to community resources and supports. Lisa is a retired social worker, and currently volunteers at her Church on Sundays.

Doug is 67 years old, and has two poodles, a 6-year-old male, Charlie and a 16-year-old female, Roxy that live with him and his wife in their house in K-W. Doug likes to work on his “hot-rod” and has pool in his backyard, where he enjoys hosting parties in the summer. Doug has had dogs since childhood and has an affinity for poodles in particular.

Gail is a 72-year-old woman, who has two cats, Cooper and Rosie that live with her in her apartment in K-W. She rescued one cat from a neighbour in her building. She is close with her daughters and grandchildren.

Shirley is a 65-year-old widow that lives down the street from her son and daughter-in-law in a little bungalow in K-W with her rescued border collie, Rocky. Shirley is proud of her

Newfoundland heritage and grew up in a large family where her older sister taught her to care for cats, dogs, guinea pigs and a variety of other animals.

Karl is a 57-year-old man who lives with his cat, Mia in a low-rise apartment building in a small town just north of Waterloo. Karl is close with his sister and two adult children – his daughter gave him Mia around 5 years ago after his former cat died. Karl loves sports and currently works a few days a week in a janitorial role for a transit company.

Photovoice.

On its own, photography is a very powerful means of storytelling. Photovoice is a research method that typically involves equipping participants with cameras to document, reflect on, and share their everyday experiences (Wang, 1999). Providing participants with cameras allows the researcher and others to gain a perspective of what is significant to the photographers (Wang & Burris, 1997). This method values the knowledge and experiences of the participants (Wang & Burris, 1997), and is often used as a method of “giving voice” to marginalized populations (Wang, 1999). However, I must be clear that I do not think I can nor should attempt to speak for/ “give voice” for another person. I find this language problematic and patronizing, rather, I viewed this study method as an opportunity to learn from and with participants as we co-created narratives using photos.

In most photovoice processes, after participants complete the photography stage, photographs are printed and further explained by participants in follow up conversations, interviews, or focus groups, in which participants have the opportunity to provide context and reflect on the photographs (Wang & Burris, 1997). In the process of storying their images, researchers begin to “hear and understand how people make meaning themselves or construct what matters to them” (Wang & Burris, 1997, p. 382). The photographer is the storyteller and

“[p]hotography provides the medium through which people’s visions and voices may surface” (Wang & Burris, 1997, p. 382). The subjective experiences of participants are valued, as the photographer chooses what and how they want to describe what is meaningful to them.

While photovoice was originally designed as a participatory action strategy to address social change (Wang, 1999), it has since been adapted, and used by researchers from various disciplines, studying a variety of topics, and with diverse participants. A number of scholars have used photovoice in research on health, for example to understand: the experience of recovery in hospital after surgery (Radley & Taylor, 2003), older women’s experiences after discharge from hospitals in Toronto (LeClerc, Wells, Craig, & Wilson, 2002), chronic pain in older adults (Baker & Wang, 2006), experiences of paraplegia in adults in Cameroon and Australia (Allotey, Reidpath, Kouamé, & Cummins, 2003), the daily lives of stroke survivors in Chicago (Levin et al., 2007), and as a method of needs assessment and evaluation in women’s health in rural China (Wang, 1999; Wang & Burris, 1997). From a human geography perspective, Latham (2003) asked participants to take photographs for a week, documenting interesting and significant places and events. With an interest in South African education, researchers used photovoice to address issues of poverty from the perspectives of teachers (Oliver, Wood, & De Lange, 2007) and highlight issues of concern for female teachers (Taylor, De Lange, Dlamini, Nyawo, & Sathiparsad, 2007). Working with students, researchers have employed photovoice to document the daily lives of schoolgirls both inside and outside of school (Bach, 1998), to empower adolescents attending an after-school teen program to be active responsible citizens (Strack, Magill, McDonagh, 2004), and to document the experiences of nursing in rural Canadian settings from the perspectives of nursing undergraduate students (Liepert & Anderson, 2012).

Photovoice has also been employed with residents living in long-term care to understand meanings of wellness (Lopez, 2012), and with persons living with dementia, with the intent to understand their personal lived experiences (Genoe & Dupuis, 2014; Wiersma, 2011) and meanings of leisure (Dupuis et al., 2012c). As a research method, it may be useful for understanding the experiences of persons living with dementia because “it does not presume the ability to read or write” (Wang & Burris, 1997, p. 372). In addition, photography is an artistic medium and means of self-expression, which many people are familiar with (Levin et al., 2007) and may have engaged in at some point in their lives. While perhaps advantageous, familiarity with photography is not entirely necessary for this method to be successfully employed.

Photovoice allows participants to actively document and share their own stories visually. More importantly, it allows persons with dementia the opportunity to be the “authors of the visual images (i.e., the pictures) that are used as data and as representation” (Wiersma, 2011, p. 206). The participants have the opportunity and freedom to choose what they would like to document, share, and show what is most important to them; in my study, this was in relation to relationships with companion animals. As such, the participants play an important role as co-researchers (Wiersma, 2011). I think this research method is particularly significant because it challenges perceptions of dementia and persons living with dementia as passive research subjects. Through their active involvement in the research process, persons with dementia are respected as equally contributing citizens. In addition, the stories they share may challenge perceptions, and raise awareness of how persons with dementia continue to live active lives (Wiersma, 2011).

Photovoice research process.

I followed the guidelines outlined by Wiersma (2011) for engaging in research using photovoice with persons living with dementia. Six participants are in the YODA group and decided it would be most convenient for us to meet and check in with one another during the weekly YODA program. The program staff were very accommodating and allowed me to use a private room adjacent to the main program area for study-related conversations. One additional participant lives in another province, so we communicated via email and Zoom, an online video conferencing platform that he was already familiar using.

I introduced each participant to the concept of photovoice, and provided them with a Study Reminder Poster (see Appendix G) to post in their home, and Information Letters and Photo Consent Forms (see Appendices H & I) in the event that they wanted to take a photograph of someone else, and for those photos to appear in research. Ultimately, only one participant included a photograph of their spouse, all other photos were either of companion animals alone or participants with their companion animals.

The use of cameras to take photographs for the study somewhat varied. Two participants used their own cameras and three participants took photographs with the support of a family member and their family member's camera. Another two participants did not own a camera, so I loaned them digital cameras to take their photographs. While these two participants were familiar with operating digital cameras, before leaving it with them we practiced the basic functions (turn on/off; zoom in/out; take a photo; delete a photo). I had initially given one participant a disposable camera to take his photographs. When I got them professionally developed, unfortunately the photos all turned out really dark and the images were not visible. He had been excited when he handed the camera back over to me and thought he had taken quite a few good

pictures. I was so disappointed when I opened the envelope of prints. He had taken 15 photos and not even one had turned out! The following week I explained what happened, showed him the black images, and asked if he would be willing to try again with a digital camera. He was also disappointed, but willing to try again with a new camera. I was so relieved and grateful for his positivity and perseverance!

I asked participants to take photographs that illustrated or demonstrated their relationships with their companion animals. Most participants took a week or two to take their photographs. For participants who used the loaned digital cameras, I picked up the cameras at the YODA program, and participants who used their own cameras emailed their photos to me. The partnership with YODA turned out to be particularly helpful, as I could check in with the majority participants in person, and in a setting that was comfortable and familiar to them. The dates that each participant started engaging in the study were somewhat staggered, so when visiting the program, I would often pick up photos from one participant, meet with another to obtain consent, and later on in the study, facilitate an interview with someone else.

Like Genoe (2009), I had initially hoped participants would take their own photographs to show what their relationships with their companion animals look like. However, most participants wanted to be included in the photographs engaging with their animals. Thus, for some participants, friends and/or family members offered support by taking (and in some instances emailing) the photographs. I appreciate the support participants were provided to participate in the study. This experience served to remind me of the collaborative nature of this project, and reinforced the value of relationships, particularly for persons living with dementia.

Two sets of photos were printed, one to be used during the conversational interview, and the second I gave to participants with their appreciation letter (Appendix K). After the photos

were printed I scheduled one-on-one conversational interviews with each participant. Six of these interviews took place at the YODA program in a small room adjacent to the main program area. And one interview was held over Zoom (an online video conferencing platform) with the one participant who lives in another province. The conversational interviews lasted between 35 and 95 minutes.

During the interviews, participants had the opportunity to discuss their photographs and story their experiences. I was guided by other researchers who have used photovoice. For example, Bach (2007) invited participants to discuss the photos of their choice, because “participants are intentional in composing their photographs – they have a story to tell, and they want to be heard” (p. 286). Wiersma (2011) suggests using the photographs as prompts and cues for discussion, such as: “‘What is this picture about?’ ‘Tell me about the significance of this picture.’ ‘Why did you include this picture?’” (p. 208). As such, I asked participants open-ended questions about their photos, for example: “Of all the photos you took, which ones most represent your relationship with your companion animal(s)?” “Tell me a story about this photo” “Tell me about how this photo demonstrates your relationship with your companion animal(s)” (see Appendix J for my full conversation guide). The number of photographs participants took for the study varied from four to 36. Like Wiersma (2011), I asked participants to identify the photographs that most illustrated their experiences. In some instances, participants chose not to discuss certain photos, and spent time focusing on a few rather than all. During the interview, I numbered the photographs as we spoke about them.

The conversation part of photovoice is an important opportunity to further reflect on the photographs and story experiences (Wang & Burris, 1997). Our conversations sometimes stretched beyond the photos in front of us, and participants shared other stories about their

animals, including stories about former companion animals. I really enjoyed engaging in conversations with participants and having the opportunity to learn more about them and their animals, their relationships, and the context beyond or behind the images. While some participants expanded on their photos with detailed stories, others provided short sentences, or a few words as explanation. Some participants also used gestures and physical expressions to communicate. For example, one participant moved her hand rhythmically back and forth, as though she was petting a cat and then made a fist as though she was holding something and repeatedly pulling it backwards. Paying attention to these motions, I asked questions like: “oh maybe do you mean brushing your cat?” With an awareness of physical expressions, I also noticed participant’s emotions shift and change throughout the interview. To me it seemed like one participant in particular was getting frustrated and overwhelmed by my very open-ended questions. She frequently asked me to repeat questions, but then would still seem unsure where to start. She furrowed her brow, sighed loudly, and tapped her fingernails on the table. Noting this physical way of communicating, I switched to close-ended type questions in an attempt to try a different approach.

During photovoice conversations Bach (2007) stresses the importance of active listening, not simply for confirmation or agreement, but opening up to the possibility of hearing something new from participants and from myself as the researcher. Bach (2007) further emphasizes: “Listening is hard work. Being available, being ‘present,’ having an open heart to the participants matters. I follow their leads, their interests, and as I write photographic field texts I look for photographs that tell a variety of stories” (p. 292). Listening is hard work indeed, I found the interview described above very challenging, I tried my best not to try to fill in her words, (which I inevitably did sometimes), and at the end I left feeling uneasy and unsure about

how the interview had gone. In photovoice, researchers invite participants to take on active roles as photographers and storytellers, and in doing so, as a researcher, I had to welcome the possibilities involved with this approach. I feel that this concept of relational reciprocity in narrative inquiry, where participants and researchers work together as storytellers and listeners, was well aligned with Baldwin's (2008) notion of narrative agency. I also feel that the conversations I had with each participant emphasised for me the co-constructed and relational nature of narratives.

The week after each interview, I returned to the YODA program to thank each participant in person for engaging in the study. I provided them with an Appreciation Letter (see Appendix K), a hand-written thank you card, an envelope with all their photos, and a framed copy of one of the photos they had identified as a favourite. Participants were happy to see their photo framed, and often took it out of the bag to show other YODA members a picture of their companion animal. The out-of-province participant shared his mailing address with me, and I so sent all of the above to him via Canada Post. And when it arrived, I received a nice thank you note email from him in return.

Transitioning from Telling Stories to Re-Telling

Throughout narrative inquiries, stories are told and shared. These stories shift and change, they are not fixed entities (Clandinin, 2013). For Clandinin (2013) the narrative storied experience involves four aspects of storytelling: living, telling, retelling, and reliving. To begin, "people *live* out stories and *tell* stories of their living" (Clandinin, 2013, p. 34). Engaging in narrative inquiry involves researchers coming "alongside participants and then inquiring into the lived and told stories *retelling* stories" (Clandinin, 2013, p. 34). Fourth, stories are *relived*, that is, "we see that we are changed as we retell our lived and told stories, we may begin to relive our

stories” (p. 34). Storytelling is a process, and as a research methodology, narrative inquiring involves both researchers and participants reflexively living, telling, retelling, and reliving stories (Clandinin & Connelly, 2000).

As much as I was interested in hearing the stories of persons living with dementia in my research, I am also a storyteller, and have begun to live out and tell new stories as a result of engaging in this narrative inquiry. My role as a curious, new novice researcher is embedded in the story of my master’s research project, and my life story more generally that has brought me to this privileged opportunity. I feel a big responsibility to honour the stories participants so openly shared with me in my re-storying and re-telling.

Narrative Analysis

There are many approaches to narrative analysis, however, two commonly used approaches include *analysis of narrative* and *narrative analysis*. *Analysis of narrative* involves researchers gathering stories as data, which are then analyzed for overlapping and cohesive categories and themes across narratives (McCormack, 2004; Polkinghorne, 1995). With this approach researchers are interested in what and who stories are about (Chase, 2011; Georgakopoulou, 2007). A *narrative analysis* approach involves researchers collecting descriptions of actions, events, and happenings as data, that are subsequently used to produce explanatory stories (McCormack, 2004; Polkinghorne, 1995). In narrative analysis, the focus is often on how stories are told; the narrating of personal experiences is as important as the stories told (Chase, 2011). I think it is necessary to note that narrative inquiry is complex, fluid, and defined differently by different academics. There are many approaches to narrative inquiry and according to Chase (2011) it is very much “still a field in the making” (p. 430).

Storying stories.

After transcribing the seven interviews verbatim, I used McCormack's (2000a, 2000b, 2004) analysis process, which involves aspects from both *analysis of narrative* and *narrative analysis*. McCormack's (2004) approach "both seeks personal experience stories and generates stories by composing stories about those experiences" (p. 220), what they term "a process of storying stories" (McCormack, 2004, p. 220). This process involves first looking at field texts from multiple lenses including: active listening, narrative processes, language, context, and moments (McCormack, 2000a, 2004). I further describe how I used each of these lenses in detail below. In the second stage of this process, I used views highlighted through the multiple lenses, to develop re-storied stories (McCormack, 2000b).

While inspired and guided by McCormack's analysis process, I did not follow it precisely. I think the usefulness of this narrative analysis approach also stems from its flexibility. McCormack (2000a, 2000b, 2004) provides a detailed outline for following the storying stories approach, however, they also advise that it is not necessarily a recipe that needs to (or should be) followed exactly. As each narrative and participant is different. Additionally, how each narrative is represented will vary based on the different views highlighted through the use of multiple lenses (McCormack, 2000b).

Active listening.

The first lens in McCormack's (2000a) analysis process is *active listening*. This involved listening to the interview audio recording multiple times and asking myself questions to "reconnect with the storyteller, the story, and his or her reactions to both of these" (McCormack, 2000a, p. 288). At this stage I considered:

- Who are the characters in this conversation?
- What are the main events? Where/When do they occur?

- As a researcher, how am I positioned during this conversation?
 - As a researcher, how am I positioned in relation to the participant?
 - How am I responding emotionally and intellectually to this participant?
- (McCormack, 2000a, p. 288).

As a researcher, I acknowledge that I am firmly embedded in the research narrative and the stories that participants choose to share with me. As McCormack (2004) suggests, I recorded my responses to the above questions in my research journal to “inform on-going interpretation and reflection” (p. 23). It is important to bring attention to my role, and I practiced reflexivity by including my experience and emotions in the analysis process (Dupuis, 1999). As an example, reflecting on my position during one of the interviews, I wrote in my research journal:

Listening to the audio of my interview with Gloria I feel embarrassed and annoyed with myself as the interviewer. While I tried to be patient and respectful, I now realize that in trying to help her find the right words, perhaps I contributed further to her frustration. She would often get stuck, trying to find the right word or phrase to complete a sentence. This was also audible in the tapping of her nails on the table as she tried to identify the word she was searching for. At one point around the middle of the interview she seems particularly frustrated with herself saying “Oh God, I can’t, I can’t remember stuff...” and I interject with “you’re doing great”. Listening to/ reading this again, my words sound somewhat condescending, rather than supportive. I remember leaving this interview with an uneasy feeling, and listening to this audio again brings me back to that feeling. I wonder how I might have been better able to support Gloria in sharing her stories? Were my responses or interjections more harmful than helpful?

Narrative processes.

The second analysis lens involved looking at the narrative processes used by the storyteller (McCormack, 2000a). As I read each interview transcript I used this lens, to identify and plot the main stories for each participant. Given the nature of dementia, some stories were shared in depth with details that clearly identified a beginning and an end to each story. Whereas other stories transpired with a few words, but equally conveyed a lot of meaning and often emotion. At this point I considered: the point of the story, why it was told, who, what, where and when, and the sequence of events/actions that occurred (McCormack, 2000a). As I paid

attention to the meanings of the stories, I considered why the storyteller chose to tell those particular stories about their companion animal(s) and what those stories conveyed about their relationships.

After reading all seven transcripts focusing on the main stories, I reflected on and identified a number of common topics and themes that stood out to me in an analytic memo. A number of these initial themes I identified early on are discussed in depth in chapter five. At this point I also started to consider how these stories connected with notions of relationality and social citizenship, which led me into the next lens of this analysis process, language.

Language.

I next read and re-read the transcripts to understand the impact of language on interpretation of the participants' stories. This process included paying attention to (1) what participants said, (2) how it is said, and (3) what remains unsaid (McCormack, 2000a). This lens brings awareness to how a "...storyteller speaks about himself or herself, about the relationships in his or her life, and about the environments in which his or her life has been or is being lived" (McCormack, 2000a, p. 287). More specifically, using this lens. I considered:

1. **What is said**, including the following: common or frequently used phrases; words or phrases a participant uses to speak about themselves; words or phrases participants use to speak about their companion animals; words or phrases participants use to describe their relationships with their companion animals; and words or phrases participants use to speak about dementia and their dementia journey.
2. **How it is said**, which I understood involves looking at the way participants communicate their stories. I focused on the use of personal pronouns, for example where *I*, *us*, and *we* are used by participants and how participants transition between these pronouns in relation to their companion animals. I also looked at the use of metaphors and analogies, and considered how stories are told (e.g., with photos, in retelling conversations, use of repetition).
3. **What remains unsaid**, which I understood involves paying attention to what is signaled or communicated through performative features. For example, I considered the participant's emotions expressed through voice (e.g., crying, laughing, sighing) and

physical expressions (e.g. tapping fingernails on table, gesturing), use of long pauses, and silence.

I found reading the stories with a lens for language to be most informative and helpful. After I had gone through all of the transcripts with the three language lenses, I went back and re-read the main words and phrases I identified and thought about how those words or phrases illustrate or demonstrate notions of relationality and social citizenship. Language is a powerful means of communicating, sharing, and understanding, and using this storying stories lens brought attention to this important aspect of narrative for my understanding.

Context.

This next lens involved paying attention to the context of culture and situation (McCormack, 2000a) which included aspects of Clandinin and Connelly's (2000) dimensions of continuity, interaction, and situation. Narratives are both informed by and informing of culture, they exist within and are impacted by the larger societal and historical forces in which the stories have been lived, told, and retold (Reissman, 2008; McCormack, 2000a). At this point, I considered: *what are the cultural forces or discourses the storyteller draws on to construct their view of relationships with their companion animals?* My reflections on this question also connect to Clandinin and Connelly's (2000) notion of *continuity*, that is a recognition and connection of past, present, and future. For example, in an analytic memo at this stage of analysis I wrote:

I wonder if the context of culture for participants also connects back to their childhood and upbringing? Almost all participants spoke about having animals at different stages throughout their lives, that is, as children growing up themselves, in adulthood, some got animals for their children when they were young, and now as older adults. At this stage in life, some participant's children have helped them adopt animals. Perhaps this is connected to the learned, embedded notion that animals are beings we care for and love, and are important family members? In the case of this study, specifically cats and dogs. The significance of animal companions is something that's been learned, maintained, and reinforced throughout participant's lives. Participant's learned from their parents and siblings, adopted animals when they became adults, and then transferred this affection or love for animals onto their own children. So, in terms of

cultural context, relationships with companion animals are fluid, familial, and embedded in family identities.

Further, a number of participants shared plans and concerns for the future of their relationships with companion animals. Some participants commented on their changing abilities and concern for their potential future (in)ability to care for their companion animals in the same way. Others think their current cat/ dog will be their last due to changing abilities, and Doug sees no future without a dog – he will continue to live with and adopt dogs for as long as he’s alive. In this way, narratives of relationships with companion animals are connected to participant’s past, present, and future.

Stories are also told within a particular situation, in this case, a conversational interview, in which the storytellers described their relationships with their companion animals after being asked by me, (the researcher) to take photographs of what their relationships look like. At this stage in my analysis I considered: *what can I learn from the place where the interview was held; what can I learn from my opening question, who asks the questions, and what types of questions were asked; what can I learn from the participant’s reactions (verbal and nonverbal) to my questions.*

Six out of the seven interviews were held in person, and one of the interviews was held over Zoom due to the geographical distance between myself and this participant. The experience of the Zoom interview was quite different from the other interviews because he was at home in his office, and me in mine. While chatting over Zoom, I was able to observe interactions between the participant and his cat. The cat was climbing on the participant, walking back and forth on his lap, and then sleeping on his lap for a long duration of the interview. The participant was petting his cat, looking down at him, and seemed relaxed and content in this exchange. Whereas, the other 6 interviews took place at the YODA program, which meets once a week, and is located within the basement of a LTC home. For these other interviews we relied more on the photographs to talk about the companion animals. I had initially intended to hold all interviews in person, however due to the unforeseen snowball sampling, an online video platform was

necessary for one interview. However, this experience highlighted the significance and difference in the context of situation. Clandinin and Connelly's (2000) second dimension of narrative inquiry also involves *situation*, what they refer to as, recognizing the impact of space and place. Having the opportunity to witness a participant interacting with their companion animal in their own home provided a new perspective into understanding their relationship, and I think future research should include opportunities for observation.

Reflecting on the above questions and considering Clandinin and Connelly's (2000) third dimension of *interaction*, I realized that I responded to participants in different ways and shared (and withheld) different parts of myself in each encounter. The storytellers and I each brought our own autobiographical context to the interviews (McCormack, 2000a, 2004) and to our partnership in the research project. My relationships developed with participants in the sharing of stories about our respective companion animals. It was in interaction and openness that we learned with and about one another. In thinking further about the development of these relationships consider one of my journal reflections:

Yesterday morning I went to the YODA group to drop off a thank you letter and small gift to a participant I had interviewed last week. I saw some other participants and stopped to say hello. Gloria gave me a big smile and said something happened that she wanted to tell me. We had already completed our interview a few weeks prior, so I was curious about what she wanted to share. She told me a story about how she had attempted to cut her cat's nails, as they were getting long. But unfortunately, she cut a nail too short that it bled, and then the cat tracked blood all over her apartment. I realized, in telling me about this, she seemed more concerned about causing pain to her cat – not the bloody mess that ensued. She said she felt terrible and was never going to try cutting the cat's nails again. I have never cut a cat's nails myself, but I do know that it can be tricky to cut dogs nail's, and you have to be so careful, as not to cut them too short, or they will also bleed. I felt so bad for her, as she seemed quite upset about it.

But reflecting on this encounter over the past day I've been thinking about how we have made a connection about animals. Even though it wasn't a happy or funny story, it was something that she wanted to share – with me. Our animals are a relatively easy and accessible point of contact, and connection, in that we almost all have stories to share about our cats and dogs - the good, the bad, the sad, and the humorous. It made me feel surprisingly flattered knowing that she wanted to continue to telling me about her

cat, despite the research interview and photography had already commenced. We have developed a relationship.

I think this experience speaks to the importance of relatedness in the entirety of this study.

Context therefore involves a consideration of storytellers as relational beings, who exist and engage with themselves, others, spaces, and society as citizens.

Moments as photos.

The final lens McCormack (2000a) describes is *moments*: “Moments may be signified by key words or phrases, descriptions of events or stories, or other forms of discourse” (p.

294). McCormack does not discuss the use of photos or photovoice in her analysis process.

However, I adapted McCormack’s *moments* lens in order to pay attention to the photographs that participants took, and discussed in their interviews. A photo can capture a moment in time, but is situated within a larger narrative context. In particular, at this stage I focused on the photographs that spoke to the identified plot of the narratives. As I mentioned above, some participants took dozens of photographs, so I paid close attention to the photographs that they chose to discuss and focus on during their interviews. Because, participants are intentional in what they choose to take photos of (Bach, 2007). At this stage, I considered: *what is happening in the photograph; who or what is in the photograph; and how participant’s stories provide context to the photographs.*

Photographs portrayed the daily lives of participants: going for a walk with the dogs, playing with the cat, cuddling on the sofa. Photos were taken inside their homes depicting: living rooms, bedrooms, dining rooms, a foyer, and office. Photos also showed people and/or their animals outside, for example: at the front of a house, in a backyard, on a walk in the neighbourhood, sitting in a park, on a bicycle. There were also some portraits of companion animals alone. The photographs are stories on their own, but when combined with the context

shared during our interviews, they work together to illustrate the dynamic lives of participants. I knew that I wanted and needed to include the photos in my data representation because they add an important visual dimension to the dementia narratives I have re-storied.

(Not) returning stories to participants.

McCormack (2000b) suggests returning interpretive stories to participants at multiple points in the analysis process. They ask participants to consider:

- Was this the story you thought you were telling me?
- Does what I have written make sense to you?
- How does this account compare with your experience?
- Have any aspects of your experience been omitted? Please include these wherever you feel it is appropriate.
- Do you wish to remove any aspect(s) of your experience from this text? (p. 299).

I decided not to ask the participants McCormack's member checking questions above. Not because I don't value their input and suggestions, but the re-storied stories are very much my interpretations, representations, and re-telling of participant's stories of relationships with companion animals. Moreover, the narratives and photos shared during our interview were one moment in time; narratives evolve and change with each re-telling and re-living (Clandinin, 2013; Clandinin and Connelly, 2000).

I was also conscious of being respectful of participants time and contributions already made to the study. We had engaged in multiple conversations, they had taken photos, arranged to get the photos to me, and then shared their time for an interview. Now, reflecting on this decision further, I could have asked participants if they were interested in taking part in this process and been upfront about the additional time commitment involved, rather than making assumptions. I think engaging participants in conversations about the re-storied narratives I came up with would have been interesting and allowed an opportunity for them to contribute to the re-storying. I am curious about their feedback, and would have liked to be able to incorporate more opportunities

for co-composition in this study if time had allowed. In this sense, from a relational perspective, my decision to forego the member-checking processes may be viewed as a potential limitation in this study.

My Re-Storying Process

As described above, I was guided by McCormack's (2000a, 2000b, 2004) *storying stories* data analysis approach. This process really allowed me to pay attention to the details and specifics of each participant's stories and ways of storytelling. During my data analysis I came to see and hear different ways of storytelling as I paid attention to each of McCormack's lenses. I listened to, read, and re-read each interview transcript multiple times with the lenses of active listening, narrative processes, language, and context. With these multiple lenses I began to understand how the participants storied their relationships with their companion animals, and noted relationality and social citizenship in these stories. The *storying stories* analysis process enabled me to perceive varied experiences, hear multiple voices, and share multiple stories. Rather than using codes, categories, and themes to generate understandings across participant's stories, *storying stories* embraces the individuality and complexity of narratives (McCormack, 2000a, 2000b, 2004).

Through this process, attention was given to differences and complexities in the narratives of persons living with dementia. Avoiding generalizations in dementia narratives is important, because each person's story is both complicated and unique. Whitman (2016) believes it is important to highlight a diversity in narratives among persons with dementia; persons with dementia are people first, that is, citizens with varied experiences, just like persons without dementia. Bringing attention to the stories of persons with dementia and their companion animals

allows for a re-storying that brings to light those differences, and also highlight some shared experiences in a narrative format.

Initially, I did not have a clear idea of how I was going to represent the narratives. The decision to form a collection of different types of re-storied narratives happened somewhat organically as I immersed myself in examples of creative writing. As I read creative representations by other researchers and academics for inspiration and guidance I became aware of the vast methods of visual and textual representation used - dialogue-based vignettes, screenplay, short stories, diary entries, conversations, email exchanges, poetry, prose, collective poetic inquiry, found poetry etc. I read non-academic short stories, graphic novels, and poetry both contemporary and historical. I also consulted Marlena Books stories, that is, books written specifically for persons living with dementia. I do not typically write creatively so I sought guidance from Natalie Goldberg's (2010) book *Writing Down the Bones: Freeing the Writer Within* and Caulley's (2008) aptly titled, *Making qualitative research reports less boring: The techniques of writing creative nonfiction*. I continued to refer back to these examples for reference and inspiration throughout my re-storying process.

Stories can teach us, challenge us, and make us feel deeply. Caulley (2008) suggests, "...the researcher should use the voice and style that best and most comfortably tell the story" (p. 441). I was inspired both by *how* storytellers told their stories in different ways during our interviews, and *what* their stories were about. How each narrative is represented varies based on the different views highlighted through the use of lenses and how storytellers told their stories (McCormack, 2000b). Like Parry and Shinew (2004), I "...wanted the interviewee's stories, experiences, comments and language to be at the heart of the representation" (p.

300). Especially, because persons with dementia are often considered incapable of telling their stories, particularly in research.

I chose to represent my re-storied narratives in different creative formats based on variations in storytelling. I composed short stories, poems, and a monologue. I also integrated participants photographs to create a photo storybook and a comic-inspired photo essay. Together, the re-storied narratives represent a short story collection, but each can be read separately or in any order. In composing the re-storied narratives my intention was not simply to tell, but rather to show the relationships persons living with dementia have with their companion animals, because evoking emotion engages the reader (Caulley, 2008).

Reading and working through each transcript involved a multi-layered analysis process (as described above). I worked through re-storying each narrative one by one, identifying key patterns, stories, words, and emotions used by each storyteller. Based on my chosen format for the re-storying, I then constructed the narrative by staying as close as possible to the storyteller's words, descriptions, and tone. Drawing on creative analytic practices (CAP) enabled me to contextualize each participant's experiences and narratives (Berbary, 2015). I have attempted to be transparent about my process for each re-storied story and the decision for each representation format at the beginning of chapter five. The final representations have been through various revisions aiming for what Richardson (2000, 2005) calls *aesthetic merit* (see below).

Richardson (2000, 2005) has developed five criteria for evaluating Creative Analytic Practice (CAP) that I referred to while developing my re-storied narratives, and you can keep in mind as you read my short-story collection:

1. Substantive contribution: Does this piece contribute to our understanding of social-life? Does the writer demonstrate a deeply grounded (if embedded) human-world understanding and perspective? How has this perspective informed the construction of the text?

2. Aesthetic merit: Does this piece succeed aesthetically? Does the use of creative analytic practices open up the text, invite interpretive responses? Is the text artistically shaped, satisfying, complex, and not boring?
3. Reflexivity: How did the author come to write this text? How was the information gathered? Ethical issues? How has the author's subjectivity been both a producer and a product of this text? Is there adequate self-awareness and self-exposure for the reader to make judgments about the point of view? Do authors hold themselves accountable to the standards of knowing and telling of the people they have studied?
4. Impact: Does this affect me? emotionally? intellectually? generate new questions? move me to write? move me to try new research practices? move me to action?
5. Expresses a reality: Does this text embody a fleshed out, embodied sense of lived-experience? Does it seem "true" – a credible account of a cultural, social, individual, or communal sense of the "real"? (Richardson, 2000, p. 254).

There are undoubtedly other ways these stories could be represented, but this is my way, and I hope this collection makes you feel something. Maybe you hate it, maybe you question it, maybe it challenges you to step outside of your comfort zone and try something different.

Despite whatever this collection makes you feel, it makes me feel proud because for so long I felt stuck and unsure of myself as a writer (and researcher). But I am proud of this research project and short-story collection.

Considering Reflexivity

Transparency is an integral component of the research process. I acknowledge that as the researcher, I have been firmly part of the research topic, process, and stories studied. I do not intend to account for all experiences, or aim to be objective, as I believe removing myself as a researcher from the research process is impossible (Dupuis, 1999). Reflexivity involves self-reflection; looking inward at "one's own actions, thoughts, feelings, values, identity, and their effect upon others, situations, and professional and social structures" (Bolton, 2010, p. 14). Being reflexive as a researcher means acknowledging my role in the setting, context, and particular area of inquiry for research (Schwandt, 2001). This involves being upfront and

forward about my positionality in the research, considering how I am connected to the world around me, and how I felt before, during, and after the research process (Dupuis, 1999).

Reflexivity differs from reflection; while reflexivity focuses on looking inward, reflection involves “an in-depth consideration of events or situations outside of oneself” (Bolton, 2010, p. 13). A reflective researcher attempts to understand “what happened, what they thought or felt about it, why, who was involved and when, and what others might have experienced and thought and felt about it” (Bolton, 2010, p. 13). Balancing looking outward at the life narratives of participants and things and events as experienced, and looking inward at my own life narrative, personal emotions, feelings, and perceptions “provide a reflective balance” in narrative inquiry (Clandinin & Connelly, 2000, p. 104).

I also acknowledge the contextual factors of a narrative approach to research. Narratives are fluidly changing stories that evolve with living, telling, retelling, and reliving (Clandinin, 2013). Clandinin and Connelly (2000) further explain: “our field texts are always interpretative, always composed by an individual at a certain moment in time. As researchers we may take a photograph as a field text, but that photograph is one telling, one shot, one image” (p. 84). My perceptions are just that, *my perceptions* of that one event or encounter, at one point in time. As such, as a narrative researcher, my perspective must be upfront and integral to the research project; “The narrative researcher’s experience is always a dual one, always the inquirer experiencing the experience and also being a part of the experience itself” (Clandinin & Connelly, 2000, p. 81).

One of the reasons I thought narrative inquiry was well aligned with my relational-citizenship framework is the co-composition that occurs in narrative inquiry. The voices and stories of both the storyteller and listener come together to weave a collaborative narrative

(Clandinin, 2013). I believe it is in the process of learning from and with others that knowledge is created. Therefore, as a narrative inquirer, I am not objective or separate from the research, but am firmly part of the topic I am studying (Clandinin, 2013). I also understand and acknowledge that as the researcher I have been involved in the research process and field texts as much as participants. As such, working with and learning from persons living with dementia and their companion animals, I have created a collaborative narrative of relationality in the dementia context where diverse stories shed light on the complexities of connections with animals.

I started practicing reflexive journaling after my proposal defence and continued throughout the research process as I applied for ethics approval, recruited participants, interviewed participants, transcribed interviews, analyzed the transcripts and photos, and re-storied the narratives. I often wrote a reflection when I reached a new stage in this journey, and when something surprising or unexpected happened. My intention was to account for my own experiences and allow myself the opportunity to think about, challenge, and process my first experience as a student researcher. I documented my feelings, emotions, stories, and experiences as I engaged in this research journey.

I also reflected throughout the analysis process as I began to think about the interviews and narratives in new ways. I drew on these reflections in writing this final thesis document to bring myself back to how I was feeling at different points along this research journey, and remind myself of events that had transpired. I have integrated some of these ideas and reflections throughout this thesis document.

Ethical Considerations

Informed consent is the typical ethical requirement in research, by which participation is voluntary, and participants understand the project, including any benefits or risks that

participants may be exposed to (Babbie & Benaquisto, 2002). However, the principles of informed consent become restricting when persons with dementia are considered. When working with vulnerable populations special attention must be given to participants' interests (Slaughter, Cole, Jennings, & Reimer, 2007). The "cognitive-competency-based approach of informed consent can make the experience daunting" (Dewing, 2008, p. 60). This is because "the person with altered abilities in communication, memory, language and perception does not experience the ritual of informed consent from the perspective of an equal participant" (Dewing, 2002, p. 159). One must not overlook participants' abilities or interests in participating in research, as this limits their opportunities to contribute, learn, and tell their stories (Slaughter et al., 2007). Persons with dementia deserve to participate in research, but need to be supported in order to do so.

An alternative to informed consent is proxy consent. When persons are deemed not legally able to provide informed consent, proxy consent is often employed (Dewing, 2002). While common, this practice is also problematic when persons with dementia are involved, as they are not included in meaningful ways (Dewing, 2002). Decisions are made on behalf of the person with dementia, and their opinions and feelings are often not considered in the research (Dewing, 2002). Researchers working closely with people with dementia recommend the use of process consent as a means to ethically engage persons living with dementia.

Process consent is an approach developed by Dewing (2002, 2007, 2008) which enables persons living with dementia the opportunity to actively participate in research as participants, rather than as mere subjects. The majority of research uses the traditional informed consent that privileges 'mental competency' or proxy-based consent methods, in which care partners, and/or loved ones give consent for persons with dementia (Dewing, 2008). Process consent is an

approach to research that values persons with dementia as active participants, who are acknowledged for their contributions, and who can willingly choose to participate in research on their own (Dewing, 2002, 2007, 2008). Dewing (2008) describes:

The principles of process consent are meant for use with persons who have an extremely limited capacity, who would generally be thought to be incapable of legally informed consent by others, but on observation can communicate and express their wishes in other ways (p. 63).

This approach therefore offers opportunities for persons with dementia to share their stories and experiences in an ethical manner. Process consent also respects the individuality of persons.

Dewing further (2008) describes how this approach,

...also recognizes that ethical decisions and actions are context-specific, and centred on interdependence within a caring relationship, and acknowledges that capacity is situational, that residual capacity can be present even after the legal threshold has been crossed and that it is often strengthened or even reinvigorated within an enabling and caring relationship (p. 61).

This process is interactional and dynamic. Persons with dementia are valued and respected as equals, and active participants in the research (Dewing, 2008).

Researchers must consider three fundamental questions with this approach: (1) “How do I know this person is consenting?”; (2) “What type of appreciation does this person have of their consent?”; and (3) “How would this person demonstrate reluctance and/or objection?” (Dewing, 2008, p. 62). Obtaining consent is a continual process that requires the researcher to interact with participants who live with dementia, “and to value and see the meaning in all types of communication made by the person and on their own critical reflection skills” (Dewing, 2008, p. 62). As persons with dementia live in the moment, the researcher must also be attuned to the present, while remaining reflective.

Dewing’s (2008) process consent method involves five fluid and non-linear aspects that researchers should do:

- Familiarize themselves with the participant, their existing capacities and abilities, and verbal and non-verbal communication patterns that would indicate interest in the research
- Develop an understanding of ‘yes’ and ‘no’ with each participant in order to establish the basis for consent, which is an ongoing process
- Be attuned to implied meanings and non-verbal forms of communicating initial consent; for each person’s needs and abilities are different
- Engage in on-going consent monitoring; consent is a process and must be continually re-established
- When feedback is necessary, persons with dementia must be in agreement and have the opportunity to “take the lead if they choose” (p. 63).

These methods provide opportunities for persons with dementia to participate in research in a way that is inclusive and respectful of their abilities and preferences. The ethical researcher must continually check in with participants and live in their moment.

I understand that there are particular ethical considerations when working with persons with dementia. However, limiting the opportunities for persons with dementia to equally participate in research, should they choose to do so, prevents them from opportunities to share their experiences. It is both paternalistic and presumptuous to assume that persons with dementia are incapable of consenting. Rather, it is traditional systems and approaches which hinder opportunities. Dewing has challenged these traditional ideologies and outlined ways that persons with dementia can engage in research as active, involved, consenting participants. I chose to employ this ethical process in my research, as this approach celebrates relatedness, and as such, aligns both with my chosen relational theoretical framework and narrative methodology.

Ethical research process.

This study received full ethics clearance from the Research Ethics Office at the University of Waterloo in spring 2019. It is important to build relationships with participants with dementia in order to develop trust and rapport (Nygard, 2006). I thought that this might present a challenge when working with persons with dementia, because I anticipated they may

not remember me. As the researcher, I was patient, considerate, flexible, and reminded the participants who I was, why I was there, and the aim of the research upon each interaction (Dewing, 2008; Nygard, 2006). As for participants with dementia, obtaining consent is a continual process (Dewing, 2008). Participants in my study were living in the community, responsible for the care of an animal, and in the early part of their dementia journey.

Participants had the option to provide written or verbal consent, given that some persons with dementia are unable to complete a written consent form, but have the capacity to verbally consent to research. I wanted to be inclusive and provide options for consenting, because each person's abilities and dementia journey are unique. All participants were able to provide their own informed consent, either verbally or written (see Appendices E & F). Further, I followed the methods of process consent as outlined above. The practices of process consent were repeated upon each interaction, and throughout each encounter to ensure the participants were actively consenting and understood that they could choose to withdraw at any point in the research process.

There are also ethical considerations when creating visual images in research. Banks (2007) recommends: "the best way to deal with ethical and intellectual issues arising from visual research [is] to work *with* research subjects rather than work *on* them" (p. 96). There is an implicit power difference between participants and researchers in a study. Despite efforts to inhibit this, power is always present to an extent. "The power not simply to look, but to record and then disseminate, is a power that social researchers who create images must reflexively address" (Banks, 2007, pp. 87-88). Developing relationships with participants and working *with* not for others is essential (Dupuis et al., 2012a). I acknowledge my privileged position as a university student and inquisitive researcher. I am also upfront about how this research project

will ultimately fulfill academic requirements and enable me to graduate with a master's degree. Despite my positionality, this is a topic I truly feel passionately about, and have chosen to give my attention. My intended outcomes of this research were to positively impact perceptions of dementia and better understand how we can support persons who have animal companions throughout their dementia journey. As such, I was not trying to exploit, but to work *with* persons living with dementia, and support them in telling their stories. Nevertheless, I need to continually be mindful of my privilege and critically reflect on my process.

In the next chapter I present the stories learned by engaging in this narrative research process. My interactions with people with dementia in this process - in the sharing of stories and photos - provided an important space for the co-construction of knowledge that was created in togetherness, in relationship. I was then able to take those co-constructed stories and re-story them in a way that would reflect the unique and complex relationships between the participants and their companion animals. These re-storied narratives form a short story collection that I am excited for readers to engage with.

CHAPTER FOUR: RE-STORIED NARRATIVES

My Role as Storyteller

I am aware that many decisions I have made throughout this study have impacted the stories I have chosen to tell. While I have stayed fairly close to the participant's own words, lived experiences, and photographs in the re-storied stories, I am the one who conducted the interviews, read and analysed the transcripts, and chose which stories to tell and the representational forms to use. I agree with Diversi (1998) who explains: "I am the author of these stories and, as such, have made important choices in the writing process that both carry my own interpretations of the lived experiences and define the possibilities of the reader's interpretations" (p. 133). I want to emphasize that the stories below are my re-storying of participant's stories shared during our conversational interviews. In the re-storying process, I used direct words/quotations that participants used in their stories of their experiences and their relationships. However, I have also added some transitional words and short sentences to help with flow, coherence, and add details to the story – to help fill out the story in a way that paints a picture of the individual relationships shared.

My decision to stay close to the lived experiences and narrative voices of participants is connected to my ambition of challenging the dominant tragedy discourses of dementia. I was surprised and moved by the insightfully deep comments participants shared on their experiences of living with dementia and impacts of stigma they have encountered. I felt privileged to learn from and with participants in this study and I hope to share with readers the insightful, surprising, and emotional perceptions of participants. This process has challenged my own perceptions of dementia and the abilities of persons who live with it. A number of small interactions with participants made me question my own assumptions of dementia. For example,

a participant said hi to me by name when our paths crossed months after the interview, another participant identified the time zone differences for our scheduled video chat in an email to me (9 am my time, 11 am your time), others returned their cameras one week after taking them home – like they said they would. My astonishment at these junctures made me reflect on why I was so surprised at each of these encounters? Why was I underestimating the abilities of participants? It is in listening to, re-telling, and re-living stories that I have realized how my own perceptions changed and shifted, something I hope other readers too will experience from reading my re-storied narratives.

Role of the Reader

The use of CAP in research allows for multiple interpretations and understandings to emerge, as each reader engages with a story in their own way (Parry & Johnson, 2007). As such, readers have a role in engaging with stories (Diversi, 2008). Randall and McKim (2008) describe:

Instead of being seen as an empty vessel into which the meaning of a work is poured, the reader is understood, therefore, to be part of an organic, creative process, where author, text, and reader come together in the act of creating meaning (p. 79).

Reading is thus creative, and involves active engagement with stories and characters (Randall & McKim, 2008). Meanings and interpretations are negotiated and impacted by “...experiences, beliefs, attitudes, and memories, plus other qualities or constraints, that individual readers bring to [the text]” (Randall & McKim, 2008, p. 80). Reflecting on what they are seeing and reading, readers might be impacted by stories in different ways, and each time they read a story. The use of CAP also allows for sharing research findings in a more accessible format to a broader audience (Parry & Johnson, 2007). This was particularly important for me, as I wanted to these re-storied narratives to be accessible to both persons living with dementia and academics alike.

My Reflections on Storytelling Methods/ Representation Styles

I spoke with seven individuals living with dementia, and each person's experiences, stories, and relationships with their companion animals were different and unique. Everyone's dementia journey is varied, ever-shifting and changing; there is an infinite range of abilities in the dementia context, and I wanted to honour and respect the abilities and strengths of the participants who took part in and contributed to this study. I am grateful to them and their willingness to share their stories with me. My re-storied narratives show diversity in dementia; I was inspired by the varied ways participants told, showed, and expressed stories about their companion animals. Before I present the re-storied stories, I provide a reflection on each participant's ways of storytelling and describe how this understanding transformed into the different narrative representational styles used.

According to Caulley (2008): "Conversations in the text can also give the reader emotion, making the text more memorable, more human, and more understandable" (p. 432). During my data analysis, I noticed that Rick shared a number of stories about previous conversations and interactions he had had with various people in regards to his current cat, Louie and former cat, Sugar. Rick is enthusiastic, personable, and a wonderful conversationalist. He is open and shares his stories because he wants to shift people's perceptions of dementia. I wanted to use Rick's conversational way of telling stories in my re-storying. Thus, I have organized and represented his stories into three dialogue-based short stories with different characters: 'I Can't Take it Anymore, It's too Lonely'; 'There's a Rescue Kitty Out There with My Name On It'; and 'A Match Made in Heaven'.

In listening to and reading through Stella's interview transcript multiple times during my data analysis process, I came to understand the importance and significance of her relationship

with her cat. During the interview, Stella spoke with a lot of emotion, that to me, demonstrated her love for her cat – at times she cried or spoke with a weepy voice, at other times she laughed and giggled. I constructed a poem, called ‘She’s My Cat’ entirely with Stella’s direct quotations, to re-story this significant relationship. Much like, Richardson (1992) and Evelyn (2004), I selected words and key phrases for the poem that spoke to Stella’s main narrative. I attempted to capture her emotion and tone in the chosen quotations, and have arranged them in a way to tell my version of her story and strong bond with her cat. For these reasons, I felt that poetry was a most suitable narrative form for re-storying Stella’s story, because poetry has a marvelous way of conveying both information and emotion (de Vries, 2007).

With Doug, our conversation was guided by the photographs he chose to take for this project. To me, the photographs depict a day-in-the-life of Doug and his dogs, and so I have re-storied in such a way that his photos are paired with text from the interview transcript to create a sort of storybook I have titled ‘I Could Never Live Without A Dog’. Doug spoke with a passion for his dogs and for their relationship. Far too often persons with dementia are not considered capable of telling their own stories. Therefore, I felt it was important to maintain a first-person account, and have Doug’s voice as the main storyteller in this short story alongside his photographs. Throughout our conversation Doug repeated some phrases and key concepts, and to me, his repetition reinforces the significance of these feelings and ideas, and so I have included repetition in my re-storied version of his story.

During my analysis I found a strong sense of self-assuredness and matter-of-factness in Lisa’s storytelling. She spoke with self-confidence and a thoughtful self-awareness of her dementia and her relationship with her dog, Max. Given this, I chose to maintain her first-person narrative in my representation, and have re-storied her interview transcript into a short narrative

that is reminiscent of a monologue or journal entry. I have named Lisa's monologue, 'He's My Everything'.

During the interview and further in my analysis, I noticed that Gloria expressed a range of emotions in regards to how she *feels* about her relationships with her cats, and also in how she *communicates* these feelings. I chose to re-story her narrative by writing a series of short poems that have a kind of broken, staccato tempo to help convey both *what she feels* and *how she expresses these feelings*. With my re-storied structure, I attempt to communicate her frustration associated with word-finding, variation in speaking patterns and intonation, and her shifting emotions, altogether delivered with a sense of humour and playfulness. I followed a similar approach with Gloria's transcript as I did with Stella's, in that I selected words and key phrases for the poems that spoke to the main narrative (Evelyn, 2004; Richardson, 1992), and drew on emotion to help show rather than tell the story (de Vries, 2007). The poems I have used to re-story Gloria's narrative are: 'Back to the Pound', 'Play', 'Brush', 'Shit, and 'Love'.

One of the things that really stuck out for me with Shirley's narrative was the way she spoke for her dog, Rocky. In reading through her transcript paying attention to language in particular, I began to notice how she often spoke as if she was interpreting Rocky's actions, thoughts, and feelings. While she was not the only participant to do this kind of thing, the repetitiveness of it throughout our conversation made me feel that it was significant to include in my re-storied version of her narrative. I added a few of her key phrases as word/thought bubbles from Rocky's perspective in my re-storied version of her comic-inspired photo essay 'I Got the Best Dog'. Shirley has a good sense of humour and I felt that this was a playful way of illustrating the mutuality and connection she feels in regards to her relationship with Rocky. While dogs obviously don't speak in words we can understand (*does one bark mean squirrel*

approaching, and two barks mean give me treats?) their actions and movements are an important way of communicating. Shirley clearly understands this.

Diving into Karl's transcript I noticed that he shared a number of stories about daily interactions he has with his cat, Mia. These simple encounters helped me to understand the complexities of their relationship and the comfort in routine and familiarity. I decided to re-story Karl and Mia's narrative as a short story – 'Wherever I Am, She Want to Be' – sort of a window into their daily lives and interactions. I pieced together different stories he shared with me during our interview to construct a scene. There is nothing particularly exciting or life-changing in the short-story, but I think it shows the everydayness of life and intimate details of their relationship.

As much as there are differences and nuances in each of the seven participant's narratives, there are also similarities and patterns that weave through the stories. The stories that follow are not meant to be all encompassing, but rather highlight the most significant and key dimensions of the data that connect back to my research questions:

1. How do persons with dementia story their relationships with companion animals?
2. How do these stories help us understand relationality and social citizenship in the dementia context?
3. How do companion animals contribute to the storying of life and leisure experiences of persons with dementia?

SHORT STORY COLLECTION

1. I Can't Take It Anymore, It's Too Lonely.

It is mid-day and although the sun is shining and birds are chirping outside the window, Rick sits pensively behind his desk scattered with sticky note reminders, old newspapers, and Alzheimer Society pamphlets plastered with his face. He wiggles his cellphone out of the front pocket on his jeans, taps “Contacts” then “Katie”, and lifts the phone to his ear waiting for that familiar voice.

“Hello?”

“Hey, Katie!” Rick energetically responds. The sound of her voice always brings out a smile.

“Oh, hi Dad! How are you?”

“I’m good thanks” Rick automatically responds. But then pauses, knowing that’s not the truth. He backtracks, “Actually” he says slowly pausing on each syllable, “I’ve been better. I’ve been having a tough time lately.”

“Oh, no. What’s going on Dad?” Katie softly responds. “You don’t sound like your usual upbeat self”.

“I’ve had something on my mind lately that I want to ask you... You know that I was heartbroken when Sugar passed away after 21 years – it was just as bad as losing a family member, just as bad for me as losing a daughter, or a son, it was that bad”.

“Yeah, it was harsh” Katie says. “I’m so sorry!”

“She died in my arms” Rick’s voice quivers and he wipes a small tear from his cheek.

“At the time, I told myself it's too emotional. I'm not getting another pet”. He pauses and takes a

breath, “I kept telling myself, hey, I can bugger off to anywhere and not worry about a pet-sitter, and this is good.... But between you and me, it is incredibly lonely. I miss that companionship.”

“Yeah, I get that, I know how important your furry friends are to you” Katie replies.

“It’s been about six months, and I can’t take it anymore. It’s too lonely, too quiet. So now I’m thinking, what the hell, maybe I can help a cat out?” He lifts his free hand palm up. “You know, strike up that magic again, right? That inherent need in us all to take care of something, even with the dementia.”

“I think that’s a great idea Dad!”

Rick shifts nervously in his computer chair and takes a deep breath, “Um, but if something goes sideways with my dementia, would you take my cat?”

Surprised by his question Katie pauses, “Uhh...sure.”

“I only ask because I dread the thought of a cat having to go back in the shelter. It’d be traumatic for them. The shelter staff is very loving. But the reality is in the shelter they have limited time. They’d lock the cat up. He’d be in a tiny little cage, and there’s lots of other animals and there’s diseases, small confined areas, lots of challenges.”

“Dad, you know I don’t really want a cat. I’ve got enough going right now with finishing my degree and working full-time. But, I’d take care of him for you.”

“Thank you, Katie, I really appreciate it. And you know it might not come to that, but for him to have to go back into that environment would just absolutely break my heart. I’ll think about maybe finding someone else that would be better suited, a back-up.”

“Alright, whatever you think is best.”

“I need someone who would make my cat feel the centre of the earth. The same way I do, that would just love him.”

2. There's A Rescue Kitty Out There With My Name on it.

Rick picks up his cellphone taps on the Google icon and searches “SPCA near me”. Scrolling through the website he clicks on “Cats for Adoption” and is immediately taken back by the number of photos of cute but also sad, sheepish faces in small stainless-steel cages; 2 months, 6 months, 8 years, 3 years, some with funny names like Nacho and Salsa, black, white, ginger, tabby, tortoiseshell, seemingly every option imaginable. The page goes on and on, as he scrolls down the endless stream of eligible furry friends. At the top of the page he taps the “Contact Us” link and hits the phone number, which automatically dials.

A perky voice answers after a few rings, “Hello, thank you for calling the SPCA, how may I help you?”

“Hello” Rick responds confidently, “I was just looking on your website, and I think there’s a rescue kitty out there with my name on it. I was wondering, do you have any near-impossible cats that you’d probably never adopt out? An older cat too.”

The young woman on the other end enthusiastically responds: “Oh, yes! You gotta come in and meet Louie, you gotta meet this cat, he’s amazing! He was saved from a severe hoarding situation, one of the worst we’ve ever seen. To be honest, we didn’t know if he was going to live, he was so sick and we nursed him back to health. And now the poor little guy has been sitting in the shelter for six months waiting for someone to adopt him.” She continues, “We don’t know why, but Louie doesn’t have a tail, and we think he has irritable bowel syndrome, either that or cancer....”

Rick takes in the cat’s story and looks around at his living room. A few unopened cardboard boxes sit on the floor near the kitchen island. He moved in a few months ago, but still hasn’t finished unpacking. The place is nice, but doesn’t quite feel like home just yet.

“Well, I do have Alzheimer’s... But who better to take care of a cat with no cure for a disease than me? I can relate to a cat that no one else wants, I’ve experienced discrimination and loss myself - my spouse broke up with me after my diagnosis! The stigma associated with dementia is real, and I think it’s the number one issue for people living with dementia. It’s not challenges with the disease, it’s the social attitudes.”

“I’m so sorry to hear that, sounds like you’ve been through a lot yourself” the woman softly replies.

“Yes, but change will come from speaking openly about dementia and our experiences. So, a big part of living well with dementia for me is having a furry friend in my life, a big part of living well” Rick responds. He looks towards the framed photo of Sugar, proudly displayed on the mantle over the fireplace – one of the first things he unpacked. “Any cat who gets me is a lucky cat because I just absolutely spoil them with love.”

“Well, if you are serious about adopting Louie, it’d be great for you to meet him soon” she emphasizes, “... as I said he’s been at the shelter for six months...and I’m sad to admit it, but seems like he’s running out of time here. We’d love to see him go to a good home sooner rather than later...” she trails off.

“Oh...” Reading between the lines, Rick begins to sense the reason for her urgency in finding Louie a home. “I think I understand what you mean” he says hesitantly. “I’d love to come in and meet Louie, it sounds like we have quite a lot in common. Thank you, this has been helpful”. Rick hangs up the phone, smiles, and declares to himself: “This little guy has been through enough, I can’t let anything else bad happen to him. I’m going to show this cat one hell of a good time!”

3. *A Match Made in Heaven.*

The condo building where Rick and Louie live is new and decorated with contemporary fixtures. The main hallway which connects all the ground floor units is carpeted in a navy and grey hexagonal pattern, light grey painted walls with white trim, and oversized re-claimed wooden doors to each unit are affixed with sleek brass handles and numbered one through 12. In the middle of the hallway a pair of elevators lead to the upper floors of the building. Louie and Rick are walking up and down the hallway of the condo, having a good time. A door across the hall from them opens and a woman walks out wearing skinny blue jeans, an oversized wool sweater, and polka dot socks. A small garbage bag hangs from her left hand.

“Oh, good morning” Rick smiles at her.

“Good morning, Rick” she replies. “How are you today?”

“Great, thanks! Just out for a stroll with this guy” he gestures at Louie who’s sniffing at number five’s door. “Oh, and thank you for those pecan bars you dropped by the other day. They were absolutely delicious! I also like to bake things and give them to people. I love to bake! Actually he,” pointing down at Louie again “likes to watch me bake. I do a lot of baking”.

“Oh yeah?” Maggie replies with curiosity.

“When I’m making a pie or butter tarts, whatever it is he’ll---- people don’t like this, but I don’t have a problem with it, he’ll jump up on the counter and just sit there and watch me. I let him do what he wants.... He has the run of the house, just like I would. My house is his house.” Rick shrugs his shoulders. “You want to walk across the kitchen counter? That’s okay” he says in a singsong voice.

Maggie laughs. “He’s quite a character. It sounds like you’re really getting to know one another.”

“When I first adopted him, I noticed the things about him that I found really odd. Like he didn't know what a TV was. So, when I turned on the TV, he would run and hide under the bed. Or when I turned on the Stereo, he would just panic and run. He didn't know what these things were. He didn't know what it was like living in a home where he had free rein, and he could do whatever he wants...So the learning curve with him, it took a while to bring him around, but now he watches The Incredible Dr. Pol with me. You ever watch that show?”

“No, I can't say I have” Maggie answers, resting the garbage bag on the carpet, giving Rick her attention.

“It's a vet show. Well, he loves those shows. He watches them with great interest,” Rick chuckles and leans his back against the wall. “I think it's cause there's animals in it. I usually lie down when I watch TV, so he'll just snuggle up, lie on my chest and watch TV with me.”

Maggie smiles, “Aw what a sweetie.”

“It took about three or four days before he sat on my lap, but the minute that happened, it was like a light bulb went off in him.” Rick snaps his fingers. “I can't get him off my lap now” he says with a chuckle. “He loves snuggles, he loves kisses. Like, when he realized it's okay to snuggle it was like this overwhelming surge of love. It was beautiful, beautiful” Rick smiles wide.

A calico cat with bright green eyes saunters out of Maggie's open apartment door and into the hallway. Rick's eyes are immediately drawn to the cat and he moves forward within reach.

“Oh, cool, you got a cat, you know I love cats, I call myself the cat whisperer.” Rick bends down, and starts patting her cat. Maggie watches Rick closely as he strokes the kitty from head to tail. The cat begins to purr and leans its face into his hand. Rick continues, “I live alone,

and so I think the big thing is the companionship Louie and I give each other, that's the number one thing. Lots of love. He's super affectionate."

"You know, I have a bearded dragon, you wouldn't think so, but turns out they're quite affectionate too" Maggie says.

"Wow – that is surprising! I wonder what it would be like to cuddle up with a bearded dragon" he laughs. Rick stands up and looks lovingly down the hall at Louie, who's now lying on his side playing with a stray leaf carried in with the wind. "My boy is a constant source of happiness, constant. Good day, bad day, he's there for me, he doesn't care... You know, I love that non-judgmental - I don't care – I love you, by the way, feed me, you know kind of goofy attitude that he has. He makes me laugh all the time, and we just cohabit. We're just constantly with each other."

Maggie reaches down to pick up the trash bag. "Yeah, I think I've even seen you outside with him on a leash and harness?" Maggie asks. She starts to slowly walk down the hall towards the garbage chute.

Walking alongside her Rick continues, "Oh, he loves to go outside, and the little shit will jump off the deck every chance he gets" Rick chuckles. "I live on the ground floor, but no matter how much reason I try and give him, you just can't trust him." Both Maggie and Rick laugh. "So, I got him a harness and I thought, well, what the hell? Like with his health issues, I can't afford to have him taking off for a couple of days at a time... So I decided, let's try walking and see if it flies. And sure as heck it did!

"Usually cats won't let you do it, I doubt mine would!" Maggie motions back down the hallway, where her calico cat is peeking out of the ajar door.

“Well, uh, he's not like a dog. He, he's in his own world. Ya know? So, the walk is on Louie's agenda, not mine. Like he'll stop and stare at a bird for five minutes... So, I stand there for five minutes while he checks out a robin pulling up worms. The whole process is super slow. But he's sweet to walk and I've taken him on some pretty cool walks on the hiking trails right near where we live...But, I have to pick him up every time someone walks by with a dog” Rick laughs.

With a hand on the garbage chute door Maggie's eyes go wide in surprise and she looks at Rick, “Oh my gosh! What makes you think of doing these types of things?” She tosses the bag in and quickly closes the door. They turn away from the lingering odour and walk back towards Maggie's unit side by side.

“I get these brainstorms to keep him stimulated. I've always been very, um, I don't know if you'd call it hyper, but I need a lot to keep me entertained” ... even with the dementia, Rick thinks to himself. “I thought, wow, you know, I should take Louie for bike rides, I got the three-wheeled version, it's got a big carriage in the back. First time I had him out on the bike, I tied him in the carriage and I'm riding on the bike. I thought it was going well. I kept looking back at him and he was just kind of lying there looking around and I said oh you know he's liking this. I didn't want to stress him out. Right? And all of a sudden, I felt this jerk on the bike and I looked to my left and Louie's walking beside me.” Both Rick and Maggie burst into laughter. “And then he runs to the condo door and sits there. I think he had enough of that” Rick chuckles. “So, I'm going to try to figure out a cover for him, he actually worked his way out of the harness” Rick and Maggie continue laughing together.

Standing outside Maggie's door once again, she asks: “Would you and Louie like to come in for some tea? I just made a fresh batch of blueberry muffins this morning.”

“I’d love to!” Rick quickly replies.

Maggie leads Rick into her unit, an open-concept style space where one room bleeds into the next. “Don’t mind the mess, it’s been a busy week, and I’m getting ready for a trip” she says. They walk into her living room, it’s furnished with an eclectic mix of vintage and modern. Plants by the windows and a soft pink throw draped over the back of the sofa. “Make yourself comfortable, I’ll put the kettle on” Maggie calls out as she walks towards the kitchen.

Rick saunters around the living room, admires the record collection, and then notices the bearded dragon, sitting stoically on a log under the warmth of the heat lamp in the vivarium (a reptile enclosure). “Wow – look at you little dragon” he whispers.

Maggie returns and places a wooden tray on the glass coffee table. She picks up the tea pot off the tray and pours a cup for each of them. Rick joins her on the sofa. “Would you like a muffin?” Maggie asks. Rick grabs one from the overflowing plate and unpeels the paper.

“You know, uh, we’re going away for the weekend” Maggie says, gesturing to a pair of carry-on size suitcases near the dining room table. “Would you watch our cat for us? You love cats.”

“Of course, I will!” Rick loudly exclaims. “We should make a deal where, you know, we’ll swap baby-sitting services.”

“That sounds perfect!” Maggie agrees.

“I’ll train you on what Louie likes... and we can clean each other’s kitty litter.” Rick pauses briefly, “But, hey... listen, you know, your cat, I should give you a heads up. I do have Alzheimer's, and I don't know if...if you feel uncomfortable with me watching your pets, I totally get it. I thought I'd be transparent with you.” Rick casually pours a splash of milk into his steaming tea.

Maggie, very matter-of-factly responds: "Oh, actually, I already knew you had Alzheimer's. I was at a conference and I heard you speak. You're a hell of a speaker, holy cow!"

Rick's cheeks flush: "Oh wow! I'm flattered as hell! I've found out that people are really cool with dementia. You just got to give them a chance, and that goes back to speaking openly. I don't hide my dementia and I speak very openly about it because I want people to be comfortable with it. I want people to just talk about it like they would diabetes, or with any other disease. And with dementia, people are not comfortable. So, I make a point to be very open."

"I do not have a problem with it" Maggie confirms.

"I probably won't remember their names, so I'll just call them dragon and kitty."

Maggie giggles, "I'm good with that!"

"This is going to be a match made in heaven" Rick says with a smile. Louie, who's been exploring Maggie's apartment, jumps up on Rick's lap and snuggles in. Rick sips his tea and relaxes into the softness of the sofa and the familiar warmth of Louie's embrace.

She's My Cat

I call her nutsy cause she's always into everything

She's a nut

She's crazy

She's funny

She just makes me laugh

I love her and I wouldn't let her go

She's got that bump, but she's mine

She doesn't have to be pretty

She's my little girl

I don't know what I'd do if I didn't have her

I love her

She's cute

She's sweet

She's a sweetheart

She loves me

If she wasn't here, I wouldn't be happy

She's my cat

I Could Never Live Without a Dog



My wife walks out the door at 7:30 am and might get home at 5:30 pm. When my wife's off to work, I got two buddies to talk to. They're good company and good to have around, they'll listen, but they don't say anything.

"Okay, what are we going to do today, Charlie?" I say.



I take them out walking every day, all I have to do is pick up that leash, and Charlie will be at the door and Roxy won't be too far behind, they're together all the time. They love to go for a walk. If I don't give them a lot of walks they come over and look at me and say: "Okay are we going out or not?"



Once they see me putting my shoes on, the little one will start barking at me to hurry me up. It's like she's like: "Come on kid, get them damn shoes on!"



I take Charlie and Roxy at the same time, they're my walking buddies. They're good walkers, they're good dogs. He's younger, he's going to be six soon, she'll be 16 years old at the end of this year.



When I'm walking with them, I always take the same route, because someday it's going to go click possibly, and I might forget. If my dementia fools me, Charlie might be the one to get me home, he's that smart. Or if I fall down and I don't get up, they would probably go home. Charlie might try to go over there and see if he could raise some hell or something like that. That's also why I always carry a cell phone when I'm walking, just in case something happens.

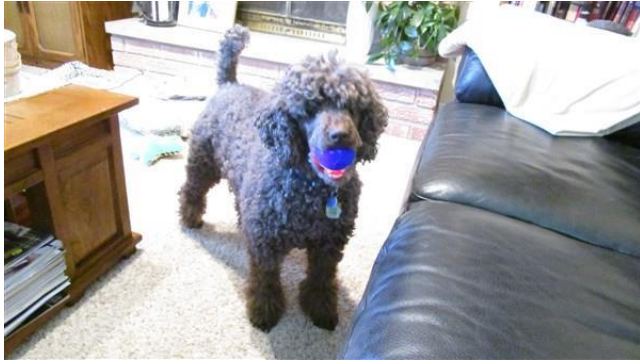


I'm out walking with them somewhere between an hour and 45 minutes and those two monkeys are with me. They go for it, they are not tired.



At the front door I say: "stay there" and they will stay there. They're pretty smart dogs.

When we get back home and go inside, they go for a drink, and I go for a drink.



He will bug me, he'll give me a nudge in the leg saying: "Hey, I'm down here! Come on!" Or he'll come over and...he'll look at me and go: "Rrrrrrr," and that means: "I want to do something, thank you." He wants me to play, he likes to play, likes to catch a ball. He can tire a man's arm, that's for sure.



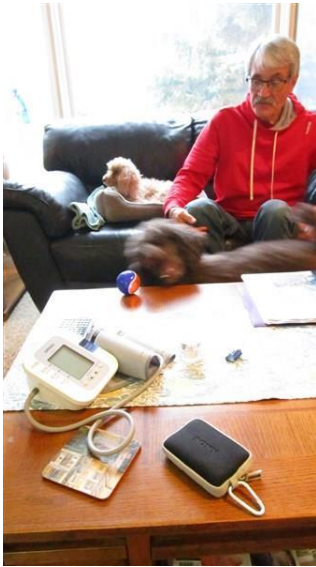
A poodle loves to play, Charlie plays in the house, and he plays outside in the backyard. He's fun and he's also a little bit of a guard dog for Roxy and for us. He's got a loud bark and he will prevent people from trying to break in the house, he thinks he's Tarzan.



Whereas Roxy is a cuddler, if I was crying about something, I'd pick up that little devil, and she'd sit there and she'd come in and lick me. If my wife is mad at me, I grab Roxy, she will cuddle up in my arms and everything goes away. And if I have a headache, she'll lay down beside me in the bedroom and we both fall asleep. But she's very old, as I said, she's going to be 16, if she gets to the end of the year, she's done great. She will make me cry for sure, if she—when she's gone.



Both Roxy and Charlie are good company, and they listen to me when I'm pissed off. This little devil, I truly believe watches TV, Charlie has not caught onto the TV.



Charlie likes to cut in on our TV time. Roxy just likes to be in her basket beside me, but Charlie wants me to roll the ball on the table with him. They're like kids, that's how I look at it. They meld very well for buddies. They're friends in our family, they're our pets, but they're pets that we love. I could never live without a dog, I love them.

If I was on my own, or if my wife was gone and these guys have already died because of their age, I'm going to find a breeder of poodles, and I will get another, I won't give up. I could not live, I couldn't live without a dog, period. If I couldn't afford to buy a poodle I would go to a vet or go to one of them shelters like we did last year, and say: "have you got any pups?" I won't take a full grown one. I'd just grab a little pup because you've got to train them. If somebody told me I had to move out of my house, I'd go find a place where I can take my dog with me, because they're my friends. I think that if people were looking for company at any age, I would always have a poodle.

He's My Everything

From the beginning I have been very accepting of my illness. People think this is weird, but I think it's a gift for me, because I got out of that stressful life. I was having breakdowns and crying when I would get home, I couldn't sleep, and I was forgetting things at work. So, I see this as a gift. I wander off sometimes and think... not like never "why me?" because, "why not me?" Sometimes I think of the things I could be doing or something like that and I can get emotional there, but I always go back to this one thing. I just remind myself, I don't have to get up and go to work tomorrow. I mean, that's amazing to me because of the state I was in. To be honest, I can't imagine doing anything different, because what can I do about it? I can't regrow brain cells. I can't cure my dementia... I could be miserable or I could be happy, you know, and I am happy.

We had another dog, Teddy for years and he was so awesome. He was not a cuddle bum, but he was so obedient and he liked to play. We didn't know 'til like the end stage, he had bone cancer and died just about maybe six months after I was diagnosed. I talked to my neurologist about Teddy and how hard that was when he died. I'm alone by myself every day during the week when my husband's at work. My neurologist said: "you know, it would be a good idea to have a dog," for the company and to get me out walking. So, he said: "here's a prescription, you need to get another dog."

Max just turned four in January, we got him when he was 12 weeks old. In a dog relationship, he's my everything... I mean my husband is my everything too, ha-ha. But, I spend wayyy more time with Max, than I do with my husband. He's basically my kid, he gives me purpose and responsibility and with him I feel like, useful! I pretty much look after him entirely. I trained him, I feed him, and I bathe him. When he is ill, I take control of all of that, and make sure he gets better. I would say that everything to do with him is my job. But if something

happens to Max, I don't think I'm in a position to train a new dog. So, I try to make sure that he's taken care of well and regularly going to the vet. I don't let just anybody walk him or sort of provide for his needs – I'm protective of him in that way.

We're there for each other, we love each other, we trust each other, and we're probably codependent. He needs me, every bit as I need him, and I'm pretty sure that I mean everything to him, like he means everything to me. We're there for each other and I don't know that I would be doing as well without him. I have a hard time doing stuff on my own. But when I'm with somebody else and we're doing it together, I can do it. So that's where Max came in with the exercise, I would never go for a walk by myself – not anymore.

One time, I was walking him in a wooded area and I got completely turned around, I had no idea where I was. I know for sure that if I need somebody at any time of the day or night I can call my husband. So, I called him and he told me: "tell Max it's time to go home". So, I did, and Max started going the right way. We managed to get home, and after that I never walked him through that wooded area alone again.

At home, Max gets me out into the fresh air...we play ball in the yard, or when I'm gardening or doing some snow shovelling he hangs out with me. Other than that, I might not get out during the week until my husband's around on the weekend. So, Max gets me outside, and he makes me laugh like crazy sometimes. That real big belly laugh, it's just the two of us, but he makes me laugh. He's funny. He's also protection for me, because I don't like people coming to the door when I'm by myself. It just freaks me out. I have no idea who's on the other side of that door. So, I trained him to bark. If somebody takes one step onto our property, he is barking - and so I know when he's doing that, that somebody is out there, he's very smart and he alerts me.

He's also very gentle... but I'm pretty sure he would bite somebody, or take them down if they were threatening me, I'm pretty sure he would.

I don't like when he's unhappy. If he says he's hungry and we've already fed him, like I know where he stands, how he stands. If he's like "mmm", "mmm" I know, he just tells me what he wants. But one of the things I wonder about is when my dementia brings me to a place where I can't be actively in control of his health and needs, then what's going to happen? Because nobody's going to love him like I do.

Back to the pound

I got her from a lady in the building.
'Cause she, I forget why she didn't want the cat.
She said, "I'm going to have to take it to back,
back to the pound."
"Oh no you won't! I'll take her" I said.
So, I had to.
'Cause I didn't want her to go
back to the pound.



Play

I play with them.
back and forth.
playing with that thing.
whatever you call it,
As soon as they see that thing come out,
they're right there.
they're going to be able to play.
They make me happy
Back and forth,
They love
That thing –
they love the best.
whatever you call it –
They know
It's fun to watch.
when we play together.

Shit

I do their-----
I do their-----
I do the-----
 um, I do their-----
 SHIT!
That's the word.
 I do their shit.
 Ha-ha-ha!

Brush

I feed them.
I play with them.
I get the thing to-to-to-
 -----to BRUSH!
 Brush the cat!

I do that.
 They love it.

Love

I love it when they lay on—sit on my lap.
 They like to sit with me,
 when I'm watching TV.

They'll sleep close to me wherever I am.
 Right there with me all the time,
 always by my side.

I'd miss them if I didn't have them.
 I thank God I can have them.
 I'd be lost without them.

I can't imagine not having a cat.
 Hopefully it doesn't come to that.
 I love them.



I Got the Best Dog

My son adopted Rocky for me. As soon as I saw him I thought, I'm already in love with you. I think they tried at one time before I got him...to do things in the rings...that they would do in shows and stuff. He didn't like working in the rings when the other animals were in the rings, or doing that kind of thing, so that's why I was lucky enough to get him.



We got a nice little house. He's got a little place of his own. We do a lot in the backyard. I've got a big backyard and he likes playing out there. So, we throw frisbees and stuff and keep him busy... And it keeps me busy, and keeps me active too. We have a lot of fun.

I think having a dog in your house when you're by yourself is the best thing – it's fantastic to have him around. I think I got the best dog going!



If Rocky wants to go for a walk, we'll go out for a walk. He loves getting out and around and I try to be out and get some exercise so I'm not staying stuck in the house and moaning and groaning, there's no good about that. So, we go out for walks, and go down to the waterfront sometimes. Both of us need it. He keeps me going, I get exercise and he gets exercise. We have a good time together.



We always had pets in my family growing up, and I have always loved dogs in particular. But he's the best! I honestly, couldn't have asked for a nicer dog. I love having him.

When we're out he loves meeting people. One day he sat down in front of a little girl and waited for her to touch him, he wouldn't move.



If he thought something was dangerous or if somebody came up to us and tried to hurt us, then he'd be right in between me and them, that's the way he is. I think he would growl or something. But very rarely do I ever hear him growl. He's such a gentle soul.



I love him and he loves me it seems. He'll be right there with me if I'm, if he thought something was wrong, he'd be right there.

If I'm down about something he'll put his head in my lap. He's a sweetheart, he's my buddy, he's the best thing going.

Wherever I am, She Wants to Be

Grabbing his keys from his jacket pocket, Karl unlocks the apartment door and is immediately greeted by a familiar *meow!* Mia in her usual crazy fashion is at the door pacing back and forth. Knowing this means she wants out Karl shakes his head and chuckles to himself as he holds the door open and patiently waits —as he does every time he gets home from work. Mia walks out about three feet into the hallway, sniffs at the neighbour's door, and stretches slowly, lifting each fluffy sock-like white foot out long behind her, one at a time. *DING!* the elevator at the end of the hall chimes and two people walk off, mid-conversation. Karl lifts his hand and waves to his neighbours. Pointy black ears pull back, tail pin straight in surprise, Mia pauses before quickly darting back into the safety of the apartment.

Karl closes the door, hangs his jacket in the closet, and carries his shopping bags the few steps to the bright white kitchen. It's small but efficient, new appliances, subway tile backsplash, easy to keep clean. Mia jumps up on the counter and watches Karl's movements as he opens and closes the cabinet doors putting away tins of tuna (her favourite), tomato sauce, coffee, boxed pasta. Produce and milk in the fridge, he turns around to find Mia standing inside the upper corner cabinet, perched gracefully on the lazy-Susan.

“You want to get locked in?” Karl jokes. “You sure do run the place... the only thing you're not doing is paying the rent!” She meows, jumps, and paces back and forth near his feet. Grabbing a tin of tuna, Karl sets it on the countertop as a reminder for himself - it's nearly Mia's dinnertime. He walks to the bathroom and places the new tube of toothpaste in the drawer, Mia on his heels. Karl putters around, places the grocery bags in the front hall closet, opens some mail, and checks the time. He grabs Mia's empty bowl off the ground and the bag of dry cat food

from the cupboard. He opens the tin of tuna and spoons a few flakes on top of the kibble. He can barely place it on the floor before Mia dives in. *Crunch. Crunch. Crunch.*

In the living room Karl sits in his favourite black leather lazy-boy chair. Mia jumps and lands on his lap, climbs up his chest and puts her nose to his, her long white whiskers tickle Karl's face.

"I love you too" Karl whispers. As they sit together Karl enjoys this moment; he knows it won't last long – she's not a cuddle cat, and doesn't like to hang around once he switches on the television. But they're working on it, Karl likes to think of it as a project. He checks his watch, nearly 7:30pm – time to watch the Leaf's game! He picks up the remote, and Mia leaps – gone.

Karl nods off, and wakes near the end of the third period, Leaf's are up 3 to 1. He switches off the TV and heads to bed. As soon as he gets in bed, lights off, *MEOW.... MEOW.... MEOW....* That familiar nighttime routine.

"Mia, I'm over here!" Karl hollers, "come on" patting the top of the comforter.

Wandering around the apartment, the patter of her paws is audible in the otherwise silent room. He feels the pull of the fabric before he hears it. *Scratch. Scratch.* She paws the side of the bed before jumping up and curling in right beside him. Reaching his hand over, Karl pets her soft fluffy fur rhythmically as they fall asleep together.

CHAPTER FIVE: A CONVERSATION ABOUT THE RE-STORIED NARRATIVES

This study illustrates the significance and complexities involved in the relationships between persons living with dementia and their companion animals. For storytellers in this study, their relationships to animal companions are signified by strong, deep connections that have developed over time spent together and through shared experiences. These relationships with companion animals are highly valued by the storytellers and impact their everyday lives. Informed by a social citizenship approach to dementia and relational theory, these lenses have guided me and impacted the perspectives and ways of reading and representing the data or field texts. The re-storied narratives presented in the previous chapter portray persons with dementia living active, engaged, social lives. There are a number of patterns that weave through the stories. My intention with this chapter is to bring together a number of these main topics and patterns shared in and across the short story collection and connect these ideas to existing research and literature, as a means to understand notions of relationality and social citizenship in the lived experiences of dementia.

First, I return to the theoretical framework guiding this study and reconnect with relational theory, social citizenship, and relational citizenship, providing a brief overview of each for the reader. Next, I reflect on the roles and responsibilities involved with caring for a companion animal and consider how this connects to a sense of purpose and continuity of life-long roles for persons living with dementia. A number of participants developed and implemented strategies that enable them to continue caring for their animals, and I suggest these strategies are a performance of social citizenship. It is evident that the individuals living with dementia in this study have close and meaningful relationships with their cats and dogs and

consider animals friends and family members. These relationships transcend appearance, age, and illness, and participants show compassion to animals that might be considered by some to be “undesirable”. Companionship is one of the most significant aspects of these relationships and contributes to feelings of belonging and togetherness. Participants enjoy spending time with their animals and some learn, grow, and are motivated to both try new things and maintain their current lifestyle. It is in spending time with their companion animals and shared experiences that they develop close bonds and form attachments. However, connection does not occur without disconnections and reconnections; participants share experiences of loss, fear of loss, and consider the future of their relationships with animal companions.

I believe the collection of short stories, poems, and photos presented in the previous chapter and the discussion that follows, illustrate the daily opportunities and relational ways that persons with dementia express and enact relationality and citizenship. In doing so, I challenge dominant tragedy and biomedical discourses of dementia by introducing narratives that are rooted in the storyteller’s own words. As a storyteller myself, I have included a few haikus throughout this discussion as my interpretation of the new narratives of dementia emerging from this research study. I was intrigued by the challenge to express my ideas both creatively and concisely (Pithouse-Morgan et al., 2014; Samaras, 2010). I decided not to be constrained by the traditional 17-syllable haiku pattern of - line one (5 syllables) – line two (7 syllables) – line three (5 syllables)- as inspired by Dwyer (2018). Haiku refers to “a brief verse that epitomizes a single moment. It uses juxtaposition of two concrete images, often a universal condition of nature and a particular aspect of human experience, in a way that prompts the reader to make an insightful connection between the two” (Modern Haiku, 2019). I felt this style and approach was

appropriate for apposing the dominant dementia discourse against the new narrative emerging from this study.

Let's Return to Theory

Returning to definitions, an awareness of *relationality* refers to recognizing interconnectedness and the significance of relationships in our lives (Jordan & Walker, 2004). Relationships are complex and multi-dimensional and connections exist with ourselves and our bodies, with others, with places, spaces, time (Arai et al., 2015; Jordan & Walker, 2004) and with animals (Beck & Madresh, 2008; Kruger & Serpell, 2006). Relationality encompasses a fluidity from connection to disconnection and reconnection. As relationships change and shift, connection is characterized by growth and development, whereas disconnection imparts isolation and suffering (Jordan & Walker, 2004). While we aim for good, strong connections, we also experience feelings associated with disconnection and loss. Strong connections are the result of: reciprocity, mutuality, mutual empathy, and openness (Jordan, 2004a). It is in and through relationships that we learn and grow (Jordan & Walker, 2004), and relationships contribute to a sense of: safety and security, belonging, purpose and meaning, continuity, achievement, and significance (Nolan et al., 2004).

A *social citizenship* approach brings attention to the citizenship of persons living with dementia. Notably, it argues for the recognition of persons with dementia as relational *citizens*, who actively participate in and contribute to society on both public and private levels (Bartlett & O'Connor, 2010). *Relational citizenship*, accounts for the body as relational and agentic and highlights more personal and micro performances of citizenship among persons living with dementia (Kontos et al., 2017). In identifying the roles, responsibilities, and contributions of persons with dementia, their agency, power, and capacities are recognized (Bartlett & O'Connor,

2010). Looking beyond personhood, social citizenship argues that persons with dementia are engaged in and negotiate various social positions and participate in society, community, and their lives (Bartlett & O'Connor, 2010). That is, they both *can* and *do* make differences in the lives of others and themselves.

Social Roles, Responsibility, and Purpose

Not patient, nor passive –
A person, engaged and active
Dementia

Roles and responsibilities.

Undoubtedly, there are obligations involved when choosing to adopt and live with any kind of companion animal. The type and level of responsibilities will inevitably vary from species to species, and from one animal to another. Caring for animals therefore involves important roles and responsibilities. And for persons living with dementia, these roles and responsibilities can contribute to daily opportunities to practice citizenship.

Firstly, there are roles connected to the status of having a companion animal and the responsibility that entails. Karl and Gloria identify a number of every-day responsibilities involved in caring for a companion animal – cleaning up “the shit,” not a glamorous aspect of having a pet but a necessity, brushing and grooming, feeding, and playing. Both Karl and Gloria live alone, and so these are solely their responsibilities.

Doug’s two dogs, Roxy and Charlie, also have daily expectations and needs to be met. Doug takes them on long walks every morning, plays with them, cuddles with them, and is the primary carer for their well-being while his wife is at work. Shirley likewise comments on taking her dog for walks and playing frisbee with him in the backyard. Lisa thinks of caring for her dog, Max as her job, and says she is in charge of almost everything to do with him (including: feeding, bathing, caring for him when he is ill, going to the vet). She spoke with a strong sense of

responsibility and takes ownership for Max's health and well-being. She is also protective of Max and thinks of him as her child. She believes no one else (not even her husband) would be able to take care of him or love him like she does.

Other responsibilities identified were connected to teaching and training their animals – something that anyone who has ever gotten a puppy or kitten knows is both necessary and a time-consuming endeavour. Rick also comments on the responsibilities involved in caring for his neighbour's cat and bearded dragon when they are on holiday. In this way, he has a social obligation to fulfil their reciprocal agreement.

Within the social citizenship framework these examples illustrate some of the social roles persons with dementia enact, and represent citizenship practices. Bartlett and O'Connor (2010) argue that it is important to consider the multiple roles and identities, as doing so opens accounts for different ways of being and interacting in the social world. These social roles are practiced on the intimate, family and community level. In this way, we can see that persons with dementia hold social roles not only tied to their diagnosis. That is, as a carer, a "pet parent", a neighbour, a teacher, and for those that adopted marginalized animals, a rescuer (more to come on this last role below).

Purpose.

Further, there is a sense of purpose that comes with fulfilling these responsibilities. For Doug, walking the dogs is not just a chore, but is meaningful. Not only do the dogs need to go out (for exercise and to relieve themselves), but they enjoy going for walks, they love it he says. In this way a sense of purpose is derived from being able to meet his dog's needs and bring them joy, which in turn also makes him happy. McDuff and Phinney (2015) similarly found that

for persons with dementia, a dog in need of a walk can contribute structure and purpose to one's day, along with promoting feelings of enjoyment.

For Lisa, changes in her life and abilities means she requires more support from her husband with certain aspects of daily life than previously needed. She always considered herself an independent person, and realizes she now needs more support with tasks that she had always been able to do herself. Persons living with younger onset dementia in Harris' (2004) study also discussed negative feelings associated with changes that impacted their ability to do things they've always been able to do before (i.e., driving, working, being financially independent, etc.), and explained how these changes make them feel more dependent on their spouses. However, for Lisa, caring for Max has not changed. She said: "[Max] needs me, every bit as I need him". Max makes her feel useful and responsible – caring for him contributes to her sense of purpose, and she considers it her job.

Among persons with younger onset dementia, the need for a meaningful sense of purpose can be particularly pronounced, as they may have been treated unfairly at work, terminated, or forced out of their jobs earlier than they felt was necessary (Roach & Drummond, 2014). Very shortly after leaving his job Rick got involved with the Alzheimer Society of Canada; for him, this new role is work – he feels it is important because he is making a difference. With his openness, he is working to change attitudes and public perceptions of dementia as an advocate.

A sense of purpose for participants is also connected to making a difference in the lives of others. Gloria, Rick, and Shirley shared stories about adopting marginalized animals. Rick commented on the inherent need he feels to care, to contribute, to make a difference. So, he chose to adopt a cat he thought no one else would want. Taylor (2009) also speaks to this feeling, in a witty essay about who or what makes the best companion for someone with dementia he

states: “Actually, what I need is to feel that I am still taking care of something” (p. 179). Persons with dementia want to make contributions and feel useful. Within the citizenship framework *purpose* is not merely about “doing” but, considering what is meaningful and important for each person. We each need “a reason to be in the world” (Bartlett & O’Connor, 2010, p. 43). For some, a feeling of fulfillment and sense of purpose are associated with the everyday roles and responsibilities of having a companion animal and contributing to their families and community.

Continuity.

Continuing to care for companion animals also supports a continuity of life-long roles and responsibilities. Caring for and living with animals is something many participants have done since childhood, it is part of their identity. By continuing to carry out responsibilities related to their animals, participants maintain social roles in the family. Stella told me that she’s always been the one to clean out the litter box. When I asked why, she said because no one else in her family wants to. As a mom, it’s always been something she’s done. Similarly, among persons with dementia in Phinney et al.’s (2007) study, continuing to enact life-long familial responsibilities helped to maintain important social roles in the family that were connected to being a helpful husband and a good father figure. Phinney and colleagues (2007) suggest, “It may be that activity provides a sense of continuity for people with dementia by allowing them to feel that their lives are fundamentally unchanged as long as they can still do those things that matter most to them” (p. 390). I think that narratives from this study suggest, it is not merely *activity* but also a sense of responsibility for, and the familiar daily-routines associated with having a companion animal that contributes to maintaining social roles and having a purpose.

Among persons with dementia in Beard et al.’s (2009) study “maintaining a sense of continuity to past interests, social roles, and relationships enriched their lives” (p. 233). Shirley

and Doug both commented on growing up with dogs as children and have always loved dogs. Shirley feels lucky and grateful to be able to have her current dog, Rocky. She admires him and appreciates his gentle nature. People with dementia want to continue to do things that are personally meaningful, connect in ways they have always done, and experience joy in doing so (Ohman & Nygard, 2005; Phinney et al., 2007).

However, sometimes modifications are required for persons with dementia to enact meaningful social roles in new ways. The desire to nurture and care for others was closely associated with a sense of purpose for one participant in Genoe's (2009) study who was a former nurse. Caring for her cat and feeding birds on her balcony enabled her to stay connected to the meaningful social role as a carer (Genoe, 2009). Lisa used to go on long walks with Max, but at the time of our interview, she very recently had to stop walking him because of emerging issues with her balance. I asked her what impact that had, and if the change was hard, and she responded: "from the beginning I have been very accepting of my illness" and with each change it takes her a few days to adjust, but she does and focuses on what she can do and carries on. Her responsibilities with Max have shifted slightly, and now they spend more time together outside in their backyard, rather than going on walks. Change is inevitable in the dementia context, however within the social citizenship framework, persons are acknowledged and appreciated for what they can do and how they continue to participate in life and relationships.

Participation and Contributions

Moreover, continuing to care for animals emphasises persons with dementia as developing and retaining skills and abilities, making important contributions to the lives of others. For some persons with dementia, meaning is connected to having a sense of purpose, being engaged, and maintaining identity (Phinney et al., 2007), and can be connected to feelings

of self-worth (Fazio et al., 1999). Fazio and colleagues further explain: “Retained skills is a critically important topic that is not often discussed in connection with dementia” (Fazio et al., 1999, p. 40), because the focus is most often on loss. Changing the narrative of dementia means we need to acknowledge the contributions, abilities, and ways in which persons living with dementia continue to help others and society (Fazio et al., 1999).

Participation in the social citizenship framework is connected to action and engagement. Bartlett and O’Connor describe, “Participate is a more active verb that recognizes that people with dementia have agency, that is, they seek self-control and act in a way that has subjective meaning” (p. 44). In this way persons with dementia are understood as active citizens (Bartlett & O’Connor, 2010). Traditionally, when this framework has been applied to persons living with dementia, the focus has remained in the care and dementia context, for example, activity offerings in care settings, how care is provided to residents, participation in dementia advocacy organizations (Bartlett & O’Connor, 2010). This study addresses Bartlett and O’Connor’s call to expand understandings of participation beyond dementia-related issues and considers how persons with dementia contribute to their own lives and the lives of others.

Unconditional compassion.

A few participants in the study described adopting and loving animals that might be considered “undesirable”. For example, Louie is ill, a senior, and missing a tail; Luna has a lump on her leg; and Roxy is sixteen years old. However, these characteristics don’t seem to impact the love and affection shared between humans and their animals. I wonder if participants feel a sense of kinship to these somewhat marginalized animals, and want to support or care for them because they relate in some way? Rick clearly articulated that he relates to Louie, in that they are both living with a health condition and have experienced abandonment. Rick in losing a close

relationship with his spouse following his diagnosis, and Louie was abused and then overlooked by prospective adopters for six months. But, Rick is proud and outspoken about living well with dementia, and does not let his diagnosis hold him back. Similarly, Louie's deplorable history is behind him, and Rick aims to show his cat, Louie how amazing and exciting life can be. Rick specifically wanted to adopt a cat that he thought would be overlooked by others. Having experienced the effects of stigma himself, Rick feels compassion for Louie and what he's been through in his previous life.

Further to this point, a few other participants also adopted animals that were not wanted by others. Gloria rescued Rosie from a neighbour, who said she was going to take the cat back to the pound. And Rocky was adopted because he wasn't suited to "working in the rings". I am still not quite sure what Shirley meant by this statement, but Rocky is a border collie, so I wonder if he was meant to be herding livestock, or perhaps he was being trained to be a show dog performing "in the rings"? Either way, apparently, he didn't enjoy that work and wasn't suited to it, as he much prefers being with people. Rick, Shirley, and Gloria's decisions to adopt these animals, rather than cute kittens or puppies, for example, shows compassion, generosity, and intentionality to help those who are marginalised. In this way, adopting and caring for cats and dogs is an expression of persons with dementia practising social citizenship. Bartlett and O'Connor (2010) describe: "Thinking about citizenship as a social practice is helpful as it broadens how the actions of people with dementia might be interpreted, and it opens up dialogue about the wider consequences of people's actions" (p. 33). In these examples, storytellers' actions had positive consequences – they essentially saved a life and opened up space at the shelter for another animal to be cared for and taken in.

Intentionality.

Rick's openness with his dementia diagnosis also helps to shape how others understand dementia and individuals living with it. Sharing his story with me shifted my perceptions of dementia and has challenged me to re-consider my own attitudes and assumptions about the abilities of persons living with dementia. Hopefully, Rick's openness with others he interacts with (i.e., his neighbour, his daughter, the shelter staff, the people who get to hear him speak at conferences, etc.) challenge their understandings and perceptions of dementia too. Certainly, Rick's neighbour Maggie was impacted by his presentation, and his dementia did not prevent her from asking him to "baby-sit" her animals. Research demonstrates that learning about dementia from persons with lived experiences of dementia offers valuable and relatable insights, because they are the experts (Dupuis & Gillies, 2014). Sharing examples of how people are living well, and highlighting their continued abilities challenges dominant discourses and perceptions of dementia, provoking personal reflection and transformation among persons living with and without dementia alike (Dupuis & Gillies, 2014).

The relationship Rick described with his neighbours is also an example of contributing to others. The "baby-sitting" agreement Rick developed with his neighbour is an example of his social role as a helpful neighbour and friend. Rick and Maggie take care of one another's animals, the relationship is mutually beneficial and reciprocal (Jordan, 2004a).

For me, the re-storied narratives articulate how persons with dementia impact the lives of others, including their companion animals, and are intentional in doing so. Historically, the capacity for intentionality has been overlooked in literature and research on dementia. Dupuis et al. (2012d) suggest that when people with dementia are only seen through a biomedical lens, the possibility for intentionality in their actions are dismissed. They are seen not to have the capacity

for intentional actions (Dupuis et al., 2012d). The social citizenship and relational citizenship frameworks trouble these ideas and demonstrate how the actions of persons with dementia are intentional and remain so throughout the dementia journey (Mitchell et al., pending). Bartlett and O'Connor (2010) emphasize, "a person's ability to participate at some level is assumed irrespective of cognitive capacity" (p. 71). That is, persons with dementia participate in and contribute meaningfully to life and to relationships, how this is expressed varies from person to person, and throughout a dementia journey (Bartlett & O'Connor, 2010; Mitchell et al., pending).

Agency and creative strategies.

A number of participants have developed and implemented strategies that enable them to continue caring for their animals, despite some challenges associated with dementia. For example:

- Doug always walks the same route with his dogs, in case one day he forgets which way to go. He also thinks if he got turned around his dogs would be able to lead him back home. And as an additional safety measure, he always carries his cellphone when going for a walk, in case something unexpected happens.
- Lisa explained that she can have a hard time doing things on her own, but if someone else is there – her dog – she feels motivated because they can do it together. For example, going for walks.
- Lisa mentioned that one time while on a walk with her dog, Max she got turned around in an unfamiliar area. She also carries a cellphone and felt a sense of relief knowing she could call her husband for help. Her husband suggested telling Max: "it's time to go home", and Max led Lisa safely back home. She decided not to go walking in that wooded area again.
- Lisa taught her dog to bark when people approach her house, because she feels uncomfortable answering the door when home alone.
- Rick formed an agreement with a neighbour to care for each other's animals when they are away on holiday. He also asked his daughter if she would step in and take his cat if things with his dementia were to change, planning ahead in case a time comes and he was no longer able to care for the cat.

These strategies involve foresight, planning, and problem solving. They also illustrate the importance of relationships. Working with and leaning on others for support (be it a family member, friend, neighbour, or a companion animal), shows that we are stronger in connection.

These types of small-scale creative practices participants have developed may not have a major impact, but are significant in the context of participant's ordinary daily lives (Bellass et al., 2019, p. 2805). Bellass and colleagues (2019) "...wish to broaden understandings of what it is like to live with dementia and to reconceptualize creativity as also being situated within everyday practices that are lived and negotiated relationally, that is, in the context of relationships with other people" (p. 2801). They suggest we should not overlook the everyday relational practices people implement, and conceive of these practices as an expression of creativity. The creative strategies some participants developed have enabled them to continue carrying out responsibilities associated with companion animals in the present and for the future.

An understanding of creativity in everydayness also challenges the common conception of persons with dementia as incapable and incompetent. In developing these strategies, participants demonstrate agency and power to make decisions, capacity to care for their animals, and an anticipation of the future and their (potentially) changing abilities. There are challenges associated with dementia and memory loss. However, these challenges are multi-dimensional and "... difficulties are influenced by personal, interactional, and environmental factors" (Beard et al., 2009, p. 231). Said challenges are the result of a combination of changes in memory and other personal abilities and, perhaps more importantly, the situations within the social world in which people live that disable and stigmatize persons living with dementia, such as with the dominant biomedical and tragedy discourses of dementia.

These strategies are also often contingent on relationships with others (both four legged and two legged). The companionship and family support to engage in meaningful activity has been explored by researchers in the dementia context (McDuff & Phinney, 2015; Phinney, Dahlke, & Purves, 2013). These other researchers have looked at the roles and impact of family

members and the family structure, where my research also includes a consideration of support from companion animals. In this way, Bellass et al. (2019) have inspired me to think about how the everyday creative practices' storytellers enact contribute to their ongoing, complex relationships with companion animals and as expressions of social citizenship. I am curious about other creative strategies participants developed and rely on that were not shared during our interviews. Perhaps, considered so common or ordinary to participants, their strategies didn't come up throughout our conversations? Also, more importantly, the focus of this study and the interviews were not specifically on strategies or creative ways of adapting to dementia in regards to relationships with companion animals. So, the ideas that were shared were initiated by the storytellers.

To help navigate challenges in daily life and social interactions it is common for persons with dementia to use coping strategies (Beard et al., 2009; Nygard, 2004). Beard and colleagues (2009) found: "The main strategies used included cognitive aids, making modifications, assistance from others, and acceptance" (p. 231). We can see some examples of cognitive aids, modifications, and support from others in the examples above. But, acceptance wasn't something that I had initially anticipated or considered a strategy. However, an example of acceptance stood out in Lisa's narrative. Lisa said to me - in regards to her dementia - "what can I do about it? I can't regrow brain cells. I can't cure my dementia... I could be miserable or I could be happy, you know, and I am happy". Her positive attitude towards dementia is both surprising and refreshing. People living with dementia continue to enjoy life to the fullest, experience joy, and have a positive attitude (Genoe, 2009; Keady, Williams, & Hughes-Roberts, 2007). While I had read about what it means to *live well* with dementia, up until that moment, I had never had a conversation about it with someone living with dementia. Beard and colleagues (2009) challenge

those of us without memory loss to imagine that dementia “is not *all* bad, *all* the time” (original emphasis, p. 234). In doing that, Lisa’s words impacted me, and re-affirmed the importance of hearing from persons with lived experiences of dementia in order to continue shifting personal and societal understandings (Dupuis & Gillies, 2014) towards citizenship.

Learning about forms of everyday creativity from persons with lived experience of dementia is an evolving and emerging field of inquiry that Bellass and colleagues (2019) believe needs to be further explored, especially with individuals who are living in their own homes. They suggest: “Especially lacking is a relational characterisation of creativity employed and experienced as [persons with dementia] traverse their everyday spaces of home, work, neighbourhood and community” (Bellass et al., 2019, p. 2809). I think my study contributes to this developing area of dementia inquiry, and further expands the notion of everyday spaces and relations, by showing some intimate relational and citizenship practices of persons with their companion animals as they navigate home, neighbourhood, and community.

Growth

Another aspect of Bartlett & O’Connor’s (2010) citizenship framework is *growth*. In this context, growth “...recognizes a person’s inner hopes, desires and capacity to contribute to life” (Bartlett & O’Connor, 2010, p. 40). For one participant in this study in particular, his relationship with his companion animal offers opportunities for growth. Rick has always been a busy, active person and enjoys continually learning and try new things. He attempts to keep his cat, Louie as active and engaged as he keeps himself. He is often brainstorming and pursuing new avenues for their shared enjoyment, such as taking Louie outside on walks, hikes, and bike rides. Rick bought a harness and leash so that he could take his cat outside, and not worry about him running

away. Rick and Louie enjoy exploring new hiking areas together, and are often stopped on the trails by others, fascinated to see a cat on such an adventure.

One of Rick's doctors warned him against cycling due to changes in his balance. Rick, not one to give up, went out and bought a three-wheeled bike, with a big basket in the back. At the time of our interview, Rick had recently introduced Louie to his bike and gone on a short ride together. But because Louie jumped out mid-way he told me he was planning to craft some sort of enclosure to secure Louie in the basket on the rear of his bike. These examples align with Dupuis et al.'s (2012c) *growing and developing* theme of the of *celebrating and living life through leisure*. Persons with dementia enjoy learning, trying new things, and challenging the body and mind (Dupuis et al., 2012c). Moreover, these practices are expressions of Rick's citizenship.

Togetherness and Reciprocity

A relationship
Together, caring and loving –
Not therapy

Relationships with companion animals foster a sense of togetherness and belonging that is characterized by mutuality and reciprocity. All participants in this study care for and about their companion animals in a multitude of ways, as described in detail in the social roles, responsibility, and purpose, participation and contributions, and growth sections above. Participants also believe their companion animals care for them in return. In a sense, they are partners-in-caring and in this way, it is not about “giving” or “receiving” but reciprocal interactions that contribute to connection. Mutuality and togetherness are nuanced and vary for each human-animal relationship. However, there are a number of threads that weave across multiple narratives. In this section I now consider how humans experience care and togetherness with their animals:

- **Animals can lend physical cues and guidance**
 - Dogs can and do help direct their human companions' home (if/ when) they get turned around while on a walk
 - Dogs bark to alert when someone is at the front door, or if something is amiss
 - Both cats and dogs communicate their needs through movements and physical expressions: i.e. walk to kitchen = wants to be fed; drops ball at feet = wants to play; sit by door = wants to go outside; place head in lap = pet me
- **Animals promote feelings of love and emotional support**
 - Both cats and dogs initiate and give affection (touch)
 - Including: place head in lap; lie down beside in bed, on couch, or in chair; lie on top of chest; jump into lap; lean bodyweight into; give kisses, etc.
 - Animals provide mental distraction from current troubles or concerns
 - Animals promote feelings of calm and relaxation
 - Animals listen, without judgement when feeling “pissed off” or frustrated and there is a need to vent
 - Animals comfort for example, by sleeping beside in bed when feeling ill
- **Animals promote feelings of joy and happiness by:**
 - doing silly things, being goofy, and making us laugh
 - consistently making participants feel happy
 - providing experiences of joy from playing with and watching animals play
 - providing a sense of entertainment
 - nourishing liveliness and activity in our homes

There is a tendency in literature and research on animal companionship and animal therapies to focus on what animals *do for*, or contribute *to* humans. In this study, participants described their relationships with companion animals as significant, meaningful, and the value in the human-animal bonds are not merely based on utility. The bonds are mutual and experiences are shared. Lisa describes her relationship with her dog as “codependent,” they are always together and do things for one another, she thinks they need each other. In regards to her dog, Shirley says: “He keeps me going, I get exercise and he gets exercise. We have a good time together.” About her cat, Stella says: “I love her” and “she loves me”. Because of the way participants conceive of and experience these relationships, I believe they can help us to broaden understandings of relationality in the dementia context.

Friends and family.

All seven participants said they love their animals, and some think that their animals love them too. The ways participants refer to themselves and their companion animals speaks to the intimacy of these relationships. Some use the term “pet,” but more often refer to their cats and dogs as: children, kids, family members, friends, furry friends, and buddies. Participants do not consider themselves “owners” but: a friend, mom, parent, and grandparent. Everyone needs friends and individuals that we feel connected with. Harris (2013) explains:

Friendships are an integral part of the human experience and provide support, an emotional closeness, and sometimes a confidant, someone with whom you can share your inner most thoughts. This need for such friendships exists across the life course regardless of a person’s age, gender, race, or impairment and contributes towards a person’s psychological well being (p. 142).

We all want to feel that we belong, are a part of things, that others understand us, and feel that we matter (Jordan, 2004a). It is in good, mutual connections that we learn and grow and can feel a sense of belonging (Jordan, 2004a).

However, relationships and friendships are complex and multi-dimensional. Among persons living with dementia, notions of friendship are diverse and range “...from more simple friendship relationships, based upon one type of shared activity, to more complex, multifaceted relationships, such as a comforter to a confidant. And family also may become friends” (Harris, 2013, p. 150). We have different kinds of relationships with different people and for varied reasons. Moreover, relationships are not static, they constantly shift and evolve (Jordan & Walker, 2004). In the context of this study, sometimes participants refer to their cat or dog as a friend or buddy, at other times a child or family member. In the re-storied narratives participants also use terms of endearment (i.e. sweetheart, my little girl, poor little guy, my boy, gentle soul, buddy, furry friend, my everything) and playful nick names (i.e. little devil, little shit, monkey,

nutsy) to describe and refer to their animals. How relationships with companion animals are experienced may also change throughout the dementia journey (Baun & McCabe, 2003; Connell et al., 2007).

Phyllis Braudy Harris has contributed much research on friendships in the dementia context, and values the perspectives of persons living with dementia. While it is common for people to lose friendships and relationships after sharing a dementia diagnosis (Harris, 2004; Sterin, 2002), a number of friendships are maintained. As Harris (2013) explains:

Perhaps the key aspect here is the ability of the friend to accept the person with dementia as a person and friend, and not let the diagnostic label overpower or overshadow the relationship. And people with early stage dementia discussed the need for themselves to still give to the friendship relationship, so it is a mutually beneficial relationship, though perhaps no longer one of equal reciprocity (p. 160).

The stigma of dementia is a factor in how people are perceived and treated by others. A number of participants in this study described that their relationships with companion animals did not change after a diagnosis of dementia; animals are not impacted by social discourse and perceptions. Moreover, despite problematic assumptions that dementia renders people incapable and unknowing, individuals living with dementia want to and *do* continue to contribute to relationships, particularly with individuals they have had strong long-standing connections with (Fazio et al., 1999; Harris, 2013; Sabat and Lee, 2011). Participants in this study contribute to and enrich the lives of their animals, and vice versa.

A number of participants have lived with their companion animals for many years, and their relationships were established before being diagnosed with dementia. For others, they adopted animals' post-diagnosis, as a result of the death of a former animal. Despite the length of time in the relationship, these connections are characterized by a sense of commitment. Harris (2013) explains: "some of the key components of commitment include dimensions of: loyalty,

constancy, trustworthiness, reciprocity, and acceptance” (Harris, 2013, p. 151). Participants are committed to their animals and to the relationships. Rick is the only participant that mentioned potentially giving his cat away if things were to shift with his dementia and impact his ability to care for Louie. However, I would argue that Rick *is* deeply committed to his cat, because before adopting Louie he developed a plan for the cat to be taken care of, if/ when his dementia changes. That is, he is committed to ensuring Louie is spoiled, enjoys the rest of his life, and does not end up back at a shelter. He was showing responsibility by planning for a circumstance where he may no longer be able to care for Louie. A few other participants mentioned they think their current companion animal will be their last, due to the progression of their disease, and future changing ability to train a dog/cat and care for their needs.

Companionship.

What remains?
Love, compassion, laughter
A need for connection

According to Nolan et al.’s (2004) *senses framework* belonging refers to feeling part of things, and in the context of caring relationships involves: “opportunities to maintain and/or form meaningful and reciprocal relationships, to feel part of a community or group as desired” (p. 50). Companionship with animals features prominently in all the storyteller’s narratives. For participants their cats and dogs are considered loyal, reliable, and good company. They spend a lot of time being with their animals, and provide comfort and companionship to each other. In reference to his cat, Karl remarks: “wherever I am, she wants to be”, and Gloria’s sentiment is very similar: “they’re always by my side”. “Good day, bad day, he’s there for me,” Rick says, referring to his cat. Shirley’s dog, Rocky is perceptive of her mood and emotions, she explains: “If I’m down about something, he’ll put his head in my lap, and say, ‘okay, you’ve got to pet me

now, you're going to feel better". The interaction and attention provided by an animal makes people feel seen and known. Dogs are social beings and perceptively respond to our emotions, and also evoke emotions in us (Irvine, 2004).

For participants, there is a sense of comfort and familiarity in the company of their animals. One of the ways persons living with dementia celebrate and live life through leisure is by "being with" (Dupuis et al., 2012c). "Being with" includes opportunities that foster connections for being social and spending time with others, with nature, or with animals (Dupuis et al., 2012c). For participants in this study, a notion of "being with" is inextricably tied to engagement with their animals. Aside from their companion animals, Gloria, Shirley, and Karl live alone. For Doug and Lisa, their spouses both work during the day, and their dogs provide company and an important sense of belonging when they would otherwise be alone for long periods of time.

Connection is also formed by do things together, spending time in each other's company, and having fun. Togetherness is varied, and ranges from hanging out while participants work on puzzles, gardening, reading, writing blog posts, and baking, to shared leisure experiences, like walking around the neighbourhood and in parks, playing fetch, watching television, and cuddling. Doug who has two dogs describes his different relationships with each dog – one likes to play, and the other likes to cuddle and watch television. In Harris' (2011) study on friendship, they found: "Despite a diagnosis of dementia, friends were still able to connect by sharing common activities that they enjoyed, and the person with dementia was still able (on whatever level) to make a contribution to that relationship" (p. 310). We often connect through shared experiences while doing things together. However, we know that leisure is not limited to activity, but definitions also include a state of mind or a personal feeling identified by an individual

(Karlis, 2004). For persons with dementia, leisure is also connected to “having fun” (Dupuis et al., 2012c). Participants described how interacting with their companion animals elicits joy, humour, and playfulness. Animals can be goofy, silly, and often do spontaneous things that make us laugh. In return participants can also express their playful side and have fun.

Companion animals also bring people together. Studies show that strangers are more likely to interact in public spaces when one or both people have a dog with them (Knight & Edwards 2008; Wood et al., 2007). Shirley’s dog is very social and when they are out in public he will stop, sit, and allow children to pet him. Shirley also enjoys these opportunities to socialize. Rick also engages with people when he is out on walks with Louie, as they are quite often surprised to see a cat engaging in such an activity. In addition, Rick and his neighbour formed a relationship over their mutual affection for cats. In this way, we not only connect with our animals, but can form relationships with other people because of our affinity for other species.

Disconnection and Reconnection

So far, this conversation has primarily focused on the experiences of connection; however, a relational awareness also includes elements of disconnection and reconnection, as relationships are always evolving. A number of participants experienced a significant sense of loss as a result of the death of former companion animals. Rick said he was “heartbroken” after the death his cat, Sugar, and compares the loss to the death of a child or family member. Sugar out-lived three romantic relationships, and over the years they had developed a deep and meaningful connection. The experience of loss and loneliness from the disconnection eventually prompted him to adopt a new animal companion, Louie, who features prominently in the re-storied narratives and discussion above. Following the death of her dog, Teddy, Lisa’s

neurologist encouraged her to get another. Lisa didn't explain what she experienced from the disconnection, but given that she discussed it with her neurologist, I take this to mean it was rather significant. Losing a companion animal is an emotional experience for many people and can impact multiple aspects of a person's life (Morley & Fook, 2005; Weisman, 1991).

Participants also spoke of a disconnection from themselves, in terms of a potential loss of ability/ changing ability. Lisa ponders her future, her changing abilities, and what that might mean for Max (interestingly, not for herself) and her role in their relationship. She maintains a parental sense of concern for him and his wellbeing, with little regard for her own. She is protective of Max and thinks of him as her child and believes no one else would be able to take care of him or love him like she does.

A few other participants spoke about a fear of future disconnection from their current companion animals. The depth of Stella's connection with Luna is indicative in her depictions of potential disconnection, and the negative impact being without the cat would impart – saying she wouldn't be happy without the cat, and doesn't know what she would do without her. When Stella spoke about potential disconnection she became emotional, teary-eyed, and had a weepy catch in her voice. Likewise, Gloria said she would miss her cats, would be lost without them, and hopes that doesn't happen. Further, she said she doesn't even want to think about what life might be like without them. Doug remarked that he will be happy to see Roxy turn sixteen, but knows he will cry when she dies. The loss of a companion animal can cause persistent grief and mourning (Weisman, 1991). Bereavement can be particularly hard because there are not typical customs and support offered for mourning the loss of a companion animal, like there are when humans die (Morley & Fook, 2005; Weisman, 1991).

As previously mentioned, Doug is completely committed to his relationship with dogs. He said: “I could not live, I couldn’t live without a dog, period.” For him, the future will always have a dog in it. If his current dogs die, he plans to get another. If his wife were to die, he would still have a dog. If he couldn’t afford a poodle (his favourite breed) he would adopt a puppy from the humane society, because he prefers to train his own dogs. Additionally, he will not move anywhere without being able to take his dog with him. This is significant, given that most LTC homes in Canada do not currently allow companion animals to live with residents in the home. Speaking with Doug about his dogs it became clear how important these relationships are, and how closely dogs are connected to his sense of identity. Ward et al. (2011) explain: “Our sense of self resides in social relationships and so asking someone to give an account of the relationships they value can reinforce a sense of identity and belonging” (p. 298). Dogs seem almost necessary for Doug, having had dogs since childhood, his identity is closely tied to relationships with them, and they have remained significant throughout the story of his life.

These variations and complexities highlight the different feelings, beliefs, and actions of participants. Each person’s relationship with their former, current, (and potentially future) companion animals are distinct. The characters in these stories are citizens with social roles, who showcase their power and agency by making contributions to the lives of others and to their companion animals. In these stories we witness the depths of connection that impact the lives of both humans and animals. Participants really seem to know and understand their cats and dogs and enjoy spending time together, having fun, learning and growing, and being themselves. These relationships are characterized by reciprocity, and expand understandings of relationships with companion animals beyond utility in the dementia context. I hope the re-storied narratives I have presented and discussed will continue to challenge the dominant tragedy and biomedical

discourses of dementia, and broaden understandings of relational theory to include relationships with canine, feline, and other non-human friends.

CHAPTER SIX: EPILOGUE

Significance and Implications

This study provides a preliminary understanding of significant relationships with companion animals from the perspectives of seven citizens living with dementia. When we see dementia and persons living with it beyond care and recipient, we can problematize these ideas and start to understand how persons with dementia exist within multiple spheres of connections. In doing this we begin to become aware of how they engage in relationships, make contributions, and provide to others.

Broadening the dementia context.

I believe this study responds to the call by Ward and colleagues (2011) to consider broader relationships in dementia: “The emphasis on the impact of dementia on the ‘caring’ relationship, i.e. the relationship between family carer and person with dementia, is only one perspective on the fundamental role of relationships for the person with dementia” (p. 289). The human-animal relationship is a new area of inquiry in the dementia context, and also in regards to relational theory and social citizenship. Considerations for relationships with non-humans can perhaps add a new dimension to how we understand relationships, and think about the practices of citizenship in dementia studies.

This study moves beyond the conceptualization of animals as health interventions and recreation therapy for persons with dementia. I sought to understand how persons with dementia storied their relationships with their own companion animals. Much of the research on animals and dementia that has come before, solicited input from staff working with persons living with dementia, and/or spouses or family members of these persons. The vast majority of previous research also focused within institutional settings (i.e., hospitals and LTC homes) where

residents are visited by therapy animals. I thought it was important to hear from people with dementia, living in their own homes, with their own companion animals. These relationships were understood as reciprocal, and as such, the impact of connection on animals was also considered.

Relational theorists argue that relationships are important to our wellbeing, growth, and identities (Jordan 2004a). We have become who we are and continue to grow because of our connections and relationships with others. As humans, we need: to feel heard and understood; to have our experiences validated; have opportunities to share and receive positive feedback; to know that we matter, and know that someone else cares about us (Jordan & Walker, 2004). These notions are fostered through connections and healthy relationships, and this sense of belonging in relationships and community is termed *relational competence* (Jordan & Walker, 2004). The narratives of this study illustrate the complex human-animal connections and how these relationships can contribute to social roles and identity and promote feelings of belonging among persons living with dementia.

This research draws upon the social citizenship and relational citizenship frameworks to understand human-animal interactions and relationships. To my knowledge, this is a unique application of the citizenship framework in the dementia context. In this study I stayed fairly closed to the lived experiences and performances of citizenship on a personal, or relational level. My conversations with storytellers did not address topics of discrimination or deeply consider how participant's citizenship might be limited or challenged. This framework challenges us to think more broadly about social, political, and cultural implications and provide more consideration for on the intersectional lives of persons with dementia; I will admit this is somewhat limited in this study, and could be expanded upon in future research.

Challenging stigma.

According to the WHO dementia is a world-wide public health priority (WHO, 2017). Alzheimer's Disease International (ADI) has called to develop effective strategies to address the stigma of dementia (Batsch, Mittelman, & ADI, 2012), and Canada launched the first National Dementia Strategy earlier this year with one of the three goals being: to improve the quality of life of persons living with dementia and care partners (Public Health Agency of Canada, 2019a). It is important to change societal understandings with relevant information from key stakeholders. ADI explains in their 2012 report: "We need to inform everyone that throughout the illness, people with dementia can engage, participate and maintain dignity whether living at home, in the community or in a care home" (Batsch, 2012, p. 12). The participant's stories in this study confront and challenge negative and stereotypical depictions of dementia. These new narratives portray persons with dementia as citizens with responsibilities who contribute to relationships on a personal level and to society more broadly. If people knew more about dementia, and how people continue to live well and live fully, the fear of dementia and persons living with it might be minimized (Basting, 2009).

While we eagerly wait for a "cure" for dementia – which may or may not come – there is something we can do. We can work towards changing attitudes and perceptions of dementia (Basting, 2009). In doing so, "we can work to reduce the paralyzing stigma and fear that wrap themselves around dementia" (Basting, 2009, p. 3). As our population ages, and people continue to live longer than ever before, more and more individuals are impacted by dementia each day (Basting, 2009). Dementia does not just impact an individual who receives a diagnosis, but also their loved ones, their broader social network, their community, and society in general (Dudgeon, 2010).

While Bond, Corner, and Graham (2004) argue that to be the most impactful, change must occur at a societal level, I believe grassroots movements should not be overlooked in their ability to enhance personal and public understanding. One of my intentions for this research is that it will perhaps in some small way help to chip away at the stigma which surrounds the word dementia, and persons who live with it. I hope that my research will illustrate to other researchers, professionals, students, and persons living with dementia that a diagnosis is not a sentence, but rather an opportunity, as Taylor (2007) suggests.

Discrimination

This study has focused on how persons with dementia practice citizenship in relation to their companion animals, however, there are also ways that this citizenship might be threatened. Because there is not much research on the experiences of persons with dementia and companion animals, I connect a number of these ideas to marginalized older adults with companion animals more broadly and also include some of my own observations.

For older adults with low incomes the costs associated with adoption fees, vet bills, grooming, and food may be prohibitive to having a companion animal (Anderson et al., 2015). Adopting an animal from a humane society or shelter is typically more economical than going to a breeder, and some shelters also offer promotions and fees on a sliding scale geared to income. There are also concerns about the lack of social and affordable housing options for low-income older adults that have companion animals. Toohey and Krahn (2017) argue, “[I]n Canadian settings and elsewhere, older adults are often expected to sever what are commonly committed, long-term relationships with their dependent companion animals in order to be considered for affordable housing” (p. 662). The same can be said for people who require a move into more supportive living environment, such as LTC homes. These policies and practices do not consider

the significance of relationships between humans and animals; animals are considered dispensable (Toohey & Krahan, 2017). An article in the *National Post* outlines the story of an older adult in Calgary who refused to get rid of her cat following a change in her building's animal policy that allowed current animals to stay, but no new animals could be brought in (McIntosh, 2015). When her dog died, she adopted a kitten, and as a result, was evicted from her affordable housing (McIntosh, 2015). She was offered the opportunity to stay in the building if she got rid of the kitten, but refused – she would rather give up her apartment than her animal.

Moving is cited as one of the most common reasons animals end up in shelters (Shore, Peterson, & Douglas, 2003). A shortage of affordable animal-friendly housing for older adults means that some people are forced to relinquish their companion animals to shelters, or risk not having an affordable place to live themselves (Toohey, Hewson, Adams, & Rock, 2017). Some older adults refuse or delay moving into supportive care, if it means they would have to part with their animals (McNichols, 2014). McNichols (2014) suggests, the potential disconnection between humans and their animal companions "...should be viewed as an important issue in any assessment prior to entry to any care facility" (p. 132). For some older adults, the transition to LTC or supportive care can be very upsetting due to losing the companionship of their beloved animals (Baun et al., 2006; McNichols, 2014). This separation from a companion animal could be an added stress for individuals experiencing many changes in their daily living routines and environment. Also, the death of a companion animal (due to euthanasia) can be significant for some, and people may be "...reluctant to discuss their difficulties with staff, feeling that pet loss was something that could be trivialised" (McNichols, 2014, p. 131). Most LTC homes do not allow animals to move in, nor are designed to be animal-friendly (Anderson et al., 2015). As such, persons with dementia may experience a profound loss of social roles, responsibility,

and/or purpose (threats to their citizenship) when they are not supported in maintaining their relationships with their companion animals throughout the course of their dementia journey.

What are the current policies in supportive care for people with companion animals? What kind of policies, programs, or services would be needed at the organizational level to ensure these meaningful relationships are maintained throughout the dementia journey?

Many aging-in-place initiatives and research has not accounted for companion animals, despite their prevalence in the lives of older adults (Toohey et al., 2017) and persons living with dementia. Toohey et al. (2017) argue for coordination and collaboration among social support services and animal welfare agencies to support marginalized persons and their animal companions. The Calgary Seniors' Resource Society (CSRS) (2019) recently implemented a Pet Assist program in which community volunteers are matched with older adults who require some support in caring for their companion animals. Volunteers are able to assist with: walks, grooming, vet appointments, medication, and feeding, with the aim to keep people and their animals together and healthy for as long as possible. Toohey et al. (2017) describe how the CSRS, "a community agency that provides supportive services to lower income and social-isolated older adults...has forged partnerships with a mobile veterinary clinic, a charity that provides financial assistance for pet care, and several local animal welfare agencies" (p.138). There is also a Canada-wide charity, Elderdog Canada (2014) that provides similar types of support and services, especially for older adults and older dogs. While the target beneficiaries for these programs are marginalized older adults and their animals, it is unclear if volunteers for these programs receive any specialized training in dementia. I can definitely see the benefit of expanding these types of supportive programs, and increasing awareness of programs like this to

ensure that as things change, and marginalized peoples (including individuals with dementia) require more support with caring for their animals, it will be available to them.

Transportation is a concern for many people living with dementia, as dementia eventually impacts the ability to drive safely (ASC, 2018). Other options for transportation might include public transit, taxis, rides from community organizations, or family and friends (ASC, 2018). Some municipalities (The Region of Waterloo included) have strict policies and guidelines that limit companion animals on public transportation to small animals that fit in crates, while larger dogs are not permitted. Taxi companies vary on whether they allow animals, and it is up to each Uber or Lyft driver to decide whether they are animal-friendly. These varied guidelines mean that taking an animal to the vet, groomer, kennel, or other place may pose a challenge for people with limited access to drives from friends or family. In addition, this may be further complicated for people who live in rural or more remote areas without access to public transportation altogether.

Persons with dementia often experience stigma related to the assumptions of their capabilities. This stigma can lead to discrimination in a number of social and political contexts (Public Health Agency of Canada, 2019b). While it did not come up in this study specifically, persons with dementia may experience discrimination from adoption agencies when trying to adopt a companion animal. Given the dominant biomedical and tragedy discourses of dementia, shelter staff may assume that someone with dementia would be incapable of adopting a companion animal, and challenge their application. Family members may also question their abilities and not encourage or support persons with dementia to adopt an animal. Moreover, individuals may have internalized stigma and think that because they have dementia, they are not

capable of having an animal, and may decide not to adopt, despite wanting to. Older adults also underestimate themselves and their abilities to care for animals (Anderson et al., 2015).

However, persons with dementia should have opportunities to enact their citizenship and their right to adopt an animal if they feel they are capable of doing so. Perhaps there are ways people can be better supported in this transition. Anderson and colleagues (2015) suggest shelters should help older adults choose a companion animal that would be best suited to a person's abilities and lifestyle. For example, while most dogs require regular exercise, cats are much more independent, and caring for animals like rabbits or birds is even less physically demanding. Shelters could allow animals to be adopted on a trial basis, so older adults can see what might work best for them and build their confidence (Anderson et al., 2015).

As an alternative to living with a companion animal and caring for them full time, there are also opportunities to regularly “baby-sit” a companion animal that might suit some people. Winifred, a woman living with dementia in the UK is part of a group called “Borrow My Doggy”, in which she spends time twice a week with a neighbour's dachshund (Alzheimer's Society, 2018). The dog is dropped off at her house and they spend the day together, sometimes the dog stays overnight too, if needed (Alzheimer's Society, 2018). Dogs have always been important to Winifred, and in this way, even though she may not be able to live with a companion animal full time anymore, she is able to practice citizenship by helping a neighbour and the dog.

I have outlined some of social and structural practices and policies limit the citizenship of persons living with dementia who have close relationships with companion animals. This discussion is by no means exhaustive, but starts to consider broader socio-political constructs

that were not considered in this research study and what might be needed to overcome or address some of these issues for persons living with dementia.

Moving Forward

I believe there are a number of possibilities and considerations for future research in this area of dementia studies. I think it would be beneficial to dive further into the creative strategies persons with dementia have developed and implemented that enable them to maintain relationships with companion animals. What other strategies could be useful throughout the dementia journey? How else can the human-animal bond be supported throughout dementia? As a society and as individuals, how can we support people when they can't be as actively involved in the care as they would like? What are animal-friendly supportive living environments in our local community? And what are their policies on animals? This could be a topic for a participatory-action research study, whereby people with dementia could come together to collaborate, share ideas, and be engaged in brainstorming and developing possible solutions. Future research should also include persons with dementia at the initial stages of planning research projects to ensure the topic is of relevance and important to them. This would also ensure the study methodology was cohesively aligned with a citizenship perspective (Bartlett & O'Connor, 2007, 2010). I think it would also be helpful to share strategies with other persons living with dementia who have companion animals, or are thinking about adopting a companion animal. Perhaps these ideas could be presented in an accessible format similar to the *By Us For Us Guides*. These guides are available for electronic download and in hardcopy (see the Research Institute for Aging website: <https://the-ria.ca/resources/by-us-for-us-guides/> for more information).

I would also love to publish the short-story collection, and make it widely accessible to all types of audiences. In order to share new narratives of dementia that reflect persons living as active, contributing citizens. Perhaps, I could include a few reflective questions at the end of the collection to engage the reader in critical reflection on their understandings of dementia, and consider how these might have shifted from engaging with the stories.

In future research on companion animals and persons with dementia I would incorporate opportunities to spend time with participants and their animals in the methodological approach. One of the things I feel is missing from this study is a stronger connection to embodiment and embodied selfhood in dementia. While participants took photos and included photos of themselves interacting with their animals, these images offer just one moment in time. What happened before and after the photos were taken? Who initiated the interaction? How? Etc. It would have been beneficial to witness how participants and their animals interact and engage with one another. I had a small window into this when I interviewed one participant over Zoom. He was in his home and I was in mine, each with our companion animals nearby. His cat actually spent a good portion of the interview alternating between walking back and forth and lying on the participant's lap. At one point I also had my dog perched on my lap (she's small, only 12 pounds), and we connected over our mutual affection for animals.

Living with dogs my whole life, I know there are shared ways of interacting and communicating that we exhibit and enact on a pre-reflexive level. My dog, Ruby and I constantly respond to one another without words. In fact, last year when trying to overcome some issues with barking and anxiety, our dog trainer suggested not talking to Ruby for a whole week. It was surprisingly hard, and I caught myself from almost talking constantly! But, you know what? Ruby and I responded to each other's actions, movements, and emotions – we don't need to

communicate with words. And by the end of the week-long exercise she was actually more relaxed (and maybe I was too). Due to the nature of dementia and variations in language abilities, having the opportunity to observe participants and their animals interacting in familiar spaces and places would lend another perspective and dimension to understanding these types of relationships and how they contribute to people's and animal's lives.

Most participants in this study have lived with and loved animals throughout their lives. It is likely that relationships with animals have always been special and important, and with dementia the significance remains. Everyone has had different life experiences and interactions with animals and companion animals, which may impact one's willingness to welcome a furry friend into their home. If someone has never been interested in having a cat or dog, it's unlikely this might change with the onset of dementia. So, with this research, I'm not trying to suggest that every person with dementia should run to the animal shelter and adopt a furry friend. Animals do require care that involves commitment, effort, time, and financial responsibility. However, I also don't want people to be over-looked by others (i.e., family members, friends, staff at the animal's shelter, etc.), or to overlook their own ability to care for a companion animal, even though they have dementia. As I have learned throughout this study, there are a number of people who are living well with dementia and choose to share their lives with companion animals – so if you want to develop a relationship with a furry friend too, it can be done! There are also various kinds of animal companions. Participants in this study just happened to have cats and dogs (the most common domestic animals), however, it would also be interesting to talk to people who have different kinds of animals to get a sense what those relationships are like and how they might contribute to the lives of persons with dementia.

This cross-sectional study focused on the experiences and stories of seven persons at one point in their dementia journey. We know that dementia is a dynamic, complex journey; the relationships with companion animals are likely to shift – as relationships are fluid and ever-changing. How will participants continue to experience relationships with companion animals as their dementia progresses? While the future of these relationships is uncertain, there is no doubt that they are currently meaningful and important. Future research could follow participants and their companion animals over a longer period of time to better understand these relationships.

Conclusion

This is a new area of inquiry, and the first study I am aware of that sought to understand the relationships with companion animals from the perspectives of persons with dementia living in their own homes. The purpose was to speak with individuals with lived experience on a topic that had received very little attention in the dementia context thus far, in order to broaden understandings of relationality and the practice of social citizenship. I believe that stories - short, long, clear, confusing, descriptive, imaginative – any kind really, are powerful and can help us to think about things in new ways. My intention is that the re-storied narratives in chapter four of this thesis will be created into a short story collection of its own and shared will both academic and non-academic audiences. These stories illustrate the everyday experiences of persons living with dementia and their cats/dogs as active, contributing, loving, and caring citizens. I believe we need more stories of dementia from relational citizenship perspectives to breakdown the stigma and dominant tragedy and biomedical narratives of dementia and introduce a new discourse based on the actions and contributions of citizens with dementia.

AFTERWORD

After completing this project, I was encouraged to reflect on this study and comment on a number of concepts that I did not initially consider, but realize do warrant my further reflection and discussion. Firstly, the language I use throughout this thesis is predominately human-centered. Like many other lay persons, both myself and participants in this study anthropomorphize our animal companions – that is, we assign meaning to, and understand our animals to have human-like qualities, traits, and emotions (Horowitz, 2009). We likely do so in an effort to understand the actions and behaviours of our animals, and use language and concepts that are familiar and have meaning to how we understand human life (Horowitz, 2009). However, doing so limits my understandings to what I already know, and disregards the actions, intentions, and behaviours of animals as separate and distinct from humans. Therefore, some language in literature and in my own work anthropomorphizes animals in a way that I had not intended. Thinking about this further, I've come to realize that, for example, when I dress up Ruby in Halloween costumes and buy her special birthday cookies, I do so for my own self-interests because it brings me joy.

Moreover, reflecting on my positionality that foregrounds this topic, approach, and understanding of animals as companions, I have come to consider how these ideas are informed and situated within a particular euro-centric, Western understanding that is specific and simultaneously exclusionary. As a white, Canadian, university-educated, cis-gender female, from an urban middle-class family I did not consider how relationships with animals could be exclusionary for some populations. The social privileges of participants in this study must also be contextualized, because opportunities for relationships with companion animals are not accessible to people in all cultures and social statuses. I will admit that I did not ask participants

questions about their cultural or ethnic origins, socio-economic status, or race. However, all participants in the study appear to be Caucasian, seem to be able to afford to care for their companion animals, and have support from family members. Like myself, these participants have had relationships with companion animals throughout their lives, characterized by positivity and a familial history of animals as a source of friendship and comfort – not as potential threats or fear. Neither myself, nor the participants experienced persecution or punishment by oppressors through the use of animals. Whereas as some marginalized groups have, for example, African American slaves in the United States who attempted to run away from their captors were often tracked down and subsequently mauled by specially trained dogs (Franklin & Schweninger, 1999). Therefore, the historical and contextual experience of animals in the lives of marginalized individuals and their ancestors are significant to consider. The prevailing narrative throughout this thesis is that companion animals and relationships with animals are good and positive, but in doing so, I did not adequately explain how these perspectives largely stem from the developed world and a euro-centric context more generally. Further, until now I did not consider how portraying companion animals in such a way disregards certain marginalized groups and serves/ supports others.

Another concept I reflected on is the ethics of “having” and “keeping” animals for human enjoyment, personal support, and/or gain. In the Canadian context, companion animals are legally considered property. I tried to distance my language from “ownership” of animals to companionship, and as such used terminology like: “having”, “living with”, and “adopting”. But in doing so, I unintentionally assigned meaning to animals as beings we “have”- and as some participants expressed – in order to feel whole or complete. Thinking about animals in this way – as a means to human-end points to their usefulness (a concept I was attempting to challenge). I

believe that companion animals have their own inherent worth, that is not affiliated with how useful they are to humans. But reflecting further on these ideas, the notion of sharing our homes with or “keeping” companion animals is complex. The centuries-long history of domestication of animals means that they are also reliant on humans for food, shelter, etc. So therefore, I think that choosing to live with companion animals is multi-dimensional, situational, and is influenced by numerous historical factors. This final reflection has forced me to think about a number of significant concepts embedded throughout my thesis in ways I had not initially considered, but will definitely shape my future work.

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APPENDIX A: Email Script for Contacting Agencies

Dear [name of agency contact],

My name is Allie Serota, and I am a Master's student in the Department of Recreation and Leisure Studies at the University of Waterloo. I am currently conducting research under the supervision of Dr. Sherry Dupuis on understanding the relationships persons living with dementia have with their companion animals (pets). I will be asking participants to take photographs of what their relationships with companion animals look like, and then we will have a conversational interview where participants will have the opportunity to describe their photographs.

I would like to set up a meeting with you so I could tell you more about the study and discuss with you how you might help me recruit potential participants. Would you be willing to meet with me? If so, what date and time would be convenient for you?

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40733).

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

Sincerely,

Allie Serota
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
416-986-7500
aserota@uwaterloo.ca

APPENDIX B: Verbal Script for Meeting with Agencies

Preamble: My name is Allie Serota and I am a Master's student in the Department of Recreation and Leisure Studies at the University of Waterloo. I am currently conducting research under the supervision of Dr. Sherry Dupuis. I would like your help in recruiting persons in the early stages of their dementia journey to participate in my research project, "Understanding relational narratives: Persons living with dementia and their companion animals".

I am conducting this study because to date, the majority of research on animals in the dementia context focuses on the use of animals as therapies and interventions within institutional settings, where animals are used as therapeutic tools to improve or modify the health and wellbeing of persons considered vulnerable, ill, or disabled. There are very few studies which have explored the relationships of persons living with dementia and their companion animals. In particular, I am not aware of any studies which have included the perspectives of persons living with dementia in relation to animals as companions. With this research, I hope to continue shifting societal discourse away from a medical, deficit focused understanding of dementia and towards an understanding that persons living with dementia are loving, relational, citizens who contribute to our world and to relationships, including with animals. This study will help myself, researchers, and other professionals working with persons living with dementia and their families to understand the significance of animal companionship in the lives of persons living with dementia. This information may be used to help understand how to continue supporting individuals and their animals throughout their dementia journey.

Here is 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. (Go through information letter with staff member).

Do you have any questions about the study I have not answered? (Allow time for staff to ask questions).

I would appreciate your help in passing this information letter on to anyone you think might be interested in participating in this study. Interested parties should then contact me or my supervisor (the researchers) directly to receive more information about participating.

Would you be willing to assist me in recruiting participants by handing out my study fact sheet to your participants? Or would you allow me to come and speak to your clients/participants and explain my study in person?

Answer: No thank you.

OR

Answer: Yes

Thank you very much for you time and assistance with recruiting participants for my study. Can we arrange a date and time for me to come and explain my study to your clients/participants? Once again, if you have any questions or concerns please do not hesitate to contact me by phone at 416-986-7500 or by email at aserota@uwaterloo.ca.

APPENDIX C: Participant Information Letter and Study Fact Sheet

Understanding Relational Narratives: Persons Living with Dementia and their Companion Animals

[Date]

Dear [participant's name],

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

What is this study about?

- **The connections people have with their animal companions (pets) are often significant and meaningful relationships.**
- As a person who has a close relationship with my own dog, I understand the significance of this important relationship in my own life and I hope to understand how these relationships can be maintained and supported throughout the dementia journey.
- **The purpose of this project is to understand how persons living with dementia describe their relationships with their companion animals (pets),** including: what these relationships look like, how they make people feel, and how they contribute to life and leisure experiences and relationships with other people.

What does participation involve?

- You will simply be asked to share your experiences of having relationships with companion animals (pets) by:
 1. **Taking photographs that illustrate your relationship with your companion animal(s) (pet)**
 - A disposable camera will be provided, or participants may choose to use their own camera
 - If participants choose to take photographs of other people, consent must be obtained from the subjects
 - Photographs will be transferred to the researcher and printed
 2. **Participating in a conversational interview of approximately 60-90 minutes in length, in which we will discuss your photographs**
 - To take place at a mutually agreed upon time and location (in person or via online video chat)
 - You will be asked to describe the photos, for example:
 - Where was the photo taken? Who is in the photo? What



is happening in the photo? What does this say about your relationship with you companion animal? How does this photo connect to your experience of leisure? Etc.

Who may participate in the study?

- In order to participate, participants must:
 - Identify as having some form of dementia
 - Have at least one companion animal (pet) that lives with them in their home
 - Have the capacity to use a camera (or with minimal assistance)
 - Provide consent to participate in both aspects of data collection, including taking photographs and participating in a conversational interview.

Is participation in the study voluntary?

- If you choose to participate in this study, I will be asking you to sign a letter formally stating your consent to participate. Participation in this study is completely voluntary.
- You may decline to answer any of the interview questions you prefer not to answer.
- You may decide to withdraw from this study at any time during the data collection process without any negative consequences by me or my advisor. Any information you provided up to that point will not be used.
- With your permission, the conversational interview about your photos will be audio recorded to facilitate collection of information, and later transcribed for analysis.

What are the possible benefits of the study?

- Participation in the study may not provide any personal benefit to you.
- I hope that the results of my study will provide important insights that may help other individuals living with dementia maintain their relationships with companion animals. I also hope that my research will contribute to the academic literature on the significance of animal companionship for persons living with dementia in the community.
- The study will also benefit the academic community by broadening understandings of dementia, and challenging the stigma associated with dementia.

What are the possible risks of the study?

- Given that the study focuses on participants' experiences living with dementia, it is possible that some of the discussion may cause you to feel upset. Please remember that participation is voluntary and you do not have to answer any questions you do not want to answer.
- If any participant experiences emotional stress, with their permission, I will connect them with the local Alzheimer Society family support persons.
- If your interview is conducted via online video chat, please note that whenever information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party



(e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.

Will my information be kept confidential?

- Identifying information will be removed from the data that is collected and stored separately. Your name will not appear in any paper or presentation resulting from this study, however with your permission quotations may be used with a pseudonym in place of your real name. Additionally, you can decide to allow photos from your participation to be used in papers and publications to help illustrate study findings. In these, although your name will not be used, your face may be seen which means participation in the study would not be confidential.
- Collected data will be securely stored for a minimum of 1 year in an encrypted folder on a password protected computer and in a locked office. Any printed photographs will be stored in a locked cabinet. Only myself and my advisor will have access to your information and photographs.
- You can withdraw your consent and have your images removed from the study by contacting the researchers up until the completion of the final thesis submission (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?

- I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40733). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

What if you have questions?

- **If you have any questions regarding this study**, or would like additional information to assist you in reaching a decision about participation, please contact me at 416-986-7500 or by email at aserota@uwaterloo.ca.
- You can also contact my supervisor, Professor Sherry L. Dupuis at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

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

Sincerely,

Allie Serota
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
416-986-7500 aserota@uwaterloo.ca



DO YOU HAVE STORIES TO SHARE ABOUT YOUR RELATIONSHIP WITH YOUR PET?

The relationships many people have with their pets are significant and meaningful. Through this research study I hope to understand how relationships with animals are experienced throughout the dementia journey. As a participant in this study, you would be asked to take photographs that illustrate your relationship with your animals and participate in a conversational interview describing your photos.



You may be eligible if:

- ***You identify as having some form of dementia***
- ***You have at least one pet (companion animal) that lives with you in your home***

To learn more about this study,
or to volunteer for this study,
please contact:

Allie Serota

M.A. Candidate, Recreation
and Leisure Studies

University of Waterloo

aserota@uwaterloo.ca

416-986-7500

This study has been reviewed by,
and received ethics clearance
through a University of Waterloo
Research Ethics Committee
(ORE# 40733).



APPENDIX E: Declaration of Verbal Consent Form for Participants

By verbally agreeing to participate, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

You have been told about the study being conducted by Allie Serota of the Department of Recreation and Leisure Studies at the University of Waterloo. As a participant, do you have any questions or clarifications? Please be aware that you may withdraw from the study without any penalty by advising Allie Serota or her advisor, Dr. Sherry Dupuis, of the decision.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40733). 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, Allie Serota, at (416)986-7500 or by email at aserota@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519-888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

Do you agree to participate in photovoice, which will include taking photographs and a conversational interview about the photos.

YES NO

Do you agree to have the conversational interview audio recorded to ensure accurate transcription and analysis.

YES NO

Do you agree to the use of quotations in any thesis, publication, or presentation that comes of this research, with the understanding that a pseudonym will be used in place of your real name.

YES NO

Do you give permission for your photographs (which may include images of you) to be used in any thesis, publication, or presentation that comes of this research? Your name will not be used, but your face may be seen.

YES NO



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

YES NO

Participant has given verbal consents, understands and agrees to the conditions of their participation.

YES NO

Participant's name

Person Obtaining Consent:

By signing this form, I confirm that:

- This study and its purpose has been explained to the participant
- All questions asked by the participant have been answered
- I will give a copy of this signed and dated document to the participant

Name of person obtaining consent

Signature

Date



APPENDIX F: 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 interview 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 and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Allie Serota of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

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

I understand that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40733). 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 all other questions, I have been told I can contact Allie Serota, at (416)986-7500 or by email at aserota@uwaterloo.ca. I can also contact Allie's supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

I agree to participate in photovoice, which will include taking photographs and a conversational interview about the photos.

YES NO

I agree to have my conversational interview audio recorded to ensure accurate transcription and analysis.

YES NO



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

YES NO

I give permission for my photographs (which may include images of me) to be used in any thesis, publication, or presentation that comes of this research. I understand that my name will not be used, but my face may be seen.

YES NO

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

YES NO

Participant's name

Signature of participant

Date

Researcher's/ Witness' name

Witness signature

Date



APPENDIX G: Study Reminder Poster

Understanding Relationships with Animals Through Photos

A research study



____[Participant's name]____



WHAT: Thank you for your interest in the research study titled:

“Understanding relational experiences: Persons living with dementia and their companion animals” by Allie Serota, a Master’s student in Recreation and Leisure Studies at the University of Waterloo.

HOW: Using the disposable camera provided, or your own camera **take photos that describe or show your relationship(s) with your pet(s).**

WHEN: Take photos anytime from now until ____[chosen date]____

WHY: The relationships many people have with their pets are significant and meaningful. Through this research I hope to understand how relationships with animals are experienced throughout the dementia journey. □

If you have any questions or concerns regarding this study please contact Allie Serota, at 416-986-7500 or aserota@uwaterloo.ca or Dr. Sherry Dupuis at 519-888-4567 ext. 36188 or sdupuis@uwaterloo.ca

This study has been reviewed and received ethics clearance through a University of Waterloo Ethics Committee (ORE#40733).

APPENDIX H: Information Letter for Photos

University of Waterloo

My name is Allie Serota, and I am a Master's student in the Department of Recreation and Leisure Studies at the University of Waterloo. Under the supervision of Dr. Sherry L. Dupuis, I am hoping to gain a better understanding of the relationships older adults have with their companion animals (pets). With my research project I am trying to understand how animals contribute to the life and leisure experiences of older adults living in our community.

As part of this project, I have asked participants to take photos that represent or illustrate what their relationships with animals mean to them. These photos will then be discussed between myself and the research participant. **With your permission, one of the study's participants would like to take your (or your child's) photograph because it contributes to or reflects an animal-human relationship.** With your consent, your photo may be used for the study and in research papers and presentations that arise from it. If your (or your child's) photo appears in papers and presentations, your name will not be used but your face may be seen which means that your involvement in the study will not be confidential.

Collected photos will be securely stored by the researchers for a minimum of 1 year in an encrypted folder on a password protected computer and in a locked office. You can withdraw your consent and have your images removed from the study by contacting the researchers up until the completion of the final thesis submission (Fall 2019). Please note that it will not be possible to withdraw your consent once study results have been submitted for publication.

If you have any questions regarding this study, please contact me at (416) 986-7500 or by email at aserota@uwaterloo.ca. You can also contact my supervisor, Dr. Sherry L. Dupuis at (519) 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40733). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

Thank you for helping the research participants in this study.
Sincerely,

Allie Serota
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
416-986-7500
aserota@uwaterloo.ca



APPENDIX I: Informed Consent for Photos

I have read the information presented in the information letter about a study conducted by Allie Serota of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions and any additional details.

YES NO

I give permission for my photo (or my child's photo) to be taken.

YES NO

I give permission for my photo (or my child's photo) to be taken and for these images to be used in papers and publications resulting from this research, with the understanding that I (or my child) will not be identified by name.

YES NO

Print participant's name

Signature of participant

Date



APPENDIX J: Interview Conversation Guide

Introductory Script:

Hi **[name of participant]**, my name is Allie Serota, and I am a Master's student in the department of Recreation and Leisure Studies at the University of Waterloo. Thank you for agreeing to participate in this interview and for agreeing to share your insights, stories, and experiences with me. I am interested in exploring the relationships persons living with dementia have with their companion animals. The focus of this conversation is to describe and reflect on the photographs you have taken over the past **[number of]** weeks. Before we begin, I would just like to remind you:

- Your participation in the interview is completely voluntary.
- During the interview, you may decline to answer any questions that you prefer not to answer.
- You may stop the interview at any time.
- Your name will not appear in any paper or publication resulting from this research, however with your permission quotations 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#40733).

With your agreement, I would like to audiotape our interview to facilitate the discussion and to ensure the accuracy of the information you share with me. Do I have your permission to audio-record this interview?

[If NO], that is fine; instead I will be taking notes throughout our conversation.

[If YES], continue...

Before we begin, do you have any questions for me? Are you ready to begin?
Turn on the audio-recorder.

Start interview:

Photovoice Conversation Guide

Today I would like to talk about the photographs you've taken over the past [insert number] of weeks. Using the photographs, we will discuss what the relationship with your companion animal(s) means to you. I have some questions I am going to ask about the photos you would like to talk about.

1. Of all the photos you took, which ones most represent your relationship with your companion animal(s)?
2. Tell me a story about this photo.
 - a. Where was this photo taken?

- b. Who is in the photo?
 - c. Tell me about what is happening in the photo.
 - d. What does this say about your relationship with your companion animal(s)?
 - e. Is anything missing from this photo, if so, what?
3. Tell me about how this photo demonstrates your relationship with your companion animal(s).
 - a. What are some of the things that you do for each other?
 - i. What do you do for your companion animal?
 - ii. What does your companion animal do for you?
 - b. How do you and your companion animal communicate?
 - c. What else can you tell me about your companion animal?
4. Tell me about how this photo connects to your experience of leisure.
 - a. What types of things do the two of you do together?
 - i. What types of things do the two of you do in your daily life?
 - ii. What types of things do the two of you do in your leisure?
 - b. What makes those experiences leisure?

Closing Script:

Thank you for taking the time to share your photographs and stories of your companion animal(s), **[name of animal(s)]**. 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#40733). I will be sending you a thank you note with contact information for the Office of Research Ethics at the University of Waterloo. If you have any comments or concerns resulting from your participation, I encourage you to please 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. Our contact information will also be included on the thank you note. Thank you again for your participation.

APPENDIX K: Participant Appreciation Letter

University of Waterloo

Date

Dear (*Insert Name of Participant*),

I would like to sincerely thank you for your participation in the study titled “Understanding relational narratives: Persons living with dementia and their companion animals”. As a reminder, the purpose of this study is to understand how persons living with dementia describe their relationships with companion animals (pets).

Animals are typically thought of as ‘therapy’ for persons with dementia. Your perspective and stories provided during your involvement in the project will contribute to a better understanding of the relationships persons living with dementia have with their own animals, beyond this therapy focus.

Please remember that your participation will be confidential unless you indicated that you would like your image to be shown in papers and publications resulting from this study. Once all the information is gathered and read, I plan to share this information with the research community through discussion groups, conferences, presentations, and articles. Once the study 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 study, please do not hesitate to contact me by email or telephone as noted below.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40733). 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, Allie Serota, 416-986-7500 or by email at aserota@uwaterloo.ca. You can 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 contributions within this study, I hope this has been an interesting experience for you.

Sincerely,

Allie Serota
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
416-986-7500
aserota@uwaterloo.ca

